

Chronic Kidney Disease  
in Children

# CKiD Study Structure

---

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

**Sponsorship: NIDDK, NICHD, NHLBI**

# Steering Committee

---

- Alison Abraham
- Susan Furth\*
- Joseph Flynn
- Arlene Gerson
- Larry Greenbaum
- Lynne Haverkos
- Judith Jerry-Fluker
- Stephen Hooper
- Frederick Kaskel
- Paula Maier
- Robert Mak
- Malot Minnick-Belarmino
- Mark Mitsnefes
- Marva Moxey-Mims\*
- Alvaro Muñoz\*
- Jackie Ndirangu
- Christopher Pierce
- George Schwartz\*
- Christine Smith
- Julia Starr
- Bradley Warady\*
- Craig Wong

\* Voting Members

# Subcommittees

## Steering

### Progression

Susan Furth, Co-Chair  
Robert Mak, Co-Chair  
George Schwartz, Co-Chair

### Neurocognitive

Stephen Hooper, Co-Chair  
Arlene Gerson, Co-Chair  
Bradley Warady, Co-Chair

### Cardiovascular

Mark Mitnesfes, Co-Chair  
Joseph Flynn, Co-Chair

### Growth

Frederick Kaskel, Co-Chair  
Larry Greenbaum, Co-Chair

### Data

Alvaro Muñoz, Co-Chair  
Craig Wong, Co-Chair

### Laboratory

George Schwartz, Chair

### Training

Jackie Ndirangu, Co-Chair  
Julie Starr, Co-Chair

### OSMB

# Central Laboratories and Repositories

---

- **Central Biochemistry Laboratory (George Schwartz, MD)**
- **ABPM Coordinating Center (Joshua Samuels, MD)**
- **Cardiovascular Imaging Core Research Laboratory (Peace Madueme, MD)**
- **NIDDK Biosample Repository (NIDDK BR) at Fisher BioServices – Rockville, MD**
- **NIH Genetics Initiative at Rutgers University Cell and DNA Repository – New Brunswick, NJ**

# CKiD Participating Sites



# Midwest Coordinating Center – CLINICAL SITES

SITE #	SITE NAME	Principal Investigator
1	Children's Mercy Hospital, Kansas City	Bradley Warady, MD
2	Medical College of Wisconsin	Cynthia Pan, MD
3	University of New Mexico Children's Hospital	Craig Wong, MD
4	Oregon Health Science University	Amira Al-Uzri, MD <sup>a</sup> ; Randall Jenkins, MD <sup>a</sup>
5	Cincinnati Children's Hospital and Medical Center	Jens Goebel, MD <sup>a</sup> ; Mark Mitsnefes, MD
6	Stanford University Medical Center	Paul Grimm, MD <sup>a</sup> ; Steven Alexander, MD
7	Children's Hospital of Boston	Nancy Rodig, MD <sup>a</sup> ; William Harmon, MD
8	British Columbia Children's Hospital	Colin White, MD, FRCPC, FAAP
9	Children's Hospital of Alabama	Sahar Fathallah, MD
10	St. Louis Children's Hospital	S. Paul Hmiel, MD
11	Case Western Reserve University	Katherine Dell, MD
12	University of Wisconsin	Sharon Bartosh, MD
13	Oklahoma University Health Sciences Center	Martin Turman, MD, PhD
15	Seattle Children's Hospital	Joseph Flynn, MD
16	Cardinal Glennon Hospital	Ellen Wood, MD
17	Children's Hospital of Winnipeg	Tom Blydt-Hansen, MD
18	LeBonheur Children's Medical Center <sup>b</sup>	Colleen Hastings, MD
20	University of California, Los Angeles	Isidro Salusky, MD; Ora Yadin, MD <sup>a</sup>
21	University of California, San Diego	Nadine Benador, MD <sup>a</sup> ; Robert Mak, MD, PhD
22	University of Texas Southwestern Medical Center	Mouin Seikaly, MD
24	Children's Hospital of Los Angeles <sup>b</sup>	Gary Lerner, MD
25	UCSF Children's Hospital	Anthony Portale, MD
27	Phoenix Children's Hospital	Bruce Morgenstern, MD
28	Egleston Children's Hospital, Emory University	Larry Greenbaum, MD, PhD
30	Northwest Pediatric Kidney Specialists <sup>b</sup>	Randall Jenkins, MD
31	Children's Kidney Specialists, Idaho <sup>b</sup>	Randall Jenkins, MD
32	Vanderbilt University Medical Center <sup>b</sup>	Deborah Jones, MD

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

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

## East Coast Coordinating Center – CLINICAL SITES

SITE #	SITE NAME	Principal Investigator
50	Johns Hopkins Children's Center	Meredith Atkinson, MD
51	Children's Hospital of Michigan	Tej Matoo, MD
52	Ann & Robert H. Lurie Children's Hospital of Chicago	Craig Langman, MD
53	Children's National Medical Center	Kanwal Kher, MD
54	Nationwide Children's Hospital, Ohio State Univ.	Hiren Patel, MD
55	INOVA Fairfax Hospital for Children	Patricia Seo-Mayer, MD
57	Riley Hospital for Children at Indiana Univ. Health	Sharon Andreoli, MD, PhD
58	University of Maryland	Susan Mendley, MD
59	University of Michigan, Mott Hospital	Debbie Gipson, MD
60	University of North Carolina, Chapel Hill	Maria Ferris, MD
61	University of Texas, Houston	Joshua Samuels, MD
63	Maria Fareri Children's Hospital at Westchester <sup>b</sup>	Dmitry Samsonov, MD
64	Children's Hospital at Montefiore	Frederick Kaskel, MD, PhD
65	University of Iowa	Patrick Brophy, MD
67	Maimonides Medical Center	Juan Kupferman, MD
68	Mount Sinai Medical Center	Jeffrey Saland, MD
70	Texas Children's Hospital, Baylor	Poyyappakkam Srivaths, MD
72	University of Rochester Medical Center, Golisano Children's Hospital at Strong	Marc Lande, MD <sup>a</sup> , George Schwartz, MD
73	University of Virginia	Victoria Norwood, MD
74	RBHS - Robert Wood Johnson Medical School	Lynne Weiss, MD
75	University of Florida	Kiran Upadhyay, MD
79	DeVos Children's Hospital at Spectrum	Yi Cai, MD
80	Carolinas Medical Center	Susan Massengill, MD
81	SUNY Downstate Medical Center	Anil Mongia, MD
82	University of Illinois, Chicago	Eunice John, MD
83	Children's Hospital of Philadelphia	Susan Furth, MD, PhD
84	Hospital for Sick Children (Sick Kids)	Rulan Parekh, MD <sup>a</sup> ; Lisa Robinson, MD
85	East Carolina University	Guillermo Hidalgo, MD
86	Children's Hospital at Dartmouth	Debora Mattosian, MD
87	Children's Hospital of Richmond at VCU	Megan Lo, MD



# CKiD Study Goals

---

- **Recruit & retain children with CKD**
- **Define risk factors for CKD progression**
- **Define effects of CKD progression on:**
  - **Neurocognitive development/function**
  - **Prevalence of CVD risk factors**
  - **Growth failure**

# CKiD Study Design

---

- **Observational Cohort Study**
  - **5 year study initially, 10 year renewal**  
(Oct 2003 – Jul 2008, Aug 2008 – Jul 2013, Aug 2013 – Jul 2018)
  - **Cohort 1 enrollment: Apr 2005 - Oct 2007**
  - **Cohort 2 enrollment: Feb 2011 – March 2014**
- **Cohort 1: Children age 1 to 16 with mild to moderate kidney dysfunction**  
sGFR: 30 – 90 ml/min|1.73m<sup>2</sup>
- **Cohort 2: Children age 1 to 16 with mildly impaired kidney function**  
eGFR: 45 – 90 ml/min|1.73m<sup>2</sup>

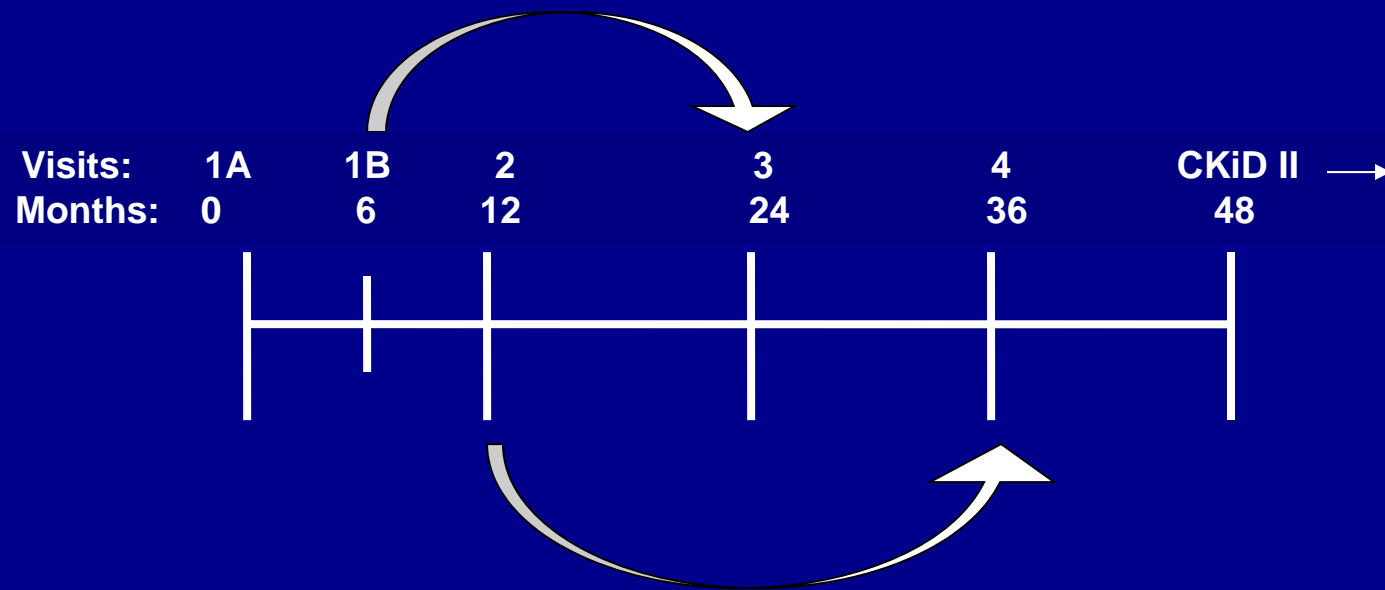
# Exclusion Criteria

---

- **Renal, other solid organ, bone marrow or stem cell transplantation**
- **Dialysis treatment within the past three months**
- **Cancer/leukemia or HIV diagnosis/treatment within last calendar year**
- **Current pregnancy or pregnancy within past year**
- **Inability to complete major data collection procedures (e.g., hypersensitivity to Iohexol, other contrast media or iodine)**
- **Current enrollment in a randomized clinical trial in which the specific treatment is unknown**
- **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)**
- **Profound developmental delay due to severe anoxic brain injury**

# Study Visit Timeline

---



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.

# Study Activities

		Pre-Study	V1A	V1B	V2	V3	V4 / V8 / V12	V6 / V10 / V14	V5 / V7	V9 / V11 / V13 / V15
	Consent	X								
Basic	Questionnaires/Forms	X	X	X	X	X	X	X	X	X
	Physical Examination		X	X	X	X	X	X	X	X
	Blood & Urine Samples		X	X	X	X	X	X	X	X
Kidney	Iohexol-based GFR		X		X		X	X		
	Cystatin C		X		X	X	X	X	X	X
	Serum Creatinine	X	X		X	X	X	X	X	X
CVD	ABPM & Lipid Profile				X		X	X		
	Echo				X			X		
Neuro	Pediatric Quality of Life			X	X	X	X	X	X	X
	Cognitive Development			X		X			X	X
	Behavioral Assessment			X		X			X	
Growth	iPTH & hsCRP			X		X			X	X
	Tanner Staging		X		X	X	X	X	X	X
Stored	<i>Biological Samples</i>			X	X	X	X	X	X	X
	<i>Genetic Sample</i>			X						

# CKiD Measurements According to Time-on-Study

Measurements	Enrollment				CKiD II	
	Year 1	Year 2	Year 3	Year 4	Odd Years from Year 5 on	Even Years from Year 6 on
<b>Kidney: Renal Panel*, CBC*, proteinuria, albuminuria, Cystatin C</b> <b>CV: Standardized BP*</b> <b>Growth: Height*, Weight*, FFQ, Tanner Stage*, Waist &amp; Hip Circumference*</b>	✓	✓	✓	✓	<b>S</b> <b>e</b> <b>e</b> <b>Y</b> <b>e</b> <b>a</b> <b>r</b> <b>3</b>	<b>S</b> <b>e</b> <b>e</b> <b>Y</b> <b>e</b> <b>a</b> <b>r</b> <b>4</b>
<b>GFR (Iohexol) (2 pt)</b>	✓	✓		✓		
<b>Echo, ABPM, Carotid IMT<sup>a</sup>, Lipids</b>		✓		✓		
<b>PedsQOL, Cognitive, Behavior Tests</b>	✓		✓			
<b>CRP, iPTH, Vitamin D, FGF-23</b>	✓		✓			

<sup>a</sup>Subcohort

\*Locally performed tests

# Cognitive and Development Assessments

---

<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

---

## 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



# CKiD Website

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



[Home](#)   [Study Information](#)   [Study Administration](#)   [Investigator Resources](#)   [Coordinator's Corner](#)   [Psychologist's Corner](#)   [Family Corner](#)   [Publications & Dossier](#)

## About CKiD

The CKiD Study is a NIH-funded, multicenter, prospective cohort study of children aged 1 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.

[Contact Us](#)

[CKiD Study Information](#)

[Key Forms for Sites](#)

### Study Aims

- To determine risk factors for progression of pediatric chronic kidney disease
- To examine the impact of CKD on neurocognitive development
- To examine the impact of CKD on risk factors for cardiovascular disease
- To examine the impact of CKD on growth

### Clinical Coordinating Centers

- Children's Mercy Hospital, Kansas City, Missouri (Bradley Warady, MD)
- Children's Hospital of Philadelphia, Philadelphia, Pennsylvania (Susan Furth, MD, PhD)

### Data Coordinating Center

- Johns Hopkins Bloomberg School of Public Health (Alvaro Muñoz, PhD)

### Central Laboratories

- Central Laboratory at the University of Rochester School of Medicine (George Schwartz, MD)
- ABPM Coordinating Center at Univ. of Texas- Houston Medical College (Joshua Samuels, MD, PhD)
- Cardiovascular Imaging Core Research Laboratory at Cincinnati Children's Medical Center (Peace Madueme, MD)
- Cardiac MRI Coordinating Center at Cincinnati Children's Medical Center (Michael Taylor, MD, PhD)

# Contact Information

---

## 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

410-614-1430

615 North Wolfe Street, E7648

Baltimore, Maryland 21205

## Central Biochemistry Laboratory

University of Rochester Medical Center

Pediatric Nephrology

Dr. George Schwartz

585-275-9784

601 Elmwood Avenue

Box 777, Room 4-8105

Rochester, NY 14642