### Gabriella Miller Kids First Pediatric Research Program (Kids First)

**NIH Common Fund Program**

Alleviate suffering from childhood cancer and structural birth defects by fostering collaborative research to uncover the etiology of these diseases and support data sharing within the pediatric research community.

### Background

Childhood cancers and structural birth defects have profound, life-long effects on patients and their families. The role of genetics in these areas is not fully understood, and this lack of understanding is impeding researchers from developing preventive, early-detection, and therapeutic interventions.

Prior to her death from cancer in 2013, 10-year-old Gabriella Miller called on Congress to increase support for pediatric research. In 2014, the Gabriella Miller Kids First Research Act was signed into law, and in early 2015, the NIH Common Fund launched the Gabriella Miller Kids First Pediatric Research Program (Kids First).

Kids First will help researchers better understand the genetic contributions to childhood cancer and structural birth defects by whole genome sequencing cohorts of children with these disorders and depositing the sequence and clinical data into the forthcoming Gabriella Miller Kids First Pediatric Data Resource. These activities will allow researchers to search and analyze the data for new causal genetic variants.

### Kids First Working Group

**Kids First is a trans-NIH effort supported by the NIH Common Fund.**

Institutes that chair the Kids First Working Group:

- Eunice Kennedy Shriver National Institute of Child Health and Human Development
- National Cancer Institute
- National Heart, Lung and Blood Institute
- National Human Genome Research Institute
- National Institute of Dental and Craniofacial Research
- National Institutes of Health, Office of the Director
- National Institute on Deafness and Other Communication Disorders
- National Library of Medicine
- National Institute on Aging
- National Institute on Alcohol Abuse and Alcoholism
- National Institute of Arthritis and Musculoskeletal and Skin Diseases
- National Institute of Biomedical Imaging and Bioengineering
- National Institute of Mental Health
- National Institute of Neurological Disorders and Stroke
- National Institute of Environmental Health Sciences
- National Eye Institute
- National Institute of Arthritis and Musculoskeletal and Skin Diseases
- National Institute of Nursing Research
- National Institute on Aging
- National Library of Medicine
- National Library of Medicine
- National Institute of Biomedical Imaging and Bioengineering
- National Institute of Neurological Disorders and Stroke

Other NIH Institutes and Centers, and HHS agencies, that are a part of the Working Group:
- NCATS
- NIDCR
- NIDCD
- NIDA
- NIDDK
- NIEHS
- NEI
- NIAMS
- NIAID
- ORIP
- CDC

### NIH Common Fund Programs

The Common Fund is a unique resource at NIH, functioning as a "venture capital" space where high-risk, innovative endeavors with the potential for extraordinary impact can be supported. The CF programs, such as the Kids First Program, are short-term, goal-driven strategic investments, with deliverables intended to catalyze research across multiple biomedical research disciplines.

### Connect with us

- **Sign up for the Kids First list-serv:** https://commonfund.nih.gov/kidsfrst/register
- **Kids First Program:** https://commonfund.nih.gov/KidsFirst
- **NIH Common Fund (CF) programs:** https://commonfund.nih.gov

### Program Vision

Alleviate suffering from childhood cancer and structural birth defects by fostering collaborative research to uncover the etiology of these diseases and support data sharing within the pediatric research community.

### Major Initiatives

#### 1. Cohort Identification & DNA Sequencing

- **Disease Areas**
  - Adolescent Idiopathic Scoliosis
  - Congenital Diaphragmatic Hernia
  - Craniofacial Microsomia
  - Disorders of Sex Development
  - Enchondromatosis
  - Ewing Sarcoma
  - Familial Leukemia
  - Hearing Loss
  - Infantile Hemangiomas
  - Neuroblastomas
  - Nonsyndromic Craniosynostosis
  - Orofacial Clefts
  - Osteosarcoma
  - Patients with both childhood cancer and birth defects
  - Structural Heart & Other Defects
  - Syndromic Cranio Dysinnervation Disorders

- **Kids First Sequencing Centers**

#### 2. Kids First Data Resource

- **The Kids First Data Resource Center (DRC) will create a resource which will serve as a centralized database to store and integrate genomic data from childhood cancer and structural birth defects patients and their families. Additionally, the Data Resource Portal will allow researchers to instantly search large genomic datasets using new data visualization tools and cloud-based data-sharing platforms. Researchers everywhere will be able to identify genetic pathways that underlie the biological causes of childhood cancer and structural birth defects.**

- **The DRC is charged with re-processing and “harmonizing” data generated by the sequencing centers, as well as clinical and phenotypic data to facilitate analyses across all Kids First datasets.**

- **Data Resource Portal**
  - Web-based, public-facing platform
  - Designed to house, organize, index, and deliverables intended to catalyze research across multiple biomedical research disciplines.

- **Data Coordinating Center**
  - Facilitate the deposition of sequence and phenotype data into relevant repositories
  - Harmonize phenotypes

- **Administrative & Outreach Core**
  - Develop policies & procedures
  - Facilitate meetings & communication
  - Educate and seek feedback from users
  - Reach out to advocacy groups

- **Kids First DRC Member Institutions**

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#### 3. Data Analysis: Data Mining & Demonstration Projects

In the future, Kids First intends to support Data Mining & Demonstration Projects for analysis of Kids First-generated and other pediatric data to uncover new insights into the biology of childhood cancer and structural birth defects, including the discovery of shared genetic pathways between childhood cancer and structural birth defects.