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# Task Force on Refusal of Blood Products

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## **Final Report**

### 2004



Children's Hospital Boston  
The first place for children



# CHILDREN'S HOSPITAL BOSTON



## TASK FORCE ON REFUSAL OF BLOOD PRODUCTS

### FINAL REPORT

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Children's Hospital Boston

*The first place for children*



# TASK FORCE ON REFUSAL OF BLOOD PRODUCTS

## EXECUTIVE SUMMARY

### Synopsis

The Task Force recommends that Children's Hospital begin laying the foundation for an approach that allows the Hospital to accommodate the informed, voluntary refusal of blood by adults with decision-making capacity and mature minors, provided that certain conditions can be met. To facilitate implementation of this recommendation, the Task Force recommends that the Hospital form 3 working groups: one to develop the clinical program; one to develop programs for staff education and development; and one to develop criteria, and a process, for evaluating mature minors.

### Current Situation

- Decisions about how to treat adults and mature minors refusing blood products at Children's are made on an *ad hoc* basis.
- The variability of the *ad hoc* approach:
  - Raises moral concerns
  - Leads to tension/dissatisfaction among patients and staff

### Question

- What approach **should** Children's take to **adults** and **mature minors** refusing blood?

### Process

- Initial review by Ethics Advisory Committee
- Formation of organizational ethics task force
- Committee charge

### Task Force Analysis

- Based on widely accepted ethical and legal principles, Task Force determines that **adult patients** should not be required to accept blood in violation of their religious beliefs or moral values.
- Two remaining options are:
  - (1) Refer or transfer such patients to another hospital
    - Minimizes the possibility of death from lack of blood at Children's
    - Reflects traditional commitment to protecting patient's health and well being
    - Helps conserve resources for the Hospital's general pediatric mission

(2) Accept such patients and treat them without blood

- Demonstrates a strong commitment to patient autonomy
- Seeks to maximize access to Children's
- Is consistent with current trends in clinical care to conserve blood

### Conclusions

- The option to "Treat without Blood" is more consistent with the mission and values of Children's, and with its role as a leader in pediatric and adolescent medicine and ethics.
- Based on the ethical principles underlying this option, and legal trends, **mature minors** who meet criteria developed by the Hospital should also, in certain circumstances, be allowed to refuse blood.
- Based on respect for staff members as independent moral agents, staff should be allowed, on religious/moral grounds, to decline to provide care to patients refusing blood (provided patients would not be abandoned).

### Recommendations

- Children's should lay the foundation for an approach that accepts the informed voluntary refusal of blood by adults and mature minors, *provided that*:
  - After accepting refusal of blood, the risk-benefit ratio of such treatment is more favorable than it is for available alternatives.
  - It is clinically appropriate to provide the treatment at Children's.
  - In the case of a minor, the patient has been determined to be capable of, and have the right to, refuse blood.
- Children's should adopt the recommended approach only if sufficient resources can be allocated so that the following can be put in place:
  - Clinical protocols/oversight enabling Children's to meet quality standards
  - Programs in staff education and development
  - Criteria and a process for evaluating mature minors
  - Administrative policies and procedures

### Next Steps

- Formation of 3 working groups
  - Clinical program development

- Staff education and development
  - Policy for evaluating mature minors
- 
- Designation of program coordinator





Children's Hospital, Boston  
Organizational Ethics Task Force

2002-2003 MEMBERSHIP DIRECTORY

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# TASK FORCE ON REFUSAL OF BLOOD PRODUCTS

## FINAL REPORT

### I. OVERVIEW OF THE WORK OF THE TASK FORCE

#### A. The Current Situation

Children's Hospital provides care to adults and mature minors who refuse to accept blood products. Currently, there is no formal process for deciding whether and how such patients will be cared for. Instead, these cases are handled on an *ad hoc* basis. Decisions as to whether or not a patient will be treated at Children's without blood are generally made by individual physicians or care teams, based on a variety of factors, and may or may not involve consultation with other staff or services of the Hospital (including the Ethics Advisory Committee, the psychiatric consult service or the legal office).

#### B. Complications

A review of several of these cases by the Ethics Advisory Committee ("EAC") revealed that the variability of the current approach raises certain moral concerns and may lead to tension or dissatisfaction among patients and staff.

First, decisions about whether to provide care without blood are not necessarily consistent from case to case. Some physicians or care teams may agree to provide care at Children's without blood in certain circumstances, while others may decline to do so. The factors used in making such decisions (which may include clinical issues, moral concerns, legal uncertainty, and/or a reluctance to become involved in a time-consuming, uncertain process) do not appear to be widely known, and may not always be shared with all members of the care team.

Second, given the *ad hoc* nature of the decision-making, staff may find it difficult to predict, and explain to patients, exactly what will happen during treatment. For example, in some cases, patients may be told that blood will not be used in their care. However, it appears that in some cases this statement may simply mean that the caregivers do not believe that blood will be needed, and it may not reflect their considered views as to what would happen if blood became necessary to save the patient's life. Further, even if one caregiver, such as the surgeon, may be willing to abide by the patient's wishes at the risk of serious harm, it is not clear that other caregivers who were not involved in the initial decision will be willing to do so. In the course of treatment, particularly if there are unexpected complications, the patient may be cared for by additional clinicians who may not feel bound by the initial decision and may feel morally obligated to administer blood.

Third, on occasion, staff members may find it difficult to practice in a manner consistent with their own moral values. For example, clinicians who have learned late in the course

## 2. Alternatives

Given this basic assumption, the Task Force concluded that there were only two logical alternatives to the current *ad hoc* approach: (1) accept adult patients refusing blood and honor their refusal, with very limited exceptions (“Policy #1: Treat without Blood”), or (2) refer or transfer such patients to other hospitals whenever possible (“Policy #2: Refer or Transfer”). The Task Force prepared two policy statements summarizing the main elements of each approach. (See Appendix G and Appendix H.) After reviewing the two alternatives in detail, the Task Force prepared a summary of the advantages and disadvantages of each. (See Two Approaches to Refusal of Blood Products by Adults and Mature Minors: Summary of Advantages and Disadvantages, attached as Appendix I.)

## 3. Advantages and Disadvantages of the Two Alternatives

The policy of “Refer or Transfer” has several advantages, including minimizing the possibility that a patient refusing blood would die at Children’s Hospital; reflecting the pediatric tradition of protecting the physical health and well-being of patients; and conserving the resources of Children’s for programs more widely used by its pediatric population. However, this approach has disadvantages as well. In particular, such an approach does not demonstrate a strong commitment to patients’ rights to personal autonomy in situations involving refusal of blood; limits access to care at Children’s for certain patients and communities of patients; and may disrupt caregiver-patient relationships and continuity of care. As a result, this approach does not reflect many of the values of Children’s Hospital. Such an approach also does not eliminate the ethical dilemma of caring for patients whose religious or moral values regarding blood are inconsistent with medical consensus about the use of blood, but merely transfers the problem to another hospital.

The other approach -- “Treat without Blood” -- has a number of significant advantages. In particular, this approach demonstrates a strong commitment by Children’s Hospital to the ethical and legal principle that patients with decision-making capacity have the right to refuse medical treatment, including blood, based on their personal values and beliefs. It seeks to maximize, rather than limit, access to Children’s Hospital. In addition, by encouraging enhanced techniques for managing patients without the use of blood, this approach may reduce the use of blood products among all patients at Children’s and is consistent with the current trend in medicine toward conserving blood as a potentially scarce resource. Of course, this approach has disadvantages as well, including the possibility that a patient refusing blood, who is cared for at Children’s Hospital rather than at another hospital, would die at Children’s. Another disadvantage is the fact that adopting this policy would require a significant commitment of staff time and energy.

The Task Force believes that either of the two policies, if carefully designed and implemented, could fall within existing ethical and legal parameters, and either would be an improvement over the *ad hoc* approach. However, after comparing the advantages and disadvantages of each approach, the Task Force reached a consensus that the



approach of “Treat without Blood” is clearly preferable: it is more consistent with the Hospital’s mission and values, and with its role as a leader in the fields of pediatric and adolescent medicine and ethics.

#### 4. Mature Minors

Having reached this consensus, the Task Force also concluded, based on the ethical principles that underlie the policy of “Treat without Blood,” that the policy should encompass mature minors as well as adults. More specifically, the Task Force agreed that the policy should provide that if patients have not yet reached the age of 18 but meet criteria developed by the Hospital for “mature minors” (such as cognitive ability, emotional maturity, well-formed moral values, personal autonomy and responsibility), then their wishes in regard to medical treatment should be considered seriously, and in certain (albeit limited) circumstances, such patients should be allowed to refuse blood products. Incorporating this provision makes the policy consistent with the recognition, in ethics and the law, that certain minors possess decision-making capacity and, in certain circumstances, have a moral claim to autonomy in medical decision-making. It also provides Children’s Hospital with the opportunity to develop a more detailed, comprehensive approach to mature minors that might be useful in other areas of the Hospital as well.

#### 5. Emancipated Minors

The Task Force used the term “emancipated minor” to refer to those minors identified in certain Massachusetts statutes as able, in certain circumstances, to consent to their own medical treatment. In general, the statutes address two different categories: (1) minors who have a condition or a disease for which treatment is deemed to be in the public interest, and (2) minors who are living “separate and apart” from their parents (such as those who are married). Minors in the first category are generally considered “emancipated” for purposes of obtaining treatment for the particular condition/disease. Depending on the facts, minors in the second category have some claim to be recognized as autonomous decision-makers in regard to other types of medical treatment as well. Because a determination of “emancipation” (and its consequences) is highly fact specific, we recommend that these determinations be made on a case by case basis, consistent with existing Hospital practice. To the extent that an “emancipated” minor is also a “mature minor,” we recommend, as noted above, that serious consideration be given to respecting his/her autonomy.

#### 6. Respect for the Moral Values of Individual Staff Members

Early in its deliberations, the Task Force also agreed that the approach it would recommend would not require staff members to provide care to patients refusing blood if to do so would violate staff members’ own religious beliefs or moral values (provided that patients would not be abandoned). This approach is consistent with certain existing policies and practices at Children’s Hospital (see, for example, Children’s Hospital Personnel Policies Manual, Section 3.05, “Requests to be Excused from Patient Care

Responsibilities, attached as Appendix J), as well as with most of the other hospital policies reviewed by the Task Force. It places a high value on respecting staff as independent moral agents. However, the Task Force did not reach consensus as to whether or how to distinguish cases involving refusal of blood from other cases in which staff are generally expected to continue to provide care even though they may disagree with the treatment choice (for example, refusal of a DNR order or consent to withdrawal of treatment). The Task Force also recognized that its recommendation to accommodate the moral values of staff members would lead to a limited exception to the policy of “Treat without Blood” for those circumstances in which insufficient staff are available who are willing to provide treatment without blood.

While the Task Force agreed that the recommended approach should generally accommodate the values of individual staff members who believe that providing care to patients refusing blood violates their own moral values, we also believe that it may be possible to address and alleviate some of staff’s concerns. For example, some objections may stem from lack of exposure to ethical reasoning applicable to such cases; lack of familiarity with Jehovah’s Witnesses and their beliefs; or lack of knowledge about the law and fear of legal consequences. These concerns could be addressed through staff education. In some cases, reluctance to provide care to such patients may stem from a desire to avoid the emotional pain resulting from the death of (or serious harm to) a patient that might have been avoided by the use of blood. While such pain cannot be eliminated, it may be made more tolerable if staff members have the support of their colleagues and of the broader Hospital community.

## **7. Conclusion**

The Task Force believes that the policy of “Treat without Blood” (with its limited exceptions) moves the Hospital in the right direction, and is the result towards which the Hospital should strive. However, we recognize that this approach requires a significant investment of resources – primarily the time and effort of Hospital staff –and that if such resources are not available, this approach may not be feasible at this time. Therefore, we are recommending laying the foundation for the policy of “Treat without Blood” over a period of time deemed reasonable by Hospital management. We are further recommending that the policy not be implemented until certain conditions can be met.

## **F. Recommendations**

1. Children’s Hospital should begin laying the foundation for an approach that allows the Hospital to accommodate the informed, voluntary refusal of blood by adults with decision-making capacity and mature minors, provided that: (1) in each case, after accepting the refusal of blood products as consistent with the patient’s deeply held values, the benefit-risk ratio of providing the treatment without blood is more favorable than the benefit-risk ratios of available alternatives; (2) it is clinically appropriate to provide the treatment at Children’s Hospital rather than at another facility; and (3) in the case of a mature minor, the patient has been determined (using

a process, and criteria, developed by the Hospital) to have the capacity, and the right, to refuse potentially life-saving treatment under the circumstances.

2. While the Hospital should undertake efforts to educate and support staff in providing care for patients refusing blood, the Hospital should allow individual clinicians to decline to participate in such care if such participation would violate the clinicians' own moral values (provided that patients would not be abandoned).
3. Children's Hospital should adopt this approach only if the following conditions can reasonably be met, given other demands on Hospital resources:
  - a. Appropriate clinical protocols can be developed so that Children's can adhere to quality standards with respect to the provision of bloodless surgical and medical care;
  - b. The Medical Staff is able to develop a mechanism for providing whatever clinical oversight and on-going quality assessment are necessary if medical and surgical treatment without blood is provided to adults and mature minors at Children's Hospital;
  - c. The Hospital is able to make resources available to develop the necessary education, development and support programs for staff consistent with quality standards for providing bloodless surgical and medical care;
  - d. The Hospital designates a staff member, and provides resources, for coordinating the development of necessary administrative policies and procedures;
  - e. The Hospital undertakes to develop a detailed, comprehensive approach to evaluating whether a minor has the maturity, and the decision-making capacity, to consent to or refuse potentially life-saving treatment with blood in certain circumstances.

## **G. Next Steps**

The Task Force recommends the following next steps for consideration by management:

1. Establish a working group, under the auspices of the Medical Staff, for clinical program development, including, as necessary, techniques for clinical management of patients treated without blood, and a process for on-going quality assessment of medical and surgical treatment provided without blood;
2. Form a working group (including, for example, representatives from the clinical staff, administration, chaplaincy, ethics and the legal office) to develop programs for staff, including an educational program regarding the religious beliefs and moral values of patients who refuse blood; the ethical and legal issues presented by such refusal; the Hospital's policy in regard to cases involving refusal of blood; and the rationale for adoption of the Hospital's policy;
3. Designate an individual to serve as coordinator of care provided to patients refusing blood, and to develop, with appropriate support, the necessary administrative policies and procedures (including procedures for identifying patients refusing blood, informing staff, reviewing the decision as appropriate, interfacing with parents of

- infants and young children who would prefer that blood not be used in the treatment of their children, and coordinating the care of patients refusing blood throughout the institution; (*Note: the Hospital's approach to infants and young children whose parents wish to refuse blood is governed by an existing policy at Children's that conforms to well-established ethical and legal standards. This approach is not under review.*)
4. Appoint a working group (including, for example, representatives from the medical staff, nursing, psychiatry, psychology, ethics and the legal office) to develop a policy for evaluating mature minors, including criteria for evaluating whether a minor has the capacity to make certain medical decisions, and a process for applying such criteria in specific cases;
  5. Determine whether there are any clinical services or areas that currently do not have sufficient staff willing to provide care to patients refusing blood and, if so, what the Hospital's approach should be (for example, exclude the services from the policy, or recruit staff willing to participate, and/or provide education and support to staff);
  6. Develop a new consent process for blood products (including a new form for consent to, and refusal, of blood).

## **II. SPECIFIC ISSUES REVIEWED; BRIEF FINDINGS AND CONCLUSIONS**

### **A. Cases at Children's Hospital; Blood Use**

#### **1. Introduction**

The Task Force reviewed specific cases that had occurred at Children's Hospital; information about the incidence and distribution of cases involving transfusion of Jehovah's Witnesses; and data about the use of blood at Children's.

#### **2. Cases**

Three cases were presented to illustrate the issues that arise in caring for patients refusing blood at Children's Hospital.

##### ***CASE #1: AB***

AB was a 15 year old Jehovah's Witness who presented with peritesticular rhabdomyosarcoma – alveolar subtype, a rare disease with a survival rate thought to be around 10-15%. AB wished to have chemotherapy treatment modified to reduce the likelihood of decreasing blood counts. He also wished to forgo transfusion therapy regardless of the situation. The oncology attending suggested that modifying chemotherapy was unlikely to adversely affect the outcome.

AB chose to be baptized as a Jehovah's Witness at age 13 and had been an active member of the church. He articulated a coherent perspective grounded in religious and spiritual concerns. He made clear that he did not want to die, but that he believed the Bible forbade taking blood. His parents supported his decision.

The ethical issues encountered were: (1) how to view adolescent decision-making and how to weigh AB's maturity, (2) how to define and protect the oncologist's integrity, and (3) how to create a system that allowed the oncologist to make an offer of modified therapy and no transfusion that would be respected by all staff throughout the treatment process ("fidelity"). With help from an ethics consultation, the oncologist agreed to provide modified therapy, and arrangements were made to help ensure fidelity.

Nine months later, AB, now 16 years old, presented for surgical resection of a periaortic retroperitoneal mass. The operation had a low likelihood of significant blood loss. AB wished to have surgery but not to accept transfusion therapy. His parents supported his decision. This case presented the same difficulties as AB's earlier request: namely, how to view adolescent and, in particular, AB's decision-making; how to accommodate the integrity of caregivers; and how to make a reliable offer to forgo transfusion therapy. Caregivers were also concerned about legal ramifications.

With help from an ethics consultation, a plan was devised to address these issues. The surgeon requested a court order authorizing AB to make decisions about potentially life-sustaining transfusion therapy. The judge found AB to be of sufficient maturity to make these decisions. Willing anesthesiologists and operating room personnel were located. Clinicians and AB agreed on acceptable interventions, and arrangements were made for follow-up intensive care consistent with the patient's wishes. AB did not receive a transfusion during the perioperative period.

#### ***CASE # 2: CD***

CD was a 17-year-old Jehovah's Witness scheduled for scoliosis surgery with a 5-10% incidence of transfusion. A long-time patient of the surgeon and Children's Hospital, CD presented the week before surgery mentally and physically prepared for surgery. She scheduled surgery for the summer to minimize disruption of school.

CD had been baptized in the faith and she wished to forgo transfusion. Her parents supported her decision. Although the surgeon was aware that CD was a Jehovah's Witness, the surgeon was unaware of the implications, and of CD's strongly held wishes. The surgeon was unwilling to proceed without permission to give transfusion therapy, based on his own moral values. This conflict between the surgeon's sense of integrity and the patient's deeply held convictions led to an abrupt severing of their relationship. CD rescheduled her procedure with an accommodating surgeon/institution. She was frustrated that her surgeon did not anticipate these problems and that she had to reschedule surgery for the winter, disrupting her schooling. CD also expressed sadness at the loss of her longstanding relationships with the physician and the Hospital.

### **CASE #3: EF**

EF was a 20-year old adult, presumed to be legally competent, with sickle cell anemia. EF was scheduled for elective hip surgery. Surgery had a low but present risk of clinically relevant blood loss.

EF's surgeon agreed to operate without transfusion therapy. EF presented to the anesthesia preoperative evaluation clinic in the normal fashion. Even though the patient was of majority age, there was still some discomfort about honoring the decision-making maturity of such a relatively young patient. The preoperative anesthesiologist agreed that the department of anesthesia would seek an anesthesiologist willing to honor the patient's wishes and a willing anesthesiologist was found. An email was sent to both the surgeon and the identified anesthesiologist suggesting methods for managing this situation (such as ensuring respect for other operating room personnel and ensuring post-operative care respectful of EF's wishes). However, there was no process for addressing these issues prior to surgery, and they remained unresolved, risking the fidelity of the agreement not to provide transfusion therapy. Further, lack of communication between surgeon and anesthesiologist as to the date of the operation strained the execution of the plan. EF did not receive transfusion therapy.

### **3. Distribution of Transfusion Therapy**

#### **Jehovah's Witness Patients, 1992-2002**

##### **All Patients (n = 54)**

Cardiac surgery / cardiology	25 (45%)
Medicine	9 (17%)
Orthopedic Surgery	9 (17%)
General Surgery	5 (9%)
Urology	3 (6%)
Other	3 (6)

##### **Patients Aged 14-17 (n = 8)**

Orthopedic Surgery	4 (50%)
General Surgery	2 (25%)
Cardiac surgery / cardiology	1 (12.5%)
Urology	1 (12.5%)

Figures: These data were determined by crossing the Chaplaincy records for Jehovah's Witnesses with blood bank records. This method identified 54 patients who had received transfusions on 66 separate admissions. While this method of analysis likely misses data, it does provide a general view of the demographics of this patient population.

#### 4. Blood Use at Children's

Issues pertaining to transfusion of whole blood and blood components such as red cells and platelets impact many areas of the hospital. Most of the patients who receive transfusions of red blood cells are the sickest patients in the hospital or are undergoing surgery. A review of blood usage over a typical 4-month period reveals that 22% of the patients transfused with red blood cells are in an ICU and 26% are in an operating room. The hematology and oncology patients constitute another 13% of transfused patients, and another 13% are outpatients transfused in the Center for Ambulatory Treatment and Clinical Research. The remaining 26% of patients receiving red cell transfusions are scattered throughout many hospital areas. Statistics concerning transfusions of other blood components such as plasma and platelets are similar.

All transfusions should be considered necessary to prevent serious morbidity or death. Since the realization of the transmission of infectious diseases (especially HIV) by blood transfusions, transfusions have been reserved for patients who, it is believed, require them. The Transfusion Committee at Children's regularly audits use of blood components and has found very few unnecessary transfusions. While the Committee cannot say for sure that any one transfusion has saved a life, they are all provided to increase chances of survival.

### **B. Other Hospital Policies and Programs**

#### 1. Introduction

We reviewed the policies of a number of other Massachusetts hospitals, including the Dana Farber, Salem Hospital (North Shore Medical Center), Lahey Clinic, Beth Israel Deaconess Medical Center, and the new draft policy from the Massachusetts General Hospital. We also reviewed the policy of the Rainbow Babies and Children's Hospital Center for Bloodless Medicine and Surgery. (All of these policies, with the exception of the draft policy from MGH, are attached as Appendix K.) We spoke with staff from Children's Hospital of Philadelphia, Rainbow Babies and Children's Hospital, Jackson Health System, and the New York Center for Bloodless Medicine and Surgery.

#### 2. Sample Policies

The Massachusetts policies we reviewed provide that adults with decision-making capacity may refuse blood (with the very limited exceptions contained in Massachusetts law). Each policy, with the exception of that of the Dana-Farber, also refers to the right of providers to decline to provide care if to do so would contravene their own moral values. Several policies note that this exception does not apply in an emergency, when the patient's life or health is in danger. The Dana-Farber policy simply states that the physician "should" honor the competent patient's refusal of blood if the patient is able to understand the risks and possible consequences.

The BIDMC policy notes that it is the physician's responsibility to determine if there are caregivers within the Medical Center willing to provide care without blood; if not, the patient may be transferred to another facility. Similarly, at Lahey it is the responsibility of the primary attending physician to assemble a team willing to participate. If the appropriate team cannot be assembled expeditiously, the physician is to offer to refer the patient to another facility. At Salem, it is the surgeon's obligation to assemble a team and be sure that team members are aware of the restrictions on blood prior to surgery.

In regard to emergencies, the BIDMC policy states that if a competent adult makes an informed refusal of blood, blood will not be administered. Under the Lahey policy, if the adult patient is capable of making an informed treatment decision (and there is no compelling evidence of abandonment of a minor child), the request for blood-free treatment should be honored, even in an emergency. At the Salem Hospital, the physician "may" honor an informed refusal by an adult, provided there is no compelling evidence that a minor child will be abandoned.

The MGH policy we reviewed is in the process of being revised. In draft form, its provisions are generally similar to those of the other policies reviewed. For example, the draft indicates that it is hospital policy to respect the rights of patients to refuse blood. It also acknowledges that a clinician is generally free to decline to treat any patient. Clinicians who are not willing to provide bloodless care are encouraged to transfer their patients to other providers. A physician who agrees to a request for blood-free treatment is responsible for making sure that other team members know about and agree with this commitment. Other relevant departments need to be informed as well, including Anesthesia, which is to be given sufficient time to make necessary care arrangements. All services are responsible for assigning staff who will honor the patient's request.

In regard to minors, these policies reflect Massachusetts law in providing that parents generally do not have the authority to refuse potentially life-saving treatment with blood on behalf of their minor children (and patients under 18 generally may not refuse on their own behalf). However, most of the policies note that emancipated minors, and in some cases mature minors, may be able to refuse treatment, and set forth procedures to follow if a minor seems to fit into one of these categories (for example, contacting administration or the legal office).

The policy of the Rainbow Babies and Children's Hospital Center for Bloodless Medicine and Surgery provides for coordination of care of all patients refusing blood. The Center's Policy is to recognize and uphold a patient's/family's decision to refuse blood within the framework of Ohio law. In most cases involving minors, Ohio law requires that a report be filed with the local child welfare authorities in the event that parents refuse blood deemed necessary to prevent death or serious harm to a child. In an emergency, while the Center will do its best not to use blood, it will override parental refusal of blood if necessary to prevent death or serious harm. In the case of adults or emancipated minors, a physician's written order stating "no blood transfusions" will override any other written or verbal order regarding blood.



### 3. Programs in Bloodless Medicine and Surgery

We reviewed the information provided on web sites, and in certain cases by telephone, from programs that offer bloodless medicine and surgery. The Robert Wood Johnson University Hospital states that it is one of the elite academic medical centers offering bloodless techniques in every surgical and medical specialty, including open heart surgery and emergency care in its Level I trauma center.

<http://www.rwjuh.edu/medserv/bloodless.html>. The Center for Bloodless Medicine and Surgery at the University of Miami/Jackson Memorial Medical Center, established in 1994 based on a model program at University Hospital in Denver, also indicates that its program is multidisciplinary. [http://www.um\\_jmh.org/JHS/Noblood/Bloodless.html](http://www.um_jmh.org/JHS/Noblood/Bloodless.html). Bridgeport Hospital (Yale New Haven Health) offers bloodless medicine and surgery services, including services in cardiology (including open-heart surgery), neonatology, and pediatrics. <http://www.bridgeporthospital.org/services/blood.html>. The University of Southern California notes that it offers transfusion-free medicine and surgery, including liver transplants. <http://www.livertransplant.org/bloodlessurgery.html>. The New York Center for Bloodless Medicine and Surgery, which includes Beth Israel, Roosevelt Hospital, St. Luke's Hospital, Long Island College Hospital, and NY Eye & Ear Infirmary, states that it treats almost any condition without the use of blood. Other institutions that indicate that they offer bloodless programs include: Riverview Hospital in Indiana (<http://www.bloodless-surgery.org/content.php3?s=2>), University Hospital in Newark, New Jersey (<http://www.theuniversityhospital.com/bloodless/>), Hartford Hospital (<http://www.harthosp.org/cbms/>) and the Eugene and Mary B. Meyer Center at Johns Hopkins (<http://www.hopkinsmedicine.org/hmn/fo1/cnews.htm/#quest>).

A number of programs indicate that they provide treatment for pediatric patients, including major scoliosis surgery, treatment for sickle cell anemia, and in some instances organ transplants. Several have neonatal programs. However, while it appears that these programs make every effort to avoid using blood, including utilizing special procedures and protocols, it also appears that these programs are likely to provide blood to young children when it is considered necessary to save their lives. In determining whether to respect refusal of blood by minors who are considered "emancipated," the programs appear to rely on the law in their states. The programs do not appear to have comprehensive, well-developed policies regarding "mature minors."

Most of the programs have one person who is responsible for coordination of care. One program indicated that it has established a multidisciplinary committee to provide oversight of the program. In general, spokespersons for the programs indicate that the programs are "successful:" patients are pleased; there is sufficient staff willing to participate; and treatment without blood has a positive outcome in most cases. However, several programs indicated that they had experienced at least one death resulting from lack of blood, and that this experience had been very distressing for everyone involved.

Several of the programs offer consulting services to institutions that wish to begin their own bloodless programs. These services include the provision of sample policies and forms.

#### 4. Accreditation

There is an agency that describes itself as an “accrediting agency” for “blood conservation programs.” The Association for Blood Conservation (previously known as the National Association of Bloodless Medicine and Surgery) states that it is a non profit resource for the development and implementation of blood conservation programs. (<http://www.associationforbloodconservation.org/>).

#### 5. NACRI Inquiry

We submitted a question through a National Association of Children’s Hospitals and Related Institutions (NACRI) listserv about whether other pediatric institutions had developed approaches to mature minors, particularly those who refuse blood. We received limited responses. In general, the institutions that responded appear to rely on state law to resolve this issue. One detailed policy on DNRs specifically recognizes the importance of the religious and moral beliefs of older minors. It indicates that physicians, together with parents/guardians, make the determination as to whether the minor patient has the capacity to make a decision about DNR (and perhaps other life-sustaining treatment) on his/her own behalf. The policy does not explain what criteria or processes are used to make this determination. Furthermore, it appears that the minor’s parents have to agree with the minor as to entry of a DNR order.

### **C. Ethical Issues**

#### 1. Introduction

A major focus of the Task Force’s deliberations was an examination of the ethical issues raised by the care of adults and mature minors who refuse blood. A number of key ethical questions had been framed by the Subcommittee of the EAC in its Summary and Recommendations, Revised December 2001. (See Appendix A.) In addressing these, and other ethical questions, we were guided by four key principles of Western biomedical ethics: autonomy, beneficence, non-maleficence and justice.<sup>i</sup> We also considered the moral values and moral agency of staff; the virtues traditionally associated with caregiving; and the value of respect for cultural and religious diversity. We reviewed concrete cases and narratives of patients and staff, both at Children’s and at other institutions. A brief summary of our ethical deliberations follows.

#### 2. Autonomy; Beneficence; Non-maleficence

Discussions of the ethical issues that arise in cases involving refusal of blood often focus on the potential conflict between the principles of respect for autonomy and beneficence. For example, in an article presenting a “new” case and commentary on refusal of blood, the authors refer to the “familiar dilemma for health care providers: the obligation to respond to this patient’s medical needs and to do what one can to promote life and, on the other hand, the duty to respect” the patient’s wishes.<sup>ii</sup>

This “duty to respect the patient’s wishes” is based on the principle of respect for autonomy. While “autonomy” has many interpretations, it generally reflects a belief that each person is of unconditional worth; that all persons are worthy of respect; and that they should be treated as “ends” in themselves, not as means to some other end. It mandates that absent compelling countervailing interests, the patient’s choice about medical treatment, based on his/her own personal values, be respected.

Beneficence is frequently described as the obligation to provide medical care that promotes the patient’s physical health and well-being – that is, treatment that is in the patient’s medical “best interests.” The idea that caregivers have an obligation of beneficence has been present in medicine throughout its history. (In the absence of the ability to benefit the patient, the caregiver should, at least, do no harm -- “nonmaleficence.”)<sup>iii</sup>

On one level, cases involving refusal of blood can be seen as creating a conflict between these two principles. Respect for the patient appears to require honoring his choice, based on his personal values. On the other hand, the obligation of beneficence seems to require administering blood when it involves low clinical risk and clear clinical benefit. If the treatment itself results in the blood loss, failing to provide blood may also seem to violate the rule of “do no harm.” However, this formulation oversimplifies the discussion.

In its broadest sense, autonomy involves not simply a right to refuse treatment but an interest in personal liberty: in the right to choose a religion (or other personal value system); to make choices based on these fundamental values; to exercise personal responsibility (moral agency). These attributes of autonomy are highly valued in Western society, and may themselves be seen as evidence of health and well-being.

Similarly, beneficence can be conceived not simply as the duty to preserve physical health, but as the obligation to advance “health” in its broadest sense, including psychological, spiritual, and moral well-being.<sup>iv</sup> Fulfilling the duty of beneficence may require more than an “attitude” of respect for patient’s autonomy, and a willingness not to “interfere” with the patient’s free choice. Instead, it may require actively strengthening the ability of patients to make autonomous choices.<sup>v</sup> Further, if the treatment provided (without blood) is more likely to benefit the patient than other bloodless options (including non-treatment), then the potential “harm” of treatment appears to be outweighed by the potential benefit.

As noted in Part I, members of the Task Force concluded early in the deliberations that, based on the value of respect for patient autonomy (and for some, the value of beneficence, as broadly interpreted), the Hospital should not require a patient with decision-making capacity to receive blood against his wishes. It was more difficult to decide between the two remaining alternatives: allowing patients to refuse blood at Children’s, or transferring them to other hospitals that would treat them without blood. (The various arguments for and against each approach are set forth in Appendix I.) However, the Task Force concluded that the option of allowing patient to receive

treatment at Children's, while refusing blood, demonstrated greater respect for patient autonomy and was consistent with an expansive interpretation of beneficence.

### 3. Moral Values and Agency of Staff

If patients are to be allowed to refuse blood at Children's, the question arises as to whether individual staff members may choose to decline to provide care to such patients, based on the staff member's own religious or moral views. Our deliberations revealed that Task Force members had different views on the issue of how to balance a caregiver's moral claim to practice in accord with his/her conscience against the caregiver's obligation to treat patients in accordance with their autonomous informed consent (or refusal).

Some Task Force members pointed out that clinicians are expected to provide care in certain other circumstances in which they may disagree with a patient's/parent's choice of treatment – provided that that choice does not violate the law or commonly accepted ethical norms. For example, staff sometimes disagree with a decision about DNR, or a decision to withdraw (or to continue) certain treatments for seriously ill children. Yet, in most cases, they continue to provide treatment. It is not always clear how the obligations of clinicians in these cases differ from their obligations in cases involving refusal of blood. However, it was also noted that caregivers are generally not required to provide care in these other circumstances either --if to do so would contravene their own moral values. (See Appendix J.)

Some Task Force members suggested that staff be encouraged not simply to do what it "required" of a caregiver, but to do what is "virtuous." To them, it is a virtue of caregiving to subordinate one's own views to those of the patient (provided the patient's views are not morally repugnant or unlawful). Although a Jehovah's Witness' choice of resurrection and eternal life—over a temporary extension of physical life through use of a blood product-- may not seem "rational" or "necessary" to some caregivers, it is not the type of choice that many would consider morally repugnant. In fact, there is a tradition (religious and secular) of valuing a person's willingness to sacrifice his/her life for religious beliefs or principles.

On the other hand, it was observed that many clinicians feel quite strongly that providing medical care under the constraints of "no blood" makes them complicit in an act that contravenes their professional and moral values, including their obligation to save life. Requiring them to participate in such care would cause them moral distress and undermine their sense of moral responsibility. Furthermore, there are strong arguments that it is important not only for individual clinicians to maintain fidelity to their values, but also for Children's Hospital to support clinicians in their exercise of moral agency. Creating an environment where clinicians practice with moral integrity ultimately is to the advantage of all patients. (This viewpoint was shared by the Jehovah's Witnesses who met with us.)

In the end, the Task Force was able to reach consensus that it would not recommend a policy that required staff to provide care in a manner that violated their own religious or

moral values, provided that patients would not be abandoned. Members reached this conclusion for different reasons, including the importance of respecting an individual staff member's moral values, the importance of encouraging moral agency among staff, consistency with existing Hospital policy and the policies of other hospitals in similar cases, and practicality.

#### 4. Religious and Cultural Diversity

Children's Hospital serves patients from a wide and diverse community – local, national, and international. It values sensitivity to different religious beliefs. Through its chaplaincy service, the Hospital demonstrates that it values not just the physical health of patients and families, but also their spiritual and moral well-being. The Task Force believes that the approach it is recommending most closely reflects these values.

#### 5. Justice (Resource Allocation)

The Task Force did not interpret its mission as including a financial analysis of alternative approaches to patients refusing blood. However, it recognized that resource allocation is important ethically – as well as practically – and that the issue should be addressed at least on a general level.

In recommending Policy #1 (Treat without Blood), the Task Force gave serious consideration to whether it is just, and consistent with Children's mission, for the Hospital to devote resources to developing a program for the relatively small number of patients refusing blood. Although implementing the Policy should not require substantial expenditures for plant or equipment, or for the hiring of new staff, it would require the investment of time and energy by existing staff, particularly during the initial stages of implementation. There would also be on-going costs of administration and quality oversight. Some of these costs could be attributed to adults receiving care at Children's.

At this stage in the analysis, these costs seem to the Task Force to be justifiable, based on the strong ethical reasons for adopting Policy #1. Further, although the actual number of patients receiving treatment without blood may be small, some of the benefits of the policy (such as increased attention to the autonomy of young adults and mature minors) would redound to the benefit of the whole Hospital. Finally, although Children's primary focus is pediatrics, it does serve adults. Nonetheless, the Task Force recognizes that resources are scarce, and makes its recommendation contingent on a determination by the Hospital, after a more detailed consideration of the costs, that it can make the appropriate resources available.

## **D. Mature Minors**

### **1. Introduction**

#### *Definitions*

In our review of the issues, we learned that there is no general consensus about the meaning of the term “mature minor.” Many people base their definitions on what they believe to be the law in their state, and the term is often used interchangeably with “emancipated minor.” Discussions with staff at Children’s indicate there may be ambiguity as to the meaning and significance of the term “mature minor” as used within the Hospital.

In its deliberations, the Task Force used the term “emancipated minor” to refer to a minor who may, under Massachusetts statutory law, be able to consent to some or all forms of medical treatment on his/her own behalf. (See Section E below.) We defined a “mature minor” as a minor who, regardless of age or status as an “emancipated minor,” actually possesses decision-making capacity.

The concept of “decision-making capacity” has been discussed extensively in the ethical, clinical, and legal literature. Nonetheless, there remains debate about the concept, and numerous variations in the way it is formulated.<sup>vi</sup> For discussion purposes, we utilized criteria that are commonly applied in evaluating the capacity of adults to make medical decisions, including: (1) the ability to understand adequately information about diagnosis and prognosis, the nature of the proposed treatment, its risks and benefits, and the risks and benefits of alternatives; (2) the possession of a coherent set of values; (3) the ability to make a decision based on an understanding of relevant information, future consequences, and personal values, free from undue influence or coercion; and (4) the ability to communicate stable choices.<sup>vii</sup>

#### *Scope of Review*

On behalf of the Task Force, Barbara Burr prepared a selected, annotated bibliography of works addressing the issue of mature minors and medical decision-making capacity, which she discussed at a meeting of the Task Force. (See Appendix L.) We reviewed some of the leading articles in this field. Our goal was to establish the groundwork for those individuals who, if our recommendations are accepted, will be charged with developing a comprehensive approach to mature minors refusing blood.

### **2. Developmental Issues**

There is much discussion in the literature as to when an individual reaches the developmental stage at which he/she has the capacity to make an informed decision about medical treatment. A number of commentators have suggested that minors over the age of 14 generally have decision-making capacities very similar to those of adults.<sup>viii</sup> However, most commentators appear to agree that the development of decision-making

capacity is a gradual process that varies from one individual to the next. Empirical research is on-going, not only in the area of medical decision-making but also in research and criminal justice.<sup>ix</sup>

### 3. Ethical Issues

Assuming that there are at least some minors who--whether or not they fall within the legal category of emancipated minors--nonetheless possess the capacity to make medical decisions, we then considered the ethical implications of a determination that a minor is mature. Mature minors would seem to have the same interest in having their values and personal integrity respected as adults. Presumably, they would suffer the same or similar harms if their values were ignored and treatment was provided against their will. For these reasons, we generally agreed with position of the Midwest Bioethics Task Force on the Rights of Minors--that all persons with decisional capacity have a strong interest in, and claim to, making their own decisions about health care <sup>x</sup> (although this claim may, in certain circumstances, not prevail). As noted by the Committee on Bioethics of the American Academy of Pediatrics: "As children develop, they should gradually become the primary guardians of personal health and the primary partners in medical decision-making, assuming responsibility from their parents."<sup>xi</sup>

Of course, caregivers also have a clear duty of beneficence toward minor patients. There is a strong tradition in pediatric medicine of active engagement in promoting the health and well-being of minor patients. The interest of parents in being allowed to raise, protect, and determine the medical care of their children is also a significant factor arguing against granting autonomy to mature minors.<sup>xii</sup> Further, society as a whole has an interest in protecting young people until they are able to protect themselves.<sup>xiii</sup>

However, the duty to protect minors, and make medical decisions for them, is closely linked to a presumption that they cannot protect themselves or make informed, autonomous decisions on their own behalf. To the extent that minors have such a capacity, the duty (and the right) to decide for them appears less justifiable. In the end, the ethical principles underlying Policy #1 (which we had accepted) led us to conclude that the Hospital's approach should include provision for mature minors to be able to refuse blood in appropriate (though perhaps limited) circumstances.

### 4. Criteria and a Process for Evaluating Maturity

Assuming that at least some minors have decision-making capacity, and that such capacity should be recognized and respected in some situations, it is still necessary to develop criteria, and a process, for evaluating the decision-making capacity of minors. In our view, the determination that a minor is mature should be a clinical one, arrived at prior to a review, with legal counsel, of the legal ramifications, and prior to a decision, made in conjunction with appropriate involved parties (such as the caregivers and the parents) whether there are any compelling reasons to attempt to override the minor's choice. We offer some guidelines for such a process in Appendix M.

## **E. Legal Issues**

### **1. Introduction**

The Task Force agreed that its recommendations would be based primarily on ethical principles. Nonetheless, it wanted to be sure that any recommendation fell within the parameters of the law. With the guidance of Richard Bourne, Hospital Counsel, the Task Force reviewed key statutes and case law applicable in Massachusetts.

The Task Force concluded that while the Hospital's current *ad hoc* approach to patients who refuse blood is not inconsistent with Massachusetts law, this approach is difficult to implement in a consistent, coordinated fashion. Therefore, it raises the potential for certain legal risks. The Task Force also concluded that either of the two alternative approaches it considered could be structured in a manner consistent with the law, although each poses slightly different challenges in implementation. More details about the legal advantages/disadvantages/risks of each of the two approaches are contained in Appendix I.

### **2. The Rights of Competent Adults to Refuse Blood**

The leading case in Massachusetts is Norwood Hospital v. Munoz.<sup>xiv</sup> In this case, the Massachusetts Supreme Judicial Court established that a competent adult may refuse blood products even if to do so might result in serious harm or death. The case involved a 38-year-old woman, who had a 5-year-old son. Mrs. Munoz had been a Jehovah's Witness for 16 years, and attended 3 religious meetings a week. Her need for blood was the result of an ulcer, and her prognosis for full recovery was excellent. The court noted that "there is no doubt" that she has the right to refuse treatment, based on the constitutional right to privacy and the common law right to bodily integrity. The court next examined whether any state interest outweighed this right. Because it was the patient herself refusing blood, the State's interest in life would not override her decision. The court acknowledged the State's interest in protecting the interests of her minor son, but concluded that he would be cared for by a loving father and other relatives, with the support of the Jehovah's Witness community. As to future cases, the court noted that in the absence of any compelling evidence that a child will be abandoned, the State's interest in protecting the well-being of children does not outweigh the competent patient's right to refuse treatment. Finally, the court reiterated that, provided that the hospital is not required to participate in the care of the patient, upholding the patient's right to refuse treatment does not violate the ethical integrity of the medical profession.

The Task Force's recommendation in regard to adult patients finds strong support in the Norwood Hospital case. Its recommendation to allow individual clinicians to decline to provide care that contravenes their own moral values is also consistent with this, and other, Massachusetts cases.



### 3. Emancipated Minors

There are several Massachusetts statutes that describe minors who are emancipated for purposes of consent to some forms of medical treatment. Of most relevance to the Hospital's policy on refusal of blood is M.G.L. ch. 112 Section 12F. While there are differing interpretations of this statute, it is generally seen as addressing two different categories of minors: (1) those who have a condition (pregnancy) or a disease (such as a disease dangerous to the public health) for which treatment is deemed to be in the public interest, and (2) those who are living "separate and apart" from their parents (such as those who are married). Minors in category one are generally seen as able to consent to treatment for the particular condition/disease. Minors in category two have some claim to be recognized as autonomous decision-makers for other forms of medical treatment as well. However, the extent to which they may consent to—or refuse—medical care in various circumstances depends on the fact and on legal interpretation. Therefore, we recommend that, consistent with existing Hospital policy, cases involving minors who may be emancipated under Massachusetts statutory law continue to be handled on a case by case basis.

### 4. Mature Minors

While the category of "mature minor" is broader than that of "emancipated minor," and is not clearly spelled out in any Massachusetts statute, the category is recognized in federal and state law. One of the early cases on abortion rights addressed the constitutionality of a Massachusetts statute limiting the rights of minors to consent to abortions. The United States Supreme Court struck down the Massachusetts statute in part because it did not allow minors who had been determined to be mature and informed to make their own decisions. The Court pointed out that while minors may not have the same Constitutional rights as adults, they surely have some. The right to personal liberty, noted the court, is not tied to age: "[N]either the Fourteenth Amendment nor the Bill of Rights is for adults alone."<sup>xv</sup>

The concept of mature minor is not limited to the area of abortion rights. Courts in other states have recognized the concept in connection with minors refusing medical treatment.<sup>xvi</sup> Further, in Massachusetts, in cases heard in probate court (but unreported), judges have determined that minors are (or are not) "mature" enough to make medical decisions, including refusal of life-sustaining treatment. Children's Hospital has had experience presenting such cases to the court for determination. In at least one case involving refusal of blood, the court ruled that the minor was, in the particular circumstances, able to refuse treatment on his own behalf.

In 1999, the Massachusetts Appeals Court issued a formal ruling, in a case involving a Jehovah's Witness, indicating that in certain circumstances minors may be able to refuse blood on their own behalf. The Court alluded to the fact that the law provides no bright line as to when a minor can make certain decisions in life. In reviewing the prior decision by the lower court in this case, the Appeals Court noted that the judge "made no

determination as to [the patient's] maturity to make an informed choice . . . we think this was error." xvii

The Task Force's recommendation that the Hospital give serious consideration to refusals of treatment by mature minors is consistent with the law in this area.

## 5. Potential Legal Risks

The Task Force heard that some staff are concerned that acceding to a patient's wish to refuse blood could result in legal liability. This concern is particularly acute if the patient is a minor. While there is always the risk of legal action, the probability that an adequately informed refusal of blood by an adult with decision-making capacity would result in legal liability is very low. The rights of mature minors fall into a gray area, and will probably require review on a case by case basis. Nonetheless, if the Hospital develops a comprehensive approach to evaluating the maturity of minors; ensuring that their refusal is informed and autonomous; and seeking judicial confirmation when appropriate, respecting their rights in appropriate circumstances should not pose significant risks. Moreover, in addition to the risks that may arise if a patient refuses blood and suffers harm, there is a risk of liability for transfusing a patient against his/her wishes, when the Massachusetts courts have established the right of adults to refuse such treatment, and suggested that in some situations minors may have this right as well.

The Task Force believes that it will be helpful to staff to include, in any educational program regarding refusal of blood, a discussion of the law and sources of potential legal liability. The Task Force contemplates that individual cases will continue to be handled by Hospital counsel.

## **F. Staff Values: Educational Material; Survey**

### 1. Introduction

The Task Force was charged with gathering information about the professional values and beliefs of staff regarding providing care to patients refusing blood, as well as establishing a process for increasing knowledge within the Hospital as to the issues raised by such refusals. The Task Force was concerned that simply asking staff questions, without background information or context, could produce potentially misleading answers. Therefore, a decision was made to combine educational material with a brief survey focusing on questions particularly relevant to the Task Force's deliberations.

A subgroup of the Task Force, consisting of Jackie Berlandi, Patricia Lincoln, Margaret McCabe, Mary Robinson and Judy Johnson, assisted by Eva Weiss, a fellow in the Division of Medical Ethics, prepared a packet of material consisting of: (1) introductory information about the Task Force and its goals, (2) background material on relevant religious, ethical, and legal issues, (3) three hypothetical cases, (4) a set of similar questions for each case, and (5) a brief set of general questions (See Appendix F.) The material was reviewed by the full Task force, and presented to two focus groups. In

response to feedback, several changes were made, primarily to the educational material. Subsequently, the educational material and survey were presented to operating room nurses, CICU staff, and members of the Anesthesia Department.

The input of Hospital staff was also solicited at a meeting of the Nursing Leadership Group, at several meetings of the Ethics Advisory Committee, and informally by individual members of the Task Force.

## 2. Focus Groups

The first focus group involved five operating room nurses (one additional nurse completed the survey after the focus group session). After completing the survey, the participants were asked for their comments. They noted that the introductory material was comprehensive but did not resolve all of their questions about the concept of “mature minor.” They also reported that they did not find the distinctions among the various “reasons” why staff might decline to participate in care (that is, based on “moral,” “religious,” or “professional” values) very meaningful. Participants asked about the Hospital’s current policy, and also questioned what the nurse’s role would be if the Hospital adopted a policy involving transfer of patients refusing blood.

Participants in the second focus group (cardiac nurses) also had questions about mature minors, including who qualifies for this designation, and what role the parents of a mature minor play in the decision-making process. They also questioned whether (and how) the issue of staff’s right not to provide care that violates their own values differs in these cases from cases involving other treatment decisions, such as DNR.

A summary of the responses of the members of the two focus groups is attached as Appendix N.

## 3. Survey Results

We believe that the responses to the Questions for Staff on Patient Care Involving Refusal of Blood are useful in enhancing thought and discussion about staff values. However, because the survey was designed and conducted in an informal manner, in only a few areas of the Hospital, the results should not be seen as a precise representation of staff values. (Summaries of the responses for each group are attached as Appendices O-Q.)

Very generally, a high percentage of respondents agreed that patients have the moral right to refuse blood. While still fairly high, the numbers declined somewhat when respondents were asked whether the patients should be allowed to refuse treatment at Children’s. The numbers declined further, and varied more, when respondents were asked if they would be willing to provide care. Respondents did not show strong support for transfusing patients against their wishes. Depending on the situation (for example, whether quality care was available elsewhere), more respondents agreed that they would support transferring the patient. Most respondents agreed that they would be more

amenable to caring for a patient who refused blood in the following three circumstances: they were informed in advance; they knew there was a coordinated plan of care; they knew there was a process for evaluating the patient's capacity to make the decision. A large number of the respondents agreed to supporting development of a coordinated program for patients refusing blood, and many of these respondents also agreed that they would be willing to participate in such a program.

## **G. Religious Issues**

### **1. Introduction**

The Task Force's Report is not limited to refusal of blood by one particular religious group. The principles underlying our recommendation are applicable to any patient making an informed, autonomous decision based on a religious faith or moral values. Nonetheless, most of the patients who refuse blood do so because they are Jehovah's Witnesses. Therefore, we engaged in a dialogue with members of the local Jehovah's Witness community. Two members of the local Hospital Liaison Committee attended a meeting of the Task force and provided us with written material. (See Appendix R.)

### **2. Jehovah's Witnesses**

At a meeting of the Task Force, Anthony Gilmer and James Lang presented a brief overview of the Jehovah's Witness faith, and the reasons why Jehovah's Witnesses refuse blood products. In general, Jehovah's Witnesses seek to preserve their health, and willingly accept medical and surgical treatment. While there are variations among individuals, most Witnesses believe that accepting blood violates God's commands as set forth in the Bible. Accepting blood voluntarily, and without remorse, results in estrangement from God, and loss of the possibility of resurrection and eternal life. While practices vary, when a Jehovah's Witness accepts blood, it raises questions about whether he/she is committed to the faith, and should be allowed to remain a part of the community. Witnesses who receive blood against their wishes do not necessary lose the opportunity for eternal life, but report feelings of physical and spiritual violation. According to Mr. Gilmer and Mr. Lang, such individuals are not ostracized from their community.

Mr. Gilmer and Mr. Lang noted that baptism into the faith takes place only when a person is considered capable of making an independent, informed decision to be a Jehovah's Witness. If a minor wishes to be baptized, elders in the faith will generally meet with him/her to try to determine whether the minor is making an informed and voluntary choice. These meetings are usually held without parents in attendance, to reduce the chance that parents are exercising undue influence over their children's religious choice. During this discussion, the prospective Jehovah's Witness is asked to consider seriously whether he/she is ready to commit to the requirement that Jehovah's Witnesses refuse blood. A minor will be baptized only if the community believes that he/she is mature enough to understand and make this commitment.

Mr. Gilmer and Mr. Lang also spoke of the sadness felt by members of the community of Jehovah's Witnesses when refusal of blood contributes to the death of one of the members. Witnesses recognize that the choice to refuse blood is not an easy one, and make that choice only because the breach of their relationship with God and the forfeiture of the possibility of resurrection are greater losses than death.

Mr. Gilmer and Mr. Lang noted that Jehovah Witness Hospital Liaison Committees are available to work with Hospital staff to maximize the possibility that blood will not be needed, and to offer support to patients refusing blood. They also noted that they had been received courteously at Children's, and expressed appreciation for physicians and other staff members who had worked cooperatively with them.

In addition to the views of Mr. Gilmer and Mr. Lang, the Task Force noted the views of some critics who argue that members of the Jehovah's Witness community attempt to exercise undue influence over individual patient choice. There have also been criticisms leveled against some members of the faith who have communicated confidential medical information about a patient to other members of the faith.<sup>xviii</sup>

## **H. Miscellaneous**

### **1. The Policy Statements**

Policy Statements #1 and #2 are designed to suggest the framework for the development of policies or approaches. They are not intended to be complete. For example, in connection with Policy Statement #1, we recognize the need to develop guidelines for obtaining the informed refusal of a patient to the use of blood. This process would generally include meeting with the patient alone, as well as with family and/or advocates. It might include a psychosocial evaluation, a determination of capacity, and in some cases an ethics consult and/or legal advice. Similarly, we recognize the need for a process for involving the appropriate members of the clinical team in the decision; providing information to staff who may be caring for the patient; and coordinating care among various services. (Policy Statement #2 would require the development of other guidelines as well, including guidelines for transfers.) These and other details remain to be developed during implementation of the approach adopted by the Hospital.

### **2. Condition for Refusal of Blood**

We recommend that patients with decision-making capacity be allowed to refuse blood at Children's Hospital if several conditions are met. One of these conditions is that, despite the refusal of blood products, the benefits of treatment outweigh the risks. While the process of evaluating the risks and benefits of treatment for a patient refusing blood is similar to that of evaluating treatment options for other patients, there is a key difference: it is not appropriate to consider treatment options involving the use of blood products – as they are not viable options. Instead, the clinicians and the patient will be comparing the risks and benefits of various treatments without blood products – these alternatives may include surgery without blood, medical treatment without blood, or no treatment.

One analogy that might be helpful in working with patients who refuse blood is that of treating a patient who is allergic to a particular drug. In such cases, the clinicians and the patient will be evaluating the risks and benefits of other available drug therapies.

### 3. Emergency Blood Transfusions

The Task Force recognizes that, in certain circumstances, blood is required immediately to prevent death or serious harm and there is no time to determine whether the patient has decision-making capacity and is making an informed, voluntary choice to refuse blood (or whether it is appropriate to accept a refusal by a health care agent and/or through another form of advance directive). In such circumstances, it would be justifiable to use blood. However, if there is time to make an evaluation of capacity and obtain the patient's consent or refusal (or time to evaluate a surrogate refusal on behalf of a patient currently lacking capacity), the policy of respecting a patient's refusal of blood would apply regardless of where care is being rendered (including the emergency department) and regardless of whether the use of blood is considered life-saving.

Completed December, 2003

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<sup>i</sup> Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*, Fourth Edition. New York: Oxford University Press, 1994.

<sup>ii</sup> Vinicky JK, Smith ML, Connors, Jr. RB Jr, Kozachuk WE. The Jehovah's Witness and Blood: New Perspectives on an Old Dilemma. *J Clin Ethics* 1990; 1(1) :65-74.

<sup>iii</sup> Beauchamp and Childress, 271-2.

<sup>iv</sup> Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

<sup>v</sup> Beauchamp and Childress, 272-3.

<sup>vi</sup> Boyle RJ. Determining Patients' Capacity to Share in Decision-Making, in Fletcher JC, Lombardo PA, Marshall MF, Miller FG, eds. *Introduction to Clinical Ethics*, Second Edition. University Publishing Group, 1997.

<sup>vii</sup> See, for example, President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions*, vol. 1. Washington D.C.: U.S. Government Printing Office, 1982; Applebaum PS and Grisso T. Assessing Patients' Capacities to Consent to Treatment. *N Eng J Med* 319:1635-38; Lantos JD. Autonomy in Adolescent Medicine. *Society for Adolescent Medicine* 1989; 10:460-66.

<sup>viii</sup> See, for example, Weir RF, Peters C. Affirming the Decisions Adolescents Make about Life and Death. *Hastings Center Report*, November-December 1997, citing the works of Grisso and Vierling, Weithorn and Campbell, and Sanford Leikin.

<sup>ix</sup> See, for example Tait AR, Voepel-Lewis T, Malviya S. Do They Understand? (Part II): Assent of Children Participating in Clinical Anesthesia and Surgery Research. *Anesthesiology* 98(3): 609-613.; The MacArthur Juvenile Adjudication Competence Study, MacArthur Network.

<sup>x</sup> See "guidelines" and supporting commentary in *Bioethics Forum*, Winter 1995. See also Weir RF, Peters C. Affirming the Decisions Adolescents Make about Life and Death. 1997 *Hastings Center Report* 27(6):29-40.

<sup>xi</sup> American Academy of Pediatrics Committee on Bioethics. Informed Consent, Parental Permission, and Assent in Pediatric Practice. *Pediatrics* February 1995; 95(2): 314-317.

<sup>xii</sup> Ross LF. Arguments Against Health Care Autonomy for Minors. *Bioethics Forum*, Winter 1995.

<sup>xiii</sup> See Scott ES, Reppucci ND, Woolard JL. Evaluating Adolescent Decision Making in Legal Contexts. *Law and Human Behavior* 1995; 19(3): 221-44; See also *In re Elisha McCauley*, 565 N.E. 2d 411 (1991).

<sup>xiv</sup> 564 N.E. 2d 1017 (Mass. 1991).

<sup>xv</sup> *Bellotti v. Baird*, 443 U.S. 622, 651 (1979), citing *In re Gault*, 387 U.S. 1, 13 (1967).

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<sup>xvi</sup> See, for example, In re E.G., 549 N.E. 2d 322 (1989); In re Swan, 569 A. 2d 1202 (Me 1990).

<sup>xvii</sup> In re Rena, 705 N.E. 2d 1115 (Mass. Ct. App. 1999).

<sup>xviii</sup> Muramoto O. Medical confidentiality and the Protection of Jehovah's Witnesses' Autonomous Refusal of Blood. *J Med Ethics* 2000; 26(5): 381-6; Muramoto O. Bioethics of the Refusal of Blood by Jehovah's Witnesses: Part 3: A Proposal for a don't-ask-don't-tell policy. *J Med Ethics* 1999; 2(6): 463-8.









**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

**FINAL REPORT**

**APPENDIX A**



## SUBCOMMITTEE ON REFUSAL OF BLOOD TRANSFUSIONS FINAL REPORT TO THE ETHICS ADVISORY COMMITTEE

The Children's Hospital, Boston  
September 28, 2001

### The Issue

Recently, two patients of Children's Hospital, who were under the age of 18 but arguably able to make informed choices about their own medical care, refused blood transfusions. These cases have brought to the fore a source of tension for Hospital staff, and distress among some patients, regarding whether Children's can or should honor patient requests for care without blood or blood products.

One case was the subject of an ethics consult. In that case, the prognosis was poor, and the minor's choice of a treatment regime that excluded blood products was considered ethically acceptable. However, there was continuing concern and discussion among the staff about the anticipated and actual course of treatment for this patient over time, which included procedures that were relatively invasive as well as less invasive. For one procedure, a court order was obtained which permitted the staff to proceed without the use of blood. This consult gave rise to a number of questions, including:

- (1) If a patient wishes treatment at Children's, without blood products, are there sufficient clinicians available who would consider it ethical to treat such a patient; and
- (2) Would it be consistent with the culture at Children's Hospital to allow such patients to refuse blood transfusions in life-threatening situations?

Although the second case apparently did not give rise to a formal ethics consult, it resulted in several clinical team meetings and a consultation with the legal office. In this case, the surgeon apparently decided he could not agree to operate in the face of limitations on the use of blood products, and the patient's care was transferred to another hospital. The decision to transfer was made relatively late in the process, after the patient had scheduled the surgery at Children's and prepared for it emotionally and physically, including self-injection with EPO. The patient, who had been treated at Children's for some years, felt the loss of her relationship with her physician here. In addition, as a result of the lateness of the referral, the procedure—which had originally been scheduled at Children's during the summer—had to be rescheduled elsewhere at a time that required the patient to miss a significant amount of time at school.

These cases have generated concern as to whether Children's Hospital should develop a policy or other institutional approach in regard to refusal of blood transfusions by "mature minors" and adults. (Children's Hospital already has a policy covering children without decision-making capacity: if necessary, the Hospital will seek judicial authority to transfuse children whose parents refuse blood transfusions on their behalf.) A subcommittee was formed to

gather information that would be helpful in determining how best to proceed, including information about how these issues might be affected by the culture of Children's Hospital. The subcommittee has begun to gather such information and has prepared this report.

## **Background**

The subcommittee initially identified a number of areas that required further exploration:

- (1) the religious foundation for refusal of transfusions by Jehovah's Witnesses, who constitute the largest group of patients who refuse blood products,
- (2) the view of Children's Hospital Office of General Counsel,
- (3) the views of clinicians at Children's Hospital who have had experience with these issues or are likely to be involved in the future if patients refuse blood transfusions,
- (4) current practices and protocols at Children's in regard to transfusions and alternatives, and
- (5) practices and protocols of other institutions that have policies on refusals of blood transfusions.
- (6) We also agreed that if a decision were made to develop a policy that allowed refusal of blood transfusions in certain circumstances, we would need to gain a greater understanding of the concept of mature minor, including a better understanding of the spiritual and moral development of minors.

## **Religious Foundation**

Members of the subcommittee met with the following representatives of the Jehovah's Witness community: James B. Lang, Hospital Liaison Committee; Anthony D. Gilmer, Hospital Liaison Committee; D.V., a minor whose care was transferred from Children's Hospital to another institution; and J.V., her father. They provided written materials (included in "Bibliography" below); discussed their religious beliefs regarding health generally and blood products specifically; and recounted the story of D.V.'s experience at Children's Hospital.

After providing a very general overview of their religious beliefs, they explained that Jehovah's Witnesses refuse blood products based on religious and health-related grounds. They believe that the Scriptures prohibit acceptance of blood products. They also believe that acceptance of blood products carries significant medical risks and that the benefits have not been scientifically substantiated.

They explained that Jehovah's Witnesses are committed to maintaining their health. They do not smoke, use illegal drugs, or drink immoderately. They seek the best possible health care for themselves and their children, excluding blood products, and generally are cooperative and appreciative patients. When Jehovah's Witnesses refuse blood products, they are not "choosing to die," but are making a decision that they believe is religiously mandated and avoids some medical risks.

Jim Lang rebutted the commonly held notion that Jehovah Witnesses "welcome" a court order for a transfusion because it takes the matter out of their hands and off their consciences. Instead, Witnesses who have received blood over their objections feel that they have been violated. (This point was reiterated by D.V.) They are not ostracized by the community, but are supported in dealing with the trauma of such personal violation. Minors who have been transfused pursuant to a court order, and their parents, are not held responsible for this breach of faith. Those who consent to a transfusion because of ill health and fear, and later regret their decision, may still be accepted within the Witness community. Those who chose transfusion, without regret, are counseled that they are probably not appropriate members of the Jehovah's Witness community.

Jim and Anthony talked about the choice that is made by each Witness to profess the faith. Infants are not baptized; instead, each person makes a commitment to the faith when he or she is ready to do so, and is subsequently baptized. A minor would be eligible for baptism if he or she appeared to be able to make an informed choice to become one of Jehovah's Witnesses. D.V. had made such a commitment, and been baptized.

Jim and Anthony also explained that while Witnesses cannot accept blood and certain blood products, they may accept other treatments, including volume expanders. In accordance with their own consciences, they may also accept minor blood fractions and, provided there is no storage or more than brief interruption of blood flow, hemodilution and intraoperative or postoperative blood salvage. (See Sample Health Care Proxy, available in the Office of Ethics.)

Jim and Anthony also made the point, several times, that there are physicians and hospitals willing to care for Jehovah's Witnesses in accordance with their beliefs. The central office in New York maintains a list of such physicians. In most cases, according to Jim and Anthony, insurance pays for the care provided to Jehovah's Witnesses. In other words (they suggest), it is financially disadvantageous for a hospital to refer Jehovah's Witnesses to other institutions.

D.V. shared with us her perception of her experiences at Children's. She first noted that a physician at Children's had treated her for a long period of time. Her condition (scoliosis) was recognized, as was the possibility that she would need surgery. She reported that her physician was aware that she was a Jehovah's Witness. Her condition deteriorated last year, and surgery was recommended sooner than had been expected. To minimize disruption of her schooling, the surgery was scheduled for summer. She prepared for the surgery emotionally and physically, including self-injection with EPO. Shortly before the date of surgery, she learned that her surgeon would not operate unless he was able to use blood products if necessary. There were various clinical team meetings and a consultation with the Legal Office. Because transfusions could not be ruled out in her case, she transferred to another surgeon and institution. D.V. expressed concern that the surgery scheduled to be at Children's had to be postponed at the last minute, despite the fact that the surgeon had known for a long time about her religious beliefs. She now has to have the surgery during the winter, and miss a significant amount of time at school. D.V. also felt the loss of her

longstanding relationship with a doctor who she had always expected would provide her surgery.

It is D.V.'s understanding that her new surgeon will not use blood products. He will use all available alternatives, and if necessary, stop the surgery.

Members of the subcommittee who have had other experiences with Jehovah's Witnesses felt that these representatives fairly presented the views of their community. However, as with other faiths, there may be a range of beliefs within the Jehovah's Witness community. While an understanding of the basic religious foundation of the faith is important, it is also important to understand the beliefs of individual patients and their families.

Members of the subcommittee read several articles in which it was suggested that the choice by a Jehovah's Witness to refuse blood may not always be fully voluntary (also included in "Bibliography"). The patient may refuse blood, at least in part, because of fear of being excluded from his or her community of family and friends. Of course, other patients, in other circumstances, may also feel pressured by family or friends to make certain medical decisions. The possibility of undue influence is always a consideration in evaluating informed consent or refusal of treatment.

While the subcommittee felt it was important to try to understand the beliefs of a group whose members are most likely to refuse blood products, the subcommittee does not recommend that any policy developed by the hospital apply only to refusals of blood products by Jehovah's Witnesses.

## Legal Issues

### Office of General Counsel: Process Issues

Mary Robinson met with Richard Bourne, counsel to the Hospital. Rick suggested that there are three basic approaches that could be taken by the Hospital:

- (1) treat each case in which a competent adult or mature minor refuses blood products on an *ad hoc* basis,
- (2) refer all competent adults and mature minors who refuse blood products to other hospitals, or
- (3) accept such patients in accordance with an explicit protocol approved by the Medical Executive Committee.

He does not recommend the first option - i.e. acting on an *ad hoc* basis. The second or third options would be acceptable.

After discussion with the subcommittee, Rick proposed that if the third option is chosen, the protocol include a requirement for review of each case involving refusal of blood products by an adolescent or young adult patient cared for by hospital staff. Each case review would routinely include an ethicist and, as feasible and appropriate, individuals from the disciplines



of psychiatry, psychology, or social work; chaplaincy; surgery or medicine; and anesthesia or intensive care medicine. The group reviewing the case could, if it thought it necessary, draw on other expertise within the hospital.

This process would provide a forum in which staff and patients could

- share their understanding of the clinical facts;
- explore whether the patient's refusal of blood stemmed from core beliefs and values, was consistent with the patient's overall goals, and was adequately informed, carefully considered, and voluntary.
- In the case of mature minors, the case review would similarly assess the views of the parents.
- In addition, those doing the case review would determine whether all of the members of the clinical staff who would be treating the patient had been identified and given an opportunity to consider carefully their moral views, thereby revealing whether there would be sufficient staff members who were willing to abide by a decision to refuse blood.

### Legal Liability

The subcommittee considered anecdotal evidence that the reluctance of some staff to participate in the care of patients refusing blood products stems from a fear of legal liability. It would be helpful to gather additional information about the extent of such concerns. In fact, lawsuits could be based either on transfusion over the objection of a competent adult or mature minor, or on acceptance of a refusal that results in harm to the patient.

The subcommittee suggests that if the Hospital decides to develop a protocol for blood refusal, there be an educational program for clinicians in regard to the possible sources of legal liability, and the likely outcome of lawsuits that challenge either an acceptance or a denial of the patient's wishes.

### **Children's Hospital: The Existing Moral Culture**

In an attempt to understand the existing culture at Children's Hospital in regard to refusal of blood products, two preliminary surveys of the Department of Anesthesia were conducted. They have revealed that only 6 of the 45 members currently express a willingness to abide by refusal of blood products by adult patients. One other informal interview with four members of the ICU staff revealed that these staff members felt that they could care for patients refusing blood, particularly if they were operating under a hospital policy. (See "Issues: Culture") These staff members felt a strong obligation to honor the patient's wishes.

The subcommittee considered two additional avenues of exploration which time has not permitted. One is a review of principles contained in other statements or policies that reflect Children's culture, such as mission statements and patient care policies. The second would involve using hypothetical scenarios to gather information about the views of staff at Children's Hospital. We considered drafting several scenarios and testing these in focus groups prior to using them more generally throughout the Hospital.

In order to fairly represent the considered views of the hospital community, the subcommittee was concerned that staff be given an opportunity to learn more about, and to reflect on, the issues before being asked to reach conclusions about the moral claims of patients refusing potentially life-saving transfusions of blood products. Individual opinion, as well as institutional culture, is probably not static but evolving. Both are susceptible to change based on increased knowledge and shared experiences. The overall culture is also dependent in part on the arrivals and departures of individual staff members.

### **Children's Hospital and Other Institutions: Clinical Practice and Protocols**

The subcommittee gathered information about clinical practices and protocols involving the use of blood products at Children's Hospital. We have been informed that the Hospital has researched artificial blood and determined that at this time it is not a viable alternative.

A potentially important logistical problem was identified from conversations with clinical staff at Children's. This problem relates to both the feasibility and the fairness of making commitments to patients to honor their refusal of blood. In order to be sure that the hospital can make and keep such commitments, it may be necessary to have a larger "critical mass" of clinicians who are comfortable with participating in a bloodless procedure and participating in follow-up care. From the standpoint of feasibility, it is necessary to be able to schedule an entire team or teams of such clinicians for any given procedure; this is less likely to be possible if the numbers of staff willing to participate are low. From the standpoint of fairness, it may be problematic to burden these clinicians with the additional pressure and inconvenience that result when special scheduling is required. Such burdens may serve as a strong disincentive to participate, even among clinicians who could be comfortable morally with the requests of patients who refuse blood. (Administrative measures, such as compensatory time, might be considered as ways to counter such disincentives if the Hospital wishes to support "bloodless" procedures.)

### **Other Institutions**

We investigated practices and protocols at some of the other Boston hospitals. The written policies of MGH and BI/Deaconess are available in the Office of Ethics. We have also communicated with NEMC regarding their draft policy on refusal of blood and blood products.

Further investigation in this area could include reviewing written material describing the experiences of clinicians who have treated patients refusing blood, and possibly meeting with colleagues at other Boston hospitals to talk with them about their experiences. It would also be useful to review any relevant information or guidelines from professional organizations such as the American Academy of Pediatrics.

## Issues

In the course of our work, the following issues surfaced:

### Clinical Uncertainty

It is unclear whether it is ever possible, in a particular case, to arrive at a medical consensus that blood products will not be necessary to save a patient's life or prevent serious harm. There will always be some degree of clinical uncertainty, and the possibility of an unexpected "worst case" scenario. It is also difficult to pinpoint the time at which "harm" might begin to occur. The nature and severity of the possible harm will evolve over time, requiring a continuous evaluation of benefits vs. burdens.

This clinical uncertainty may have implications for the quality of a patient's informed consent (see "Informed Consent"), as well as for the standards to be used by clinical staff in evaluating each case.

### Spiritual Assessment

Although the subcommittee initially thought it might be important to conduct a spiritual assessment of a patient refusing blood on religious or spiritual grounds, we now believe that this is not advisable. We have identified a number of problems with such a proposal.

First, there is a limited research and a lack of reliable standards for spiritual competence or maturity. Different religious groups define spiritual maturity in different ways—some by study, some by ritual initiation—so that the age and criteria vary widely. It does not appear to be possible to articulate a universal standard of spiritual maturity. The work by James W. Fowler, perhaps the best known effort to establish such a standard, has been criticized as equating the liberal Protestant value of autonomy with spiritual maturity. We question whether autonomy is an ultimate or supreme spiritual value across all cultures, or even across all groups served by Children's Hospital.

Further, even if one were to use Fowler's standards for spiritual maturity, they are probably unrealistically high. Fowler's stage 4 calls for the capacity to question critically and have sufficient autonomy to claim one's own tenets of faith apart from or within the community. Fowler anticipates that only 6% of 13-20 year olds, and only 40% on 21-30 year olds, would meet that high standard.

To adopt any purportedly universal standard would raise questions of consistency. Should we require a higher level of spiritual maturity of our minors than we do for adults? May a patient refuse on the basis of any spiritual or moral belief, even if it is unique? Must the belief be consistent with an organized religion? Must there be a community of like-minded believers? Must the belief be firmly held?

Some aspects of a patient's choice to reject life-saving care – such as voluntariness or consistency with the person's overall goals and values – may be relevant to considerations of capacity and informed consent. This is true whether the choice is based on religious or secular grounds. The subcommittee believes it is more appropriate that these factors be addressed in the specific context of capacity (especially in the case of patients we seek to treat as mature minors) and consent, as they would be for other patients. No specifically “spiritual” assessment seems feasible or desirable.

### Spiritual Support

It is possible to respect and support a person's religious, spiritual and moral concerns without evaluating spiritual maturity. The chaplain has a critically important role as an advocate for a person's moral/spiritual /religious beliefs and as a spiritual caregiver in times of spiritual distress. The services of a chaplain should be offered to any patient who refuses the recommended plan of care on spiritual grounds, or who is transfused against religious/spiritual/moral beliefs. Chaplains are trained to value and understand a person's beliefs and can often interpret them for the care team in helpful ways, honoring patients' confidentiality and freedom to make a decision free from coercion by their religious community or the hospital staff.

### Psychosocial Assessment

The subcommittee considered whether there should be a blanket requirement for a psychosocial assessment in each case of refusal of blood. This proposition raised problems similar to those regarding the spiritual assessment. If such an assessment were to be done in each case, there would need to be some guidance as to what questions are to be asked, and what “standard” is to be applied. One possible standard we discussed is whether the mature minor has the capacity to differentiate his or her thinking from that of his or her parents. However, this standard may be higher than that used to determine capacity in an adult (see “Consistency” and “Mature Minors”).

### Informed Consent

The clinical experience of subcommittee members suggests that discussions with patients who are refusing blood transfusions may not clearly address the issue of death, and/or that patients may not accept that death is a real possibility. It also seemed to us that D.V.'s understanding of what might happen in her upcoming surgery at another institution might not be fully informed. (See “Religious Foundation” above.) She appeared to believe that if any problems arose, the surgery could be stopped without risking her life or health. She did not appear to have contemplated that she might actually die. (However, because we did not feel it appropriate to raise that issue with her, we may not know the full extent of her understanding.) Of course, patients facing other treatment decisions may not always fully comprehend the risks.

Our initial findings suggest the need for a process for evaluating informed consent in cases involving refusal of potentially life-saving blood products. This should include explicit discussion of the prospect of death, as well as consideration of the patient's overall value system and any sources of potential coercion (whether familial, religious or professional).

### Consistency

An issue that surfaced repeatedly is whether the approach to refusals of blood should be consistent with the approach to refusals of health care in other circumstances. For example, one potential inconsistency would be the high level of spiritual maturity required of patients/parents refusing blood if such patient/parents were assessed for spiritual competency. Another potential inconsistency could arise if there were a requirement that there be a psychosocial assessment in all cases of refusal of blood (as opposed to requiring such an assessment only when there is evidence of psychosocial problems). Neither spiritual nor psychosocial assessments are *routinely required* for patients refusing other potentially life-saving medical treatments.

These potential inconsistencies are of concern, in part, because the Jehovah's Witness community may, as a general matter, have a higher percentage of people of color than other religious groups represented at the Hospital. Its members may also, as a general matter, have more socioeconomic disadvantages than members of other communities served by the Hospital. Thus a hospital protocol requiring spiritual and psychosocial assessment might appear unfairly discriminatory, even though it came instead from concern about the particular benefit/burden ratio in these cases, where the benefit of blood is seen as high and the burden of transfusion as low, especially when the patient's prognosis is otherwise very good. As we have learned, however, Jehovah's Witnesses do not share the same view of the benefit/burden ratio since the benefit of accepting blood products to save their lives means that in so doing they lose their souls or forfeit salvation and eternal life.

### Institutional Approach

Although not a new issue, the question of an institutional approach to refusals of blood by adults and mature minors was considered an important one by the subcommittee. An institutional approach would help to prevent situations in which a problem is not identified on a timely basis. It may also help avoid the inconsistency and confusion that, according to anecdotal evidence, currently characterize some of these cases (e.g. lack of knowledge by some staff about the patient's refusal, commitments by some clinicians without the knowledge of others, inconsistent messages to patients).

### Coordination of Care of Patients Refusing Blood

Another issue to be explored, if the Hospital develops a protocol that contemplates treatment of adults and mature minors who refuse blood transfusions, is coordination of the entire process of care. Among other things, such coordination is necessary to ensure that all involved staff are aware of the patient's wishes and that standards of fidelity can be

maintained (see "Fidelity"). Some pediatric hospitals (e.g. Children's Hospital in Kansas City) have looked to the chaplaincy service to provide a "point person" to coordinate the care process. It may be that some combination of medicine, nursing, social services, and/or chaplaincy at Children's Hospital could serve a similar role.

### Resource Use

Depending on the protocol adopted by the Hospital, review of cases of adults or mature minors refusing blood transfusions might be complex, and require a significant commitment of resources. On the other hand, automatic referral of these cases to other institutions would presumably require less staff and time but would divert revenue that would have come from caring for such patients.

### Institutional and Staff Responsibilities and Rights

One critical ethical question is what, if any, responsibility does the Hospital and/or its staff have to provide care in accordance with the wishes of Jehovah's Witnesses: (1) who are already patients of the Hospital/physicians, (2) who are seeking care available only at Children's, or (3) who wish to receive their care at Children's? How should these responsibilities be met? If the existing culture at Children's makes it difficult to care for such patients, does Children's have a responsibility to review its culture? Should Children's provide education to staff about the values and cultures of those who refuse blood? Or even attempt to recruit staff members who might be willing to accept these values?

Similarly, what are the claims/rights of the Hospital and its staff in regard to declining to provide care inconsistent with the Hospital's culture and/or with the beliefs (religious, moral, professional) of members of its staff? How should these claims/rights be protected? (For further thoughts on the possible ethical obligations/rights of staff, see Attachment A.)

### Fidelity

The subcommittee discussed the importance of fidelity or faithfulness to any promises made to patients. The Hospital and staff need to examine carefully what commitments it and they are prepared to fulfill.

### Process

Our current thought is that if Children's decides to adopt a protocol for treating adults and mature minors who refuse blood, then the protocol should, at least initially, include a process for reviewing individual cases, such as that described above (See, "Office of General Counsel: Process Issues"). However, we understand that such a process itself raises practical and ethical issues. If the responsibility for conducting case reviews were given to the EAC, for example, the committee's resources would be utilized to perform what some may not regard as an "ethics consult." Another pressing concern is that the hospital must be able to articulate a sound, ethical basis for requiring such a process for these cases. To be fair, it will be necessary to

articulate the standards by which cases will be reviewed. Under what circumstances would a case review include a recommendation that the patient be referred elsewhere? Would this be a recommendation only?

### Mature Minors

The subcommittee considered how to evaluate whether a minor should be treated as an adult for purposes of being allowed to make an informed choice to refuse blood without constraints. Literature related to this issue is listed in the Bibliography. Please see the Attachment B: How Should Mature Minor Status Be Assessed?

### Emancipated Minors

We are currently considering emancipated minors as “adults,” subject, however, to the same review process and standards.

### Pregnant Women

Because of the lack of consensus not only in ethics but in the law about refusal of treatment by pregnant women when such refusal may adversely affect the fetus, the review process in such cases will be more complex, and should involve legal counsel.

### **Next Steps**

From the subcommittee’s initial information-gathering, we recognize that these and other issues raised by a decision about whether to treat adults and mature minors who are refusing blood transfusions in accordance with their wishes will need to be more fully addressed in the appropriate forum.

### **Bibliography**

Vinicky JK, Smith ML, Connors RB, Kozachuk WE. The Jehovah’s Witness and blood: new perspectives on an old dilemma. *J Clin Ethics* .

Family Education and Resource Program, Children’s Hospital. Multicultural Information and Resources: Religious Traditions—Jehovah’s Witness.

Barnes LL, Plotnikoff GA, Fox K, Pendleton S. Spirituality, religion, and pediatrics: intersecting worlds of healing. *Pediatrics* 2000; 104:899.

New England Medical Center Hospital’s, Inc. Policy regarding consent and refusal of blood or blood products. Draft of 3/8/00.

Derish MT, Heuvel KV. Mature minors should have the right to refuse life-sustaining treatment. *J of Law, Medicine & Ethics* 2000; 28:109.

Canadian Blood Agency. Building a Blood System for the 21st Century. Proceedings and Recommendations, November 3-4, 1977.

Dixon JL, Smalley GM. Jehovah's Witnesses: the surgical/ethical challenge. *JAMA* 1981; 246:2471.

Ridley DT. Accommodating Jehovah's Witnesses' choice of nonblood management. *Perspectives in Healthcare Risk Management* 1990: 1.

Atabek L, Spence RK, Pello M, Alexander J, Carnishion R. Pancreaticoduodenectomy without homologous blood transfusion in an anemic Jehovah's Witness. *Arch Surg* 1992; 127:349.

Muramoto O. Bioethical Aspects of the recent changes in the policy of refusal of blood by Jehovah's Witnesses. *British Medical Journal* 322 (6 January 2001) 37-39.

Muramoto O. Medical confidentiality and the protection of Jehovah's Witnesses' autonomous refusal of blood. *Journal of Medical Ethics* 2000 26:381-386.

Derish MT, VandenHeuvel K. Mature minors should have the right to refuse life-sustaining medical treatment. *Journal of Law, Medicine & Ethics* 28 (2000): 109-124.

Frader J. Younger yet wiser: courts should allow mature minors medical autonomy. *The Park Ridge Center Bulletin*: July-August 2000: 3-4.

Scott, ES, Reppucci, ND and Wsoolard, JL. Evaluating adolescent decision-making in legal contexts. *Law and Human Behavior* 19(3) 1995: 221-244.

Publications of the Watchtower

Sample Health Care Proxy for Jehovah Witnesses



## **Attachment A: On the Possible Ethical Obligations and Rights of Staff**

To: Subcommittee on Refusal of Blood  
From: Judy Johnson  
Date: April 11, 2001

For discussion purposes, I have prepared the following thoughts and questions on whether physicians, other caregivers, or the hospital have any obligation to provide medical treatment to individuals who refuse blood products (or whether it is at least virtuous or morally commendable to do so).

### **Individual Caregivers: Physicians**

1. If a physician has established a relationship with a patient, does he or she have an obligation to continue to care for the patient, despite the fact that the patient has refused blood transfusions (even if medically appropriate), in any of the following three cases: (a) the patient can be transferred to another physician with little or no risk and/or only minor inconvenience, (b) the patient can be transferred but will incur some moderate risk and/or moderate to serious inconvenience, (c) the patient cannot be transferred without significant risk (i.e., the desired treatment is only available from this physician)?
  - a. **Obligation:** Very generally, physicians are thought to have an obligation (fidelity? loyalty?) to provide needed medical care for their patients. Failing to do so, without having effected an appropriate transfer to another physician, is considered "abandonment" (ethically and legally). There is also fairly widespread agreement that physicians, in most cases, must respect their patients' autonomy. They must obtain informed consent to treatment (and must accept informed refusals of care). Despite these obligations of fidelity and respect for autonomy, it is usually accepted that a physician may transfer the care of a patient to another physician if the patient's autonomous choice violates the physician's ethical principles. (See Beauchamp and Childress) Transferring a patient in such a case is sometimes compared to "conscientious objection." Particularly if the patient would suffer little risk of harm from such a transfer, there would seem to be ethical consensus that there is no obligation to continue to provide care that violates the physician's principles. However, in articles examining cultural differences in health care, there is some discussion about the need for physicians to examine the nature, depth, and personal importance of their ethical principles before refusing to care for patients whose medical decisions are informed by different values. (See discussions by Nancy Jecker and others)
  - b. **Virtue:** Given the importance of the principle of autonomy, as well as the strength of a physician's obligation to care for his/her patient, it might be argued that while not required, it would be commendable for a physician to respect his/her patient's strongly held (and often religiously based) beliefs, provided doing so did not

morally compromise the physician. (See questions below about the nature of a caregiver's objection to providing treatment to those who refuse blood.) It might be considered virtuous for a physician, having compassion for his/her patient's desire to have medical care while remaining faithful to the teachings of his religion, to provide such care. (I have found little discussion of this idea.)

- c. It is unlikely that an increase in inconvenience to the patient would change the analysis. However, moderate risk (e.g. because of delay of care or lack of expertise elsewhere) might influence the analysis for some ethicists and physicians.
- d. If the physician is the only one who can provide the medical care ("sole source"), and the care is potentially life-saving or life-prolonging (even though there is a risk that the patient will die or be harmed because of blood loss), the analysis might change. The consensus would probably still be that the physician has the moral right to decline to provide care, even though the patient will die. However, some ethicists might think differently. (I have not found anything yet on this subject; it may be that there are no "sole sources.") The law might also treat the case differently. In several "right to die" cases, the courts have noted that if the patient could not be transferred, then the facility/physicians had to render care in accordance with the patient's legal rights. (To my knowledge, it has always been possible to transfer the patient.) Even if there is no ethical obligation to provide the care, some might at least argue that it would be virtuous for the physician to provide care if there is no other source of care.
- e. Hospital Patient and Staffing Issues: The issues become more difficult when the patient has been accepted by one physician, and is receiving care at the Hospital. What happens when the original physician is not available (shift change), or other physicians (e.g. anesthesia, intensivists) are needed to provide treatment? While theoretically they may be entitled to decline to accept the person as a patient (or to transfer a person who is already a patient), what if no one else is available to provide the care for someone who has already been "accepted" into the Hospital system? It is possible that the patient could still be transferred, but also possible (e.g. in recovery room) that he could not. Failing to provide care, resulting in harm to the patient, would seem to be ethically questionable (and legally risky). Transfusing against the patient's wishes would also seem problematic.

## 2. What if the person seeking care is not already a patient?

- a. **Obligation:** Generally speaking, a physician has no obligation to nonpatients, even if care is potentially life prolonging or life-saving. An exception might be if the situation were akin to a "rescue." Some ethicists argue that, in an emergency, everyone has an obligation to save even a stranger if it can be done without risk to

- self. (See Beauchamp and Childress) In most cases, situations involving medical care for non-patients refusing blood do not arise as emergencies, however.
- b. Sole Source: What if the physician is the only one who can provide the needed treatment? If there is no consensus that a physician who already has a relationship with a patient must provide treatment if he/she is a sole source, there would seem to be even less basis for requiring a physician to enter into a relationship with a patient simply because the physician is the "sole source."
  - c. Virtue: Even with a nonpatient, however, some might believe it virtuous for the physician to care for that person if the physician is the only one who can provide life-saving or life-prolonging care.

### 3. Emergency Room Physicians

In an emergency room, the person seeking care is generally considered a patient. Thus, an ED physician may not have the ability to "choose" who his/her patients will be. In many "emergency" circumstances, a physician might be justified in transfusing, in light of the limited time available to obtain fully informed refusal. However, it is possible that an emergency room physician could be faced with a competent, fully informed refusal of blood. (See Shine v. Vega for a case involving competent refusal of care in the emergency department) Not treating the patient at all could be considered abandonment. Transfer might be difficult in an emergency (and is problematic under the Anti-Dumping Law). In such a case, if the physician transfused, he/she might be violating the patient's legal rights and perhaps the patient's moral rights (particularly if the patient had no reason to think that his refusal would not be honored). In regard to moral rights, it might be a defense that failing to transfuse would violate the physician's personal beliefs. (Does a hospital have an obligation to provide notice that anyone entering the ED will receive a blood transfusion if necessary? Is disclosure, in advance, a minimum ethical requirement when individuals or institutions are going to override a patient's refusal of blood?)

#### **Individual Caregivers: Others**

Other individual caregivers are involved in providing direct medical care, in particular, nurses (in the OR, recovery, and on the units). The analysis would seem to be similar, except in regard to whether the person is a patient. In the hospital setting, in most cases the nurse, while he/she may have the moral right to decline to provide treatment, does not have the opportunity to prevent the person from becoming a patient. He/she has the moral responsibility for providing nursing care to patients whom he/she may not have admitted, and to whom he/she has not made any commitment regarding blood. While theoretically the nurse can simply decline to participate, what happens if no other nurse is available? Can the nurse require that the patient be transfused if the nurse must participate in the care? Can a nurse require that the patient be transferred?

## **Hospital**

As a charitable health care institution with a specific mission, the Hospital may have its own obligations, separate from those of its staff, to provide health care to its community. This obligation is most likely to exist if the person seeking care is a child or, if an adult, he/she was formerly a patient and still needs unique services the Hospital offers.

The Hospital may have an ethical obligation to facilitate care, for example by providing interpreters. It may also have an obligation to respect cultural practices if they do not compromise care. The more difficult question is does it have an obligation to make care available in a manner that it considers medically inadvisable? Even if it does not, does it have an obligation to investigate fully all means of providing care without blood; to use bloodless techniques whenever possible; to hire staff skilled in such techniques; to accept some amount of risk to accommodate competent patients' wishes?

- a. Even if the person seeking care is a child (a mature minor) who is already a patient of the Hospital, it could be argued that as long as he/she can be transferred with little or no risk, Children's has no ethical obligation to offer care (recruit staff, make policy) in a manner that violates its principles. (But does the institution have "principles? How are they arrived at? Communicated to the community?)
- b. If the Hospital has a service that no other institution offers, perhaps it has an obligation to make it available to all members of the community. Can it argue that it only needs to make it available on reasonable terms – i.e., in accordance with reasonable medical standards?

## **Mature Minor v. Adult**

It is difficult, ethically to differentiate between these two types of patients. Once a determination has been made that a person is mature enough to make the decision, and that the decision being made is informed and voluntary, the ethical analysis would seem to be the same.

## **Caregivers' Objections**

What is the ethical or moral principle underlying a caregiver's moral right to refuse to participate in providing treatment to a patient who is refusing blood? Is the caregiver asserting that the patient's choice is morally wrong? And that the caregiver should not participate in a moral wrong? Or that the patient's religious beliefs are incorrect and therefore do not justify the patient's moral choice? Why does providing treatment (including surgery) but withholding blood at the patient's request compromise the caregiver? Is providing what the caregiver believes is "standard medical care" a moral right? Is there a moral right to avoid the patient's death by providing blood, even if the patient chooses physical death rather than what he or she perceives to be a violation of God's will?

## Attachment B

### How Should Mature Minor Status Be Assessed?

#### I. Ethical considerations

- Autonomy vs paternalism (by medical providers and/or family)
- Respect for adolescent's values, religious beliefs, control of body, etc

#### II. Should assessment be approached from the perspective that adolescent needs to demonstrate competence (is assumed to be incompetent) OR vice versa?

#### III. Should all adolescent Jehovah's Witnesses who wish to refuse blood transfusions be evaluated? By whom? What about other adolescent patients who wish to either consent to or refuse medical care for themselves?

#### IV. Should standards for assessing adolescent patients be more stringent than those used for adults?

- Pro: adolescents are more influenced by authority figures, peers, etc, are more apt to take risks, not consider the future, etc, than adults. They are less experienced decision-makers.
- Con: adolescents (and possibly especially those who have dealt with illness) are generally well-equipped to consider what sort of care is in their own best interest.

#### V. Other considerations:

- Care should be taken that any process developed to assess a minor not undermine or usurp family involvement and support.
- Facilitating adolescent decision-making may promote a more positive alliance with medical caretakers, and may result in adolescent taking more responsibility for his/her health care in the long run, feeling more a "partner" in the health care system.
- Do standards for allowing a minor to make medical decisions need to be somewhat different depending upon whether the medical situation is terminal, life threatening or curable; chronic or acute? (ie, should there be more latitude allowed for pt whose condition is more or less hopeless?)
- Evaluation process should be sensitive, with the emotional well-being of the

adolescent remaining a priority throughout. The same applies to the family: the parent-child relationship should be respected and supported by the process in any way possible.

#### **VI. Assessment of "maturity"**

- Not a unitary concept, different in different domains of adolescent's life
- Need to avoid stereotypes about adolescents, such as a time of extreme turmoil etc (normative research does not support this).
- No absolute test available
- NOT exactly the same thing as assessment of competency to make medical decisions (ie, competency might be assessed by examining adolescent's understanding of the medical situation, treatment options, risks and benefits, etc; the process of decision making; the coherence of beliefs and values underlying the decision making).
- Biases and beliefs of clinician clearly color assessment of maturity
- Maturity might be judged by:
  - General capacity for and experience in making decisions
  - Capacity to appreciate the effect of one's behavior and actions on others
  - Ability to consider future (as opposed to just the immediate) impact of choices and behavior
  - Capacity to entertain multiple points of view
  - Stable relationships with peers and family
  - Ability to seek help when appropriate
  - Spiritual beliefs are well-formed, relatively free from parental pressure
  - JUDGMENT, not simply cognitive ability
  - Choices are made for reasons other than just rejection of or opposition to parental or other adult authority

#### **VII. Confounding factors**

- Psychiatric problems: depression, oppositional behavior disorder, anxiety, others
- Learning disabilities, difficulty verbalizing opinions, etc
- Unfamiliar or unusual family, cultural, spiritual beliefs

#### **VIII. Future need is to develop a flexible, fair, open-ended (ie obtaining narrative**

information) and semi-structured interview in order to standardize the assessment process and allow the process to be relatively independent of observer bias.

Barbara Burr

26 September 2001





# **SUMMARY AND RECOMMENDATION**

## **Subcommittee Report on Refusal of Blood Products**

**Ethics Advisory Committee  
Children's Hospital, Boston  
Revised December 2001**

### **Background**

#### *Cases*

In the past year, two cases involving adolescents wishing to refuse blood transfusion therapy were presented to the EAC. In one case, a 17 year-old woman had her long-scheduled surgery cancelled at the last minute due to misunderstandings about her ability to refuse transfusion therapy, even though she had been clear about her preferences. The patient, who had been treated at Children's for some years, felt the loss of her relationship with her physician here. The late cancellation also resulted in an interruption in her schooling.

In the other case, a 16 year-old man desired major abdominal surgery with the proviso that he be permitted to refuse transfusion therapy. A significant amount of work by members of the departments of anesthesia, surgery, legal, and the office of ethics led to court permission to proceed with surgery under the stated conditions. Even after the court hearing, however, there were concerns about whether there were sufficient staff members willing to participate in his care.

The EAC also heard anecdotal evidence of concerns, including cases in which individual clinicians may have made private commitments to their patients that: (1) were not communicated to other staff caring for the patients, (2) were morally troubling to other staff members, or (3) overstated the extent to which the patient could place restrictions on the use of blood products at the Hospital.

#### *Interim Responses*

Two responses followed. On a practical level, the Department of Anesthesia established an informal process to facilitate perioperative communication and coordination of such cases whenever possible. The EAC also appointed a subcommittee to review the issues. The subcommittee issued an interim draft report in January, 2001 supplemented by two memoranda in April, 2001, and then requested further direction from the EAC.

In September 2001, the EAC asked the subcommittee to summarize: (1) the problems facing the Hospital, (2) several possible approaches for dealing with the issue, and (3) a process for determining which approach is most appropriate for the Hospital. Although a number of subcommittee members were no longer available, 5 members of the subcommittee (BB, CH, JJ, MRR, DBW) prepared this Summary and the attached Report of the Subcommittee with two memoranda.

## **The Problem: Conflict among Legitimate Values**

The complexities of caring for adult patients or adolescents who wish to refuse transfusion therapy arise from a conflict among legitimate values, including the following:

1. Competent patients are generally regarded as having an ethical and a legal right to have their treatment preferences honored. Patients approaching the age of majority are also seen as having an ethical and a legal right to actively participate in medical decisions. A growing recognition of the adolescent's moral claim to autonomy in decision-making, a respect for his or her developing religious and moral values, and a desire to avoid spiritual harm, support acceptance of a mature and informed refusal of care—including blood transfusion therapy. However, there is no clear consensus about how to evaluate an adolescent's ability to make informed voluntary, value-based decisions.
2. Caregivers have an obligation to promote the health and well being of patients and to avoid causing harm, especially in vulnerable patients like children. Some caregivers interpret this obligation as proscribing withholding potentially life-sustaining transfusion therapy.
3. In non-emergent circumstances, caregivers have a right not to participate in care they believe to be morally wrong or questionable. For some caregivers, withholding blood products is a violation of professional values. The hospital has an interest in honoring the moral values of caregivers.
4. Caregivers have an interest in avoiding restrictions on the patients for whom they may care. This interest is rooted in the general concept of professional autonomy as well as in the importance of being able to provide continuity of care to patients as they progress from childhood to adulthood.
5. The hospital and its staff have an interest in promoting desirable societal values, such as respect for those of different beliefs, and in not estranging communities of patients.

## **Recommendation**

The cases that have arisen have caused moral discomfort, and the moral values implicated in the cases are important both to patients and caregivers. In addition, the current *ad hoc* method of approaching such cases has serious ethical problems.

*Therefore, we recommend that the Hospital convene a multidisciplinary task force comprised of representatives from those areas of the Hospital most affected (including surgery, anesthesia, nursing, legal counsel, administration, and ethics) to consider the issues and develop a consistent Hospital-wide approach to adults and adolescents who wish to refuse blood products.*

There are a number of possible outcomes of the review by the multidisciplinary task force. Three factually possible outcomes are:

*Option 1:* The hospital chooses to continue to deal with each case on an *ad hoc* basis, but modifies this approach by adopting standard practices and procedures designed to minimize the ethical problems that have been identified.

*Option 2:* The hospital develops an approach for accepting such patients, and, subject to a review process in each case, treats them in accordance with their wishes.

*Option 3:* The hospital chooses an approach limiting the ability of patients to refuse the use of blood products while obtaining care at Children's Hospital. Those who prefer care without blood products would be transferred to another health care facility willing to treat them, respecting their restrictions.

Without further information-gathering and ethical deliberation amongst the most involved staff, the Ethics Advisory Committee cannot find any of these options ethically acceptable, or ethically preferable over the others. Such ethical deliberation may include consideration of the following questions:

- (a) Is it ethical for a clinician at Children's Hospital to provide treatment to an adult patient while abiding by the patient's voluntary, informed refusal of blood even if blood is necessary to prevent death or serious harm? If it is ethical, and the clinician wishes to care for such a patient, does the clinician and/or the Hospital have a responsibility to try to ensure that there is sufficient staff to provide continuity of care?
- (b) Assuming it is ethical to treat such adult patients in accordance with their wishes, is it obligatory? Or may the Hospital choose to refer such patients to other institutions either because staff at the Hospital disagree about the ethical course of action or because the Hospital believes there are too many practical problems?
- (c) Is it ethical for a clinician at Children's Hospital to provide treatment to a minor patient while abiding by the patient's voluntary, informed refusal of blood even if blood is necessary to prevent death or serious harm—*provided that* the minor has been determined by staff (and by the courts, if appropriate) to be mature enough to make such a choice? If it is ethical, and the clinician wishes to care for such a patient, does the clinician and/or the Hospital have a responsibility to try to ensure that there is sufficient staff to provide continuity of care?
- (d) Assuming it is ethical to treat such mature minors in accordance with their wishes, is it obligatory? Or may the Hospital choose to refer such patients to other institutions either because staff at the Hospital disagree about the ethical course of action or because the Hospital believes there are too many practical problems?

(e) Is it possible to design a case-by-case approach that reduces sufficiently the moral problems that have characterized the *ad hoc* approach to date?

Respectfully submitted,  
*Barbara Burr*  
*Charlotte Harrison*  
*Judy Johnson*  
*Mary Redner Robinson*  
*David B. Waisel*





**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

**FINAL REPORT**

**APPENDIX B**





## **APPENDIX B**

### **SUMMARY OF ORGANIZATIONAL ETHICS PROCESS AT CHILDREN'S HOSPITAL**

#### **Recommendations re organizational ethics:**

Rather than creating a new committee or administrative structure, we recommend the establishment of a simple process that allows all affected interests and disciplines, including ethical interests, to be represented and have input.

1. The Office of Ethics will forward to the CEO all issues it receives which it believes can benefit from this process. Others, such as administrators, professional staff, auditors, risk managers, community groups, family committees, or the EAC can forward requests either to the Office of Ethics or directly to the CEO.
2. The CEO will discuss all issues he receives with Robert Truog and Christine Mitchell to evaluate their appropriateness for this process.
3. The CEO, in consultation with the Office of Ethics (and others as the CEO deems appropriate) will prepare a charge, and will appoint a short-term ad hoc multidisciplinary committee and chair(s) to address the issue.
4. The Office of Ethics will provide administrative support for ad hoc organizational ethics committees.
5. Reports and recommendations (including, if appropriate, proposed guidelines, principles, or policies) from the ad hoc committees will be presented to the CEO for consideration and action.







**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

**FINAL REPORT**

**APPENDIX C**



## TASK FORCE ON REFUSAL OF BLOOD PRODUCTS

### COMMITTEE CHARGE

Upon the recommendations of the Ethics Advisory Committee (EAC) and the Senior Management Team, President and Chief Executive Officer James Mandell is appointing a multidisciplinary Task Force to Review Issues Related to the Hospital's Care of Adults and Mature Minors Who Refuse Blood. The Task Force is charged with the following responsibilities:

1. To review the Report of the EAC Subcommittee on Refusal of Blood, including the Subcommittee's recommendations regarding ethical issues for deliberation;
2. To gather empirical data on the type of cases at the Hospital involving refusal of blood products by adults and mature minors; the Hospital's current approach to such cases; and the approach of other hospitals to similar cases;
3. To consider current legal and ethical opinions about refusal of blood by adults and mature minors;
4. To consider psychological and developmental issues regarding decision-making by mature minors;
5. To establish a process for increasing knowledge and sensitivity within the Hospital community to the clinical, religious, ethical, legal and psychological/developmental issues raised by refusals of blood by adults and mature minors;
6. To gather information about the professional values and beliefs of staff regarding their participation in caring for patients who refuse blood;
7. To identify options for caring for adults and mature minors who refuse blood;
8. To recommend a Hospital-wide approach to the care of adults and mature minors who refuse blood.

June 6, 2002









**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

**FINAL REPORT**

**APPENDIX D**



**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**  
**Agenda**  
**February 5, 2003**

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**A. Welcome and Introductions**  
*John Emans, Judy Johnson*

**B. What is “Organizational Ethics”?**  
*Robert Truog*

**C. Presentation and Discussion of Clinical Cases**  
*David Waisel*

**D. Summary of Hospital’s Response**  
*Judy Johnson*

- **Process**
- **Report and Recommendation of the Subcommittee of the Ethics Advisory Committee**

**E. The Task Force on Refusal of Blood: The “Committee Charge”**  
*John Emans*

**F. Next Steps**

**TASK FORCE ON REFUSAL OF BLOOD  
AGENDA  
MARCH 5, 2003**

1. **Review of the Committee Charge: Progress to Date**
2. **Proposals for Discussion**

[Non Emergency Cases]

- **Whatever recommendation the Task Force makes, the recommendation will not require a staff member at Children's Hospital to participate in treating a patient who is refusing blood, if such participation would violate the staff member's conscience.**
- **Whatever recommendation the Task Force makes, the recommendation will not require a competent adult patient to be treated with blood against his/her wishes, if such treatment would violate the patient's conscience.\***

3. **Discussion of Options for Competent Adult Patients Who Refuse Blood**

[Non Emergency Cases]

- A. **Refer or Transfer**
- B. **Accept and Honor Refusal of Blood\***
  - **Provided there is sufficient staff willing to participate**

**Variation B-1. Accept and Honor Refusal of Blood\***

  - **Provided there is sufficient staff willing to participate, and**
  - **Provided the risk of needing blood is low**
- C. **Agree to Try Not to Use Blood, but Accept only if Patient Consents to Blood in event of Risk to Life/Limb**

4. **Committee Charge: Plan for Completing Other Elements**

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**\*Possible exceptions: patient's death would result in abandonment of dependent minor; patient is pregnant and fetus is viable**

**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**  
**AGENDA**  
**APRIL 2, 2003**

1. Follow-up on Handouts; New Material
2. Selected Bibliography on Adolescent Decision-Making
3. Letter to Patient
4. Consensus on Proposals/Options Discussed at March Meeting

**Proposal:** Children's Hospital will not require a competent adult patient to be treated with blood against his/her wishes, if such treatment would violate the patient's conscience.\*

**Therefore,** the options for dealing with competent adult patients who refuse blood are:

- A. Refer/Transfer
- B. Accept and Honor Refusal of Blood\*
- C. Combination of A & B
  - (i) Accept if procedures/ treatments have low risk of blood loss; otherwise transfer
  - (ii) Accept if procedures/treatments have favorable risk-benefit ratio; otherwise transfer

Other possible variables

- (iii) Accept only patients who have history of treatment at Children's
- (iv) Accept only patients who cannot receive comparable care elsewhere

*\*Possible exceptions: patient's death would result in abandonment of dependent minor; patient is pregnant and fetus is viable; insufficient staff willing to participate*

**Proposal:** Children's Hospital will not require a staff member to participate in treating a patient who is refusing blood, if such participation would violate the staff member's conscience.\*\*

- (i) Which "staff members" are included?
- (ii) What constitutes "conscientious objection"?

*\*\* Unless serious harm to patient would occur*

5. Committee Charge; Next Steps

**ORGANIZATIONAL ETHICS TASK FORCE  
AGENDA  
MAY 7, 2003**

1. Report of the Subgroup on Staff Values and Beliefs
2. Review of Legal Issues involved in Cases of Refusal of Blood
3. Discussion of Sample Policy Statements on Adult Patients
4. Recommendation regarding Approach to Adult Patients
5. Implications of Recommendation
6. Schedule



# **ORGANIZATIONAL ETHICS TASK FORCE ON REFUSAL OF BLOOD**

**JUNE 4, 2003**

## **AGENDA**

1. Discussion with representatives of the Jehovah's Witness Hospital Liaison Committee
  
2. Questions for Staff on Patient Care Involving Refusal of Blood
  - a. Results of focus groups
  - b. Proposed revisions to survey
  - c. Use of survey with additional staff
  
3. Review of Mandate of the Task Force
  
4. Next steps in Comparing Policy Statement #1 and Policy Statement #2
  
5. Schedule

# **ORGANIZATIONAL ETHICS TASK FORCE ON REFUSAL OF BLOOD**

**JULY 2, 2003**

## **AGENDA**

1. Comparison of Policy Statements #1 and #2
  - a. Implications (or consequences) of each
  - b. "Best Case" in support of each
  
2. Mature Minors
  - a. Basic Concepts
  - b. Incorporation into Policy Statements #1 or #2
  
3. Updates
  - a. Staff Questionnaires
  - b. Nursing Leadership Group and MSEC
  - c. Suggestions for Other Groups

# **ORGANIZATIONAL ETHICS TASK FORCE**

## **AGENDA**

**August 6, 2003**

1. Draft Recommendation to Management
2. Draft Summary of Advantages and Disadvantages
3. Minors with Decision-Making Capacity ("Mature Minors")
4. Update on Survey Results
5. Next Steps

**TASK FORCE ON REFUSAL OF BLOOD  
AGENDA  
SEPTEMBER 3, 2003**

**A. Review of Draft Documents: Key Issues**

1. Overview of Work of the Task Force
  - a. Tone of the Document
  - b. Part B, "Complications"
  - c. Part E, 2, "Alternatives"
  - d. Part E, 3, "Advantages and Disadvantages"
  - e. Part E, 5, "Respect for the Moral Values of Individual Staff Members"
  - f. Part E, 6, "Conclusion"
  - g. Part F, "Recommendations"
  - h. Part G, "Next Steps"
  - i. Mature Minors (Part E, 4 and II, E) and Emancipated Minors
2. Executive Summary
3. Contents of the Report

**B. Review of Ethical Question posed by the EAC**

If it is ethical for a clinician at Children's to provide treatment while abiding by the patient's refusal of blood, does the clinician and/or the Hospital have a responsibility to try to ensure that there is sufficient staff to provide continuity of care?

**C. Additional Outreach to Hospital Community**

1. EAC meeting September 9
2. Other

**E. Next Steps**

**Task Force on Refusal of Blood  
Agenda  
December 3, 2003**

1. Review and Approval of Final Report
2. Executive Summary
3. Three Points for Presentation to Management
4. Three Thoughts on Organizational Ethics
5. Thanks









**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

**FINAL REPORT**

**APPENDIX E**



## APPENDIX E

### LIST OF SELECTED HANDOUTS FOR TASK FORCE

1. Summary and Recommendations, December 2001.
2. Final Subcommittee Report, September 28, 2001  
Appendix A – *On the Possible Ethical Obligations and Rights of Staff*  
Appendix B – *How Should Mature Minors Be Assessed?*
3. Janicemarie K. Vinicky, Martin L. Smith, Russell B. Connors, Jr., Walther E. Kozachuk, “The Jehovah’s Witness and Blood: New Perspectives on an Old Dilemma, *Journal of Clinical Ethics*; 64-75.
4. Jonsen A, Siegler M, Winslade W., “2.5.1 Refusal on Grounds of Unfamiliar Belief,” *Clinical Ethics* 4<sup>th</sup> Ed., McGraw-Hill, New York, 1998; 74-77.
5. Children's Hospital, Boston Internal Web Page, Multicultural Information and Resources, “Religious Traditions – Jehovah’s Witnesses,”  
<http://web2.tch.harvard.edu/family/multicultural/jehova/html>
6. Children's Hospital, Boston, Ethics Advisory Committee Web page “Terminology in Ethics,” <http://web2.tch.harvard.edu/ethics/ethts.html>
7. Beauchamp TL, Childress J. Selections from Principles of Bioethics 4<sup>th</sup> Edition, Chapters 3, 5, and 8.
8. Albert R. Jonsen, selection from The Birth of Bioethics, Chapter 10, 1998.
9. Selection from “Adolescence to Adulthood: Discussion,” *The Mount Sinai Journal of Medicine*, Vol. 51, No. 1, Jan-Feb 1984.
10. Beth Israel Deaconess Blood or Blood Product Refusal Policy.
11. DFCI Policy for Patients Refusing Blood or Blood Products.
12. Lahey Clinic Care of Patients Requesting Blood-Free Treatment Policy.
13. MGH Draft Policy, “Transfusion Therapy: Patients Who Decline Treatment with Blood or Blood Products.”
14. Rainbow Babies & Children’s Hospital, Center for Bloodless Medicine & Surgery (CBMS) Policy.
15. Children's Hospital, Boston Personnel Policy Manual, Policy 1.01: Content and Definitions.
16. Children's Hospital, Boston Personnel Policy Manual, Policy 2.08: Requests to be Excused from Patient Care Responsibilities.
17. Frank Feigenbaum, MD, Daniel P. Sulmasy, MD, PhD, Edmund Pellegrino, MD, Fraser C. Henderson, MD, “Spondyloptotic Fracture of the Cervical Spine in a Pregnant, Anemic Jehovah’s Witness: Technical and Ethical Considerations,” *Journal of Neurosurgery*, v87, September 1997: 458-463.
18. Barbara Burr, “Adolescent Decision Making: A Selected Bibliography,” Annotation.
19. Supreme Judicial Court of Massachusetts, Norfolk. “Norwood Hosp. v. Munoz,” Cite as 564 N.E.2d 1017 (Mass 1991): 1017-1026.

20. Commonwealth of Massachusetts Probate and Family Court, Docket No. 91E006. Beth Israel Hospital, Plaintiff vs. Earline Stockton, individually and as next friend of her minor children, Defendants. May 30, 1991: 1-5.
21. CP Maness, RN; S. M. Russell, RN; P. Altonji, MD; P. Allmendinger, MD, "Bloodless Medicine and Surgery," *AORN Journal*, January 1998, Vol. 67, No. 1.
22. Children's Hospital Boston, Internal Web page, "Jehovah's Witnesses: General Guidelines."
23. Judith C. Marsh, David H. Bevan, "Haematological Care of the Jehovah's Witness Patient [Annotation]," *British Journal of Haematology*, Vol. 119(1), October 2002: 25-37. <http://gateway1.ovid.com/ovidweb.cgi>
24. Janet Cogliano, APRN; Debbie Kisner, RN, "Bloodless Medicine and Surgery in the OR and Beyond," *AORN Journal*, November 2002, Vol. 76, No. 5.
25. Scott ES, Reppucci N, Woolard JL. "Evaluating Adolescent Decision Making in Legal Contexts." *Law and Human Behavior*, Vol. 19, No. 3, 1995.
26. Oberman M., "Minor Rights and Wrongs." *Journal of Law, Medicine & Ethics* 24 (1996): 127-38.
27. Weir RF, Peters C., "Affirming the Decisions Adolescents Make about Life and Death." *Hastings Center Reports* 27, no. 6 (1997): 29-40.
28. In the Matter of Elisha McCauley, 409 Mass. 134 (1991); In the Matter of Rena, 99-P-199 Appeals Court.





**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

**FINAL REPORT**

**APPENDIX F**





## **QUESTIONS FOR STAFF ON PATIENT CARE INVOLVING REFUSAL OF BLOOD**

### **Introduction**

During the last few years, a number of cases at Children's involving refusal of blood products by adolescents and young adults have caused tension for Hospital staff and distress for some patients and families. Upon the recommendation of the Ethics Advisory Committee ("EAC") and the Senior Management Team, Dr. James Mandell appointed a multidisciplinary Task Force to review issues related to the Hospital's care of such patients. The Task Force is co-chaired by Dr. John Emans, Department of Orthopedics, and Judy Johnson, EAC. Members of the Task Force include representatives from anesthesia, the blood bank, chaplaincy, the emergency department, the legal office, the MICU, nursing, the Office of Ethics, and psychiatry. The goal of the Task Force is to recommend a Hospital-wide approach to the care of adults and mature minors who refuse blood.

To assist in its deliberations, the Task Force is gathering information about the professional values and beliefs of staff regarding providing care for patients who refuse blood. The attached scenarios, involving patients who refuse blood, are followed by a series of questions about staff's views on providing care to such patients. The scenarios are hypothetical, but are based on cases that have occurred. You may be asked to respond to the questions orally or in writing. In either case, your name will not be associated with your answers. However, it would be helpful if you would provide the requested information about your clinical practice.

Thank you for sharing your thoughts with us.

### **Background**

The following background material is designed to offer a brief summary of some of the religious, ethical and legal issues that arise in such cases. Please review this information before answering the questions.

#### **Why Patients Refuse Blood**

In most cases, patients who refuse blood are Jehovah's Witnesses. In general, Jehovah's Witnesses willingly accept medical and surgical treatment. However, while there are individual variations in the beliefs of Jehovah's Witnesses, most believe that acceptance of blood is a violation of God's dictates as contained in the Bible. According to their beliefs, a Jehovah's Witness who voluntarily and without remorse accepts blood becomes estranged from God; forfeits the possibility of resurrection and eternal life with God; and may be shunned by the religious community. While Jehovah's Witnesses who are given blood against their will do not necessarily lose the opportunity for eternal life, they report feelings of physical and spiritual violation and, depending on their community, they may be ostracized.

## **Ethical Issues**

In general, there is ethical consensus that adults with decision-making capacity have the right to refuse blood even if such refusal could result in serious injury or death. This consensus is based on respect for a patient's bodily and spiritual integrity and for his or her right to make autonomous decisions based on religious or moral values. (Some ethicists would make exceptions --for example, if refusal could result in harm to an unborn fetus or abandonment of a minor child.) There is also ethical consensus that parents do not have the moral authority to refuse blood on behalf of infants and young children. There is less clarity about adolescents who are not yet 18 years old but who appear to have the capacity and maturity to make decisions on their own behalf (so-called "mature minors"). Some ethicists believe that the autonomy and integrity of mature minors should be respected and that such minors should be allowed to make their own decisions about medical care. Others believe that society's interest in protecting the health of minors -- even those who are mature -- should prevail, especially if the minor's decision could result in serious injury or death.

## **The Law**

There is legal consensus that adults with decision-making capacity have the right to refuse blood even if such refusal could result in serious injury or death. (Limited exceptions exist if refusal could result in harm to an unborn fetus or abandonment of a minor child.) There is also consensus that parents do not have the legal right to refuse medically necessary blood products on behalf of infants or young children. There is less clarity in regard to mature minors. In some cases, mature minors have been granted the legal right to refuse medically necessary blood products on their own behalf. In other cases, courts have ordered blood transfusions, either because the court was not convinced that the minor was mature or because the court determined that society's interest in protecting the minor should prevail.

## **Medical Caregivers**

There is no ethical or legal requirement that caregivers accept all those who seek treatment. Furthermore, in most cases, ethics and the law recognize the right of medical caregivers, as independent moral agents, to decline to participate in medical care that violates their religious or moral beliefs. However, the rights of caregivers to decline to provide care must be balanced against their obligation not to abandon their patients. There may be a greater obligation to provide care if adequate treatment cannot be obtained elsewhere.

## **Case Scenarios and Questions**

### **Case # 1**

The patient is 23 years old and is considered an adult under the law. He has aortic stenosis and has been a patient of Children's Hospital since birth. He has had previous cardiac catheterizations (the last one approximately 4 years ago). To date, he has not needed blood. He

now needs another cardiac catheterization and probable valve dilation. The risk of bleeding from such procedures is approximately 1%.

The patient experienced emotional difficulties as an adolescent, and is estranged from his parents. Three years ago, he married a Jehovah's Witness, and converted to the Jehovah's Witness faith. He and his wife are active in their religious community, and he has expressed happiness at finally finding acceptance and a purpose to his life.

The patient has consented to the procedures but, because he is now a Jehovah's Witness, has refused all blood products, based on his belief that accepting blood would result in estrangement from his wife, his religious community, and God. The clinical team believes that the patient understands the benefits and risks of treatment, including the increased risk resulting from his refusal of blood. The clinical team does not believe that there is any basis for questioning the patient's capacity to make medical decisions.

Questions: Scenario #1 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. This patient has the moral right to refuse blood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I would be willing to provide care to this patient if he were allowed to refuse blood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I would honor this patient's refusal of blood, even if blood became necessary to save his life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I believe that a staff member should be allowed to decline to provide care to this patient:				
a. based on the staff member's religious beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. based on the staff member's moral views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. based on the staff member's professional values	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I would support overriding this patient's decision and transfusing him against his will.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I would support transferring this patient to another hospital for treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Case # 2:**

The patient is 17 years old and has been a Jehovah's Witness all her life. She has expressed a strong commitment to her faith, and has recently been baptized. She refuses to accept blood

products. The clinical team believes that the patient understands the risks and benefits of surgery; has a coherent value system; and has used this value system to arrive at her decision. Her parents are Jehovah's Witnesses who share her belief that God prohibits the acceptance of blood products. They support her decision to refuse blood.

The patient has been a patient of Children's Hospital for many years. She is scheduled to have scoliosis surgery, and has been preparing for surgery by giving herself injections with EPO. There is a small risk of bleeding from the surgery.

For purposes of answering the following questions, assume that the clinical team has been advised that respecting the patient's decision would be consistent with the law.

Questions: Scenario #2 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. This patient has the moral right to refuse blood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I would be willing to provide care to this patient if she were allowed to refuse blood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I would honor this patient's refusal of blood, even if blood became necessary to save her life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I believe that a staff member should be allowed to decline to provide care to this patient:				
a. based on the staff member's religious beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. based on the staff member's moral views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. based on the staff member's professional values	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I would support overriding this patient's decision and transfusing her against her will.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I would support transferring this patient to another hospital for treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Case #3**

The patient is 19 years old, and is considered an adult under the law. He was receiving routine care at Children's Hospital, when he unexpectedly experienced significant blood loss and was admitted to the MICU. His hematocrit is 15 and is continuing to fall. The clinical team believes that it is likely he will die without a blood transfusion.

The patient's physician knew that the patient was a Jehovah's Witness, but did not expect the issue of blood transfusions to arise, as the therapy the patient was receiving posed minimal risk of blood loss. The clinical team in the MICU has spoken at length with the patient, who is awake and alert. The team believes that the patient understands his condition, his prognosis, and the need for blood products, and that he has decision-making capacity.

The patient has requested the presence of a Jehovah's Witness advocate, who has come to the Hospital. The patient has steadfastly refused all blood products based on his religious convictions, and the advocate has supported this refusal.

The patient is too sick to be transferred to another institution.

Questions: Scenario #3 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. This patient has the moral right to refuse blood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I would be willing to provide care to this patient if he were allowed to refuse blood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I would honor this patient's refusal of blood, even though blood is considered necessary to save his life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I believe that a staff member should be allowed to decline to provide care to this patient:				
a. based on the staff member's religious beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. based on the staff member's moral views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. based on the staff member's professional values	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. only if another staff member is available to provide care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I would support overriding this patient's decision and transfusing him against his will.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Additional Questions	Check one box from strongly agree to strongly disagree			
	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. I would support transferring an adult refusing blood to another hospital:				
a. in all circumstances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. only if it is more likely than not that the patient will need blood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. only if good care is available at the other hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. only if the patient does not have an existing relationship with Children's	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I would support transferring a mature minor refusing blood to another hospital:				
a. in all circumstances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. only if it is more likely than not that the patient will need blood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. only if good care is available at the other hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. only if the patient does not have an existing relationship with Children's	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I would support transfusing a patient over his or her objections if the need for blood was caused at least in part by medical negligence.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I would be more willing to care for a patient refusing blood if:				
a. I was informed about the refusal in advance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I knew there was a coordinated plan for treating the patient without blood	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I knew there was a process within the Hospital for determining that the patient has decision-making capacity and that he or she is making an informed, voluntary choice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I would support development of a coordinated program for caring for adults and mature minors refusing blood based on religious or moral values.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I would be willing to participate in such a program.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Please provide us with some general information about your practice.**

Profession:

Clinical Specialty:

Years of Experience:

Department or Unit:

Have you had any experience treating patients who have refused blood? If so, please describe your experience.









**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

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**APPENDIX G**



## APPENDIX G

### **DRAFT POLICY STATEMENT** **CHILDREN'S HOSPITAL POLICY ON REFUSAL OF BLOOD BY ADULTS**

#### *Option #1: Treat without Blood*

#### Adult Patients at Children's Hospital

Most of the patients treated at Children's Hospital are minors (below 18 years of age). However, from time to time Children's provides treatment to adults in need of certain specialized care or continues to provide treatment to patients who have reached the age of 18.

#### Underlying Principle

There is general consensus that, in most circumstances, adults with decision-making capacity have the moral and legal right to refuse blood products based on their religious beliefs or moral values, even if such refusal will lead to death or serious injury. Based on respect for the patient's autonomy and integrity, it is ethical, in those circumstances, for staff members to honor the patient's refusal. However, ethics and the law also recognize that physicians and other medical caregivers are moral agents, who have the right to decline to participate in such treatment if participation would violate their conscience, provided they do not abandon patients in need of care. This policy is designed to maximize the possibility that the values and rights of adult patients will be recognized and honored without compromising the values and rights of staff.

#### Policy on Adult Patients with Decision-Making Capacity

It is the policy of Children's Hospital to abide by the voluntary, informed refusal of blood by adult patients with decision-making capacity, provided that it is clinically appropriate to offer such treatment at Children's Hospital. The attending physician will work with the Coordinator to facilitate such treatment in accordance with the patient's wishes. If the physician cannot provide such treatment consistent with his/her own religious or moral beliefs, the physician and/or the Coordinator will inform the patient as soon as possible and refer or assist in the transfer of the patient to another physician at Children's or, if none is available, to another physician/institution, provided that transfer is consistent with the Hospital's legal obligations.

Exceptions to this policy may occur if the patient's death/serious injury could result in abandonment of a minor child or harm to a fetus. In addition, there may be rare circumstances in which, despite the efforts of the attending physician and the Coordinator, there is insufficient staff who can agree, consistent with their own religious and moral views, to provide treatment without blood. In such cases, the attending physician and/or the Coordinator will inform the patient as soon as possible and refer or assist in the transfer of the patient to another physician/institution, provided that transfer is consistent with the Hospital's legal obligations.

### Policy on Adult Patients without Decision-Making Capacity

If blood is being refused by a surrogate on behalf of an adult patient without decision-making capacity, it is the policy of Children's Hospital to abide by the refusal in the same circumstances in which it would abide by the refusal of an adult with decision-making capacity, provided that the surrogate has authority to refuse and that it is clear that he/she is acting in accordance with the patient's advance directive or substituted judgment.

### Policy on Mature Minors

If patients have not yet reached the age of 18 but meet criteria developed by the Hospital for "mature minors" (such as cognitive ability, emotional maturity, well-formed moral values, personal autonomy and responsibility) then their wishes in regard to medical treatment should be considered seriously and, in certain (albeit limited) circumstances, such patients should be allowed to refuse blood products. The criteria for evaluating maturity, and the process for applying the criteria in particular cases, remain to be developed.

### Policy on Emancipated Minors

There are various categories of "emancipated minor" under Massachusetts statutory law. The extent to which an emancipated minor may consent to – or refuse – medical treatment, including potentially life-saving treatment with blood, depends on the facts and circumstances, and on legal interpretation. Therefore, consistent with existing Hospital policy, cases involving minors who may be emancipated under Massachusetts statutory law will be handled on a case-by-case basis.

### Implementation

To implement this policy, Children's Hospital will:

1. Conduct educational sessions for staff regarding the religious beliefs and moral values of patients who refuse blood; the ethical and legal issues presented by such refusal; and the Hospital's policy in regard to cases involving refusal of blood by or on behalf of adults;
2. Provide staff with written procedures\* to follow when adults or their surrogates refuse blood;
3. Designate a staff member (the Coordinator) to coordinate cases involving refusal of blood;
4. Identify those types of treatment and procedures appropriately done at Children's Hospital without blood;
5. Maintain a referral list of physicians and institutions that accept adult patients refusing blood;
6. Develop and utilize special informed consent/release of liability forms for refusal of blood by adults or surrogates;

7. Disseminate this policy to members of the Jehovah's Witness Hospital Liaison Committee and others through [            ].

*[There would be a cross-reference to Hospital policy on circumstances in which a staff member may decline to participate in care.]*

**\*Written Procedures**

The procedures to be developed will address: (1) discussion with adult patients (or surrogates) in advance of treatment; (2) documentation of the discussion; (3) role of the Coordinator; (4) determination of whether the treatment/procedure is appropriately done at Children's without blood; (5) use of special consent/release of liability forms; (6) evaluation of authority of surrogate to refuse blood; (7) steps to be taken in the event that a team cannot be assembled to provide treatment without blood; (8) referrals to other physicians/institutions; (7) circumstances under which legal counsel should be contacted.









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**APPENDIX H**



## **APPENDIX H**

### **DRAFT POLICY STATEMENT CHILDREN'S HOSPITAL POLICY ON REFUSAL OF BLOOD BY ADULTS**

#### *Option #2: Refer or Transfer*

##### Adult Patients at Children's Hospital

Most of the patients treated at Children's Hospital are minors (below 18 years of age). However, from time to time Children's provides treatment to adults in need of certain specialized care or continues to provide treatment to patients who have reached the age of 18.

##### Underlying Principle

Ethical and legal principles support the choice of adults with decision-making capacity to refuse blood products, in most circumstances, based on their religious beliefs or moral values, even if such refusal will lead to death or serious injury. However, ethics and the law also recognize that physicians and other medical caregivers are moral agents, who have the right to decline to participate in such treatment if participation would violate their conscience, provided they do not abandon patients in need of care. This policy is designed to assist adult patients in obtaining treatment in accordance with their choice to refuse blood without compromising the values and rights of staff.

##### Policy on Adults with Decision-Making Capacity

Based on respect for the diverse moral values of its staff, it is the policy of Children's Hospital to refer or assist in the transfer of any adult patient with decision-making capacity who refuses medically necessary blood products and whose treatment carries more than a minimal risk of the need for such products. In the event that an adult patient with decision-making capacity being treated at Children's Hospital unexpectedly requires blood or has an emergency medical condition, and the patient cannot be transferred consistent with the Hospital's legal obligations, the Hospital will attempt to comply with the patient's refusal of blood,\* to the extent possible without violation of the moral integrity of staff.

##### Adult Patients without Decision-Making Capacity

If blood is being refused by a surrogate on behalf of an adult patient without decision-making capacity, it is the Hospital's policy to refer or assist the surrogate in the transfer of the patient in the same circumstances under which it would refer or assist in the transfer of an adult patient with decision-making capacity. If blood is being refused on behalf of an adult patient being treated at Children's Hospital who unexpectedly requires blood or who has an emergency medical condition, and the patient cannot be transferred consistent with the Hospital's legal obligations, the Hospital will attempt to comply with the surrogate's refusal of blood,\* provided that the surrogate has authority to refuse and it

is clear that he/she is acting in accordance with the patient's advance directive or substituted judgment, to the extent possible without violation of the moral integrity of staff.

*\*Exceptions may occur if the patient's death/serious injury could result in abandonment of a minor child or harm to a fetus.*

### Policy on Mature Minors

It is the Hospital's policy to provide blood to minors when medically necessary. Under certain circumstances, the Hospital may refer or assist in the transfer of a "mature minor" who appears to have decision-making capacity, who refuses medically necessary blood products, and whose treatment carries more than a minimal risk of the need for such products.

### Policy on Emancipated Minors

There are various categories of "emancipated minor" under Massachusetts statutory law. The extent to which an emancipated minor may consent to – or refuse – medical treatment, including potentially life-saving treatment with blood, depends on the facts and circumstances, and on legal interpretation. Therefore, consistent with existing Hospital policy, cases involving minors who may be emancipated under Massachusetts statutory law will be handled on a case-by-case basis. However, as a general matter, it is the Hospital's policy to refer or assist in the transfer of minors determined to be emancipated for purposes of refusal of blood, who refuse medically necessary blood products and whose treatment carries more than a minimal risk of the need for such products.

### Implementation

To implement this policy, Children's Hospital will:

1. Conduct educational sessions for staff regarding the religious beliefs and moral values of patients who refuse blood; the ethical and legal issues presented by such refusal; and the Hospital's policy in regard to cases involving refusal of blood by or on behalf of adult patients;
2. Provide staff with written procedures to follow when adults or their surrogates refuse blood;\*\*
3. Designate a staff member (the Coordinator) to coordinate the referral and transfer of adults who refuse blood products directly or through a surrogate;
4. As appropriate, identify types of treatments and procedures that carry more than minimal risk that the patient will need blood, and for which adult patients should be referred or transferred;
5. Maintain a referral list of physicians and institutions that accept adult patients refusing blood;

6. Develop and utilize special informed consent/release of liability forms for refusal of blood by competent adults or surrogates in those limited circumstances described in the Hospital's policy;
7. Disseminate this policy to members of the Jehovah's Witness Hospital Liaison Committee and others through [                    ].

*[There would be a cross-reference to Hospital policy on circumstances in which a staff member may decline to participate in care.]*

**\*\*Written Procedures**

The procedures to be developed will address: (1) discussion with adult patients (or surrogates) in advance of treatment; (2) documentation of the discussion; (3) role of the Coordinator; (4) determination of whether the treatment/procedure involves more than minimal risk; (5) use of special consent/release of liability forms in those limited circumstances described in the Hospital's policy; (6) evaluation of authority of a surrogate to refuse blood; (7) steps to be taken in the event of an unexpected need for blood or refusal of blood or on behalf of an adult patient with an emergency medical condition; (8) referrals and transfers to other physicians/institutions; (9) circumstances under which legal counsel should be contacted.









**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

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**APPENDIX I**



## APPENDIX I

### TWO APPROACHES TO REFUSAL OF BLOOD PRODUCTS BY ADULTS AND MATURE MINORS SUMMARY OF ADVANTAGES AND DISADVANTAGES

#### POLICY STATEMENT #1: TREAT WITHOUT BLOOD

##### Advantages

1. The approach described in Policy #1 would be consistent with the widely accepted ethical principle that adult patients with decision-making capacity have the right to refuse medical treatment, including treatment with blood products, regardless of whether such treatment is considered necessary to prevent harm or death.
2. By accepting and treating patients with decision-making capacity, who are refusing blood in accordance with their profoundly held religious beliefs or moral values, Children's Hospital would be demonstrating respect for patient autonomy and moral integrity.
3. This approach would be consistent with the well-established legal right of competent adult patients to refuse medical treatment, including treatment with blood products. To the extent there may be limited exceptions (for example, in cases of potential harm to a viable fetus or possible abandonment of minor children), this policy would incorporate these exceptions.
4. This approach would convey respect for the diversity of religious faiths and moral values of the Hospital community. It would be consistent with the manner in which the Hospital provides chaplaincy services.
5. To the extent that the principle of beneficence implies fostering a patient's autonomy, self-respect, and moral agency, this approach would fulfill the professional obligation of beneficence toward patients.
6. To the extent that respecting a patient's autonomy avoids harm to a patient's health, in the broadest sense, which includes psychological and spiritual health, this policy would help caregivers fulfill their obligation to do no harm.
7. This approach would be more likely to avoid the harms of coercion or treatment against a patient's will.
8. Adopting Policy #1 would encourage even greater efforts toward developing techniques for managing patients without the use of blood. Enhanced skills in clinically managing patients who refuse blood could benefit other patients who do not refuse blood but who might, in certain circumstances, fare better clinically without the use of blood products. The development of such skills might also increase the likelihood that infants and young children whose parents object to the use of blood could be treated safely without blood. Such techniques would be consistent with the current trend in medicine toward conserving blood as a potentially scarce resource, and would be helpful to Children's in the event that blood were to become even scarcer or new concerns were to arise as to its safety.
9. Under this policy, patients who are unable to accept blood based on their religious/moral convictions, would nonetheless have the opportunity to obtain the

high quality, specialized care offered by Children's. Children's would not be perceived as denying care to those who need it because of their religious beliefs or moral values.

10. This approach would foster continuity of care, in that young patients whose values preclude acceptance of blood would not have to be transferred as they become mature minors or adults.
11. Adopting an approach that accedes to the interests and rights of patients, despite the discomfort and stress imposed on caregivers, would evidence a commitment by the Hospital and its staff to the virtue of altruism.
12. Adopting this approach would be consistent with the growing ethical and legal recognition that certain minors possess decision-making capacity and, in certain circumstances, have a moral and legal claim to autonomy in medical decision-making.
13. Policy #1 would be consistent with the principle of developmental psychology that adolescents are in the process of developing, and at some point may acquire, the capacity and maturity to make decisions about potentially life-saving medical care.
14. Adopting this policy could lead to the development of a comprehensive approach to evaluating whether minors who appear to have decision-making capacity should be allowed to refuse treatment in certain circumstances. Such an approach could serve as a model for the Hospital as a whole and for other institutions as well.
15. It is likely that this approach would reduce the possibility that a patient with decision-making capacity would receive a blood transfusion against his wishes, and thus reduce the possibility of a claim of "battery" or lack of informed consent.
16. This approach would be less likely to pose the risk of an inappropriate or unsafe transfer.
17. Children's Hospital would gain even greater support from the Jehovah's Witness community.
18. Whatever approach is adopted, there will inevitably be circumstances in which a patient at Children's, who has decision-making capacity, refuses blood and cannot be transferred. If Policy #1 were in place, it would be more likely that the patient's wishes could be accommodated, consistent with the patient's moral and legal rights.

### **Disadvantages or Costs**

1. Adopting Policy #1 would mean accepting the possibility that, at some point, a patient at Children's Hospital, who might have been saved by the use of blood products, would die. Because the Policy contemplates that at least in some circumstances a minor might be allowed to refuse blood, the patient who dies might be a minor. Such a death could cause emotional distress for staff and potentially adversely affect the Hospital's reputation.
2. This approach would not be consistent with the traditional view that the professional obligation of beneficence requires a caregiver to act to preserve the patient's physical health. Under this policy, caregivers might feel that they could not fulfill their obligation of beneficence because they could not (in some circumstances) utilize a readily available, low risk treatment to preserve their patient's life and health.

3. This policy would have the disadvantage of potentially placing caregivers in the position of performing medical treatment on patients (e.g. chemotherapy or surgery) that results in a need for blood, which they would then be unable (based on the patient's refusal) to meet, which could be perceived as "doing harm" to the patient.
4. Adopting this approach would require an investment of resources, for a small number of patients, when these resources could be used instead to further Children's core mission. These resources could include:
  - Time and commitment of Hospital leadership to achieve the organizational change necessary to support the policy;
  - Educational efforts for all Hospital staff, and in particular for clinical staff who would be caring for patients refusing blood;
  - Development of administrative procedures for handling patients refusing blood;
  - Time and commitment of a "coordinator" for patients refusing blood;
  - Investigation of clinical practices in managing patients who refuse blood;
  - Clinical oversight of bloodless procedures performed at Children's;
  - Procedures for staff who choose reassignment;
  - New consent protocols and forms;
  - Development of criteria, and a process, for evaluating mature minors
5. This approach could require the reassignment of staff who choose not to provide care to patients refusing blood.
6. This approach could cause disharmony among staff and isolation of those staff members who treat patients refusing blood, particularly if a patient suffers harm or death.
7. The stated "policy" under this approach would be to abide by the refusal of blood by adults with decision-making capacity. Adopting this approach would seem to suggest that in most cases the Hospital would be able to find sufficient staff to provide care to patients refusing blood. Therefore, if Children's Hospital failed to abide by a patient's refusal of blood, because of insufficient staff willing to provide such care, then the Hospital could be seen as breaching its "promise" (even though the policy contains an exception for such situations).
8. Policy #1 would be inconsistent with the views of those who believe that minors generally lack the ability to make fully informed, voluntary, sound choices about potentially life-saving medical care.
9. Because the concept of "mature minor" is not clear, and there appears to be no consensus about when a mature minor should be allowed to refuse life-saving treatment, Children's Hospital would be operating in a "gray area," which poses challenges and risks.
10. Although Children's Hospital cares for some adults, it has a pediatric focus and adopting this policy could result in more adults seeking care at Children's.
11. If a patient who has refused blood suffers harm or dies during treatment, there would be some risk of legal action alleging negligence in: (1) not meeting the requisite standard of care by using blood when medically appropriate, (2) not meeting the requisite standard of care for treatment without blood, and/or (3) not transferring a

patient to hospitals/physicians more experienced in providing the treatment without blood.

12. Under this approach, there could be a lack of consensus about whether a treatment is “clinically appropriate” to be done at Children’s Hospital.

## **POLICY #2: REFER OR TRANSFER**

### **Advantages**

1. The approach described in Policy #2 would be consistent with the traditional concept of beneficence. Because patients refusing blood would generally not be treated at Children’s Hospital, caregivers (except in limited, unexpected situations) would be able to act to preserve patients’ health and physical well-being by treating with blood when medically indicated.
2. Under this policy, if treatment provided (e.g. chemotherapy or surgery) resulted in the need for blood, caregivers would be able to provide it, consistent with the obligation to “do no harm”.
3. This approach would also be consistent with the pediatric tradition of protecting the health and well-being of minors.
4. While Children’s Hospital treats some adults, it has a pediatric focus, and transferring adult patients refusing blood would be consistent with that focus.
5. This approach would minimize the possibility that a patient at Children’s Hospital (including a minor) who might have been saved by blood products would die or suffer harm. Thus, this approach would also minimize the stress and emotional cost to staff, as well as the potentially adverse publicity, of such a possibility.
6. Adopting this approach might result, overall, in better care for patients refusing blood, as they would be transferred to hospitals experienced in providing bloodless medicine/surgery and committed to respecting patients’ refusal of blood.
7. Adopting this approach would allow Children’s Hospital to conserve resources that could then be used to advance its core mission as a pediatric hospital.
8. Once this approach was implemented, it would reduce the possibility of disharmony among staff members over the care of patients refusing blood.
9. This policy would be consistent with the views of those who believe that minors generally lack the ability to make fully informed, voluntary, sound choices about potentially life-saving medical care.
10. Because this approach requires referral or transfer of all patients who might be allowed to refuse blood products, including “mature minors,” it would be more likely to avoid the “slippery slope” of trying to determine which minors have the capacity, and should have the right, to refuse blood.
11. The “promise” made by the Hospital under Policy #2 is more limited (that is, in those circumstances in which a patient with decision-making capacity is refusing blood and cannot be transferred, the Hospital would attempt to respect his/her wishes, provided there is sufficient staff willing to provide care.) Therefore, adopting this policy would reduce the risk that the Hospital would not be able to keep its “promise” to patients.



12. This approach would provide the less controversial, less demanding resolution of an ethical dilemma that has troubled caregivers, hospitals, ethicists and the courts for many years.
13. This approach would reduce the likelihood of potential liability for harm to a patient resulting from failure to provide blood.

### **Disadvantages or Costs**

1. By referring or transferring patients (with decision making capacity) who are refusing blood in accordance with their profoundly held religious beliefs or moral values to other institutions, Children's Hospital would be demonstrating an unwillingness to support these patients' autonomy and moral integrity.
2. This approach would not serve to advance patient health by fostering autonomy and moral agency and could cause psychological and spiritual harm.
3. This approach could result in the disruption of relationships between physicians and other caregivers and their patients. For example, if a patient indicated that he/she would refuse blood (and there was more than a minimal risk that blood would be needed), the patient would have to be transferred--even if the patient's physician and other caregivers were willing to treat without blood.
4. Young patients and their families (likely to refuse blood) would need to be apprised of the possibility of transfer in the future, undermining the development of trust, and continuity of care.
5. This approach would compromise the ability of Children's Hospital to offer its high quality, specialized care to patients from the community who are seeking such care.
6. To the extent that Children's Hospital is a resource of society, this approach would deny access to this resource to some patients.
7. Children's Hospital might be perceived as denying care to patients based on religious beliefs.
8. This approach towards adults with decision-making capacity is inconsistent with the stated policies of most hospitals that treat adults (including the other Harvard teaching hospitals whose policies we reviewed).
9. Limiting access to its services, transferring patients to other institutions, and declining to respect patient autonomy in certain cases could be perceived as inconsistent with the culture of Children's Hospital.
10. Children's Hospital's reputation in the community could be damaged.
11. Policy #2 would not completely avoid the problem of dealing with patients who refuse blood because there would be unexpected situations in which a patient refusing blood would be too sick to be transferred.
12. Under this policy, Children's Hospital would need to develop referral relationships, procedures for identifying patients to be referred or transferred, and procedures for making safe and timely referrals and transfers. Failure to develop and follow these policies in a reasonable way could pose the risk of liability.
13. Under this approach, the ethical dilemma of dealing with patients whose religious belief about blood appears to conflict with medical consensus about the use of blood would not be eliminated or resolved but simply transferred to another hospital.

14. The policy could be coercive, as sick patients might be frightened of being transferred (abandoned), and thus might consent unwillingly to treatment with blood.
15. It might be difficult to reach consensus as when patients should be transferred or referred. There could be differing views as to the meaning of "minimal risk," and as to what treatments/surgeries should (or should not) be done at Children's. Similarly, because patients' conditions change, and patients mature at different rates, it would be difficult under this Policy to decide when to refer or transfer patients. Disagreements on these issues could lead to inconsistent decisions about transfers/referrals, a recurrence of the problems encountered under the current *ad hoc* approach, and potential liability.
16. Under this approach, there would be a greater likelihood that a patient refusing blood, who could not be transferred, would be given blood products. This could result in psychological or spiritual harm to the patient, as well as possible allegations of battery or negligence (lack of informed consent) against the Hospital.
17. Policy #2 is inconsistent with the view that adolescents are in the process of developing, and at some time before the age of adulthood may acquire the capacity and maturity to make medical decisions.
18. If Children's were to take this approach, it would miss the opportunity to increase knowledge/understanding in the care of adults and mature minors, including an understanding of how to evaluate the decision-making capacity and rights of mature minors.
19. If this approach were adopted, Children's would miss the opportunity to develop enhanced clinical skills in the management of patients without blood.





**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

**FINAL REPORT**

**APPENDIX J**



In appropriate circumstances, the Hospital will consider a request by a staff member not to participate in aspects of a patient's care or treatment when such care or treatment conflicts with a staff member's bona fide ethical or religious beliefs or cultural values. Refer to the <http://web2.tch.harvard.edu/ethics> **Ethics Advisory Committee** internal web page for additional information. Under no circumstances will such a request be granted if there is any possibility that a patient's care or treatment will be adversely affected.

## **Guidelines**

Situations may arise in which a prescribed course of patient treatment or care may be in conflict with legitimate ethical or religious beliefs or cultural values of a staff member. Examples of such treatment or care include, but are not limited to, abortion (e.g., counseling before/after), seclusion, a child abuse case, Do Not Resuscitate (DNR), or comfort care (e.g., withholding or providing only comfort care). If such a situation arises and the staff member wishes to be excused from participating in the patient's care or treatment, it is the staff member's responsibility to promptly notify his or her supervisor or manager of his/her wishes and that aspect of care or treatment that presents a conflict.

The supervisor or manager decides to grant or deny the staff member's request after taking into account the needs of the patient, other patients, and the operations of the patient care unit. The supervisor or manager will make a reasonable effort to accommodate the staff member's request provided that such accommodation does not adversely affect the care or treatment of any patient or the proper functioning of the patient care unit.

The staff member making a request to be excused from participating in any aspect of the care or treatment of a patient is responsible for providing appropriate care and treatment until such time as approval of the request is given and alternative care arrangements are in place. Any refusal to provide or delay in providing care or treatment will result in disciplinary action up to and including termination of employment.

Staff members may request a transfer to a position in which conflicts regarding care and treatment issues are less likely to occur. Such requests shall be made and processed in accordance with policy and guidelines on transfers.









**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

**FINAL REPORT**

**APPENDIX K**



**Beth Israel Deaconess Medical Center  
Policy Manual**

**Title: BLOOD OR BLOOD PRODUCT REFUSAL**

**Policy #: PR-06**

**Purpose:**

Beth Israel Deaconess Medical Center abides by the informed treatment decisions of patients that are consistent with law and the professional ethics of caregivers. The following procedures represent the policy of Beth Israel Deaconess Medical Center with respect to a patient whose treatment at the Medical Center may involve the administration of blood or blood products, and who states that he or she does not wish to receive such treatment. These procedures also apply if a legal guardian, health care proxy agent or next of kin states that he or she will refuse to consent to administration of blood or blood products for an incompetent or a minor patient. Beth Israel Deaconess Medical Center will not require a caregiver to participate in a procedure that violates his or her professional ethics or conflicts with cultural values or religious beliefs.

**Policy Statement:**

Whenever possible, the Medical Center expects the physician to determine his or her patient's objections to the use of blood in advance of admission to the Medical Center, and to advise the patient of the Medical Center's policy. If a physician cannot by reason of conscience be responsible for the patient's care, the physician is expected to make alternative arrangements for the patient's care before the patient is admitted or the procedure performed.

**Definitions:**

**Capacity - The ability to understand the information regarding the nature and consequences of a procedure(s), its risks, possible complications, and alternatives; and to make an informed choice.**

**Competent- A person is considered competent unless determined legally incompetent by a court of law.**

**Emergent-** immediate services are required for the alleviation of severe pain or immediate diagnosis and treatment of unforeseeable medical conditions are required, if such conditions would lead to serious disability or death if not immediately diagnosed and treated.

**Non-emergent-** anything not defined as emergent

**Guideline(s) for Implementation:**

The attending or admitting physician shall determine if a patient objects to the use of blood or blood products; if the patient objects to the use of blood

-or blood products, the physician shall:

## A. Competent Adult Patients

### 1. Non-emergent

- Review the Guidelines for Patient Refusal of Blood or Blood Products with the patient
- Notify the Department of Anesthesia and Critical Care, the Blood Bank, and the Operating Room of a patient's intent to refuse blood or blood products. NOTE: Includes a patient who is scheduled for a minor procedure under local anesthesia who is not scheduled for admission to the Medical Center.
- Document in the patient's record the discussion with the patient regarding the risks and benefits of receiving, and not receiving, blood or blood products, the alternatives to transfusion, and the patient's decision. The discussion should include inquiry as to whether the patient is a parent, guardian, or primary caretaker of a minor child and as to the provision of care for the child.
- Have the patient sign the *Release of Liability for Blood Free Treatment* (Appendix B), notify the Department of Anesthesia and Critical Care (7-3112), the Blood Bank (7-3648), and the Operating Room of the patient's decision, and process the forms as follows:

*Original:* Patient's Record

*First Copy:* Send to Department of Anesthesia and Critical Care and the Operating Room

*Second Copy:* Send to Blood Bank

- Determine if there are willing caregivers within the Medical Center. ***If willing care givers are not available, the patient may be transferred to another facility; if the patient cannot be transferred, notify the Administrator-On-Call.***

2. **Emergent -If a competent adult, in an emergency, refuses treatment with blood or blood products, blood or blood products will not be administered.**

### 3. Special Circumstances

#### a. Parent of a Minor Child

Determine if the patient is a parent, guardian, or primary caretaker of any minor child; if so, have the patient sign the *Statement Regarding Arrangements for Care of a Minor Child* (Appendix A) and place the signed consent in the patient's record.

***If there is reasonable cause for concern that a minor child would not be adequately cared for by others, notify the Administrator-***

**On-Call.**

b. Pregnant Patient

Where issues arise regarding refusal of blood or blood products in the treatment of a pregnant patient, contact the Administrator-on-Call.

**B. Incompetent Adults**

1. Non-emergent

a) Health Care Proxy Agent or Legal Guardian Available

If the adult patient is **incompetent\***, a duly appointed health care proxy agent or a guardian may make treatment decisions on the patient's behalf. (See Medical Center Policy on Health Care Proxy for additional information on health care agents.) Request a copy of the Health Care Proxy or Guardianship Decree and place in the patient's medical record.

\* **Incompetent = The attending physician has determined and documented that the patient is unable to make or communicate treatment decisions.**

- If the adult patient is **incompetent** and there is a health care proxy agent or legal guardian, the physician shall observe the guidelines outlined above for the competent adult patient.

b). No Health Care Agent or Legal Guardian

- If the adult patient is **incompetent**, there is no health care proxy agent or legal guardian, and the situation is **non-emergent**, the physician shall:
  - Document evidence of the patient's wishes. If next of kin are available, discuss risks, benefits, and alternatives of treatment with and without blood and blood products, and elicit information, if any, regarding the patient's preferences. Document these discussions in the patient's medical record.
  - If there is convincing evidence of the patient's choice, have the next of kin sign the *Release of Liability for Blood Free Treatment* (Appendix B), process the form as outlined above in item III, A, 1 and notify the Department of Anesthesia and Critical Care, the Blood Bank, and the Operating Room of the patient's refusal of blood or blood products.

~ **Consult the Administrator On Call in all cases where there is no guardian or health care proxy agent.**

2. Emergent

If the adult patient is **incompetent**, there is no available surrogate decision maker, (health care proxy agent, guardian or next of kin) and the situation is **emergent**, the patient shall be transfused.

C. **Minor Patients**

If the patient is a **minor** and **absent a judicial determination**, emergency life-saving treatment, including transfusion of blood or blood products, shall be administered to the patient.

In the event that a parent or legal guardian is refusing transfusion of blood or blood products for a minor patient, contact the Administrator-On-Call.

**Notify the Administrator On Call when a surrogate decision maker is unavailable or when there is conflict or confusion regarding the course of treatment. Legal consultation is available. Where necessary, a Court determination, will be sought.**

**Vice President Sponsor: Ken Sands, M.D.**

**Approved By:**

**Operations Council**

**Sharon O'Keefe  
Chief Operating Officer**

**Medical Executive Committee**

**DeWayne Pursley  
Chair, MEC**

**Academic Council**

**Chair, Academic Council**

**Requestor Name: Jeff Driver**

**Date Approved: 10/01**

**Next Review Date: 10/04**

**Revised:**

**Eliminated: (Date)**

**References: See Refusal of Blood or Blood Products in BIDMC Manual of Clinical Practice. Changes made to this document must also be made in the Manual of Clinical Practice.**



**DANA-FARBER CANCER INSTITUTE**

**PATIENT CARE POLICY MANUAL**

**POLICY FOR PATIENTS REFUSING BLOOD OR BLOOD PRODUCTS**

**PURPOSE:** To describe the hospital's policy concerning a patient's right to refuse blood or blood products and the process to be followed in accomplishing that refusal.

**SCOPE:** This policy applies to all DFCI employees involved with patient care.

**POLICY:**

It is the hospital's policy to recognize the competent adult's declared right to refuse blood or blood products, and to obtain the patient's release of the hospital, its staff, and physicians, from liability for any injury resulting from the refusal of blood or blood products. It is also the hospital's policy to follow court rulings with respect to emergency treatment of minor patients.

This policy is consistent with the ruling of Massachusetts's courts that a competent adult may refuse medical treatment including the administration of blood products and its rulings concerning administration of blood products to minor patients.

**PROCEDURE:**

**Inpatients.** DFCI inpatients are admitted to DFCI beds at Brigham and Women's Hospital ("BWH"). Under the terms of the Joint Venture between DFCI and BWH, BWH policies and procedures generally govern patient services delivered to DFCI inpatients. Accordingly, BWH policies and procedures concerning the administration of blood or blood products, including consideration of the patient's right to refuse such administration in the context of a particular case, apply to DFCI inpatients. It is understood by the Offices of General Counsel at BWH and DFCI that whenever the OGC at BWH is consulted on a case involving a DFCI inpatient, that the OGC at BWH shall notify the OGC at DFCI, if possible, so that the two offices may consult together on the case.

**Outpatients.**

**1. Competent Adult Patients**

The physician should honor the competent patient's refusal of blood or blood products if the patient is able to understand the risks and possible consequences of that refusal. The patient's refusal and reasons for refusal should be documented in the physician's progress/dictated notes.

If a parent with one or more minor children refuses blood or blood products, and the children would be abandoned if the parent dies, the Social Work Office (632-3301),

Administrator on Call (632-3352), and the Office of the General Counsel (632-3606) should be notified immediately.

When appropriate, the clinician should discuss alternatives to blood products such as plasma expanders or growth factors, but shall advise the patient of the circumstances when these products may not be sufficient.

## 2. Incompetent Adult Patients

It may be appropriate to withhold blood or blood products when a patient cannot make or communicate treatment decisions, if prior to becoming incompetent the patient has signed a document such as living will stating a refusal of blood or blood products; or the patient appointed another person as a health care agent to make medical decisions, and that agent refuses treatment with blood or blood products on behalf of the patient. However, before failing to provide blood or blood products to an incompetent patient, the Office of General Counsel (632-3606) should be consulted.

## 3. Pregnant Patients

A pregnant woman presents a complicated legal situation because of the state's interest in the life of her fetus. In the latter stages of pregnancy, the administration of blood or blood products may be justified to preserve the life of the viable fetus. Before failing to provide blood or blood products to a pregnant patient, the Office of General Counsel should be consulted. (632-3606) After delivery, the mother has the right to refuse blood or blood products for herself unless any minor child would be abandoned if she died, but it would be prudent to consult the Office of General Counsel before failing to provide blood or blood products (632-3606).

## 4. Minor Patients

The courts have generally intervened to order hospitals to give blood transfusions to minors over the religious objections of their parents, stating that the state's interest in the welfare of children will override the parent or guardian's right to refuse blood or blood products on behalf of the child. Thus, if a minor child needs blood, and the parents refuse to consent to the administration of blood, the Office of General Counsel should be contacted (632-3606) to obtain a court order authorizing the blood transfusion.

Emergencies. In the event of an emergency that is life threatening, blood may be administered to the minor at the same time that the Office of General Counsel is being contacted to obtain a court order. (The Office of General Counsel may obtain a court order during or as soon as possible after the emergency transfusion.)

Mature minors. Mature minors may be permitted to make decisions for themselves under certain circumstances. If a child of 15 or older refuses to receive blood or blood products, consult the Office of the General Counsel. (632-3606), whether or not the child's parents agree or disagree with the child's decision.

Cross-Reference: Consent Guidelines PCP 4.01

Approved: Senior Management Committee, 04-96

Revised: Senior Management Committee, 03-99

Medical Staff Executive Committee 03-99; 01-02

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## **Blood: Care of Patients Requesting Blood-Free Treatment**

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### **Policy**

#### **I. Introduction**

The Lahey Clinic recognizes that an adult patient who is capable of decision-making generally has the right to refuse treatment, including blood transfusion, even if such refusal is likely to result in death. The Lahey Clinic also recognizes and affirms the right of physicians and other health care providers to refuse to engage in what they consider to be inadequate or unethical medical practice. The Clinic will not require a caregiver to participate in the care of a patient when doing so is inconsistent with the caregiver's professional or personal ethics, except in an emergency when a patient's life or well-being is in danger, and no other Lahey staff is available and willing to participate.

In order to assure that consensus exists between the patient and the attending physician as well as other members of the health care team, it is essential that at the earliest possible opportunity in the physician-patient relationship, the attending physician discuss with the patient the patient's wishes and alternatives to the use of blood or blood products. The physician should thoroughly document the content of such discussions in the patient's medical record.

#### **II. Non-Emergency Medical Or Surgical Admissions**

##### **A. Adult Patients Capable of Decision-Making**

1. The attending physician should determine prior to admission whether the patient will consent to the administration of blood and/or blood products. Where applicable, this discussion should include alternatives to the use of blood or blood products, such as autologous transfusions and the utilization of a cell saver, and the patient's wishes regarding such alternatives.
2. It is the responsibility of the primary hospital attending physician to determine whether treatment can be managed at the Lahey Clinic with reasonable safety and to assemble a team that is willing to participate in the patient's care while respecting the patient's request for blood free treatment. Where surgical procedures are involved, this requires discussion with the anesthesiologist.
3. If the appropriate team cannot be assembled expeditiously, the physician should offer to refer the patient to another facility that is able to care for the patient.
4. A physician who, in an elective situation, elects not to treat a patient who requests blood free treatment, should offer to transfer the patient's care to another Lahey Clinic physician who is willing to provide treatment or to a non-Clinic physician.
5. Prior to an elective admission, the patient who wishes blood-free treatment and has made that wish known must complete and sign the "Request for Blood-Free Treatment". This form is designed to apprise the patient of the risks of refusing to accept blood or blood products and to release Lahey Clinic, its physicians, and its support staff from liability for any injury that may result from the patient's request for blood-free treatment. This form will be available in all ambulatory clinics, in Ambulatory Surgery, and in the Hospital Admissions Department.
6. If the patient has a minor child or is pregnant, the patient must also complete and sign the "Statement Regarding Arrangements for Care of Minor Child". The name of the individual who will be accepting this responsibility must be provided. The purpose of this form is to notify the patient of the circumstances in which blood would be administered against their wishes in an emergency situation.

##### **B. Adult Patients Incapable of Decision-Making**

###### **1. Patients with Health Care Agents**

If, prior to becoming incapable of decision-making, the patient had appointed a health care agent under the Massachusetts Health Care Proxy Act or a similar advance directive statute from another state, and Lahey Clinic has been presented with a copy of the advance directive document, the agent may make treatment decisions, including the decision to request blood-free treatment, on the patient's behalf. Please refer to the Lahey Clinic Policy on Advance Directives for a description of the specific steps which the attending physician must take to activate the

agent's decision-making authority. The health care agent should complete the release form (including the statement of provision for care of minor child(ren) if applicable). If the patient objects to the treatment decision made by the patient's health care agent, Risk Management (Monday – Friday, 0800 – 1630) or the Administrative Supervisor (evenings, nights, weekends, holidays) should be contacted.

**2. Patients with Guardians**

If a patient has a court-appointed guardian for health care decisions, and Lahey Clinic has been presented with a copy of the guardianship decree, the guardian may make treatment decisions, including the decision to request blood free treatment, on the patient's behalf. The guardian should complete the release form (including the statement of provision for care of minor child, if applicable).

**3. Patients without a Guardian or Health Care Agent**

**a. Patients with Next of Kin**

In circumstances in which a patient is not competent to make treatment decisions and has no guardian or health care agent, next of kin may make treatment decisions on the patient's behalf, including the decision to request blood free treatment, in accordance with the Lahey Clinic's Guidelines on Informed Consent. The responsible next of kin should complete the release form (including the statement of provision for care of minor child(ren) if applicable). If disagreement among next of kin in the same class as to the proper treatment decision cannot be resolved through family meetings, ethics consultations or other conflict resolution strategies, if there is reason to doubt the good faith of the decision-maker, or if the patient objects to the treatment decision made by the patient's next of kin, Risk Management (Monday – Friday, 0800 – 1630) or the Administrative Supervisor (evenings, nights, weekends, holidays) should be contacted.

**b. Patients without Next of Kin**

If a patient has no next of kin available to make treatment decisions on the patient's behalf, Risk Management (Monday – Friday, 0800 – 1630) or the Administrative Supervisor (evenings, nights, weekends, holidays) should be contacted to facilitate the initiation of guardianship proceedings to make treatment decisions on the patient's behalf. If because of an unanticipated emergency, there is not sufficient time to utilize the formal judicial procedures during business hours for appointment of a guardian, administration should be contacted through Risk Management or the Administrative Supervisor to activate the Judicial Hotline to resolve treatment decisions on the patient's behalf. If the patient's medical condition is so urgent that there is not sufficient time to activate the Hotline, emergency medical treatment, including the administration of blood, should be provided.

Note: Absent an emergency, health care agents, guardians and next of kin cannot authorize the administration of blood over a patient's objections, even if the attending physician has determined that the patient is incapable of decision-making. In such circumstances, Risk Management (Monday – Friday, 0800 – 1630) or the Administrative Supervisor (evenings, nights, weekends, holidays) should be contacted to facilitate the seeking of a judicial determination of the patient's competency and appointment of a guardian to make treatment decisions on the patient's behalf. If the situation is an emergency, the procedures described in 3(b) above should be followed.

**III. Emergency Medical or Surgical Admissions**

**A. Adults Patients Capable of Decision-Making**

1. In an emergency situation, if the patient is capable of making an informed treatment decision and there is no compelling reason to believe that a minor child would be abandoned by the patient's death, the patient's request for blood free treatment should be honored.
2. The patient will be required to complete the "Request for Blood-Free Treatment" form and, if applicable, the statement of provision for care of a minor child. If the patient is physically unable to sign this form, it may be signed by a family member of the patient at the direction of the patient. If due to the urgency of the situation it is not possible for a signature to be obtained, the attending physician should thoroughly document the circumstances.

3. It is the responsibility of the primary hospital attending physician to assemble an appropriate care team willing to care for the patient in accordance with the patient's desire to receive blood free treatment. If the attending physician is unable to assemble the required team within a reasonable period of time, and the patient can be stabilized, the patient may be offered the option of being transferred to another facility which is willing and able to care for the patient in accordance with the patient's wishes. All such transfers must satisfy the requirements for an "appropriate transfer" as defined by the federal Emergency Medical Treatment and Active Labor Act ("EMTALA").
4. If a team willing to perform the procedure according to the patient's wishes cannot be identified, and the patient cannot be stabilized and transferred to another facility, Lahey Clinic physicians and staff shall provide appropriate care.
5. A psychiatric consultation should be obtained if the attending physician has reasonable doubts about the patient's capacity to understand the risks, benefits, and alternatives to the proposed treatment. Consultation with family members may be helpful in determining whether the patient's request for blood-free treatment is in accordance with the patient's settled beliefs. If the situation is so urgent that there is not sufficient time to obtain a consult, blood may be withheld upon the consent of the patient's health care agent (provided that Lahey Clinic is provided with a copy of the advance directive), guardian (provided that Lahey Clinic is provided with a copy of the guardianship decree) or next of kin as described above in section II (B). If the situation is so urgent that there is not sufficient time to obtain a consultation and no surrogate decision-maker is available, the physician should administer blood as necessary to preserve the patient's life or health.

**B. Adult Patients Incapable of Decision-Making**

Follow the guidelines at II (B) above.

**IV. Special Cases**

**A. Minors**

Under Massachusetts law, parents may not prevent a child from receiving life-saving medical treatment, such as a blood transfusion, on the grounds that the treatment is contrary to the wishes and/or beliefs of the parents. Parents should be informed that, absent a judicial determination to the contrary, blood will be administered over parental objection if necessary to preserve the life or health of a minor child.

If there is evidence that a minor child would be considered a mature minor for purposes of making health care decisions, Risk Management (Monday – Friday 0800 – 1630) or the Administrative Supervisor (evenings, nights, weekends, holidays) should be contacted.

**B. Pregnant Women**

If a pregnant woman refuses a blood transfusion, or a blood transfusion is refused on her behalf, the guidelines relating to other adult patients (See II and III above) will apply, prior to the probable viability of the fetus. For purposes of this policy, a fetus is considered to be viable from the age of 24 weeks onward. The "Request for Blood-Free Treatment" should be completed.

If the fetus is viable, the Statement Regarding Arrangements for Care of Minor Child(ren) should also be completed. If the refusal threatens the life or health of a viable fetus, the patient should be informed that the Clinic has an obligation to the fetus and will transfuse the patient unless time permits obtaining a judicial determination of the state's interest in protecting the fetus. Risk Management (Monday – Friday, 0800 – 1630) or the Administrative Supervisor (evenings, nights, weekends, holidays) should be contacted immediately to facilitate the administrative response in all cases involving requests for blood-free treatment by a woman with a viable fetus. In the event that an obstetrician is not available to determine the age of the fetus, the attending physician should make an estimation of fetal age based upon the information which is available.

Contact: Donna Cameron, J.D.  
Vice President, Legal Affairs

References: David Steinberg, M.D., Ethics Committee  
Elders - Jehovah's Witness Community

Origination date: 1991  
Reviewed/Revised: 1993, 1995, 1996, 1999, 2002  
Approved by: Medical Practice and Utilization  
Board of Governors  
Operations





## **Rainbow Babies & Children's Hospital Center for Bloodless Medicine and Surgery (CBMS) POLICY**

### **Definition**

The Center for Bloodless Medicine and Surgery is dedicated to the right of each family/individual in requesting non-blood medical treatment.

The Center for Bloodless Medicine and Surgery will identify physicians to support the goals and objectives of the bloodless program through patient care protocols, education, and innovative research in the field of bloodless medicine.

### **POLICY**

It is the policy of the Center for Bloodless Medicine and Surgery program within Rainbow Babies & Children's Hospital to uphold the following:

- A. All patients entering the Center for Bloodless Medicine and Surgery (CBMS) program will be screened by a CBMS program coordinator who will coordinate the medical, emotional, physical, spiritual and mental needs of the patient/family. The coordinator will work closely and in harmony with the patient, patient's family, physicians, nursing staff, and ancillary personnel.
- B. To recognize and uphold within the framework of Ohio's legal guidelines a patient's/families decision to refuse (all or part): whole blood, blood plasma, packed red blood cells, white blood cells, platelets, blood fractions®, or blood derivatives. \*
- C. For a patient/family to receive direct ongoing communication with the primary physician with regard to medical interventions and risks related to the administration of or the refusal of blood products. \*

D. To observe in the adult or emancipated minor the primary physician's written orders stating "no blood transfusions" which will override any other written or verbal order regarding the use of blood or blood products.

E. In the event a patient's condition would require the need of a consulting physician, the primary doctor will consult, wherever possible, with a team member of the Center for Bloodless Medicine and Surgery program.

F. The physician participants will agree that in urgent and/or emergent medical care situations when the treating physician deems the use of blood products and/or blood transfusion necessary, to prevent death or serious bodily harm to a child, the treating physician will discuss this with the parent. If the parent still refuses, the physician will report the parent's refusal to the local child welfare authorities. Physicians are required to do so by law. However, every attempt to notify the parents will be made if any such report is contemplated.

G. If, in the rare occasion during the course of treatment an emergency suddenly arises which allows no time to report the matter to child authorities, the medical team will still do its best to honor your refusal and treat your child without blood, using all alternatives available and/or appropriate. However, if the treating physicians deem blood is immediately necessary to prevent death or serious bodily harm to the minor, the law permits them to administer blood without your consent.

H. A physician member who is part of the Center for Bloodless Medicine and Surgery program may withdraw from this program at any time. He/she should contact the CBMS Coordinator, in writing, to withdraw from participation in this program.

\* Note: See policy 6.1, Consent for Procedure, and policy 1.C in the Administrative Policy & Procedure Manual, Vol.II.

"Adult": A person who is 18 years of age or older. In cases involving minors thought to be emancipated, the attorney on call should be consulted.

- "Minor": A patient under the age of 18.

® The Jehovah's Witness religious understanding does not absolutely prohibit the use of components such as albumin,

immunoglobulins, and clotting factor preparations; each patient must decide individually if he will accept these.

### **RBC Ethics COMMITTEE**

If, at any time, a conflict should arise related to any aspect of the above policy, the RBC Ethics Committee may be consulted.

### **RESPONSIBILITY**

Director/Coordinator of the Center for Bloodless Medicine and Surgery, in collaboration with the RBC Ethics Committee, is responsible for interpretation, review and update of this policy as frequently as necessary, but not less than every three years.

Revised: January 2002

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THE NORTH SHORE MEDICAL CENTER <i>SALEM HOSPITAL</i>	Policy Number: II-E-5b
Title: Patients Refusing Blood or Blood Products	Page: 1 of 4
Approved by:	Date this issue: February 2001 Date last issue: 7/98
For Further information, contact: David B. Wright	

**POLICY:**

It is the Hospital's policy to recognize the competent adult's declared right to refuse blood, and to obtain the patient's release of the Hospital, its staff, and physicians, from liability for any injury resulting from the refusal of blood. If the patient has any minor children, the patient must also sign a separate statement naming the other parent or a parent substitute as caretaker for the minor children, including any newborn.

**NOTE:** This policy is consistent with the decision of Massachusetts courts that a competent adult may refuse medical treatment, including the administration of blood. As recognized by the courts, this right is conditioned upon there being no compelling evidence that a minor child would be abandoned in the event of the patient's death. Where there are minor children, there must be evidence that the other parent or a substitute parent is ready and able to care for the minor children.

The Massachusetts courts also recognize the rights of health care providers to refuse to perform or participate in medical procedures if doing so is contrary to the providers' ethical beliefs. In such cases, the physician and hospital shall assist the patient in locating alternative care and treatment.

**PROCEDURE:**

1. Competent Adult Patients.

In a **non-emergency situation**, the physician may honor the patient's refusal and have the patient sign a Release of Liability for Blood-Free Treatment. If he or she has any minor children, the patient must also complete the Statement Regarding Arrangements for Care of Minor Child. If the patient has a spouse, the spouse must also sign the Release of Liability for Blood-Free Treatment and Statement Regarding Arrangements for Care of Minor Children forms. Signatures must be witnessed. If the patient does not do so or if there are questions about the suitability of any person named as caretaker, hospital legal counsel should be consulted before treatment proceeds.

In an **emergency situation**, where the patient requires an immediate transfusion to prevent death or a serious impairment of his or her physical condition, the physician may honor the patient's refusal of blood if the patient is able to understand the risks and possible consequences of that refusal, and there is no

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compelling evidence of abandonment of any minor child. A signed Release (and Statement Regarding Arrangements for Care of Minor Child, if applicable) should be obtained, including the signature of the patient's spouse, as described above. If that is not possible, the circumstances should be thoroughly documented in the medical record. If in an emergency case the physician has ethical objections to proceeding with a blood restriction and alternative care and treatment cannot be arranged, the physician should proceed with transfusion.

In the case of a **surgical procedure**, it is the surgeon's obligation to assemble a surgical team that agrees to participate in the surgery and respect the patient's refusal of blood, whatever the outcome. For instance, the surgeons, anesthesiologists and nursing personnel who will be caring for the patient must be aware of the restriction in advance of the surgery. Hospital staff who have moral objections are not required to participate in such surgery (except in an emergency if there is no one else available).

## 2. Incompetent Adult Patients

In a **non-emergency situation**, the physician may honor a refusal made on behalf of the patient only in the following circumstances:

- a. Where a healthcare agent makes such a decision upon presentation of a valid Health Care Proxy; or
- b. Where there is evidence that the patient, if competent, would have refused the transfusion. The process of determining the patient's wishes is referred to as "substituted judgement". For example, the patient when competent at an earlier time, may have informed the physician of his or her wish not to have a transfusion. Alternatively, the patient may have executed a document when competent, such as a living will, expressing his or her wish to refuse a transfusion. There may be an obligation to honor such a patient's wishes, depending on the manner in which the patient indicated the refusal; the likelihood that the patient would need a transfusion at the time of the refusal; the medical circumstances at the time of the patient's refusal, whether contemporaneous or otherwise; and the

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- c. length of time between the patient's refusal and the proposed transfusion.  
Any questions should be referred to hospital legal counsel.

In an emergency situation, where the incompetent patient requires an immediate transfusion to prevent death or a serious impairment of his or her physical condition, the physician should proceed with the transfusion.

### 3. Minors

In a **non-emergency situation**, the physician should not accept the refusal of a transfusion by a patient who is under eighteen years old, nor should he or she accept a refusal on the patient's behalf by the patient's parent, other family member or guardian. When a minor or the minor's representative refuses a transfusion, the physician should contact hospital legal counsel. If necessary, the Hospital will request a court order for the transfusion and any other relief needed to render medically necessary treatment to the child.

In an **emergency situation**, where the minor requires an immediate transfusion to prevent death or a serious impairment of his or her physical condition, the physician should proceed with the transfusion.

In the case of an **emancipated minor**, the policy relating to Competent Adult Patients shall be followed.

### 4. Pregnant Patients

In a **non-emergency situation**, the rights of the mother to refuse a transfusion depend upon the viability of the fetus. Where the fetus is non-viable, the physician may honor the refusal of the mother to accept a transfusion and have the patient, as well as the patient's spouse, sign a Release of Liability for Blood-Free Treatment form. Where the fetus is viable, the physician should contact hospital legal counsel and if necessary, the hospital will request a

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court order for the transfusion. Where there are questions as to viability, an obstetrical consultation should be obtained.

In an emergency situation, where the mother requires an immediate transfusion to prevent death or a serious impairment of her physical condition, the physician should proceed with the transfusion.

5. Informed Consent/Refusal of Treatment

It is often the case that family members or friends of the patient may wish to be present at and participate in the discussion of informed consent or in this case, a refusal of treatment. Given the confidential nature of the physician - patient relationship and the personal nature of decisions relating to acceptance or refusal of blood or blood products, it is recommended that the discussion involve only the patient and his or her physician.

6. Alternative Treatment/Procedures

In an effort to accommodate the patient who refuses blood or blood products, consideration should be given to alternative treatment or procedures. For example, in the case of a Jehovah's Witness, any device, which provides for the continuous flow of blood, such as a cell saver, may be acceptable.



**RELEASE OF LIABILITY FOR BLOOD-FREE TREATMENT**

TREATMENT/PROCEDURE: \_\_\_\_\_

I request that I receive no blood or blood products during hospitalization for this treatment/procedure or delivery even if such treatment is deemed necessary in the opinion of the attending physician or surgeon or any of his or her assistants to preserve my life or promote recovery. I fully understand and have carefully considered the possible consequences, up to and including death, which may result from the withholding of blood.

I hereby release The North Shore Medical Center, Salem Hospital, their trustees, medical staff, employees, and all other agents from all responsibility and from all liability to me, my dependents and my estate which may be caused by my refusal to permit the use of blood or blood products, including without limitation, liability for any injury, harm or damages suffered by me resulting from the negligence, provided that the injury, harm, or damages from such negligence could have been avoided had the hospital and its staff been able, contrary to my express desires, to administer blood or blood products to me.

COMPLETE AS APPLICABLE:

\_\_\_\_\_ I further state that I have no minor children and, if female, that to the best of my knowledge I am not pregnant.

\_\_\_\_\_ I have \_\_\_\_\_ minor children and/or if female, I am pregnant, I have completed and attached a statement of the arrangements I have made for the care of my minor children and/or newborn in the event of my death.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature (Patient)

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature (Spouse)

\_\_\_\_\_  
Witness







**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

**FINAL REPORT**

**APPENDIX L**



Adolescent Decision Making  
A Selected Bibliography  
Annotation by Barbara Burr for meeting 4/2/03

Neither Youth nor Childhood is Folly or Incapacity. Some Children are Fools and So are  
some Old Men. –William Blake

Clinical Perspectives:

1. King NMP, Cross AW. Children as decision makers: Guidelines for pediatricians. J Pediatr 1989;115:10-16.

*The authors recognize that as in adult decision-making, it is important to assess reasoning ability, understanding, voluntariness and the nature of the decision when assessing childrens' capacity for informed consent. They imply that the pediatrician on a case by case basis should in the course of the doctor patient relationship assess the child's capacities to participate in decision-making and that this is a fundamental part of this relationship.*

2. Leikin S. A proposal concerning decisions to forgo life-sustaining treatment for young people. J Pediatr 1989;115:17-22.

*The child's interest in his own health care is more important than that of any other party. The author sees the physician as obligated to determine the level of maturity of the seriously ill juvenile and to facilitate the child's self-determination concerning his medical fate. He feels maturity is best determined by the patients overall understanding of the situation combined with his experience with illness as opposed to using standardized psychological measurements. He includes assessing a patient's comprehension of death, its significance and finality.*

3. Frader J. Younger yet wiser. The Park Ridge Center Bulletin Jul/Aug 2000:3-4.

*Describes a case of a 17y/o Jehovah's Witness with leukemia in which the Illinois Supreme Court judged the girl to be adequately mature to refuse blood transfusion and that her mother's agreement did not constitute neglect. This decision reflects a legal trend recognizing the arbitrariness of using age as the criterion for determining decision making capacity. Questions raised include: whether decisions based on religious convictions are different from decisions based on other sorts of prior beliefs and experiences, and whether we use different standards for minors than for adults in determining whether a choice is "rational." This author concludes that minors ought to have a chance to win the respect of judges and clinicians, and that it should not matter whether the choice involves spiritual beliefs or other issues.*

4. Roth LH, Meisel, Lidz CW. Tests of competency to consent to treatment. Am J Psychiatry 1977;134:279-284.

*There is no single test of competency. Tests fall into five categories: 1) evidencing a choice, 2) "reasonable" outcome of choice, 3) choice base on "rational reasons", 4) ability to understand and 5) actual understanding.*

Factors in the selection of competency tests:

<i>Patient's Decision</i>	<i>Risk/Benefit Ratio of Treatment</i>	
	<i>Favorable</i>	<i>Unfavorable/Questionable</i>
<i>Consent</i>	<i>Low test of competency</i>	<i>High test of Competency</i>
<i>Refusal</i>	<i>High test of competency</i>	<i>Low test of Competency</i>

5. Lawry K, Slomka J, Goldfarb J. What went wrong: Multiple perspectives on an adolescent's decision to refuse blood transfusions. Clinical Pediatrics June 1996:317-321.

*A case is described in which a 17y/o Jehovah's Witness adolescent urgent need for surgery was delayed due to a low hct. His care was compromised by lack of consensus about treatment planning among his physicians and by an inadequate understanding of the social context of the patient's problems. The authors advocate for a strong patient doctor relationship to resolve treatment impasses.*

Theoretical Perspectives:

\*1. Scott ES, Reppucci ND, Woolard JL. Evaluating adolescent decision making in legal contexts. Law and Human Behavior 1995;19:221-244.

*While it is often asserted that many adolescents can make decisions as well as adults, the empirical basis for this assertion is shaky. Early researchers based competence in making decisions on reaching the cognitive stage of formal operations as described by Piaget (often around 11). Currently most psychologists believe that children at a given stage more likely than not reason differently depending upon the task. Additionally, personal and environmental characteristics may differentially enhance and impair performance. Most studies do not compare adolescent and adult decision making in legally relevant contexts or under conditions that*



*resemble daily life. Thus the authors suggest that scientific authority for adolescent decision making is tentative at best.*

*The authors also suggest that adolescent decision making should consider judgment as well as understanding, in that adolescents as a class may have poorer judgment than adults, and therefore to accord them similar freedoms in decision making may have greater costs (and there may be societal interest in preventing harm). Three developmental factors that may differentially affect decision making of adolescents and adults are 1) changing relationships with peers and parents, 2) assessment of and attitude toward risk and 3) differences in temporal perspective with adolescents likely to weigh more heavily the short term rather than long term consequences of decisions. Additionally, family structure and dynamics as well as the larger cultural environment may constrain or enhance autonomy and decision making opportunities. The authors advocate more research in context specific and naturalistic settings on "judgment factors" as they influence decision making, including whether giving adolescents increased participation in treatment decisions might increase adherence.*

2. Weir RF, Peters C. Affirming the decisions adolescents make about life and death. Hastings Center Report 1997;27:29-40.

*This paper traces both historical changes in pediatric thinking about children's decision making and evolving legal views including such concepts as emancipated minor, mature minor, and minor treatment statutes. The paper argues for practice guidelines to be developed for recognizing the preferences of terminally ill, critically ill or chronically ill adolescents and suggests steps that may be taken to do so. They suggest that adolescents be allowed to execute advanced directives, similar to adults.*

3. Lewis CC. How adolescents approach decisions: Changes over grades seven to twelve and policy implications. Child Development 1981;52:538-544.

*The decision advise of 108 adolescents at 3 grade levels was investigated in a simulated peer-counseling situation (no adult comparison group was used). With increasing grade level from 7th to 12th, there were increases in the mention of risks, future consequences of decisions, recognition of vested interests of adult professionals and greater likelihood of suggesting that advise of independent specialists be sought. Children at all grade level recommended seeking advise from parents and peers. The author cautions that the relationship between "advice-giving" and "decision making" is unknown. Also that the study cannot be generalized to adolescents who have had substantial experience making life decisions.*

## Legal/Ethical Perspectives

1. Gardner W, Scherer D, Tester M. Cognitive development and adolescent legal rights. *American Psychologist* 1989;44:895-902.

*This article examines scientific arguments presented (by the American Psychological Association) as legal briefs in court cases involving adolescent abortion rights. Among the requirements of informed consent is generally that a patient appreciate the personal consequences of treatment alternatives, a potentially complex undertaking. The briefs concluded that data suggests there is no difference between adolescents and adults in capacity to make sound health care decisions. The authors argue that data suggests cognitive development is not in fact stage like (in the sense of Piaget formal operations) and there is no single competence necessary to consent to medical treatment. They caution that there exists a tension between our duties to be effective partisans for social goals and disinterested critics of our ideas. Overstatement of social and scientific findings has costs both to psychology and to the legal system in that decisions may endow false claims with social authority.*

2. Derish MT, Vanden Heuvel K. Mature minors should have the right to refuse life-sustaining medical treatment. *Journal of Law, Medicine, & Ethics* 2000; 28:109-124.

*Minors are presumed under law incompetent to make their own medical decisions. Parental authority to make decisions for them is based on the presumption parents will act in their child's best interests, and on the constitutional right to privacy in family matters. The American Academy of Pediatrics, starting in the 1980's, began to argue that children facing high stakes choices in medical situations should have a major role decisions. However, guidelines regarding who should determine the capacity to consent have been strikingly lacking. Several court cases upholding a mature minor's right to consent are reviewed. The authors conclude that the mature minor doctrine does not yet offer a legal framework that can accommodate a child who wishes to make autonomous medical decisions. The authors distinguish life-sustaining medical treatment from life-saving treatment. For the former, they propose that the medical and legal professions work together to develop a process to resolve these problems. They further suggest that the Patient Self Determination Act (PSDA) be amended to include minors.*

3. Ross LF. Health care decision making by children: Is it in their best inters? *Hastings Center Report* 1997;27:41-45.

*The author makes the argument that competency of minors is a necessary but not sufficient basis for respecting a minor's decision making. Reasons offered for limiting children's autonomy include: 1)that children need a protected period in which to develop "enabling virtues" including*

*self-control, 2) that children's decisions are based on limited life experiences, 3) that parental autonomy promotes the needs of parents and children and 4) that health care rights are not so different from a variety of other rights our society does not grant to minors. The author strongly advocates that parents be final decision makers.*

4. Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics* 1995; 95:314-317.

*The committee on bioethics of the American Academy of Pediatrics proposes that parents and physicians not exclude children and adolescents from decision making without persuasive reasons. The committee states: "physicians have an ethical (and legal) obligation to obtain parental permission to undertake recommended medical interventions. In many circumstances, physicians should also solicit a patient assent when developmentally appropriated. ...adolescents, especially those age 14 and older, may have as well developed decisional skills as adults for making informed health care decisions...and the Academy encourages physicians to obtain the informed consent of the patient..."*

### Textbooks

1. Group for the Advancement of Psychiatry. *How Old is Old Enough? The Ages of Rights and Responsibilities*. Report No. 126. New York, NY: Bruner/Mazel; 1989.

2. Grisso T, Appelbaum PS. *Assessing Competence to Consent to Treatment*. Oxford: Oxford University Press; 1998.

3. Lewis M, Volkmar F. *Clinical Aspects of Child and Adolescent Development*. (3rd Ed) Philadelphia, PA: Lea & Febiger; 1990.







**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

**FINAL REPORT**

**APPENDIX M**





## Assessment of Decision-making Capacity of Adolescent Patients

Preliminary thoughts regarding development of a semi-structured interview:

### -Purpose

1. Provide excellent, respectful clinical care
2. Presume that for an adolescent, a higher level of scrutiny regarding decision-making capacity than for adults is ethically and clinically appropriate given developmental uncertainties etc.
3. Promote adolescent's ability to articulate his/her point of view
4. Support patient's unique cultural, spiritual and family values
5. Understand role of spiritual beliefs in medical decision making
6. Assess cognitive and emotional resources for making decisions
7. Provide support, understanding, further information if needed, while maintaining openness and honesty about the evaluation process and purpose
8. Gather sufficient information so that the care team can make a reasonable judgment about letting adolescent make an autonomous decision

### -Process

1. Expand and modify a tool such as the MacArthur Competence Assessment Tool (Grisso and Applebaum: Assessing Competence to Consent to Treatment) which probes patient's understanding and appreciation of his/her disorder, risks and benefits of alternative treatments, reasoning behind decisions including consequential thinking, logical consistency etc. and ability to make a choice.  
Modifications should address:
  - a. Appreciation for how the adolescent functions in family, school and social situations.
  - b. Role of parents or other adults in making medical decisions
  - c. Level of ambivalence or conviction regarding making decisions independently in general and regarding the particular decision in question
  - d. Adolescent's past experience making difficult decisions or coping with complex situations.
  - e. Future plans and goals, and capacity to appreciate impact of choices on the future including possibility of death, effect on family etc.
2. Screen for depression, anxiety and other emotional or learning difficulties which might impair decision-making
3. Assess general ability to cope with medical situations, including prior ability to assume responsibility







**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

**FINAL REPORT**

**APPENDIX N**



**Summary of Focus Group Results Total Sample = 24**

**June 4th 2003**

Questions Scenario #1 Check one box from strongly agree to strongly disagree

	<b>Strongly Agree</b>	<b>Somewhat Agree</b>	<b>Somewhat Disagree</b>	<b>Strongly Disagree</b>	<b>N/A</b>
1. This patient has the moral right to refuse blood.	87.5	8.3	4.2		
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	75.0	12.5	12.5		
3. I would be willing to provide care to this patient if he were allowed to refuse blood.	54.2	20.8	16.7	8.3	
4. I believe that a staff member should be allowed to decline to provide care to this patient:					
a. based on the staff member's religious beliefs	37.5	29.2	16.7	16.7	
b. based on the staff member's moral views	16.7	37.5	20.8	20.8	4.2
c. based on the staff member's views as to what constitutes good medical care	29.1	37.5	12.5	4.2	16.7
5. I would support overriding this patient's decision and transfusing him against his will.		4.2	8.3	87.5	
6. I would support transferring this patient to another hospital for treatment.	54.2	25.0	8.3	8.3	4.2

Questions Scenario #2 Check one box from strongly agree to strongly disagree

	<b>Strongly Agree</b>	<b>Somewhat Agree</b>	<b>Somewhat Disagree</b>	<b>Strongly Disagree</b>	<b>N/A</b>
1. This patient has the moral right to refuse blood.	75.0	16.7	4.2		4.2
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	62.5	16.7	12.5	4.2	4.2
3. I would be willing to provide care to this patient if she were allowed to refuse blood.	50.0	16.7	25.0	8.3	
4. I believe that a staff member should be allowed to decline to provide care to this patient:					
a. based on the staff member's religious beliefs	16.7	20.8	20.8	16.7	25.0
b. based on the staff member's moral views	12.5	25.0	16.7	16.7	29.2
c. based on the staff member's views as to what constitutes good medical care	12.5	37.5	25.0	4.2	20.8

5. I would support overriding this patient's decision and transfusing her against her will.	37.5	4.2	16.7	41.7	
6. I would support transferring this patient to another hospital for treatment.	50.0	16.7	8.3	16.7	8.3

Questions Scenario #3 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	N/A
1. This patient has the moral right to refuse blood.	83.3	4.2	4.2	4.2	4.2
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	62.5	26.0	4.2	4.2	4.2
3. I would be willing to provide care to this patient if he were allowed to refuse blood.	54.2	20.8	12.5	8.3	4.2
4. I believe that a staff member should be allowed to decline to provide care to this patient:					
a. based on the staff member's religious beliefs	12.5	29.2	4.2	25.0	29.2
b. based on the staff member's moral views	12.5	37.5	8.3	16.7	25.0
c. based on the staff member's views as to what constitutes good medical care	20.8	33.3	12.5	4.2	29.2
d. only if another staff member is available to provide care	20.8	16.7	12.5	20.8	29.2
5. I would support overriding this patient's decision and transfusing him against his will.	8.3	12.5	16.7	54.2	8.3



Additional Questions Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	N/A
1. I would support transferring an adult refusing blood to another hospital:					
a. in all circumstances	41.7	16.7	16.7	16.7	8.3
b. only if I believe that good care is available at the other hospital	20.8	33.3	4.2	12.5	29.2
c. only if the patient does not have an existing relationship with Children's	4.2	16.7	12.5	41.7	25.0
2. I would support transferring a mature minor refusing blood to another hospital:					
a. in all circumstances	41.7	16.7	16.7	16.7	8.3
b. only if I believe that good care is available at the other hospital	16.7	33.3	4.2	12.5	33.3
c. only if the patient does not have an existing relationship with Children's		4.2	20.8	41.7	33.3
3. I would support transfusing a patient over his or her objections if the need for blood was caused at least in part by medical negligence.	4.2	12.5	20.8	37.5	25.0
4. I would be more willing to care for a patient refusing blood if:					
a. I was informed about the refusal in advance	58.3	20.8	16.7	4.2	
b. I knew there was a coordinated plan for treating the patient without blood	66.6	16.7	4.2	8.3	4.2
c. I knew there was a process within the Hospital for determining that the patient has decision-making capacity and that he or she is making an informed, voluntary choice	54.1	33.3	4.2	4.2	4.2
5. I would support the development of a coordinated program for caring for adults and mature minors refusing blood based on religious or moral values.	75.0	8.3	8.3	4.2	4.2







**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

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**APPENDIX O**



now needs another cardiac catheterization and probable valve dilation. The risk of bleeding from such procedures is approximately 1%.

The patient experienced emotional difficulties as an adolescent, and is estranged from his parents. Three years ago, he married a Jehovah's Witness, and converted to the Jehovah's Witness faith. He and his wife are active in their religious community, and he has expressed happiness at finally finding acceptance and a purpose to his life.

The patient has consented to the procedures but, because he is now a Jehovah's Witness, has refused all blood products, based on his belief that accepting blood would result in estrangement from his wife, his religious community, and God. The clinical team believes that the patient understands the benefits and risks of treatment, including the increased risk resulting from his refusal of blood. The clinical team does not believe that there is any basis for questioning the patient's capacity to make medical decisions.

Questions: Scenario #1 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. This patient has the moral right to refuse blood.	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I would be willing to provide care to this patient if he were allowed to refuse blood.	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
4. I would honor this patient's refusal of blood, even if blood became necessary to save his life.	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
5. I believe that a staff member should be allowed to decline to provide care to this patient:				
a. based on the staff member's religious beliefs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
b. based on the staff member's moral views	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
c. based on the staff member's professional values	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
6. I would support overriding this patient's decision and transfusing him against his will.	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
7. I would support transferring this patient to another hospital for treatment.	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Case # 2:

The patient is 17 years old and has been a Jehovah's Witness all her life. She has expressed a strong commitment to her faith, and has recently been baptized. She refuses to accept blood

products. The clinical team believes that the patient understands the risks and benefits of surgery; has a coherent value system; and has used this value system to arrive at her decision. Her parents are Jehovah's Witnesses who share her belief that God prohibits the acceptance of blood products. They support her decision to refuse blood.

The patient has been a patient of Children's Hospital for many years. She is scheduled to have scoliosis surgery, and has been preparing for surgery by giving herself injections with EPO. There is a small risk of bleeding from the surgery.

For purposes of answering the following questions, assume that the clinical team has been advised that respecting the patient's decision would be consistent with the law.

Questions: Scenario #2 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. This patient has the moral right to refuse blood.	10	2	7	<input type="checkbox"/>
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	7	9	1	1
3. I would be willing to provide care to this patient if she were allowed to refuse blood.	4	5	1	3
4. I would honor this patient's refusal of blood, even if blood became necessary to save her life.	4	4	2	2
5. I believe that a staff member should be allowed to decline to provide care to this patient:				
a. based on the staff member's religious beliefs	7	2	1	3
b. based on the staff member's moral views	7	2	2	2
c. based on the staff member's professional values	6	3	1	3
6. I would support overriding this patient's decision and transfusing her against her will.	2	3	7	4
7. I would support transferring this patient to another hospital for treatment.	5	6	2	<input type="checkbox"/>

Case #3

The patient is 19 years old, and is considered an adult under the law. He was receiving routine care at Children's Hospital, when he unexpectedly experienced significant blood loss and was admitted to the MICU. His hematocrit is 15 and is continuing to fall. The clinical team believes that it is likely he will die without a blood transfusion.



The patient's physician knew that the patient was a Jehovah's Witness, but did not expect the issue of blood transfusions to arise, as the therapy the patient was receiving posed minimal risk of blood loss. The clinical team in the MICU has spoken at length with the patient, who is awake and alert. The team believes that the patient understands his condition, his prognosis, and the need for blood products, and that he has decision-making capacity.

The patient has requested the presence of a Jehovah's Witness advocate, who has come to the Hospital. The patient has steadfastly refused all blood products based on his religious convictions, and the advocate has supported this refusal.

The patient is too sick to be transferred to another institution.

Questions: Scenario #3 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. This patient has the moral right to refuse blood.	11	2		
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	11	2		
3. I would be willing to provide care to this patient if he were allowed to refuse blood.	5	5	1	2
4. I would honor this patient's refusal of blood, even though blood is considered necessary to save his life.	4	6	2	1
5. I believe that a staff member should be allowed to decline to provide care to this patient:				
a. based on the staff member's religious beliefs	5	2	3	3
b. based on the staff member's moral views	5	2	3	3
c. based on the staff member's professional values	5	2	3	3
d. only if another staff member is available to provide care	3	7	2	1
6. I would support overriding this patient's decision and transfusing him against his will.	2	4	3	4

Additional Questions

Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	
1. I would support transferring an adult refusing blood to another hospital:					N/A
a. in all circumstances	2	3	6	1	1
b. only if it is more likely than not that the patient will need blood	2	2	5	2	2
c. only if good care is available at the other hospital	5	2	3	1	2
d. only if the patient does not have an existing relationship with Children's		1	8	2	2
2. I would support transferring a mature minor refusing blood to another hospital:					
a. in all circumstances		4	5	2	2
b. only if it is more likely than not that the patient will need blood		5	5	1	2
c. only if good care is available at the other hospital	3	5	3	1	1
d. only if the patient does not have an existing relationship with Children's		1	8	2	1
3. I would support transfusing a patient over his or her objections if the need for blood was caused at least in part by medical negligence.	1	9	6	1	1
4. I would be more willing to care for a patient refusing blood if:					
a. I was informed about the refusal in advance	8	4			1
b. I knew there was a coordinated plan for treating the patient without blood	8	4			1
c. I knew there was a process within the Hospital for determining that the patient has decision-making capacity and that he or she is making an informed, voluntary choice	8	3	1		1
5. I would support development of a coordinated program for caring for adults and mature minors refusing blood based on religious or moral values.	9	2		1	1
6. I would be willing to participate in such a program.	5	4	1	1	1





**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

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**APPENDIX P**



Questions Scenario #1 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. This patient has the moral right to refuse blood.	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	<input type="checkbox"/> 7	<input type="checkbox"/> 2	<input type="checkbox"/>	<input type="checkbox"/>
3. I would be willing to provide care to this patient if he were allowed to refuse blood.	<input type="checkbox"/> 7	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/>
4. I believe that a staff member should be allowed to decline to provide care to this patient:				
a. based on the staff member's religious beliefs	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/> 3	<input type="checkbox"/> 5
b. based on the staff member's moral views	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 3	<input type="checkbox"/> 4
c. based on the staff member's views as to what constitutes good medical care	<input type="checkbox"/> 3	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 4
5. I would support overriding this patient's decision and transfusing him against his will.	<input type="checkbox"/> 2	<input type="checkbox"/>	<input type="checkbox"/> 1	<input type="checkbox"/> 6
6. I would support transferring this patient to another hospital for treatment.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 2	<input type="checkbox"/> 4

Questions Scenario #2 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	
1. This patient has the moral right to refuse blood.	<input checked="" type="checkbox"/> 7	<input type="checkbox"/> 2	<input type="checkbox"/>	<input type="checkbox"/>	
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	<input type="checkbox"/> 6	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/>	
3. I would be willing to provide care to this patient if she were allowed to refuse blood.	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>	
4. I believe that a staff member should be allowed to decline to provide care to this patient:					
a. based on the staff member's religious beliefs	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/> 2	<input type="checkbox"/> 6	
b. based on the staff member's moral views	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 6	
c. based on the staff member's views as to what constitutes good medical care	<input type="checkbox"/> 3	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 4	
5. I would support overriding this patient's decision and transfusing her against her will.	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 4	1 ☐ answer
6. I would support transferring this patient to another hospital for treatment.	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 4	1 ☐ answer



Questions Scenario #3 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. This patient has the moral right to refuse blood.	<input type="checkbox"/> 7	<input type="checkbox"/> 2	<input type="checkbox"/>	<input type="checkbox"/>
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	<input type="checkbox"/> 6	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/>
3. I would be willing to provide care to this patient if he were allowed to refuse blood.	<input type="checkbox"/> 8	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/>
4. I believe that a staff member should be allowed to decline to provide care to this patient				
a. based on the staff member's religious beliefs	<input type="checkbox"/> 2	<input type="checkbox"/>	<input type="checkbox"/> 2	<input type="checkbox"/> 5
b. based on the staff member's moral views	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 5
c. based on the staff member's views as to what constitutes good medical care	<input type="checkbox"/> 3	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 4
d. only if another staff member is available to provide care	<input type="checkbox"/> 2	<input type="checkbox"/> 2	<input type="checkbox"/>	<input type="checkbox"/> 5
5. I would support overriding this patient's decision and transfusing him against his will.	<input type="checkbox"/>	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 5

1 no answer

Additional Questions Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
<b>1. I would support transferring an adult refusing blood to another hospital:</b>				
a. in all circumstances	<input type="checkbox"/> 1	<input type="checkbox"/> 3	<input type="checkbox"/>	<input type="checkbox"/> 5
b. only if I believe that good care is available at the other hospital	<input type="checkbox"/> 2	<input type="checkbox"/> 2	<input type="checkbox"/>	<input type="checkbox"/> 4 (1 no answer)
c. only if the patient does not have an existing relationship with Children's	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 2	<input type="checkbox"/> 4
<hr/>				
<b>2. I would support transferring a mature minor refusing blood to another hospital:</b>				
a. in all circumstances	<input type="checkbox"/> 2	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 4
b. only if I believe that good care is available at the other hospital	<input type="checkbox"/> 3	<input type="checkbox"/> 1	<input type="checkbox"/>	<input type="checkbox"/> 4 (1 no answer)
c. only if the patient does not have an existing relationship with Children's	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 5
<hr/>				
<b>3. I would support transfusing a patient over his or her objections if the need for blood was caused at least in part by medical negligence.</b>				
	<input type="checkbox"/> 1	<input type="checkbox"/> 1	<input type="checkbox"/> 4	<input type="checkbox"/> 3
<hr/>				
<b>4. I would be more willing to care for a patient refusing blood if:</b>				
a. I was informed about the refusal in advance	<input type="checkbox"/> 4	<input type="checkbox"/> 4	<input type="checkbox"/> 1	<input type="checkbox"/>
b. I knew there was a coordinated plan for treating the patient without blood	<input type="checkbox"/> 6	<input type="checkbox"/> 3	<input type="checkbox"/>	<input type="checkbox"/>
c. I knew there was a process within the Hospital for determining that the patient has decision-making capacity and that he or she is making an informed, voluntary choice	<input type="checkbox"/> 7	<input type="checkbox"/> 2	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>				
<b>5. I would support the development of a coordinated program for caring for adults and mature minors refusing blood based on religious or moral values.</b>				
	<input type="checkbox"/> 7	<input type="checkbox"/> 2	<input type="checkbox"/>	<input type="checkbox"/>





**TASK FORCE ON REFUSAL OF BLOOD PRODUCTS**

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**APPENDIX Q**



**RN FINAL TALLY**

Questions: Scenario #1 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. This patient has the moral right to refuse blood.	29	9	0	0
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	25	10	2	1
3. I would be willing to provide care to this patient if he were allowed to refuse blood.	21	11	5	1
4. I would honor this patient's refusal of blood, even if blood became necessary to save his life.	17	8	8	5
5. I believe that a staff member should be allowed to decline to provide care to this patient:				
a. based on the staff member's religious beliefs	19	10	3	4
b. based on the staff member's moral views	16	10	5	4
c. based on the staff member's professional values	17	9	7	4
6. I would support overriding this patient's decision and transfusing him against his will.	2	4	13	18
7. I would support transferring this patient to another hospital for treatment.	7	10	7	15

Questions: Scenario #2 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. This patient has the moral right to refuse blood.	29	9	0	0
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	25	9	2	3
3. I would be willing to provide care to this patient if she were allowed to refuse blood.	21	8	5	4
4. I would honor this patient's refusal of blood, even if blood became necessary to save her life.	18	4	5	10

5. I believe that a staff member should be allowed to decline to provide care to this patient:

a. based on the staff member's religious beliefs	23	7	4	3
b. based on the staff member's moral views	18	8	6	3
c. based on the staff member's professional values	18	8	7	3

6. I would support overriding this patient's decision and transfusing her against her will.

6	7	8	17
---	---	---	----

7. I would support transferring this patient to another hospital for treatment.

9	10	9	10
---	----	---	----

Questions: Scenario #3 Check one box from strongly agree to strongly disagree

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. This patient has the moral right to refuse blood.	26	9	1	1
2. This patient should be allowed to refuse blood while being treated at Children's Hospital.	21	8	6	2
3. I would be willing to provide care to this patient if he were allowed to refuse blood.	19	13	2	5
4. I would honor this patient's refusal of blood, even though blood is considered necessary to save his life.	16	8	5	9
5. I believe that a staff member should be allowed to decline to provide care to this patient:				
a. based on the staff member's religious beliefs	18	8	3	5
b. based on the staff member's moral views	19	9	3	5
c. based on the staff member's professional values	18	8	5	4
d. only if another staff member is available to provide care	13	8	8	7
6. I would support overriding this patient's decision and transfusing him against his will.	6	8	7	17



Additional Questions	Check one box from strongly agree to strongly disagree			
	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
1. I would support transferring an adult refusing blood to another hospital:				
a. in all circumstances	7	9	10	8
b. only if it is more likely than not that the patient will need blood	3	9	12	7
c. only if good care is available at the other hospital	5	11	10	5
d. only if the patient does not have an existing relationship with Children's	2	5	12	11
2. I would support transferring a mature minor refusing blood to another hospital:				
a. in all circumstances	6	6	8	14
b. only if it is more likely than not that the patient will need blood	2	8	8	10
c. only if good care is available at the other hospital	4	12	8	7
d. only if the patient does not have an existing relationship with Children's	0	8	10	11
3. I would support transfusing a patient over his or her objections if the need for blood was caused at least in part by medical negligence.	4	5	11	13
4. I would be more willing to care for a patient refusing blood if:				
a. I was informed about the refusal in advance	18	10	1	4
b. I knew there was a coordinated plan for treating the patient without blood	22	10	0	1
c. I knew there was a process within the Hospital for determining that the patient has decision-making capacity and that he or she is making an informed, voluntary choice	26	7	1	1

- |  |    |    |    |   |
|--|----|----|----|---|
| 5. I would support development of a coordinated program for caring for adults and mature minors refusing blood based on religious or moral values. | 26 | 7  | 10 | 2 |
| 6. I would be willing to participate in such a program.  | 20 | 12 | 2  | 2 |





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**APPENDIX R**

See attached folder entitled Medical Alternatives to Blood Transfusions.





