THE DARE TO DREAM PROJECT
Transforming treatment and care for kids with blood cancer.

LEUKEMIA & LYMPHOMA SOCIETY® DARETO Dream PROJECT
WE NEED SAFER, LESS TOXIC, MORE EFFECTIVE

40% Of Pediatric Cancers Are Blood Cancers

Approximately 80% Of Childhood Cancer Survivors Develop Chronic Health Issues From Treatment

Only 5% Of Oncology Drugs Have Been Approved For First Time Use In Children
THE DARE TO DREAM PROJECT!

After launching The LLS Children’s initiative and LLS Pedal, with more partners onboard and much more interest, we’ve reached a new milestone. So, we are deepening our commitment with a bigger, bolder initiative, The Dare to Dream Project.

With The Dare to Dream Project, we will:

▪ Create greater awareness and understanding of our program.

▪ Reach out to a wider audience and more parents of children with blood cancer.

▪ Deliver a broader narrative of how LLS is leading the charge to change how pediatric blood cancer is treated and supported.
LLS is raising $175 million over the next five years to fund *The Dare to Dream Project*, a next-level global, groundbreaking approach to:

- Expedite pediatric blood cancer research.
- Bring new, safer treatments to more kids through the PedAL Master Clinical Trial.
- Grow our education and support services as well as drive advocacy for young patients with blood cancer and their families.

BECAUSE KIDS ARE DIFFERENT
THE ROADBLOCKS TO FINDING SAFER TREATMENTS

- Pediatric cancer is a rare, and the cost-benefit analysis for drug developers isn’t favorable.
- The “one drug at a time” model is inefficient for targeted therapies.
- More targeted approaches require many sites which adds to cost, and many patients are screened to find few candidates, wasting children’s lives.
- Pediatric data is siloed.
- All historical data does not have analysis according to biomarker defined subsets, making it difficult for developers to define efficacy targets.
- Regulations require pediatric development for all adult marketed drugs, but this leads to testing ONLY of adult drugs and the biology in pediatric cancers is often substantially different.
OUR APPROACH

**LLS PedAL MASTER CLINICAL TRIAL**
Test new, safer therapies on kids with acute leukemia who are matched to treatments based on their unique tumor biology in this, the first integrated, global, pediatric AML master clinical trial.

**RESEARCH**
Focus on global collaboration, uniting doctors, pharmaceuticals, and scientists to expedite pediatric blood cancer cures and care.

**POLICY & ADVOCACY**
Drive policy to advance research for childhood cancers, break down barriers to care.

**PATIENT EDUCATION & SUPPORT**
Expand free education, 1:1 support, and financial services for children and their families.

DAREtoDREAM PROJECT
Transforming treatment and care for kids with blood cancer.
▪ Drastically increasing our pediatric-focused multi-year research grants since The Children’s Initiative’s inception, from $11M in 2018 to $30.5M in 2022, with a goal of reaching $52M by 2027.

▪ Funding over 32 pediatric-specific grants, researching long-term treatment side-effects and improving detection of relapse.
**LLS PedAL** has already achieved so much:

- Launched the **first integrated, global, pediatric leukemia master clinical trial** to test new, safer therapies on young patients to match a specific treatment to a specific type of cancer.

- Partnered with UChicago to create the **first pediatric Data Commons**, a platform that ensures consistency in global data collection and reporting.

- Collaborated with UChicago to fund **GEARBOx**, a unique search tool to help physicians quickly match patients’ cancers to available clinical trials, based on their unique tumor biology.
GLOBAL COLLABORATION ACROSS DISCIPLINES

- Nonprofit Collaborators
- Sample and Data Management Vendors
- Clinical Sites
- Clinical Research Organization
- Pharmaceutical Companies
- Genomics Provider
- Philanthropy
- International Collaborators
- Bioinformatics Partners
- Regulatory Agencies

LLS PedAL
LLS PEDAL SCREENING SCREENING

LLS PedAL Master Trial

Children newly diagnosed with AML

Children with relapsed AML

Every child with AML to get sequenced

Biopathology Center

Immunoflow cytometry

Sequencing

PedAL Screening Protocol

These patients directed to standard care or other clinical trials

PedAL Biomarker Discovery

PedAL Preclinical Discovery

Center for Research Informatics

PedAL Sub-Trial Protocols

Outcome data

Relapse/refractory

LLS Screened Treatments

Other

PedAL enrolment

UPIN

Patients not enrolled at diagnosis can enroll on Project EveryChild at any time

medidata

Project EveryChild
PedAL PROGRESS

174 sites
229 patients
Screening trial

70 sites
24 patients
Therapeutic subtrial
PROVIDING A WIDE ARRAY OF FREE EDUCATION, FINANCIAL, AND 1:1 SUPPORT.

- Our Information Specialists offer one-on-one support, and access to educational resources like the caregiver workbook and nutrition consultations.
- LLS offers several types of financial assistance, to help with living expenses and medication costs easing the financial burden of a child’s cancer care.
- Clinical trial support nurse navigators help locate clinical trials for patients and provide support throughout the process.
Caring for Kids And Adolescents with Blood Cancer workbook is written for the parent/guardian of a minor child (up to age 18), and includes information about caring for your child, treatment options, school, nutrition, financial and legal issues, and more.

Caregivers may order a copy of the full workbook by calling (800) 955-4572.

LLS.org/FamilyWorkbook
Our pediatric blood cancer resources continue to grow each year. They are available as physical materials to order, downloadable resources, webcasts dedicated to pediatric specific issues, YouTube videos and mobile apps. LLS.org/ChildhoodCancer
NEW & UPCOMING

Children’s trilogy now available as an audiobook.

Future book for siblings focused on Olivia’s brother, Daniel.

New resource in development to help educators with issues specific to pediatric cancer patients.
The "Just for Teens" webpage is a dedicated site for teenagers with blood cancer faced with navigating school, friendships, and other issues. Adolescent specific resources can be found here.

LLS.org/Teens
In two years, 205 survivors of pediatric and AYA blood cancers have been awarded up to $7,500 each to pursue post secondary education opportunities.

Year 3 applications increased yet again.

214 volunteer scholarship reviewers on board for this year (164% increase over last year).
Securing federal funding needed to stimulate the development of new, safer pediatric treatments.

Reforming FDA processes and guidance to recognize and respond to the unique nature of childhood cancer.

Helping to ensure no child is denied the quality cancer care they need.

Serving the unique, long-term needs of childhood cancer survivors through research on survivorship and protections for those with pre-existing conditions.
DARE TO DREAM SUMMIT

October 17–19, 2023 • Washington, DC
Dare to Dream Plan

**Goals**

- Accelerate engagement with, and support from, existing and potential volunteers, partners & donors.

- Build momentum behind LLS pediatric policy priorities.

**Key Take-Aways for attendees**

- Dare to Dream is changing the paradigm of pediatric cancer research and support NOW.

- LLS has credibility with multiple stakeholders and is the only organization positioned to make something like Dare to Dream happen.

- LLS is an organization that is invested locally.

- There are others – just like me – from across the country invested in this issue.
Lobby Day

Two Primary Issues Identified to Emphasize

• Accelerating Kids’ Access to Care Act (AKACA), eliminating red tape to speed up access to treatment for kids on Medicaid needing specialized care outside of their home state.

• Full funding of $80 million for childhood cancer research included in appropriations for the already-approved STAR Act and the National Cancer Institute’s Childhood Cancer Data Initiative (CCDI).

Lobby Day by the Numbers

• 248 advocates

• 186 meetings with Hill offices, 33 with the Member of Congress

• 41 new sponsors to the AKACA (33 House, 8 Senate) added following the summit!
LLS CAN SUPPORT YOU AND

- Contact our **Information Resource Center** for FREE one-on-one support: 1-800-955-4572

- Connect with a pediatric nurse in our **Clinical Trial Support Center**: askPedAL@lls.org

- Learn more about The Dare to Dream Project at: [www.lls.org/daretodream](http://www.lls.org/daretodream)
THANK YOU