

## Editorial

# Reaching out to our youth about organ donation

As readers of *Pediatric Transplantation*, we are all painfully aware of the difficult state of affairs that awaits organ failure patients. Many modifiable barriers to organ donation have been identified, and despite increases in living donations (1), we still are not making a dent in the number of people waiting. Therefore, as discussed by Cantarovich and colleagues, maybe a wider net needs to be cast that reaches a segment of the population largely left out of organ donation and perhaps who are most impressionable...our youth.

As I write this, I recall the first time that I ever thought about organ donation. I was 16 and obtaining my driver's license. When I was asked whether I wanted to be an organ donor, I had no idea what to say; I had never thought about this before. And then, before I did so, my mother answered for me. Apparently, *many* years later, my experience is still quite commonplace (2). A recent study from Hawaii found that only 18% of adolescents with a driver's license are listed as organ donors, although somewhat higher rates have been found in other states such as Florida (27%; 3) and Washington (24%; 4). The main reasons for the low rates in the Hawaiian study were summarized as lack of knowledge, misconceptions, and parents responding on behalf of the child. Of note, the rates below other states found in Hawaii may be reflective of the even more formidable problem of fewer donors available from some ethnic groups (5), which was also echoed in the Washington study (4).

This article presents the work of a global forum aiming to discuss strategies for educating youth about organ donation and transplantation that can be disseminated into the easiest place to reach large numbers of them, at school. The authors provide critical guidance into how this sort of material could be devised and successfully integrated into the school setting. The conversation and conclusions documented offer a starting point for those who wish to spearhead this sort of intervention. Below, from the perspective of a

pediatric psychologist, I will summarize some of the key strengths as well as areas for further development as we try to take this important work forward.

The material that the forum advocates dispersing is linked to empirically based targets. In general, lack of knowledge and misconceptions are modifiable barriers to organ donation that may be even more salient for youth (4). Research that has specifically examined the perceptions of donating among youth found that young people do not realize there is a dire need for organs (6). From a practical standpoint, they do not know how to become organ donors (6). They also believe many fallacies about organ donation that are propagated by television especially (6). And perhaps not surprisingly, the "ick" factor (7), experiencing disgust about the idea of organ donation, appears applicable to youth as well (6). The forum offers plans to address these formative problems of lack of knowledge and misconceptions.

The forum included a broad range of participants, thereby offering an array of perspectives. Excitingly, tackling this devastating problem was taken on with a diverse mindset in that 16 countries from Asia, Europe, North and South America were represented. Perhaps most significantly, representatives from different faiths (Buddhism, Catholicism, Hinduism, Islam, and Judaism) were in attendance. A recent meta-synthesis of the qualitative literature on organ donation determined that the two most common barriers to organ donation pertained to misconceptions (mistrust of the organ recovery process) and religion, specifically "the need to maintain bodily integrity to safeguard progression into the after-life" (8, p. 9). Evidence suggests that among youth as well, confusion about the compatibility between religious beliefs and organ donation is common (4). Indeed, the contribution of religious leaders may be critical for allaying a well-established barrier to organ donation in

addition to getting school personnel and parents on board.

A glaring omission, although from the forum, is the perspectives of parents. In many places, the bottom line is that parental consent is required for a child to donate his/her organ. But, beyond the legal role of parental involvement is a much broader consideration. Wouldn't education to youth be more effective if the message was supported at home? In general, prevention science has told us that education directed at children is more effective if parents are involved (9, 10). Therefore, for these critical reasons, it seems that education efforts targeting youth under age 18 must include parents. The forum and others emphasize that education packages should promote meaningful discussions with parents, for example. One might argue that this is too late. Parents should be included in generation of such materials so that they are not surprised or even angry about such discussions going on outside of the home. One can only imagine the varied reactions to asking "how was school today?" and hearing in reply "great Mom, someone told me to donate my organs and that sounded really cool." Although we hope that children have their own voice and the decision is not simply that of their parents, ideally, this choice would be made together.

Related to that, the forum discusses targeting a wide age range of youth perhaps even as young as 10 years of age. Certainly, there are reasons to address topics of this magnitude as early as is appropriate. The same is done regarding other public health crises like obesity, smoking, and bullying. But, although briefly mentioned in the forum's report, materials must be substantially modified based on youth characteristics. Youth vary widely in regards to core developmental constructs like moral reasoning, and this will need to be taken into account. Furthermore, delivering the material in a way that is sensitive to how dramatically youth vary in regard to comprehension and anxiety will be important as well. It would be detrimental to such efforts if children simply misunderstand or become frightened because the way a 10-year-old receives such education is so different than how a 16-year-old might.

Finally, a promising idea offered by the forum is to spread this message to "university" students. As advocated by the authors, education on organ donation should "provoke high order thinking skills, expand opportunities for meaningful discussion, and facilitate thoughtful decision making." These seem to be values that are cultivated on college/university campuses. Many universities, for example, have classes specifically

designed to address social justice and such venues would be ideal for meaningful conversations about this topic.

The forum offers a comprehensive package aiming to cultivate our youth's interest in organ donation. Young people do not have much exposure to this, and it may be that school-based discussions could open their minds to the idea. The approach is innovative, perhaps especially the intent to cut across cultures and religions. If we are to head in this direction, infusing a developmental perspective and, most importantly, the voices of parents could be instrumental for successful dissemination. It is imperative that, if given an opportunity to reach our youth and their families, we do so with the same compassion that we are hoping to elicit.

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