



# KIDS FIRST 2.0

## Kids First Research Act 2.0 (HR 623)

Additional funding is needed to continue much needed research for childhood cancers and other disorders that strike our Nation's children. The Kids First Research Act 2.0 would extend the program for five additional years beginning in 2024 in existing funds to the Gabriella Miller Kids First Pediatric Research Program at the National Institutes of Health.

### What does this bill do?

This bill authorizes funding for pediatric research initiative to the Division of Program Coordination, Planning and Strategic Initiatives. For the purpose of carrying out section 282(b)(7)(B)(ii) of this title, there is authorized to be appropriated out of the Pediatric Research Initiative Fund described in section 9008 of the title 26, and in addition to amounts otherwise made available under paragraph (1) of this subsection and \$25,000,000 for each of the fiscal years 2023 through 2027.

The bill expresses the sense of Congress that the Director of the National Institutes of Health should continue to oversee and coordinate research that is conducted or supported by the NIH for research on pediatric cancer and other pediatric diseases and conditions, including through the Pediatric Research Initiative Fund.

The bill also amends the Public Health Service Act to require the NIH to prioritize pediatric research that does not duplicate existing NIH research activities.

NIH to report on progress and investments in pediatric research not later than 5 years after the date of enactment of this Act.

For a full text of the bill, [click here](#).

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### Why is it needed?

Pediatric conditions, such as childhood cancers and birth defects, have profound, lifelong effects on patients and their families.

- Each year, 15,780 children from birth to 19 will be diagnosed with cancer. Cancer is the leading cause of death by a disease in children.
- One in 33 infants born in the United States has a birth defect. Birth defects are the leading cause of death during the first year of life and they account for half of all pediatric hospitalizations.

### Current progress and next steps

The program, created in 2014, collects genomic information on childhood cancers and structural birth defects. Under this program, more than two dozen pediatric research-focused laboratories with more than 67 grants have generated the largest molecular and clinical data sets with over 50,000 genetic sequences that are shared with the entire research community to accelerate the development of prevention, early detection, and therapeutic interventions.

This is just the beginning. We need to continue and expand this program to develop an even more robust comprehensive shared-data resource for scientists researching hundreds of different pediatric cancers and structural birth defects and support the development of computational tools to analyze these large, complex genomic and clinical data sets.

For more information on the program, [click here](#).