100 Blood Cancer Advocates Visit Washington, Urge Lawmakers to Act

Lawmakers were asked to support the NIH Clinical Trials Diversity Act and kids' access to cancer care.

June 20, 2023 By Leukemia & Lymphoma Society

For the first time in four years, blood cancer advocates convened in Washington, DC, this spring. Together, they shared a single, critical purpose: to fight for better health care for cancer patients.

Nearly 100 volunteers — including patients, survivors, and caregivers — urged members of Congress to champion two key pieces of legislation that will transform lives. Through their unique experiences, and their powerful voices, they're already making an impact.

How They Did It

LLS volunteers spent one day learning about the legislation we're fighting for, and they had the opportunity to prepare as a group for their meetings. The next day, they arrived at the U.S. Capitol to meet with lawmakers — sometimes having as many as six meetings in a single day. By sharing their experiences with elected officials and their staff, they made a compelling case for much-needed reforms.

NIH Clinical Trial Diversity Act

Not all patients have the same opportunity to participate in clinical trials: people of color, young adults, older patients, and patients living in rural areas are all underrepresented. That's why advocates asked their Senators and Representatives to help make clinical trials available for all eligible patients by supporting the NIH Clinical Trial Diversity Act.

The bill requires trial sponsors to develop clear recruitment and retention goals to ensure diverse patients are represented in trials. And it will make follow-up visits to trial participants less burdensome, to increase the participation of diverse populations. A bipartisan group of lawmakers officially introduced the bill the day just one day after hearing from advocates.

"Lawmakers on both sides of the aisle agree: Improving diversity in clinical trials is good science –

and common sense," said Dr. Gwen Nichols, Chief Medical Officer at LLS, in a press release endorsing the legislation.

Accelerating Kids' Access to Care Act

When kids with cancer need specialized care, they often must travel outside their home state. But doing so can require bureaucratic steps that cause dangerous delays in treatment. That's especially true for the 50% of kids covered by Medicaid or the Children's Health Insurance Program.

The Accelerating Kids' Access to Care Act would reduce paperwork required of doctors treating children from out-of-state. Advocates encouraged lawmakers to support this important bill.

As 12-year-old survivor Charlotte Nathanson – the youngest LLS advocate who attended – said so eloquently: "While kids like me are fighting for our lives, adults are fighting about paperwork."

Our Impact

While blood cancer patients were on Capitol Hill, hundreds of others participated virtually. They sent nearly 2,500 letters to Congress, reaching 425 Senators and Representatives. That's 80% of Congress! And advocates reached out to nearly 400 lawmakers on social media.

What You Can Do to Help

- Sign up to become an LLS advocate here, and we'll let you know when we need you to send an important message to your members of Congress about clinical trials, access to pediatric cancer care, or other issues that impact blood cancer patients.
- Watch a two-minute video about the importance of legislation that can improve the diversity of clinical trials and a two-minute video about how we're striving to eliminate needless delays in pediatric care.

This article was originally published May 24, 2023, by Leukemia & Lymphoma Society. It is republished with permission.
