

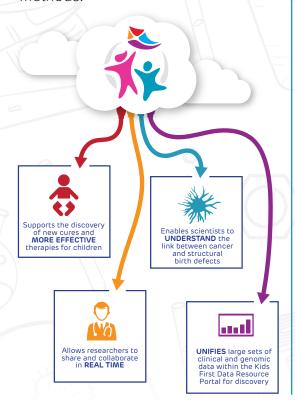
Rare Disease Day at NIH

The vision of the Gabriella Miller Kids First Pediatric Research Program is to alleviate suffering from childhood cancer and structural birth defects by fostering collaborative research to uncover the etiology of these diseases and supporting data sharing within the pediatric research community.

Kids First Program Overview

The Gabriella Miller Kids First Pediatric Research Program (Kids First) was created in 2015 to provide researchers with a more complete understanding of the genetic relationship between childhood cancer and structural birth defects.

The Kids First Program is collecting information such as clinical data, DNA and RNA to understand the characteristics of structural birth defects and pediatric cancer. The genomic and associated clinical data will be added to the Kids First Data Resource Center, which will allow scientists to compare and analyze these genetic disease types and collaborate together to develop more effective treatment methods.



How Can Patients & Families Get Involved?

Collaborate and partner with Kids First researchers to support new discoveries in your specific disease interest area

Collaboration between researchers, clinicians and the patient community is essential to understanding the shared biological pathways between pediatric cancers and structural birth defects. Patient families can encourage researchers to share data with the scientific community to help accelerate research discoveries for more effective therapies.



What are the benefits of data sharing?

- Enables data generated for a given study(s) to be used to explore a wide range of additional research questions
- Increases statistical power by combining separate datasets and increasing sample size
- Allows validation of research results
- Promotes innovation of methods and tools for research
- Facilitates development of improved therapeutic and diagnostic strategies for patients

2 Volunteer to become a beta or early release tester for the Kids First Data Resource Center website and portal

Beta testers provide the Kids First web and portal development teams with valuable feedback throughout the website and portal development process, which will help them better understand how to meet the needs of the patient community.

What does a beta tester do?

- Review Kids First website and portal content
- Review messaging and website content for patient audiences through surveys and other resources
- To sign up to become a Kids First beta tester, email support@kidsfirstdrc.org



- Join the Kids First email listsery & connect on social media
- To sign up for the email listserv, visit https://commonfund.nih.gov/kidsfirst/register
- Connect with the Kids First Data Resource Center on Facebook & Twitter
 @kidsfirstDRC



