

access team fast facts

What: LLS recognizes that finding cures is not enough; we need to ensure that patients have access to the treatments they need to live longer, better, healthier lives. The LLS Access Team is dedicated to removing barriers to care. By providing our network of advocates a powerful voice, the Access Team drives policies that accelerate the development and approval of innovative treatments and ensure that patients have sustainable access to quality, affordable coordinated care.

Why: Critical challenges remain in the development of new therapies and many blood cancer patients still face significant barriers to accessing the care they need. Regulatory agencies and legislative bodies at both the state and federal levels play a pivotal role in addressing these problems. The Food and Drug Administration (“FDA”) creates the regulatory pathway for new treatments and the Centers for Medicare and Medicaid Services (“CMS”) set health insurance standards that affect the vast majority of blood cancer patients. With the implementation of the Affordable Care Act, many patients are facing narrower provider networks and patients both inside and outside the new healthcare exchanges continue to report challenges with high cost sharing in their insurance plans.

Recent Accomplishments:

- Brought 250 patient-advocates to Washington, D.C., to lobby for increased access to life-saving treatments. Testified before a committee in the United States House of Representatives on the importance of providing meaningful insurance coverage to patients with pre-existing conditions.
- Convened a group of healthcare stakeholders - including major insurers, providers, physicians and biopharmaceutical companies – to find solutions to the challenge of bringing innovative, life-saving therapies to blood cancer patients in a sustainable, affordable way.
- In Oregon, eliminated a 2 year waiting period for transplants for previously uninsured patients for all insurance plans in the state health exchange.
- Led coalitions in six states to pass patient-friendly oral parity bills that ensure patients taking self-administered treatment aren't required to pay more than those taking physician administered therapies.

Access Team Priorities:

- Ensure that patients have access to adequate network of providers and services Protect patients from high out of pocket costs that limit access to life saving treatments. Work with members of Congress, White House staff and CMS to ensure that Medicare reform is patient-centered and includes the use and development of quality measures that best meet the needs of blood cancer patients.
- Work with members of Congress and CMS, to preserve Medicare Part D provisions for prescription drug coverage.
- Ensure that the patient's voice is heard throughout the FDA decision making process by nominating patient representatives to FDA Advisory Committees
- Work with FDA and other stakeholders to predict, prevent and minimize the effects of drug shortages.

The LLS Access Team is dedicated to removing barriers to quality, affordable, coordinated care for blood cancer patients. The Leukemia & Lymphoma Society (LLS) exists to find cures and ensure access to treatments for blood cancer patients. We are saving lives not someday, but today.

- Work to improve the availability of expanded access programs.
- Work with the FDA to formulate clinical trial guidelines that will accelerate the development, review and approval of new therapies.

Who We Are:

The Access Team is staffed by legislative and regulatory affairs experts and advocacy professionals. In addition to the team in our Office of Public Policy in Washington DC, we have chapter-based and regional staff throughout the US.

What You Can Do:

The power to change policy resides within our extensive advocacy network of volunteers. Patient stories bring issues to life, and profoundly resonate with elected officials.

The Access Team actively recruits, trains, and mobilizes advocates to help us drive changes in government policy at both the state and federal level.

Any individual that has had his or her life touched by a blood cancer can be an effective advocate. We empower our Advocates Network with information and tools to connect with and persuade policymakers to protect the interests of patients and their families. We ask our Advocates Network to share timely information on emerging barriers to access.

WHERE:

LLS Office of Public Policy
10 G St. NE, Suite 501
Washington, DC 20002

FOR ADDITIONAL INFORMATION:

To contact the Access Team or to join the LLS Advocates Network, please call (202) 969-1804 or visit <http://lls.org/advocacy> and click the “Sign up” link.

About The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society® (LLS) is the world's largest voluntary health agency dedicated to blood cancer. The LLS mission: Cure leukemia, lymphoma, multiple myeloma, and improve the quality of life of patients and their families. LLS funds lifesaving blood cancer research around the world, provides free information and support services, and is the voice for all blood cancer patients seeking access to quality, affordable, coordinated care.

Founded in 1949 and headquartered in White Plains, NY, LLS has chapters throughout the United States and Canada. To learn more, visit www.LLS.org. Patients should contact the Information Resource Center at (800) 955-4572, Monday through Friday, 9 a.m. to 9 p.m. ET.