



Allie Stevens pictured with other volunteers at the Dare to Dream Summit in Washington, D.C.

# LLS brought hundreds of patients and survivors (like me) to D.C. to support kids with cancer

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## • **Brianna Wilson**

Following

Published Nov 2, 2023 (Edited Nov 2, 2023) • 4 min read

Allie Stevens pictured with other volunteers at the Dare to Dream Summit in Washington, D.C.

By Allie Stevens

Nearly 300 advocates, including LLS staff, parents of pediatric patients, donors, and pediatric survivors – like myself – convened in Washington, D.C., Oct. 17-19

for LLS's Dare to Dream Summit. We all had one goal: ensuring our nation's laws and rules help pediatric patients get the best care possible.

I am a 19-year-old pediatric acute myeloid leukemia survivor, lucky enough to be over three years in remission. To get there, I endured five rounds of chemotherapy at Cincinnati Children's Hospital, along with an ICU trip for injured lungs, a spinal fluid leak, and a lifesaving spinal procedure. My doctors told me that without immediate care, I would have had maybe three days left to live – so I know firsthand how important it is for kids to get care without delay.

You may recognize my name; I presented at the Enterprise meeting in August. Now, I'm an intern at LLS's Office of Public Policy (OPP), and I feel grateful to have attended the Dare to Dream Summit. This event gave people like me – with unique experiences and powerful stories – the chance to urge our members of Congress to continue supporting research programs and legislation that will transform the lives of pediatric patients nationwide.

## **About the event**

During the first day of the Summit, we learned about LLS's Dare to Dream Project and how it ensures kids don't just survive treatment—but that they thrive afterward. In the morning, Dare to Dream staff presented information on the latest research and treatments. They then shared information about how LLS supports pediatric families through financial assistance and educational resources. Later, Office of Public Policy staff trained us on how to effectively organize our meetings with members of Congress – and, most importantly, how to share our personal stories in a way that would resonate.

## **What we asked Congress to do**

### **Accelerating Kids' Access to Care Act (AKACA)**

When kids with cancer need specialized care, they often must travel outside their home state. However, doing so can require bureaucratic steps that cause

dangerous delays in treatment. That is especially true for the 50% of kids covered by Medicaid or the Children's Health Insurance Program.

When kids get sick, they need specialized care right away. The bipartisan [Accelerating Kids' Access to Care Act](#) would reduce the paperwork required of doctors treating children from out-of-state. Advocates urged lawmakers to cosponsor this bill.

### **Continued investment in childhood cancer research**

The second focus of LLS advocates was to retain the federal financial support for two existing research programs that currently provide \$80 million to support pediatric cancer research, including programs that focus on survivorship.

## **Our Impact**

Advocates broke into dozens of groups to meet with lawmakers and their staff. Some groups, like mine, met up to six Congressional offices in a day! We poured our hearts out, and it paid off. Following the event, 25 new lawmakers cosponsored the Accelerating Kids' Access to Care Act.

Together, we had nearly 200 meetings with U.S. Senators and Representatives. And while Summit participants were on Capitol Hill, hundreds of others joined in from home, sending nearly 4,400 letters about these issues to Congress.

## **How you can help**

- Ask your members of Congress to cosponsor the Accelerating Kids' Access to Care Act today by clicking [here](#).
- Sign up to become an LLS advocate [here](#), and we'll let you know when we need you to send an essential message to your members of Congress about access to pediatric cancer care or other issues that impact blood cancer patients.
- View and download the LLS "Pediatric Policy Brief," which shows how LLS is advocating for state and federal laws that serve the needs of children and young adults facing cancer.