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Protecting the Selfless: Toward More Comprehensive Care for Pediatric Related Stem Cell Donors

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In this issue of the journal Pulsipher et al. [1] describe findings from the multi-institutional National Heart, Lung, and Blood Institute–funded RDSafe study, a prospective North American trial evaluating hematopoietic stem cell (HSC) donors of all ages predonation through 1 year after the collection procedure. After an earlier report from the study showed that many pediatric donors experience decreased health-related quality of life after donation [2], a more detailed assessment of pain, toxicities, and serious adverse events was undertaken in 294 donors younger than age 18 years. They found that although most reported pain peridonation, under 15% had persistence of symptoms 1 month later. This is somewhat reassuring, but further analysis revealed that adolescent girls had a significantly increased risk of pain peridonation when compared with boys and younger girls. In addition, almost one-fourth of adolescent donors of both genders failed to return to predonation pain levels 1 year after the procedure. Thus, considering donors under age 18 years as a homogeneous cohort is misleading and underestimates the level of pain experienced by older girls and the time course for complete recovery for all adolescent donors.

This report is an important contribution to the literature on HSC donation for many reasons. Donation is an invasive and potentially dangerous procedure that confers no medical advantage to the donor. In adults the decision to donate arises from humanitarian motives, and thus the team and the community caring for these selfless individuals bear a great responsibility to ensure outcomes are optimized. In this context the paucity of literature on donor outcomes must be addressed. Driven in part by registry regulations, the preponderance of information is on volunteer unrelated donors describing periprocedure and short-term events. Of interest, as in the current study, these studies previously identify female gender as a risk factor for increased toxicity [3,4]. Unfortunately, the information gap on outcomes is most striking in the case of pediatric donors. One could posit that this is in fact the population where extensive short- and long-term follow-up is most crucial, a position supported by the American Academy of Pediatrics' 2010 policy statement [5]. Pediatric donors cannot by definition give legal consent to donate, and younger donors cannot even provide assent. Parents are in the difficult position of representing the interests of 2 of their children: the potential donor and a child who could benefit from a stem cell transplant using the donor. Children are also occasionally evaluated as donors for a parent, a situation that will likely become more common with the increasing use of haploidentical transplantation. Here, the situation is perhaps even more complicated. The parent is also the patient and deserves to have detailed information about the impact of donation on the child to allow potential risk to the child to benefit the parent. In addition, these pediatric donors are almost always in good health and are expected to live for decades after the procedure. Chronic pain or disability would thus have far-reaching consequences.

This study, through its multi-institutional approach, has accrued a large number of patients and thus has the ability to generate robust data addressing this understudied area. It importantly allows for subset analysis, informing providers about donors at the highest risk of not only immediate but also long-term complications, an arena where information is particularly lacking. The impact of this study will be significant. At the least these data will allow for better parent and donor predonation counseling about the expected course of recovery, and counseling can now be tailored based on the demographics of the donor. In the relatively infrequent situation where 2 matched donors are available, these results could affect donor selection with priority given to younger donors if other factors such as patient–donor size are not an issue. In addition, HSC regulatory bodies could consider mandating longer follow-up for 5 or 10 years to better understand the total impact of the procedure. Ideally, this work will serve the essential function of generating future studies to determine the etiology of the increased pain experienced by older female patients and slower recovery time seen in all adolescent patients. One would imagine that this could impact not only HSC donors but illuminate aspects of

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mental and physical health generalizable to a much broader adolescent population.

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