

Letter of Support for Gabriella Miller Kids First Research Act 2.0 H. R. 623



The Honorable Jennifer Wexton
US House of Representatives
1217 Longworth House Office Building
Washington, DC 20515

The Honorable Peter Welch
US House of Representatives
2187 Rayburn House Office Building
Washington, DC 20515

The Honorable Tom Cole
US House of Representatives
2207 Rayburn House Office Building
Washington, DC 20515

The Honorable Gus Bilirakis
US House of Representatives
2227 Rayburn House Office Building
Washington, DC 20515

Re: H.R. 623 - The Gabriella Miller Kids First Research Act 2.0

Dear Ms. Wexton, Mr. Cole, Mr. Welch, and Mr. Bilirakas,

The undersigned organizations and advocates are writing in full support of H.R. 623 - The Gabriella Miller Kids First Research Act 2.0. Each year, approximately 16,000 children are diagnosed with childhood cancer and thousands more are diagnosed with rare disease. Childhood cancers and adult cancers are not the same. Chemotherapies are designed to kill the fastest growing cells (cancer) in an adult's body. Due to a lack of research, and the fact that only four child-appropriate drugs are available, most children have to rely on adult cancer drugs and therapies. Chemotherapy used on children also kills fast-growing cells, but that is the major problem, because all cells in a child's heart, bones, body, and vital organs are fast growing. Survivors of childhood cancer are at a 15-fold increased risk of developing congestive heart failure and six times more likely than the general population to be diagnosed with breast cancer later in life. Today, there are over 500,000 childhood cancer survivors in America and more than two-thirds will have serious, life-threatening health issues before age fifty.

According to the National Cancer Institutes' NCI Funded Research Portfolio, from 2007 until 2018, only 4.08% of the NCI budget was used for childhood cancer research.

In 2014, Congress passed the Gabriella Miller Kids First Research Act which established the Ten Year Pediatric Research Initiative Fund and authorized \$12.6 million in annual funds for childhood disease research, including important areas of emerging scientific opportunities, rising public health challenges, and knowledge gaps. Since it was enacted, the bill has provided \$88 million to childhood cancer and disease research. It is expected to provide another \$38 million over the remaining three years.

As funding will expire in fiscal year 2023, H.R. 623 - The Gabriella Miller Kids First Research Act 2.0 will provide a new and continuing source of funding for the Kids First Research Initiative Program. This new source of funding, which is expected to be exponentially larger, does not have an end date, is not supported with taxpayer funding, and is invaluable to consistently improve the outcomes of children fighting cancer and other rare diseases.