



The Gabriella Miller Kids First Research Act 2.0 (H.R. 6556)

Additional funding is needed to supplement much needed research for childhood cancers and other diseases that strike our Nation's children. The Kids First Research Act 2.0 would transfer to the Gabriella Miller Kids First Pediatric Research Initiative Fund at the National Institutes of Health existing and future funds derived from registered persons under the Federal Food, Drug and Cosmetic Act for penalties and fines from violations of laws

What does this bill do?

This bill amends Section 30A of the Securities Exchange Act of 1934 (15 U. S. C. 78dd-1):

- (1) Penalties recovered under this section, section 13(b)(2), or section 32(c) from persons registered under section 510(b)(1) or Section 510(i)(A)(i) of the Federal Food, Drug, and Cosmetic Act, the Department of the Treasury shall transfer an amount equal to the sum of all such penalties recovered under the above sections, including any disgorgement or prejudgment interest, as of the date of the enactment of this bill to the 10-Year Pediatric Research Initiative Fund.
- (2) The bill expresses the sense of Congress that the Director of the National Institutes of Health should 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 10-Year Pediatric Research Initiative Fund.
- (3) 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.

For a full text of the bill,
<https://www.govtrack.us/congress/bills/116/hr6556>

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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 Gabriella Miller Kids First Pediatric Research Program, created in 2014, is in the process of collecting genomic information on childhood cancers and structural birth defects. Under this program, more than two dozen pediatric research-focused laboratories have generated vital genomic data that will be 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 expand this program to develop a 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,
<https://commonfund.nih.gov/kidsfirst>