



American Society of Pediatric Nephrology

6728 Old McLean Village Drive, McLean, VA 22101, ph. 703.556.9222; fax 703.556.8729

The American Society of Pediatric Nephrology (ASPN) is an organization of more than 700 pediatric nephrologists and affiliated health care professionals in North America, whose primary goals are to promote optimal care for children with kidney disease through advocacy, education and research, as well as to disseminate advances in clinical practice and scientific investigation related to childhood kidney and urinary tract disorders.

Experts in Pediatric Kidney Disease. The ASPN is the only organization devoted specifically to addressing the needs of children and adolescents with kidney disease. An estimated 150,000 children and adolescents currently suffer from kidney disease; about 10,000 of them suffer from chronic kidney failure, receive chronic dialysis, or have a kidney transplant. Children and adolescents undergoing dialysis or transplants are unique, and very different from adults. The causes for end-stage renal disease (ESRD) in children predominantly include congenital abnormalities, glomerular diseases and rare genetic disorders, not hypertension and diabetes as seen in adults. Children are dependent on adult caregivers and ESRD in children has widespread impact on the other family members. Children with ESRD also suffer from impaired growth and development, including impaired neurocognitive development. They also have different drug metabolism, which changes over time as they grow to be adults. Renal transplantation is the best treatment for children with ESRD, as transplant allows better growth, regular school attendance and a more normal life for affected children and families. The ASPN works to educate the public, Members of Congress and their staffs, and the medical community about these unique needs of pediatric patients with kidney disease.

The ASPN supports improving the quality of life for pediatric kidney patients, especially those with kidney transplants, through the following initiatives:

- **Increased research focused on the prevention and early identification of pediatric kidney disease to decrease the growing need for renal transplantation.** The dramatic increase in childhood obesity puts more than 15 percent of America's children at risk for Type 2 diabetes, hypertension, and chronic kidney disease later in life. The fastest growing segment of patients waiting for a kidney transplant today have ESRD related to complications of diabetes and hypertension, making it ever more difficult for the available donors to keep up with the demand for kidney transplants. The ASPN advocates for more research to address ways to keep children with Type 2 diabetes and hypertension from becoming adolescents and young adults with ESRD.
- **Education about the unique medical and financial challenges faced by children and adolescents with chronic kidney disease and ESRD.** The ASPN works to ensure that children covered by Medicare for ESRD, and especially for renal transplantation, are not forgotten.
- **Improved transition of patients from pediatric to adult medical care.** The ASPN collaborates with pediatric and adult nephrology professionals to improve the transition of adolescents to adult care. The ASPN advocates for better access to medical insurance coverage and anti-rejection medications for transitioning patients to help reduce the high incidence of loss of transplant function in adolescents and young adults.

How extensive is pediatric kidney disease?

Kidney disease continues to be a major cause of illness and death among the most vulnerable segment of the population—our children. An estimated 150,000 children and adolescents currently suffer from kidney diseases for which a cure or treatment does not exist; about 10,000 of them suffer from chronic kidney failure, are on dialysis or have a kidney transplant. Unless scientists are able to find cures or more effective treatments:

- 300,000 children and adolescents will require evaluation for proteinuria, one of the early signs of progressive kidney disease; 100,000 will need treatment for diabetes and ultimately require dialysis;
- Up to four percent of children and adolescents have hypertension, a precursor of kidney failure and cardiovascular disease. Early treatment, which may include lifestyle changes and/or antihypertensive medication, is crucial to prevent adult cardiovascular disease such as heart attacks and strokes.
- 20,000 children will be born with congenital kidney and urinary tract abnormalities; 2,000 infants will die from genitourinary disease; and
- 1.2 million children under the age of 7 will develop urinary tract infections that can permanently damage kidney tissue.

Why distinguish between pediatric and adult kidney disease?

The pediatric population suffers from a different spectrum of kidney diseases than do adults and encounters unique problems related to the disruption of normal growth and development. The effects of kidney disease on the developing brain may also lead to significant learning and neurocognitive disabilities. In the absence of cures and more effective treatments, these young people will be sentenced to a lifetime of suffering and costly care.

Treatment advances leading to improvements in transplant survival among adults have not been as effective in children, whose immune systems are much more likely to reject the transplanted kidney. Infants, children and adolescents suffering from kidney disease therefore require special consideration. Additional research is needed to better identify optimal treatment options, including the unique effects of pharmaceuticals among different age groups. Additionally, scientific and technological innovation are critically needed to develop devices tailored to serve the small size and blood volumes of children with acute kidney failure and ESRD.

Pediatric nephrologists are specially trained and qualified to manage kidney diseases that affect the pediatric age group. Their expertise encompasses knowledge of physical and psychological growth and development, understanding of the changing nature of pediatric drug metabolism and nutritional requirements with age, and skills to manage the unique aspects of dialysis and transplantation in infants, children and adolescents.