



American Society of Pediatric Nephrology

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February 18, 2020

The Honorable Alex M. Azar, II
Secretary
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

The Honorable Thomas J. Engels
Administrator
Health Resources and Services Administration
5600 Fishers Lane, Room 13N82
Rockville, MD 20857

Re: Removing Financial Disincentives to Living Organ Donation (HRSA-2019-0001)

Dear Secretary Azar and Administrator Engels:

On behalf of the American Society of Pediatric Nephrology (ASPN), thank you for the opportunity to submit comments on the proposed rule to remove financial barriers to organ donation by expanding the scope of reimbursable expenses incurred by living organ donors to include lost wages, child-care and elder-care expenses incurred by a primary care giver.

Founded in 1969, ASPN is a professional society composed of pediatric nephrologists whose goal is to promote optimal care for children with kidney disease and to disseminate advances in the clinical practice and basic science of pediatric nephrology. ASPN currently has over 700 members, making it the primary representative of the Pediatric Nephrology community in North America.

Children with chronic kidney disease (CKD), including its most severe form end-stage renal disease (ESRD), suffer tremendously from impaired growth and development. Chronic dialysis in children can be life-saving, but it is fraught with technical challenges and substantially reduced duration and quality of life. For the majority of children, dialysis is a bridge to kidney transplantation which provides opportunities for children to grow and develop normally so that they can thrive into adulthood. Children often receive kidneys from many categories of living donors, including parents and other family members, family friends or community members, and even individuals with no prior relationship to the child or family who may just wish to donate to a child. Therefore, the patients treated by our members are impacted by the policies proposed in this rule and we offer the following comments.

According to the latest USRDS data, 36.3 percent of children received a kidney transplant within their first year of ESRD care.¹ In 2016, the most recent year of available data, 1,119 children were wait-listed for a kidney transplant, including 785 patients listed for the first time, and 334 listed for repeat transplants. The median wait time for first transplant was 12.94 months, while children on the repeat transplant list on average wait 3 to 4 times longer to receive a transplant. While outcomes for pediatric transplantation from living donors are better than those from deceased donors, the rate of living donor kidney transplantation has decreased over the last ten years.² Living donors accounted for 35.7 percent of kidney transplants in 2016, a 17.7 percent decrease since 2009.

¹ https://www.usrds.org/2018/download/v2_c07_ESRD_Pediatric_18_usrds.pdf

² Sigurjonsdottir, Vaka Kristin; Grimm, Paul Charles. *Living or deceased donor kidney transplantation in children*. Pediatrics: April 2019 - Volume 31 - Issue 2 - p 232-236. doi: 10.1097/MOP.0000000000000740.

ASPN supports the agency's proposal to add three new expense categories to be considered incidental non-medical expenses incurred by donating individuals to the current program through the National Living Donor Assistance Center (NLDAC). Allowing donors to be reimbursed for lost wages, childcare expenses, and elder care expenses will reduce the burden on living donors, who willingly give of themselves to promote the long-term health and well-being of children with CKD.

As noted above, although many living donors may be family members or have a close relationship with the child, others may find motivation to be a donor solely because of altruism, a group often now referred to as non-directed donors. We would encourage that any new mechanism for reimbursement be all-inclusive in terms of the scope of living donors it covers, and not unintentionally restricted to family members or those with a close personal relationship, or in any way relying on seeking reimbursement from an identified donor or donor family.

Along these same lines, in the case of non-directed donors, there may be expenses related to travel or the process of donation that must now be personally covered, without the potential support that might exist if donating to a family member or close friend, that we would urge also be considered for reimbursement. Such coverage would be especially important with non-directed donors since there is no known recipient with these individuals when the process begins, and thus no way to know in advance if the recipient household income will exceed the threshold for reimbursement. Moreover, since pediatric patients do not have access to the same individual financial resources that an adult patient may have, and since children are not involved in decision making about allocation of financial resources that exist within a family, we would particularly urge that there be no supposition that these new programs be accessed only after a recipient or recipient family contribute somehow to defray costs.

While we are encouraged that the agency projects a four- to six-fold increase in the number of applications to the NLDAC with these proposed changes to the reimbursable expense categories, we agree with our partners in the kidney community that the increase would be even greater if the current income levels for eligibility were to be increased. ASPN supports the recommendation from Kidney Care Partners for HRSA to increase the upper threshold for living organ donor and organ recipient household incomes, and we look forward to future rulemaking on this issue.

Thank you again for the opportunity to submit comments on the proposed rule to remove financial disincentives to living organ donation. Please contact our Washington representative, Erika Miller, at (202) 484-1100 or emiller@dc-crd.com, if we can provide additional information or clarification regarding ASPN's comments.

Sincerely,



Patrick Brophy, MD, MHCDS
President, American Society of Pediatric Nephrology