

The Leukemia & Lymphoma Society (LLS) is increasing its investment in pediatric research and patient access. Our goal is for children to not only survive cancer—we want them to thrive after treatment.



Doing more to improve care for young blood cancer patients

Pictured Above: Myrrah was diagnosed with acute lymphoblastic leukemia (ALL) when she was six years old. When her cancer returned after a year of intense treatment, Myrrah and her father met with LLS-funded researcher, Dr. Andrew Kung. After another year of treatment and a bone marrow transplant, Myrrah's lab work showed no sign of cancer. Today, she loves cooking and is thriving in school.

Blood cancers pose a particular threat to children, like young Myrrah above, and take a tremendous physical and emotional toll on the children and their families.

Thirty-five percent of pediatric cancers are blood cancers. It is estimated that more than 5,000 children and young adults under the age of 20 are diagnosed with leukemia or lymphoma in the U.S. every year.

Pediatric cancers are biologically distinct from adult cancers, and the way young physiologies respond to and recover from treatment is unique as well. But there is

insufficient knowledge about the distinct molecular underpinnings of pediatric cancers, knowledge essential to improving treatments.

Furthermore, for the children who survive, the lifelong impact of pediatric cancer treatment can include secondary cancers, severe physical and cognitive impairments, cardiac problems, and a range of ailments the medical community is only beginning to understand.

We believe that cures are achievable. With the LLS Children's Initiative, we are determined to realize them.

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At five years old, Austin had been dealing with leukemia for most of his young life and had relapsed for the third time. His parents enrolled him in an LLS-funded clinical trial in CAR T-cell immunotherapy. It was their only hope.

Today, at age 10, Austin is in remission. He is one of the success stories, thanks to LLS donor support.

To drive more breakthroughs faster, we are

doubling our investment in pediatric research.

New drugs and therapeutic approaches are needed now.

As part of the LLS Children's Initiative, we have more than doubled our investment in pediatric research. In June 2018, we issued a call for pediatric research proposals: Our goal is curative therapies that will reduce the long-term complications of current therapies.

This expansion involves doubling our investment in pediatric blood cancer research. To identify high impact research with a clear bench-to-bedside trajectory, submissions are being reviewed by a panel of experts in pediatric cancers. We aim to fund at least five major pediatric grants to advance innovative research that translates basic biomedical knowledge to clinical application.

A major initiative for children

This research expansion is just the first step in accelerating breakthroughs and cures. LLS

has convened a significant multi-institutional collaboration to advance new research and drive change in pediatric clinical trial development. By leveraging relationships with the nation's leading pediatric blood cancer physicians and scientists, the Food & Drug Administration, the National Cancer Institute, biotechnology leaders, advocacy organizations, pharmaceutical companies, and other leaders, we can change the paradigm of pediatric oncology drug discovery and development.

How you help

In launching this focused initiative for children, LLS relies on the philanthropy of committed volunteers, donors and community leaders who will make cures for childhood blood cancers a reality.

In supporting LLS, you partner with the most gifted researchers worldwide and fund the most promising projects to realize a better, healthier future for children.

Research You Make Possible



HEMA DAVE, MD, MPH

*Children's Research
Institute*

One challenge with Hodgkin lymphoma (HL) is that the microenvironment surrounding the tumors actually supports the cancer by allowing it to suppress the antitumor activity of T cells and evade the immune system. With this project, Dr. Dave seeks to change the tumor microenvironment and unleash the antitumor immune responses of killer T cells in patients with high-risk HL, with a goal of achieving long-lasting cures with fewer side effects than conventional chemotherapy.



TODD DRULEY, MD, PHD

*Washington University
in St. Louis*

In children and young adults, acute myeloid leukemia (AML) accounts for 25 percent of leukemia cases but half of leukemia deaths. This is due to the inadequacy of tests for detecting microscopic amounts of residual AML still remaining after treatment, leading to relapsed disease to which most children (and adults) will ultimately succumb. Dr. Druley and his team are developing a methodology to accurately identify the mutations which will indicate residual disease.



**BARBARA
SAVOLDO, MD, PhD**

*University of North Carolina
at Chapel Hill*

A powerful new treatment, chimeric antigen receptor T cell immunotherapy (CAR T-cell therapy) uses genetic engineering to reprogram the patient's own immune system cells (T cells) to find and kill cancer cells. However, CAR T cell therapy can have severe and potentially lasting side effects. Dr. Savoldo seeks to eliminate these side effects using a drug that affects only the engineered T cells and controls their life span and their number. The ultimate goal of this study is to heighten the benefits of a lifesaving new treatment.



DAVID TEACHEY, MD

*Children's Hospital
of Philadelphia*

Dr. Teachey seeks to improve care for children with acute lymphoblastic leukemia (ALL) by using the drug daratumumab, which is already being used successfully to treat adults with myeloma or lymphoma. Extensive lab studies are being conducted to confirm the drug's effectiveness and to understand why some patients are resistant to the drug. The next step will be to combine the drug with other therapies that deliver potent treatment in order to selectively kill the cancer cells while leaving healthy cells unharmed.

Current LLS Grants

Through the LLS Children's Initiative, donors invest in what matters most—cures for children, teens and young adults with blood cancer. LLS has committed to more than doubling our investment in pediatric research, supporting every stage from basic research to translational research and clinical trials. This will bring our total commitment in pediatric research to more than \$20 million over the next five years. Donor support is urgently needed to meet this ambitious goal and realize better treatments and new cures for children **now**.

Omar Abdel-Wahab, MD
Memorial Sloan Kettering
Cancer Center

Peter Adamson, MD
Children's Hospital
of Philadelphia

Carl Allen, MD, PhD
Baylor College of Medicine

Smita Bhatia, MD, PhD
University of Alabama
at Birmingham

Tomek Cierpicki, PhD
University of Michigan

Hema Dave, MD, MPH
Children's Research Institute

Todd Druley, MD, PhD
Washington University in
St. Louis

Carolyn A. Felix, MD
Children's Hospital
of Philadelphia

Zhaohui Gu, PhD
St. Jude Children's
Research Hospital

Yong-Mi Kim, MD, PhD
Children's Hospital,
Los Angeles

E. Anders Kolb, MD
Nemours/Alfred I. duPont
Hospital for Children

Mingon Lo, MD
University of California,
San Francisco

Soheil Meshinchi, MD, PhD
Fred Hutchinson
Cancer Center

Charles Mullighan, MD
St. Jude Children's
Research Hospital

Barbara Savoldo, MD, PhD
University of North Carolina
at Chapel Hill

Xiaobing Shi, PhD
University of Texas MD
Anderson Cancer Center

David Teachey, MD
Children's Hospital
of Philadelphia

Support & Policy Advocacy

Because new treatments are beneficial only if patients can access them, LLS is increasing outreach to children and their families. The leading source of blood cancer information and support for patients, survivors, families, and health professionals, LLS helps parents ensure that their children receive the best care possible.

Masters-level oncology social workers help families through all aspects of coping with the disease: understanding the symptoms, choosing the best physician, and knowing what to expect from treatment. Specially trained nurses help parents navigate clinical trials and identify the trials most suited to their child's disease and the family's needs. LLS also provides financial assistance and connects families with resources to deal with insurance and travel obstacles. All of these programs will be expanded as needs increase and resources allow. We are also developing a range of new educational materials to educate and support families coping with cancer.

A national leader in advocating for pediatric research and treatment, LLS has influenced the passage of important legislation in recent years. As we expand our efforts, our plans for policy advocacy in 2019 and beyond include working with officials to further strengthen the legislative incentives for pediatric drug development, with particular emphasis on incentives for cross-company cooperation that will streamline drug development research and enable clinical trial design that accelerates the delivery of meaningful treatment advances to pediatric patients.

Donors provide children and their families with support, education, and assistance and fund promising and powerful research by gifted scientists and physicians from around the world. Join us in this mission to cure children with blood cancer.

CURES AND CARE FOR CHILDREN

The Leukemia & Lymphoma Society is taking on children's cancer from every direction, disrupting the status quo with our bold vision for young patients – to not only survive their cancer, but thrive in their lives after treatment.



\$50 MILLION

MULTI-YEAR
ENDEAVOR



40%

OF PEDIATRIC CANCERS
ARE BLOOD CANCERS



APPROXIMATELY

80%

OF CHILDHOOD
CANCER SURVIVORS
develop one or more
chronic health
conditions as a result
of their treatment



ONLY

4

ONCOLOGY DRUGS
have been approved
for first use in children
in 40 years

RESEARCH

INVESTING IN BREAKTHROUGH RESEARCH



LLS IS COMMITTING
\$25 MILLION

to new grants to support childhood cancer research over the next five years.

LLS has a long history of supporting some of the most impactful research to advance lifesaving therapies for children with blood cancers.

PATIENT EDUCATION & SUPPORT

EDUCATION AND SUPPORT FOR PATIENTS, PARENTS AND CAREGIVERS

LLS believes no one should have to face cancer alone. We are expanding our robust array of support, education and financial services for young patients and their families.



One-on-one support



Financial assistance



Education resources

POLICY & ADVOCACY

We are driving policies to advance research for childhood cancers and breaking down barriers to treatments and care.



MORE THAN
100,000
VOLUNTEER ADVOCATES

join our Office of Public Policy in advocating for policy changes at the state and federal level.

OUR MASTER CLINICAL TRIAL – LLS PedAL

LLS is leading a global precision medicine clinical trial to test multiple targeted therapies for children and young adults with acute leukemia.

LLS PedAL will align scientific, medical, corporate and regulatory partners to test multiple targeted therapies simultaneously at up to

200
CLINICAL SITES IN THE UNITED STATES & AROUND THE WORLD.

What is The LLS Children's Initiative?

The Leukemia & Lymphoma Society (LLS) is taking on children's cancer from every direction, disrupting the status quo with our bold vision for young patients: to not only survive their cancer, but thrive in their lives after treatment.

The LLS Children's Initiative is a comprehensive \$50 million multi-year endeavor to help children with cancer through every facet of our mission:

- More than doubling our investment in pediatric cancer research grants
- Expanding education and support services for children and families
- Advocating for and driving policies to accelerate the development of new treatments and break down barriers to care
- Launching LLS PedAL (Pediatric Acute Leukemia), a groundbreaking global precision medicine clinical trial in acute pediatric leukemia

Our goal is a wholesale shift in the standard of care for pediatric patients, moving from toxic chemotherapies that leave survivors with lifelong health challenges, to effective, safe treatments that precisely target cancer without harm to the rest of the child's body.

Why The LLS Children's Initiative?

The need is urgent.

Blood cancers account for more than 40 percent of all childhood cancers, and most children are treated with the same toxic combinations of chemotherapies developed decades ago. Too many children succumb to their cancer, and many who survive are left with lifelong complications. Though there has been significant progress in advancing new therapies for adults with cancer, only four oncology drugs have been approved for first-use in children over the past four decades.

Children are not mini-adults and we need to do better.

LLS IS COMMITTING \$25 MILLION

TO NEW GRANTS TO SUPPORT CHILDHOOD
CANCER RESEARCH OVER THE NEXT FIVE YEARS.

- We are expanding our investment in leading-edge research to find safer, lifesaving therapies for children, teens and young adults with blood cancers.
- We aim to understand the drivers of pediatric cancer and develop targeted therapies and immunotherapies that are less harsh and more effective than traditional treatments.

Our Patient Education and Support Services

Fundamental to The LLS Children's Initiative is helping patients and their families cope with the financial, emotional and psychological impacts of a cancer diagnosis. We are expanding our comprehensive array of free support, education and financial services for young patients and their families.

- One-on-one support, including personalized assistance from master's level oncology professionals, clinical trial nurse navigators, and a registered dietician with expertise in oncology nutrition.
- Free information, materials and programs for parents and educators to help ease a child's return to school after an absence due to a cancer diagnosis.
- Peer-to-peer support through our *Patti Robinson Kaufmann First Connection Program*, which matches individual patients, parents and caregivers with trained volunteers who have "been through it."

- Free online and in-person support through our social network, LLS Community; online chats; caregiver support; local support groups, blood cancer conferences; and free education resources, including webcasts, podcasts, videos and booklets.
- Financial assistance through our *Co-Pay Assistance*, *Patient Aid*, *Susan Lang Pay-It-Forward Patient Travel Assistance* and *Urgent Need* programs.

Our Policy & Advocacy Efforts

LLS supports a policy agenda aimed at accelerating the development of new cancer treatments and breaking down barriers to care.

- LLS co-chairs the Children's Cancer Alliance in Washington, D.C., helping drive policies to advance research for childhood cancers and ensure access to care. Through the alliance, we played a key role in the enactment of the The Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act, the most comprehensive federal childhood cancer law ever passed by Congress.
- We advocated for the RACE for Children Act (Research to Accelerate Cures and Equity for Children Act), requiring companies developing drugs for adults to also test them in children if the molecular target of the drug is deemed relevant in pediatric cancer.
- More than 100,000 volunteer advocates join our Office of Public Policy in advocating for policy changes at the state and federal level.

Our Master Clinical Trials — LLS PedAL

LLS is leading an unprecedented collaboration to launch a global precision medicine clinical trial to fundamentally change how children and young adults with acute leukemia are treated.

- As a patient-focused nonprofit organization, we are uniquely positioned to convene the vast collaboration and resources necessary to bring the promise of precision medicine to children with acute leukemia.
- Our leadership and experience is evidenced by our long track record of supporting the most impactful blood cancer research, including our Beat AML® Master Clinical Trial, a paradigm-shifting, precision medicine trial for adults with acute myeloid leukemia.
- LLS PedAL will consolidate pediatric cancer data from multiple institutions into a single data set, establish a common language to define and analyze the data, and make that data available to researchers worldwide.

LLS PedAL will align scientific, medical, corporate and regulatory partners to test multiple targeted therapies simultaneously at up to

200 CLINICAL SITES IN THE UNITED STATES AND AROUND THE WORLD.

Through The LLS Children's Initiative we are committed to ushering in a new era of pediatric drug development, research, patient support and advocacy, and transforming care for children with blood cancer.

Get in touch with us:

INFORMATION AND SUPPORT: Call our Information Resource Center or visit our website:

800.955.4572 or **www.LLS.org**

LOCATIONS: Find one of our 50+ local chapters in the U.S. and Canada: **www.LLS.org/chapters**

GET INVOLVED: Learn how you can volunteer or donate: **888.HELP.LLS** or **www.LLS.org**