

Chronic Kidney Disease  
in Children

<http://statepi.jhsph.edu/ckid/>

# CKiD Study Structure

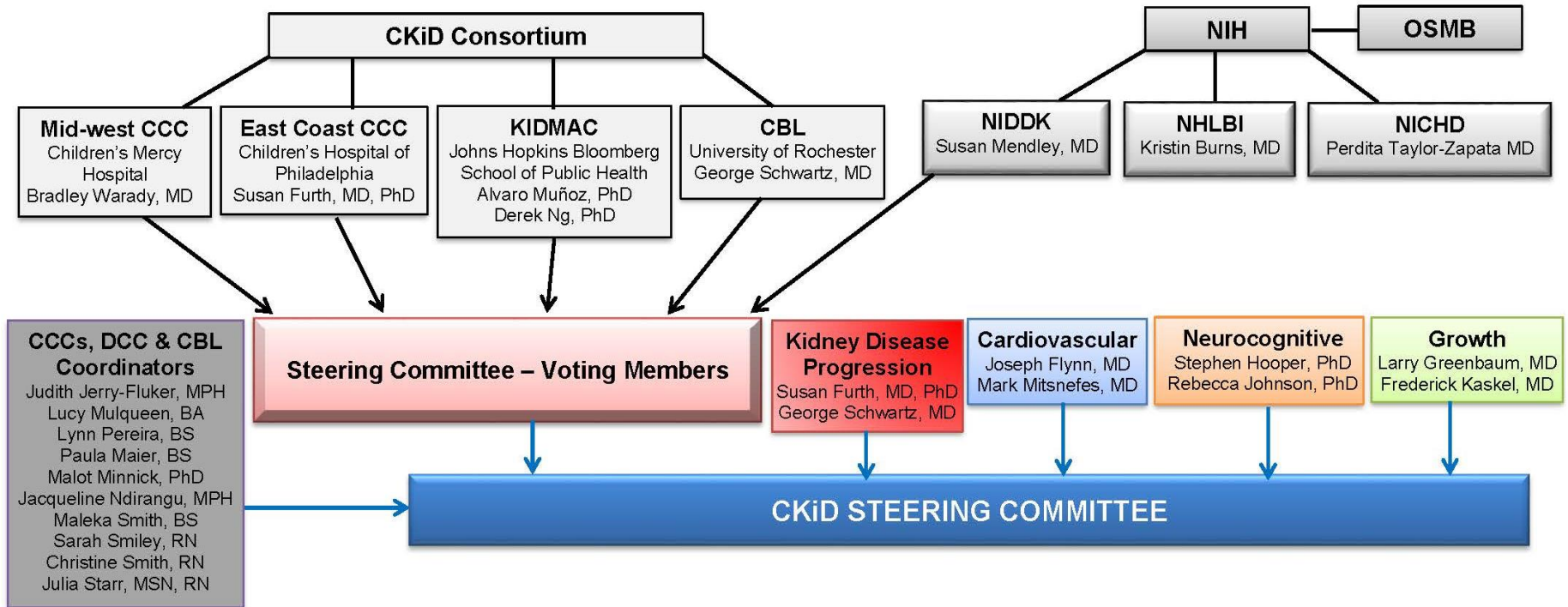
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- **Clinical Coordinating Centers**
  - Midwest (Warady)
  - East Coast (Furth)
- **Data Management and Analysis Center**
  - KIDMAC (Muñoz, Ng)
- **Central Laboratory**
  - University of Rochester (Schwartz)

**Sponsorship: NIDDK, NICHD, NHLBI**



# Study Structure



# Steering Committee

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- Alison Abraham
- Kristen Burns
- Susan Furth\*
- Joseph Flynn
- Arlene Gerson
- Larry Greenbaum
- Lynne Haverkos
- Judith Jerry-Fluker
- Stephen Hooper
- Rebecca Johnson
- Frederick Kaskel
- Paula Maier
- Robert Mak
- Susan Mendley\*
- Malot Minnick-Belarmino
- Mark Mitsnefes
- Alvaro Muñoz\*
- Jackie Ndirangu
- Derek Ng\*
- Joshua Samuels
- George Schwartz\*
- Sarah Smiley
- Christine Smith
- Maleka Smith
- Julia Starr
- Bradley Warady\*
- Craig Wong

\* Voting Members



# Central Laboratories and Repositories

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**Central Biochemistry  
Laboratory (George Schwartz, MD)**

**Ambulatory Blood Pressure  
Monitoring Coordinating  
Center (Joshua Samuels, MD)**

**Cardiovascular Imaging Core  
Research Laboratory  
(Pamela Winterberg, MD)**

**Cardiac MRI Coordinating  
Center (Michael Taylor, MD)**

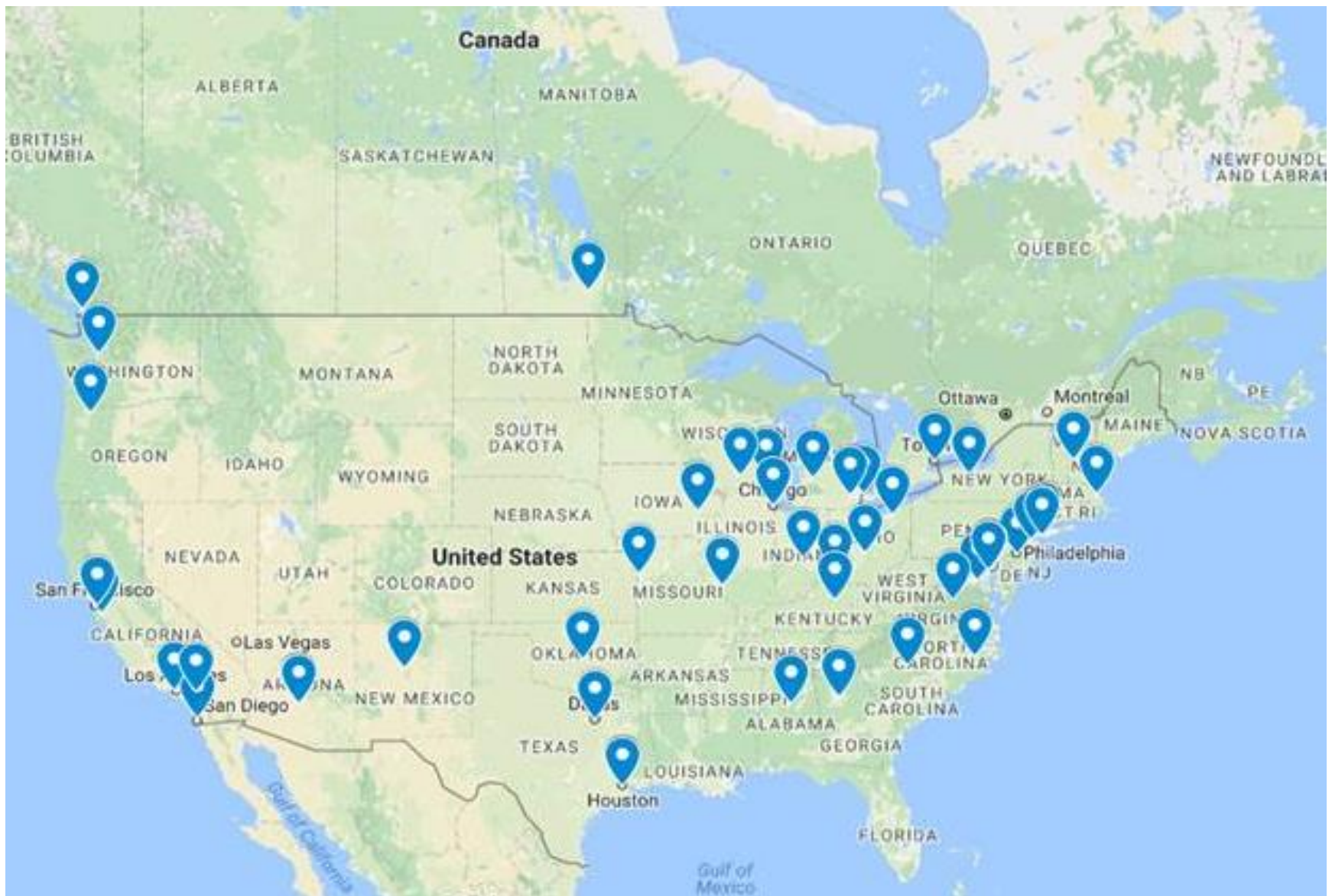
**NIDDK Data Repository  
at Information  
Management Services  
(IMS) – Calverton, MD**

**NIDDK Biosample  
Repository at Fisher  
BioServices –  
Rockville, MD**

**NIH Genetics  
Repository at Rutgers  
University Cell and  
DNA Repository –  
Piscataway, NJ**

# CKiD Participating Sites

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# Clinical Sites\*

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## Midwest Coordinating Center

British Columbia Children's Hospital  
Case Western Reserve University  
Children's Hospital of Alabama  
Children's Hospital of Boston  
Children's Hospital of Winnipeg  
**Children's Mercy Hospital**  
Cincinnati Children's Hospital and Medical Center  
Egleston Children's Hospital, Emory University  
Medical College of Wisconsin  
Oklahoma University Health Science Center  
Oregon Health and Science University  
Phoenix Children's Hospital  
Seattle's Children's Hospital  
St. Louis Children's Hospital  
Stanford University Medical Center  
University of California – Los Angeles  
University of California – San Diego  
UCSF Children's Hospital  
University of New Mexico Children's Hospital  
University of Texas Southwestern Medical Center

## East Coast Coordinating Center

Ann & Robert H. Lurie Children's  
Hospital of Chicago  
Carolina Medical Center  
**Children's Hospital of Philadelphia**  
Children's Hospital of Michigan  
Children's Hospital at Dartmouth  
Children's Hospital at Montefiore  
Children's National Medical Center  
DeVos Children's Hospital  
at Spectrum  
East Carolina University  
Hospital for Sick Children (Sick Kids)  
Icahn School of Medicine  
at Mount Sinai  
INOVA Fairfax Hospital for Children  
Johns Hopkins Children's Center  
Nationwide Children's Hospital, Ohio State  
University  
Riley Hospital for Children at Indiana  
University Health  
RBHS-Robert Wood Johnson Medical  
School  
Texas Children's Hospital  
University of Florida  
University of Illinois at Chicago  
University of Iowa  
University of Maryland  
University of Michigan  
University of Rochester Medical Center,  
Golisano Children's Hospital at Strong  
University of Texas, Houston  
University of Virginia

\* List excludes sites that enrolled participants but are no longer participating in study



# Midwest Coordinating Center – CLINICAL SITES

| Clinical Site   | Principal Investigator(s)                             |
|---|---|
| Arizona Kidney Disease and Hypertension Center <sup>c</sup> | Gina Marie Barletta, MD                               |
| Boston Children's Hospital                                  | Nancy Rodig, MD <sup>a</sup> ; William Harmon, MD     |
| British Columbia Children's Hospital                        | Tom Blydt-Hansen, MD, FRCPC                           |
| Cardinal Glennon Hospital <sup>b</sup>                      | Ellen Wood, MD  |
| Case Western Reserve University                             | Katherine Dell, MD                                    |
| Children's Hospital of Alabama                              | Sahar Fathallah, MD                                   |
| Children's Hospital of Los Angeles <sup>b</sup>             | Gary Lerner, MD                                       |
| Children's Hospital of Winnipeg                             | Allison Dart, MD, MSc, FRCPC                          |
| Children's Kidney Specialists, Idaho <sup>b</sup>           | Randall Jenkins, MD                                   |
| Children's Mercy Hospital, Kansas City                      | Bradley Warady, MD                                    |
| Cincinnati Children's Hospital and Medical Center           | Donna Claes, MD <sup>a</sup> , Mark Mitsnefes, MD     |
| Egleston Children's Hospital, Emory University              | Larry Greenbaum, MD, PhD                              |
| LeBonheur Children's Medical Center <sup>b</sup>            | Colleen Hastings, MD                                  |
| Medical College of Wisconsin                                | Cynthia Pan, MD                                       |
| Northwest Pediatric Kidney Specialist*                      | Randall Jenkins, MD                                   |
| Oregon Health and Science University                        | Amira Al-Uzri, MD <sup>a</sup> ; Randall Jenkins, MD  |
| Phoenix Children's Hospital                                 | Martin Turman, MD, PhD                                |
| Seattle Children's Hospital                                 | Joseph Flynn, MD                                      |
| St. Louis Children's Hospital                               | Keefe Davis, MD                                       |
| Stanford University Medical Center                          | Cynthia Wong, MD <sup>a</sup> ; Steven Alexander, MD  |
| UCSF Children's Hospital                                    | Elaine Ku, MD, MAS                                    |
| University of California, Los Angeles                       | Isidro Salusky, MD; Ora Yadin, MD <sup>a</sup>        |
| University of California, San Diego                         | Nadine Benador, MD <sup>a</sup> ; Robert Mak, MD, PhD |
| University of New Mexico Children's Hospital                | Craig Wong, MD, MPH                                   |
| University of Oklahoma Health Sciences Center               | Anjali Nayak, MD                                      |
| University of Texas Southwestern Medical Center             | Mouin Seikaly, MD                                     |
| University of Wisconsin                                     | Sharon Bartosh, MD                                    |

<sup>a</sup> Clinical Site Principal Investigator

<sup>b</sup> No longer participating site that enrolled children in the study

<sup>c</sup> New participating site for cohort 3 recruitment

\* Combined with Oregon Health and Science University



# East Coast Coordinating Center – CLINICAL SITES

| Clinical Site   | Principal Investigator(s)                         |
|---|---|
| Ann & Robert H. Lurie Children's Hospital of Chicago            | Craig Langman, MD                                 |
| Carolinas Medical Center  | Susan Massengill, MD                              |
| Children's Hospital at Dartmouth                                | Adam Weinstein, MD                                |
| Children's Hospital at Montefiore                               | Frederick Kaskel, MD, PhD                         |
| Children's Hospital of Michigan                                 | Tej Matoo, MD                                     |
| Children's National Medical Center                              | Larry Patterson, MD                               |
| Children's Hospital of Philadelphia                             | Susan Furth, MD, PhD                              |
| DeVos Children's Hospital at Spectrum                           | Alejandro Quiroga, MD                             |
| East Carolina University  | Guillermo Hidalgo, MD                             |
| Hospital for Sick Children (Sick Kids)                          | Rulan Parekh, MD <sup>a</sup> ; Lisa Robinson, MD |
| Icahn School of Medicine at Mount Sinai                         | Jeffrey Saland, MD                                |
| INOVA Fairfax Hospital for Children                             | Patricia Seo-Mayer, MD                            |
| Johns Hopkins Children's Center                                 | Meredith Atkinson, MD                             |
| Loma Linda University <sup>c</sup>                              | Cheryl Sanchez-Kazi, MD                           |
| Maimonides Medical Center <sup>b</sup>                          | Juan Kupferman, MD                                |
| Maria Fareri Children's Hospital at Westchester <sup>b</sup>    | Dmitry Samsonov, MD                               |
| Nationwide Children's Hospital, Ohio State Univ.                | Amy Kogon, MD                                     |
| Riley Hospital for Children at Indiana Univ. Health             | Amy Wilson, MD                                    |
| Rutgers - Robert Wood Johnson Medical School                    | Joann Carlson, MD                                 |
| State University of New York, Downstate Med Center <sup>c</sup> | Anil Mongia, MD                                   |
| Texas Children's Hospital, Baylor                               | Poyyapakkam Srivaths, MD                          |
| University of Florida <sup>b</sup>                              | Kiran Upadhyay, MD                                |
| University of Illinois, Chicago                                 | Eunice John, MD                                   |
| University of Iowa  | Jason Misurac, MD                                 |
| University of Kentucky <sup>c</sup>                             | Steffan Kiessling, MD                             |
| University of Maryland*   | Meredith Atkinson, MD                             |
| University of Michigan, Mott Hospital                           | Dave Selewski, MD                                 |
| University of North Carolina, Chapel Hill <sup>b</sup>          | Maria Ferris, MD                                  |
| University of Rochester Medical Center,                         |   |
| Golisano Children's Hospital at Strong                          | Marc Lande, MD <sup>a</sup> , George Schwartz, MD |
| University of Texas, Houston                                    | Joshua Samuels, MD                                |
| University of Virginia  | Victoria Norwood, MD                              |

<sup>a</sup> Clinical Site Principal Investigator

<sup>b</sup> No longer participating site that enrolled children in the study

<sup>c</sup> New participating site for cohort 3 recruitment

\* Combined with Johns Hopkins Children's Center

# CKiD Study Goals

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- **Recruit and Retain CKiD participants**
- **Define risk factors for CKD progression**
- **Define effects of CKD progression on:**
  - **Cardiovascular Disease risk factors**
  - **Neurocognitive development/function**
  - **Growth failure**



# Exclusion Criteria

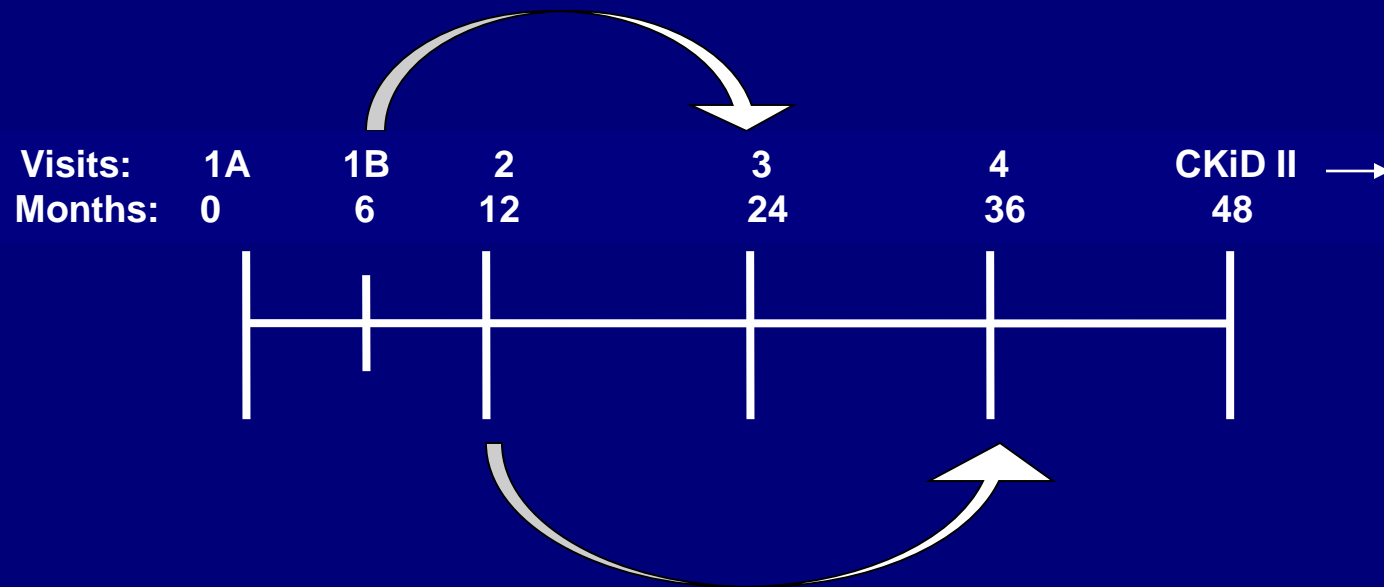
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- Renal, other solid organ, bone marrow or stem cell transplantation
- Dialysis treatment within the past three months
- Cancer diagnosis or HIV diagnosis/treatment within last twelve months
- Current pregnancy or pregnancy within past twelve months
- Inability to complete major data collection procedures
- Current enrollment in a randomized clinical trial in which the specific treatment is unknown
- Not fluent in English or Spanish
- Plans to move out of area of any participating CKiD site  
(Families can be transferred to another CKiD site if they move)
- History of structural heart disease
- Genetic syndromes involving the central nervous system  
(e.g., Down syndrome)
- History of Severe to Profound Mental Retardation  
(i.e., IQ < 40, significant impairment in adaptive functioning and/or inability to independently execute self-care skills)
- For cohort 3, children who are expected to receive renal replacement therapy within 6 months of date of enrollment will not be recruited



# Study Visit Timeline

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Furth, S.L., Cole, S.R., Moxey-Mims, M., Kaskel, F., Mak, R., Schwartz, G., Wong, C., Munoz, A., Warady, B.A. Design and Methods of the Chronic Kidney Disease in Children (CKiD) Prospective Cohort Study. Clinical Journal of American Society of Nephrology 1:1006-1015, 2006.

# Data Collection

|               |  | Pre-Study | V1A | V1B | Even Follow-up | Odd Follow-up  |
|---------------|--|-----------|-----|-----|----------------|----------------|
|               | <b>Consent</b>                           | ◆         |     |     |                |                |
| <b>Basic</b>  | <b>Questionnaires/Forms</b>              | ◆         | ◆   | ◆   | ◆              | ◆              |
|               | <b>Physical Examination</b>              |           | ●   | ●   | ●              | ●              |
|               | <b>Blood &amp; Urine Samples</b>         |           | X   | X   | X              | X              |
| <b>Kidney</b> | <b>Iohexol-based GFR</b>                 |           | X   |     | X              |                |
|               | <b>Estimated GFR</b>                     | X         | X   |     | X              | X              |
| <b>CVD</b>    | <b>ABPM &amp; Lipid Profile</b>          |           |     |     | ■              |                |
|               | <b>Echocardiogram</b>                    |           |     |     | ■ <sup>a</sup> |                |
| <b>Neuro</b>  | <b>Pediatric Quality of Life</b>         |           |     | ▲   | ▲              | ▲              |
|               | <b>Cognitive Development</b>             |           |     | ▲   |                | ▲              |
|               | <b>Behavioral Assessment<sup>b</sup></b> |           |     | ▲   |                | ▲ <sup>a</sup> |
| <b>Growth</b> | <b>Tanner Staging</b>                    |           | ●   |     | ●              | ●              |
|               | <b>iPTH &amp; hsCRP</b>                  |           |     | ●   |                | ●              |
| <b>Stored</b> | <b>Biological Samples</b>                |           |     | X   | X              | X              |
|               | <b>Genetic Sample</b>                    |           |     | X   |                |                |

<sup>a</sup> Echo & cIMT performed only at V2, V6, V10, V14

<sup>b</sup> Behavioral Assessment discontinued beginning at V9

# Cognitive and Development Assessments

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|   |                           |
|---|---------------------------|
| <b>Mullen Scales of Early Learning (Mullen Scales)</b>                                | <b>12 to 29 months</b>    |
| <b>Wechsler Preschool and Primary Scale of Intelligence-Third Edition (WPPSI-III)</b> | <b>30 months to 5 yrs</b> |
| <b>Wechsler Abbreviated Scales of Intelligence (WASI)</b>                             | <b>6 to 18 years</b>      |
| <b>Conners' Kiddie Continuous Performance Test (K-CPT)</b>                            | <b>4 to 5 years</b>       |
| <b>Conners' Continuous Performance Test II (CPT-II)</b>                               | <b>6 to 18 years</b>      |
| <b>Delis-Kaplan Executive Function System Tower Subtest</b>                           | <b>6 yrs and older</b>    |
| <b>Wechsler Intelligence Scale for Children 4th Ed (WISC-IV)</b>                      | <b>6 to 16 yrs</b>        |
| <b>Wechsler Adult Intelligence Scale 4th Ed (WAIS-IV)</b>                             | <b>17 yrs and older</b>   |

# Behavioral Assessments

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## Behavior Assessment System for Children Second Edition (BASC-2)

- Parental Rating Scales (BASC-PRS) 2 to 18 years
- Self-Report of Personality (BASC-SRP) 8 to 18 years

## Quality of Life: Pediatrics Quality of Life Scale

- Parent Report 2 to 18 years
- Child Report 8 to 18 years
- Young Adult Report 18 to 25 years

## Behavior Rating Inventory of Executive Function

- Preschool Version (BRIEF-P) 2 to 5 years
- BRIEF 6 to 18 years
- Adult Version (BRIEF-A) 18 yrs and older





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[Investigator  
Resources](#)

[Coordinator's  
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[Psychologist's  
Corner](#)

[Family  
Corner](#)

[Publications  
& Dossier](#)

## About CKiD

The CKiD Study is a NIH-funded, multicenter, prospective cohort study of children aged 6 months to 16 years with mild to moderate impaired kidney function. The primary goals of CKiD are to determine the risk factors for decline in renal function and to define how progressive decline in renal function impacts biomarkers of risk factors for cardiovascular disease; neurocognitive function and behavior; and growth failure and its associated morbidity. Two clinical coordinating centers (CCCs) (at Children's Hospital of Philadelphia and at Children's Mercy Hospital in Kansas City), a central biochemistry laboratory (at the University of Rochester), and a data coordinating center (at Johns Hopkins School of Public Health) formed a cooperative agreement to conduct the CKiD Study.

### Study Aims

The specific aims are to:

- Identify novel and traditional renal disease risk factors for the progression of CKD (e.g. decline of GFR) in children
- Characterize the impact of a decline in kidney function on neurodevelopment, cognitive abilities, and behavior
- Identify the prevalence and evolution of traditional and novel cardiovascular disease risk factors in progressive CKD
- Examine the effects of declining GFR on growth and the treatment of growth failure, and to assess the consequences of growth failure on morbidity in children with CKD

[Contact Us](#)

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[Key Forms for Sites](#)

[Online BP Certification](#)

# **KIDMAC Data Coordinating Center at Johns Hopkins University**

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- **Alison Abraham**
- **Aisha Betoko**
- **Megan Carroll**
- **Christopher Cox**
- **Judith Jerry-Fluker**
- **Shuai Jiang**
- **Matthew Matheson**
- **Lucy Mulqueen**
- **Alvaro Muñoz**
- **Derek Ng**
- **Lynn Pereira**
- **Jennifer Roem**
- **Michael Schneider**
- **Gayle Springer**
- **Sol Su**
- **Jingjun Sun**
- **Won Yoo**

# Contact Information

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## Clinical Coordinating Centers

### **East Coast Clinical Coordinating Center**

Children's Hospital of Philadelphia

Dr. Susan Furth

215-590-2449

3535 Market Street

Philadelphia, PA 19104

### **Mid West Clinical Coordinating Center**

Children's Mercy Hospital

Dr. Bradley Warady

816-234-3812

2401 Gillham Road, M172

Kansas City, Missouri 64108

## Data Coordinating Center

Johns Hopkins University

School of Public Health

Dr. Alvaro Muñoz

Dr. Derek Ng

410-614-1430

615 North Wolfe Street, E7648

Baltimore, Maryland 21205

## Central Biochemistry Laboratory

University of Rochester Medical Center

Pediatric Nephrology

Dr. George Schwartz

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601 Elmwood Avenue

Box 777, Room 4-8105

Rochester, NY 14642