



CHILDREN'S MERCY KANSAS CITY PLAYS LEAD ROLE IN FIRST-EVER NKF PEDIATRIC CKD CONFERENCE

MEDICAL EXPERTS GATHER IN ATLANTA TO BETTER UNDERSTAND CKD IN CHILDREN

Despite the collection of substantial data via two recent large cohort studies on the progression of chronic kidney disease and its comorbidities, few well-founded recommendations for long-term CKD management in children have been developed. The National Kidney Foundation decided the time was right to change that and to enhance the care of children with CKD.

The result was the first-ever NKF Scientific Workshop on CKD in Children, which was held Dec. 6 and 7 in Atlanta. Event co-chairs were Bradley A. Warady, MD, Director, Division of Nephrology at Children's Mercy Kansas City, and Susan Furth, MD, PhD, Director, Division of Nephrology at Children's Hospital of Philadelphia.

Dozens of experts, including pediatric nephrologists, nurses and bioethicists, attended this truly multidisciplinary event, where all perspectives were welcome. Also invited were patients and families, because their perspectives on treatment recommendations and their role in medical management are crucial to patient outcomes.

WORKGROUPS TACKLE KEY ISSUES IN CKD CARE

In addition to hearing keynote speakers, conference attendees were divided into workgroups, with each

focused on one of five important issues facing CKD patients:

- Factors that lead to progression of CKD
- Heart disease and anemia
- Poor growth and bone disease
- Patient and parent perspectives
- Transition and transfer to adult kidney care

First, these groups reviewed the available literature related to their topics. Next they worked together to generate consensus recommendations for care.

Ultimately, the group will author a white paper that details all of their recommendations, to be shared broadly within the health care community. In addition, white paper content will be repurposed into educational materials for primary care providers, along with patients and families. The white paper is expected to be completed in the fall.

PATIENTS AND FAMILIES OFFER IMPORTANT PERSPECTIVE

Before the conference, rarely had patient and family perspectives been factored into care guidelines. In the workgroup on patient and parent perspectives, attendees shared their experiences with daily care activities, such as managing a restrictive diet, obtaining and administering medications, and monitoring blood pressure 24 hours a day. They offered insight into the difficulties of juggling the many care requirements, all while attempting to create a sense of normalcy in a setting of chronic illness.

PATIENTS AND FAMILIES OFFER IMPORTANT PERSPECTIVE

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This conversation offered a reality check for the providers and further highlighted the importance of a strong partnership between parents and providers, and the fact that treatment guidelines must be infused with a sense of realism to be effective.

In late 2018, NKF sponsored the development of an online community for parents of children with CKD. Children with CKD are relatively rare, which can create feelings of isolation in parents. This community will connect families to others in the same situation, and provide the opportunity for the sharing of experiences and the generation of a network of support.

PLANNING FOR A SUCCESSFUL TRANSFER OF CARE

Another workgroup discussed the challenges related to the transfer of patients with CKD from pediatric to adult-centered care. Many of these patients have received care for their entire lives at a pediatric center, where the pediatric nephrology team typically spends significant

time attending to each and every patient need. That same approach is often not feasible in adult medicine, creating anxiety for these patients and their parents – and a potentially negative impact on outcomes. According to the literature, attendance at regular clinic visits

may fall soon after transfer to adult care. For those young adult patients who have undergone a kidney transplant,

increased rejection rates can occur when inadequate planning is carried out in preparation for the transfer of care.

The group developed goals for young adults to achieve before their care is transferred, including setting clear educational expectations for these patients before their initial visit with an adult provider. Discussion centered on the need for a transition program that educates patients progressively from ages 12 to 21, to ensure they understand key elements of their own care, including the following:

- What is chronic kidney disease? What is my kidney disorder? What factors might cause my disease to worsen?
- How does my insurance work?
- What medications do I require? What does each one do for me? How do I obtain refills?

Ultimately, the goal of a transition program is to provide education on a variety of health-related topics so that patients feel confident and able to take on much of the responsibility for their own care as they approach adulthood – a dramatic shift from their care as children.



Children's Mercy played a lead role in first-ever NKF pediatric CKD conference, with Dr. Warady as co-chair.



LEARN MORE ABOUT CHILDREN'S MERCY KANSAS CITY.

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