



March 23, 2018

Yolanda Becker, MD  
President  
Board of Directors  
Organ Procurement and Transplantation Network  
United Network for Organ Sharing  
PO Box 2484  
Richmond, Virginia 23218

**Re: Concept Paper on Improving the OPTN/UNOS Committee Structure**

Dear Dr. Becker:

The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) welcomes the opportunity to comment on the concept paper for improving the Organ Procurement and Transplantation Network/ United Network for Organ Sharing (OPTN/UNOS) committee structure.

NASPGHAN is comprised of more than 2,000 pediatric gastroenterologists in 46 states, the District of Columbia, Puerto Rico, Mexico and 8 provinces in Canada. The mission of NASPGHAN is to advance understanding of normal development, physiology and pathophysiology of diseases of the gastrointestinal tract and liver in children, improve quality of care by fostering the dissemination of this knowledge through scientific meetings, professional and public education, and policy development, and serve as an effective voice for members and the profession.

As highlighted in the executive summary, the concept paper is the product of a two-year workgroup that was formed to assess the OPTN/UNOS committee governance structure and how to improve committee recruitment, selection and engagement. According to the concept paper, the current committee structure was identified as needing improvement because it limits opportunity for broader transplant community participation. While the idea of incorporating perspectives of different constituencies throughout the volunteer workforce is a laudable objective, the changes outlined in the concept paper may actually reduce the diversity of perspectives.

NASPGHAN rejects the proposal to eliminate the Pediatric Transplantation Committee and replace it with a Pediatric Transplant Specialists Expert Council on the grounds that an expert council will not have regional representatives and will not have the ability to present proposals to the Board. While the concept of expert councils and their cross-cutting roles may have merit, there must be a subject

committee that is specially charged with prioritizing the unique needs of children awaiting a transplant or who have received a transplant — needs that are markedly different than those of the adult population. The National Organ Transplant Act established this critical distinction by stating that “the OPTN shall recognize the differences in health care and in organ transplantation between children and adults throughout the system and adopt criteria, policies and procedures that address the unique health care needs of children.” A Pediatric Transplant Committee, and its requirement to have regional representation, also ensures that regional differences, problems and disparities for pediatric transplant candidates are not overlooked.

According to the minutes of the January 2018 meeting of the Pediatric Transplant Committee, members generally supported the goals of the project and recognized the current structure of OPTN committees is not optimal, including the lack of pediatric representatives on all of the organ specific committees. However, members were “very concerned” with the proposal to change the standing of the Committee to an “expert council.” We agree with the sentiments of Committee members that there needs to be a clear pediatric perspective within the OPTN.

NASPGHAN finds merit in the idea that a pediatric transplant expert council could co-exist with a Pediatric Transplant Committee, thereby ensuring that the pediatric voice is present throughout the volunteer workforce while preserving the important role the Committee serves in developing and putting forth for consideration evidence-based policies aimed at fostering pediatric candidate access to transplantation and good outcomes for patients involved in pediatric transplantation.

We ask the Executive Committee to reconsider its proposal to eliminate the Pediatric Transplant Committee and encourage it to continue to work with the pediatric community to identify a committee governance structure that fulfills the needs of the volunteer workforce and preserves the strength of pediatric transplant voice.

Should you have any questions or wish to engage with NASPGHAN leaders further on this this important topic, please contact Camille Bonta, NASPGHAN policy advisor at (202) 320-3658 or [cbonta@summithealthconsulting.com](mailto:cbonta@summithealthconsulting.com).

Sincerely,

A handwritten signature in black ink, appearing to read "James Heubi".

James Heubi, MD  
President, NASPGHAN