

CKiD RECEIVES NIH FUNDING FOR NEW PHASE OF STUDY

STUDY BROADENS FOCUS TO ENTIRE SPECTRUM OF CHRONIC KIDNEY DISEASE

The Chronic Kidney Disease in Children (CKiD) study and Children's Mercy Kansas City were recently approved to receive an additional \$4.8 million of funding by the NIH over the next five years, making 20 consecutive years of funding for this seminal research effort. CKiD is currently enrolling an additional 190 children in its third patient cohort.

Bradley Warady, MD, Director of the Division of Pediatric Nephrology and Director of Dialysis and Transplantation at Children's Mercy Kansas City, is one of two principal investigators of the study, which has generated more than 100 publications over the past 15 years.

In earlier phases of the study, when participants developed end-stage kidney disease, they discontinued regular follow-up visits at one of the participating centers of this multicenter initiative. The new phase of the study will focus on the entire spectrum of the disease, with enrollment of children with early chronic kidney disease (CKD) during infancy, as well as the continued study of those children who progress to kidney failure, requiring dialysis and transplantation.

Over the next five years, a major goal of the study is to find ways to change the course of CKD and its complications at both ends of the spectrum. The team will work to define strategies to significantly delay or prevent the progression of CKD by detecting abnormalities early in the disease process for more timely interventions. It also plans to obtain data that will support the development of new management strategies designed to improve the outcomes of patients with end-stage kidney disease. The study

protocol will also make use of new technology by including the remote collection of blood pressure, exercise and sleep-related data.

Finally, the CKiD team is aiming to share insights gleaned from the study with primary care providers who care for children with CKD outside academic centers. CKiD nephrologists and biostatisticians are working together to further refine a risk calculator based on CKD clinical parameters to help pediatricians and other primary care providers estimate the risk of disease progression in their patients. It is expected to be available in 2019.

CKiD PATIENT COHORT

CKiD is currently enrolling 190 children with nonglomerular disease and CKD for < 5 years in duration in its third patient cohort. The prior cohorts entered the study at 1-16 years of age and since the study has been in progress for 15 years, some participants are now 25 years old. Fifty-four pediatric centers across North America are participating in the CKiD study and, to date, more than 1,000 children have participated in this research project.

RESEARCH TO DATE

Over the 15-year course of the CKiD study, its findings have regularly contributed to a greater understanding of pediatric CKD, its comorbidities and the risk factors that can influence patient outcomes. The study has informed many aspects of care because of the depth and breadth of the investigations, which have addressed many systems that are affected by CKD, such as growth, neurocognition, bone disease and cardiovascular disease.

RESEARCH TO DATE

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In fact, three highlights of the study to date have been:

1. Creation of a better glomerular filtration rate (GFR) estimating equation for children with CKD.
2. Better definition of risk factors for progression of CKD.
3. Recognition of the prevalence and severity of cardiovascular disease in children with CKD.

The CKiD estimating equation has now been accepted as the most clinically applicable means to estimate the kidney function of North American children with CKD. In the current funding cycle, additional work will be carried out to evaluate the accuracy of the current equation in children with only mild CKD. The use of the equation will also allow CKiD investigators to further evaluate the impact of a variety of risk factors, especially those that are modifiable, on the progression of CKD and the development of comorbidities.

Because of the significance of heart issues on the outcome of children with CKD and the relationship between high blood pressure (BP) and heart disease, home blood pressure monitoring aided by modern cloud technology will be a new component of the CKiD study, added to the regular performance of 24-hour ambulatory blood pressure monitoring (ABPM), a core procedure in CKiD since the study was initiated. In part as a result of the data derived from CKiD, a combination of office visit BP readings and 24-hour blood pressure monitoring is now recommended for the routine evaluation of pediatric patients with CKD. The reason is simple: Many of these patients have masked hypertension, a diagnosis that can be made only via the performance of 24-hour BP monitoring. This thorough evaluation of BP in children with CKD should result in better blood pressure control and more favorable cardiovascular outcomes.

ENHANCING THE STUDY

The continued study of patients who have advanced to dialysis will provide a unique opportunity to learn more about the changes in heart function that occur in

association with severe kidney disease. The expanded study and plans to continue to follow subjects even after they transfer to adult care will also help fill a knowledge gap regarding CKD-related clinical issues that arise between adolescence and adulthood in the so-called “emerging adult,” an age group that has been understudied.

Another area of emphasis in CKiD over the next five years will be ethics. An ethics advisory group is currently being developed, and CKiD has had the good fortune of adding John Lantos, MD, Director of the Children’s Mercy Center for Bioethics, and Benjamin Wilfond, MD, Director of the Treuman Katz Center for Pediatric Bioethics at Seattle Children’s Research Institute, as members of the team.

Genetic studies are now regularly carried out in CKiD and other research collaboratives. However, how to best interpret the results is not always clear. And clinicians grapple with questions about what parents should or should not be told about genetic findings that are potentially worrisome, but not definitively predictive of future problems. The CKiD study offers a unique opportunity for clinicians, patients and parents to analyze these ethical issues and develop policies that can be implemented in the setting of kidney disease or any other chronic disorder.

“The fact that CKiD will be funded by the NIH for an additional five years has provided the nephrology community the opportunity to further impact the course of CKD in children. We are confident that the combined efforts of a great many people within the CKiD project will help define better strategies to significantly delay or prevent the progression of CKD early in its course, as well as refine management strategies for improving the outcomes for dialysis and transplant patients. While the challenges to achieve these goals are great, the potential rewards for our patients make all of our efforts extremely worthwhile.”

Bradley A. Warady, MD



LEARN MORE ABOUT CHRONIC KIDNEY DISEASE RESEARCH AND CARE.

Bradley Warady, MD, Nephrology Division Director
bwarady@cmh.edu • (816) 302-3010
transformpeds.childrensmercy.org

For consults, admissions or transport call: 1 (800) GO MERCY / 1 (800) 466-3729.

