

TALKING POINTS

MINIMUM AGE FOR BONE MARROW & STEM CELL DONATION

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What is the issue?

To allow those between 15 and 17 years of age, who meet health screening requirements, to register and become unrelated blood and marrow donors with parental permission.

Why is legislation needed to allow teens to register as unrelated donors?

Currently the policy of the National Marrow Donor Program (NMDP), and its affiliated blood centers which register donors, is to permit only those between the ages of 18 and 60 to register as donors.

The NMDP position on the subject of minimum age of unrelated donors is accessed at www.marrow.org:

Q: Why does a person have to be 18 to be a donor? Can't my parents sign the consent form for me?

A: NMDP standards require that volunteer marrow donors must be between the ages of 18 and 60. This is standard medical practice. The reason an individual must be 18 to donate marrow is because the donation is done through a surgical procedure, and the person undergoing the procedure must be able to give his or her informed consent. A guardian or parent is not able to sign a release or give consent because unrelated marrow donation is a voluntary procedure and is not beneficial or lifesaving to the donor. Because the patient's physician may request either donation procedure, a volunteer must be medically eligible for both procedures.

There are many reasons why it reasonable, logical, and appropriate for teens who wish to become unrelated BMT donors to be able to do so. At last year's hearings on HB 1293 in Maryland, a spokesman for the NMDP stressed that teens were immature and might change their minds about a donation if called upon, and thus they should not be allowed to register. It has been documented that a small number of adults who have registered as BMT donors do in fact decline to donate when requested. While it may be that some teens might decline donation in the future, it is not possible to conclude that their rate of refusal would be any different than that of adults. Since teens as a group have not been permitted to register in the majority of US states, there is also no track record of their donor retention or attrition on which to base such a conclusion. It should be remembered that potential donors have the right to refuse to donate and may not be coerced into

donation. And it would seem that instead of projecting that some teens might in the future decline to donate, that the NMDP would better devote its energies to more intensive upfront donor education and support to help lower the rate of donor attrition.

The following are perspectives on ethical issues that directly relate to reason why teens should be allowed to register as unrelated BMT donors

Guidelines of the World Marrow Donor Association (www.worldmarrow.org)

The WMDA provides oversight and recommends policy for all member registries worldwide. In 2003, their Ethics Working Group recommended that:

".... The minimum age for a volunteer must be determined by the legal requirement covering general anesthesia and blood donation in the country in which the donor resides. The maximum age will be determined by the policy of the responsible Registry (1).

Guidelines of the American Medical Association (2)

The AMA guidelines state that minors should not be categorically prohibited from serving as organ or tissue donors. They recommend that such donations be limited to situations with low to moderate risk to the donor, such as blood or bone marrow donation, as compared to serious risk donations such as of a lung or partial liver. The policy language further states that:

If a child is capable of making his or her own medical treatment decisions, he or she should be considered capable of deciding whether to be an organ or tissue donor.

Doctrine of the Mature Minor

In most states of the US, 16 is the minimum age for donating blood with parental consent. In a variety of instances, teens are able to consent to, or refuse, medical treatments including surgery. It is customary that 14 is the age of consent for confidential reproductive health services, including elective abortions; substance abuse treatment and counseling; and for consent or refusal of mental health services, even when parents feel that a child's life may be in danger (3).

The legal concept of the mature minor is well established in case law nationwide(4). It governs such topics the age of consent to engage in sexual activity, to marry, and to make independent and confidential decisions about medical care. The following list of rights extended to teens serves as a good illustration of this concept. Many of these rights involve activities that carry varying amounts of risk, may have both psychological and physical health consequences, and may be neither beneficial nor life-saving. While the laws vary in each state, teens commonly have the right to:

- to make decisions as to one's own guardian or custodial parent at 12
- to travel and to purchase a ticket to travel by public conveyance anywhere in the US at age 13 without parental permission

- to be employed at 16, but to engage in agricultural work at age 12, in other occupations at 14, with certain jobs being exempt from any age limits
- to obtain a license and drive a motor vehicle at age 16
- to have one's body pierced at age 16 without parental consent
- to enlist in the military at age 17 ,with parental consent
- to petition the court to become an emancipated minor with cause
- to make decisions on behalf of a child parented by one's self at any age

No minimum age for related BMT donors

No discussion of the minimum age for unrelated blood & marrow donors would be complete without examining how such an eligibility criteria fits into the context of familial donors. Children of all ages, from infancy on, serve as donors to siblings. Many of these children certainly are not of an age where they might be expected to accurately understand what they are doing, nor understand their sibling's illness. While it is customary to expect solidarity within a family unit, especially in times of crisis, it is also important to understand the impact of the illness on the entire family and to recognize that family dynamics vary greatly. It is not impossible that there could be coercion for a child to serve as a sibling's donor. And it is now well known in the field of psycho-social oncology that siblings of children with cancer also are impacted by the disease, often on a long-term basis. The impact is felt regardless of the outcome of treatment, with special needs often arising for the donor when a sibling BMT recipient does not survive.

In rare instances, there are also cases of children serving as donors for parents. These situations also may bring about a complicated set of dynamics.

And when speaking of family BMT donations and age of consent, one also cannot ignore that the new field of pre-implantation genetic diagnosis (PGD) is allowing families of means to create an infant specifically meant to serve as a BMT donor for an ill sibling. While this procedure is still rare, it is hailed in the popular media as a life-saving measure, and its use for BMT has been reported in the medical literature as well. PGD raises many ethical questions, not the least of which is that of donor consent.

Shortage of Minority Donors

The case currently before the Maryland Assembly also highlights another important issue about the critical need for unrelated blood & marrow donors: the tremendous shortage of minority donors. Because the characteristics of the blood cells that determine a compatible match for BMT use are genetically transmitted, patients who do not have a match in the family—who constitute some 70% of patients in need of a BMT-- are most likely to find their match among a donor of similar heritage. But due to the many factors that have led to health disparities in our country, there are not currently enough potential volunteers of diverse backgrounds in the donor pool to ensure that every patient will have an equal chance of finding a match (5).

The fact that the driving force behind the bill currently under consideration are teens of African-American heritage is a prime example of how education and motivation could

help to eliminate the extreme disproportionality of donors that now exists. But instead of welcoming this group of responsible and concerned citizens who have made a well-thought out decision to help save lives, they have been turned away, been told that they are too young and immature to know what they are doing.

In Maryland, the bill's backers should be recognized as an asset to their home state and as role models for the nation. There is no logical reason why teens who have made a thoughtful decision, have consent of their parent or guardian, should continue to be barred from joining the pool of unrelated volunteer donors. The fact that they could offer HLA types in critically short supply to the donor registry makes such a denial even more reprehensible. It is of note that the pioneering case in 2000 in Washington state that successfully lowered the donor registration age, was also spearheaded by a teen of minority heritage, in that case of mixed ethnicity (6).

Furthermore, they should not be restricted to only directed donations, as the odds of finding that type of match are similar or less than that of familial donations.

Most teens, just like most adults, do not consider becoming blood & marrow donors, and patients suffer and die as a result. Those who want to should be encouraged, not denied.

Citations

1. Rosenmayr, A. et al on behalf of the Ethics Working Group of the World Marrow Donor Association. (2003) "Informed consent- suggested procedures for informed consent for unrelated haematopoietic stem cell donors at various stages of recruitment, donor evaluation, and donor workup". *Bone Marrow Transplantation* 312: 539-545 (<http://www.wmda.org>)
2. American Medical Association (1994), AMA Policy, E-2.167 *The Use of Minors as Organ and Tissue Donors*. (http://www.ama-assn.org/apps/pf_new/pf_online?f_n=browse&doc=policyfiles/HnE/E-2.167.HTM)
3. Stenger, RL. (1999-2001) "Exclusive or Concurrent Competence to Make Medical Decisions for Adolescents in the United States and United Kingdom", *Journal of Law and Health*, 14(2):209-41.
4. Forman, DL. (1998) *Every Parent's Guide to the Law*. (pp. 87-154) New York: Harcourt Brace.
5. NMDP Minority Facts & Figures (2002) (<http://www.parentsguidecordblood.com/loMpetition.html>)
6. Miller, T. "Caring Teen Fought for His Right to Help Save a Friend" (April 25, 2000). *Seattle Post-Intelligencer* (<http://seattlepi.nwsource.com/local/tuck25.shtml>)