



# EXPANDING THE Possible



#### **ANNUAL REPORT 2021**





### **TO EXPAND** is to push boundaries... to go beyond established limits.





# **THE POSSIBLE** is what is plausible... able to happen.





Our 2021 triumphs were numerous; future possibilities are boundless.

## LLS: EXPANDING THE Possible





the trailblazing LLS-funded researchers seeking better, safer, and more accessible treatments for blood cancer patients.

#### Dear Friends,

From its inception, The Leukemia & Lymphoma Society® (LLS) has been all about possibility. We were founded by parents—Rudolph and Antoinette Roesler de Villiers—who sought a cure for the acute lymphoblastic leukemia (ALL) that took their son Robbie at age 16. Thanks to their initiative and to over 70 years of LLS leadership in the fight against blood cancers, ALL five-year survival rates have climbed from nearly zero to more than 90%.

#### That's expanding the possible.

For decades, LLS has served as a "change enthusiast," playing a role in expanding possibilities for nearly every blood cancer patient. Our mission remains unchanged: Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. More than ever, we are committed to leveling the playing field in blood cancer research and care, and addressing the needs of previously underserved populations to ensure a future of expanded hope for all members of our community.

Of course, for us, the ultimate expansion of possibility will be a world where blood cancer is no longer a death sentence, and can be cured. On behalf of the 1.3 million Americans living with—or in remission from—blood cancer, we will not stop until *mission impossible* turns into *mission possible*. With your help we will get there.



Louis J. DeGennaro, PhD President and Chief Executive Officer

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Raph E. Lawrom

Ralph E. Lawson Chair of the Board

#### 2021 achievements include...

- ...**initiated first-of-its-kind research on COVID-19 vaccine efficacy**—using data submitted from patients serving as "citizen scientists"—to facilitate vaccine decision-making
- ...promoted a treatment modality that barely existed four years ago and is now creating long remissions in patients on the brink of death
- ...increased financial assistance for patients and families by 70% over last year
- ...enhanced efforts to expand equitable access to care—including clinical trials—for all blood cancer patients, making inroads in communities that have been traditionally overlooked
- ...**Iaunched a new program to fund health services research**, to ensure enhanced access to blood cancer care and services
- ...advanced the design of a landmark global master trial that promises to revolutionize pediatric standard of care for acute leukemia
- ...**set records in fundraising** despite global pandemic challenges, allowing for reinvestment into ongoing research and patient programs

Read more inside about our leadership and 2021 accomplishments.

# EXPANDING THE POSSIBLE:

## **\$226 MILLION** Total Multi-Year Funding

# INNOVATIVE APPROACHES Broaden Research Landscape

At LLS, we are pushing boundaries toward powerful new therapies. We propel groundbreaking cancer treatments through all phases of the drug approval process and are proud that our support has been key to advancing 75% of the almost 100 blood cancer treatment approvals over the last five years.

As we continued to support the search for lifesaving and less toxic treatments in 2021, we invested in exciting research frontiers, including precision medicine, immunotherapy, and links between mutations and blood cancer—advancements that are changing the paradigm of cancer treatment. In the process, we propelled several novel science initiatives to new heights—many of which hardly seemed possible just a short time ago.



The LLS track record in accelerating lifesaving blood cancer treatments is unparalleled, and the continuity of our funding — from preclinical through clinical research demonstrates our commitment to

supporting innovative therapies as they move from the laboratory into practice."

- Lee Greenberger, PhD, LLS Chief Scientific Officer

#### Immunotherapy Exploration Intensified, Bringing New Hope to Patients

LLS has dedicated more than \$100 million to investigate game-changing treatments that harness the power of the immune system to fight blood cancers, expanding possibilities for patients previously facing few treatment options. LLS was among the earliest supporters of the CAR-T approach, which re-engineers a patient's own immune (T) cells to kill tumor cells. CAR T-therapies have received eight FDA approvals since 2017 and have become a mainstay of blood cancer care in patients with advanced disease, producing long-lasting remissions.

Throughout the year, we invested \$10 million to explore next generation immunotherapies. One example is allogenic CAR-T therapy, which uses donor T-cells to increase efficacy, reduce costs, and make CAR-T more quickly accessible. We also invested in harnessing other parts of the immune system, such as macrophages and natural killer cells, in the fight against cancer. We supported immunotherapies that identify and target proteins that drive specific types of cancer, for example BCMA and CD371, which play key roles in multiple myeloma and AML, respectively.

**\$43.0 M** (19%) Aggressive NHL

**RESEARCH INVESTMENT:** 

\$57.5 M (25%)

ΔΜΙ

**\$29.5 M** (13%) Myeloma

**\$24.3 M** (11%) MDS/MPNs

**\$17.5 M** (8%) General Lymphoma

**\$15.9 M** (8%) Indolent NHL

\$14.5 M (6%)



(1%) CML

General Leukemia

**\$4.7 M** (2%) Hodgkin Lymphoma



"In the early days, few thought CAR T would work. Some of our first substantial funding was from LLS. That was really critical. Without the early support from LLS and a few other visionary sponsors, we might not be where we are today with CAR T-cell therapies."

 Carl June, MD, the Richard W. Vague Professor in Immunotherapy in Pathology and Laboratory Medicine at the Perelman School of Medicine at the University of Pennsylvania, and Pioneer of Chimeric Antigen Receptor T cell (CAR-T)

#### Therapy Acceleration Program Forged Exciting New Collaborations

Since 2007, our innovative venture philanthropy initiative, the LLS Therapy Acceleration Program® (TAP), has partnered with biotechnology companies and academic researchers to extend the therapeutic landscape in leukemia, lymphoma, and multiple myeloma.

After examining more than 80 applications per year, LLS TAP makes strategic investments—up to \$10 million annually—in a few carefully-selected, innovative ideas with a high potential to improve patient outcomes, that others may consider too high-risk to invest in. LLS TAP's scientific expertise and investment due diligence often motivates other investors to commit additional funds for clinical trials. Returns on our investments are used to further support the LLS mission.

In 2021, we made six new investments in companies developing new immunotherapies including "off the shelf" CAR T-cell therapy and "in vivo" therapy that generates cancer-fighting CAR cells inside the body. We also invested in two first-in-class antibodies that target novel checkpoints to release the brakes and activate immune cells so they can fight cancer and CAR-macrophage (CAR-M) therapy to treat cancers where checkpoint inhibitors tend to be less effective.



Funding from leaders like LLS TAP supports the clinical development of our CRISPR genomeedited, next-generation

anti-CD19 CAR-T cell therapy for patients with B cell non-Hodgkin lymphoma."

– Rachel Haurwitz, PhD, President and Chief Executive Officer of Caribou Biosciences, an LLS TAP partner

## National Patient Registry Provided Pivotal COVID Information

The ongoing COVID-19 pandemic engendered a host of fears and questions for the blood cancer community. When patient concerns arose about whether the new vaccines would protect them, LLS stepped in to find answers. In February, we activated The LLS National Patient Registry, a project supported by Ethel and Bernard Garil in memory of their son Michael, who succumbed to acute lymphoblastic leukemia. More than 10,000 blood cancer patients answered our call to join the Registry as "citizen scientists." This allowed us to generate the largest data set reported to date on vaccine safety and efficacy (including boosters) across all major blood cancer and treatment types. This information has helped patients, healthcare providers, and public health officials make more informed choices about COVID-19 prevention.

#### First-of-its-Kind IMPACT Research Grants Announced, Expanding Clinical Trial Access

To address unequal representation of underserved populations in clinical trials, in May we introduced IMPACT (Influential Medicine Providing Access to Clinical Trials) research grants. An initial five-year investment of \$3.75 million was allocated to Mayo Clinic, Vanderbilt University Medical Center, and Weill Cornell Medicine.

The IMPACT grants will help these major cancer centers expand clinical trial access to local community-based hospitals and clinics with substantial underserved populations. The goal is to increase trial enrollment among traditionally underserved populations, including racial and ethnic minorities, rural residents, and individuals with low income, to at least 20%, thereby expanding access to stateof-the-art therapies to a broader swath of newly diagnosed blood cancer patients.

# EXPANDING THE POSSIBLE:

# PIVOTAL DISCOVERIES SPELL PROGRESS Across disease states



## **SURVIVOR LAURIE ADAMI**

Thanks to CAR T-cell treatment more than 3 years ago, long time Stage IV follicular lymphoma patient Laurie Adami is thriving in remission. An enthusiastic trekker, Laurie is literally ascending to new heights—setting a personal goal of taking on a new big challenge with Team In Training in 2022. In the meantime, she swims five days a week and hikes—including Wyoming's Tetons and New Hampshire's Mount Washington. At age 61, Laurie ran her first marathon with Team In Training in November, with a goal to raise \$250,000 for LLS-funded immunotherapy research. Laurie has also made anti-COVID-19 antibodies after vaccination, which was uncovered via the LLS Registry.

At LLS, our mission is to increase possibilities for patients with all types of blood cancer. Our history of investments **more than \$1.5 billion** since our founding—has made us the largest nonprofit funder of blood cancer research.

Our unwavering commitment to research that uncovers and advances breakthrough treatments continued in 2021 as we dedicated \$35 million in new multi-year funding to support more than 260 active research programs. Progress in novel areas including precision medicine, genomics, and immunotherapy fueled notable advances, with 25 treatments receiving FDA approval.

#### Leukemia

With more than \$65 million currently committed to leukemia research, we continue to lead the way toward cures. We invested nearly one quarter of our annual research dollars in hard-to-treat **acute myeloid leukemia (AML)**. Our Beat AML® Master Clinical Trial, the first collaborative precision medicine trial for blood cancer, which marked its fifth anniversary in November 2021, has reported better patient survival rates when genomic analysis is used to match patients to gentler, targeted therapies versus traditional "one size fits all" treatment.

LLS continues to explore next generation immunotherapies, epigenetic therapies, and identification of pre-leukemia conditions and metabolic vulnerabilities.

#### Lymphoma

FDA approved 9 new lymphoma treatments in 2021, expanding therapeutic possibilities across multiple lymphoma sub-types. Among them are LLS-supported CAR T-cell treatments that dramatically improve the outlook for patients with **diffuse large B-cell lymphoma** and **follicular lymphoma**, an indolent form of **non-Hodgkin lymphoma (NHL)**.

To build on these successes, LLS has \$73 million committed to ongoing lymphoma drug development. Areas of emphasis include **NHL**, where research focuses on exploring less costly CAR T-cell treatments and other targeted approaches.

#### **Multiple Myeloma**

Multiple myeloma has long been a primary focus of LLS research, with more than \$30 million currently allocated to fund more than 30 active laboratory and clinical research projects. In March, the FDA's approval of LLS-supported idecabtagene vicleucel extended revolutionary CAR T-cell therapy to multiple myeloma. This is the first CAR T-cell therapy to target the BCMA protein. BCMA is present on nearly all myeloma cells, but is rarely found elsewhere in the body, making it a great target for multiple myeloma treatment. Another important advance was FDA approval of the antibody daratumumab in a new formulation deliverable in minutes by subcutaneous injection, versus the hours needed for intravenous administration.

Moving forward, we are focused on preventing pre-myeloma from advancing to myeloma, identifying mutations that cause

myeloma, and understanding therapeutic resistance.

#### **Other Blood Cancers and Conditions**

LLS is proud to support research across the entire range of blood cancers. In 2021 we continued investing in areas such as advanced genomics and molecular research to help us understand the causes of **Myelodysplastic Syndromes** (**MDS**), and improve our ability to diagnose, treat, and stop it from progressing to AML.

Along with the MPN Research Foundation, we are sustaining our search for therapies for polycythemia vera (PV), essential thrombocythemia (ET) and myelofibrosis (MF)—the group of blood cancers collectively known as **myeloproliferative neoplasms**.

## LEADING RESEARCHERS Aligned with our mission

LLS is honored to support the cutting-edge blood cancer investigations of visionary scientists including...



#### Courtney DiNardo, MD MD Anderson Cancer Center

Studying an all-oral precision medicine treatment for patients who have AML with the IDH1 or IDH2 mutation



#### Caron Jacobson, MD Dana-Farber Cancer Institute

Examining CAR T-cell therapy for non-Hodgkin lymphoma



#### Jonathan Licht, MD

**University of Florida Health Cancer Center** Studying how the abnormal regulation of genes affects cell growth and development in multiple myeloma and ALL



#### Ravindra Majeti, MD PhD Stanford University

Understanding leukemia stem cells at the DNA level and ways to stop their progression from pre-leukemia to AML



#### Jennifer Trowbridge, PhD The Jackson Labs

Examining the underlying effect of age-related changes on the emergence of myeloid leukemias



#### Saad Usmani, MD, MBA *Memorial Sloan Kettering Cancer Center* Optimizing multiple myeloma treatment strategies using immunotherapy

#### **2021 NEW FDA APPROVALS**

| Leukemia   |  |
|--|--|
| Pediatric AML  | daunorubicin and cytarabine (Vyxeos®)*   |
| Acute Lymphoblastic<br>Leukemia  | asparaginase erwinia chrysanthemi<br>(recombinant)-rywn (Rylaze™)<br>brexucabtagene autoleucel (Tecartus®)*  |
| Philadelphia<br>Chromosome-Positive<br>Chronic Myeloid<br>Leukemia   | asciminib (Scemblix®)  |
| Pediatric Mature<br>B-cell acute leukemia  | rituximab (Rituxan®) with chemotherapy   |
| Lymphoma   |  |
| Diffuse Large B-cell<br>Lymphoma   | loncastuximab tesirine-Ipyl (Zynlonta <sup>™</sup> )<br>Iisocabtagene maraleucel (Breyanzi®)*  |
| Pediatric ALK-Positive<br>Anaplastic Large Cell<br>Lymphoma  | crizotinib (Xalkori®)  |
| Lymphoblastic<br>Lymphoma  | asparaginase erwinia chrysanthemi<br>(recombinant)-rywn (Rylaze™)  |
| Follicular Lymphoma  | axicabtagene ciloleucel (Yescarta®)*<br>umbralisib (Ukoniq™)*  |
| Marginal Zone<br>Lymphoma  | umbralisib (Ukoniq™)*<br>zanubrutinib (Brukinsa®)*   |
| Waldenström's<br>Macroglobulinemia   | zanubrutinib (Brukinsa®)*  |
|  |  |
| Pediatric lymphomas <sup>+</sup>   | rituximab (Rituxan®) with chemotherapy   |
| Pediatric lymphomas <sup>†</sup><br>Multiple Myeloma   | rituximab (Rituxan®) with chemotherapy   |
|  | rituximab (Rituxan®) with chemotherapy<br>daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with pomalidomide (Pomalyst®) and<br>dexamethasone   |
| Multiple Myeloma<br>Relapsed/Refractory  | daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with pomalidomide (Pomalyst®) and  |
| Multiple Myeloma<br>Relapsed/Refractory  | daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with pomalidomide (Pomalyst®) and<br>dexamethasone<br>daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone<br>idecabtagene vicleucel (Abecma®)*   |
| Multiple Myeloma<br>Relapsed/Refractory  | daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with pomalidomide (Pomalyst®) and<br>dexamethasone<br>daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone  |
| Multiple Myeloma<br>Relapsed/Refractory  | daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with pomalidomide (Pomalyst®) and<br>dexamethasone<br>daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone<br>idecabtagene vicleucel (Abecma®)*<br>isatuximab (Sarclisa®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone  |
| Multiple Myeloma<br>Relapsed/Refractory<br>Multiple Myeloma  | daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with pomalidomide (Pomalyst®) and<br>dexamethasone<br>daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone<br>idecabtagene vicleucel (Abecma®)*<br>isatuximab (Sarclisa®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone  |
| Multiple Myeloma<br>Relapsed/Refractory<br>Multiple Myeloma  | daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with pomalidomide (Pomalyst®) and<br>dexamethasone<br>daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone<br>idecabtagene vicleucel (Abecma®)*<br>isatuximab (Sarclisa®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone  |
| Multiple Myeloma Relapsed/Refractory Multiple Myeloma Other Blood Cancers and Advanced Systemic Mastocytosis   | daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with pomalidomide (Pomalyst®) and<br>dexamethasone         daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone         idecabtagene vicleucel (Abecma®)*<br>isatuximab (Sarclisa®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone         d Conditions         avapritinib (Ayvakit**)         daratumumab and hyaluronidase<br>(Darzalex Faspro**)* in combination<br>with bortezomib (Velcade®),<br>cyclophosphamide, and  |
| Multiple Myeloma         Relapsed/Refractory         Multiple Myeloma         Other Blood Cancers and         Advanced Systemic         Mastocytosis         Amyloidosis         Chronic Graft | daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with pomalidomide (Pomalyst®) and<br>dexamethasone         daratumumab plus hyaluronidase<br>(Darzalex Faspro®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone         idecabtagene vicleucel (Abecma®)*<br>isatuximab (Sarclisa®)* in combination<br>with carfilzomib (Kyprolis®) and<br>dexamethasone         dconditions         avapritinib (Ayvakit <sup>™</sup> )         daratumumab and hyaluronidase<br>(Darzalex Faspro <sup>™</sup> )* in combination<br>with bortezomib (Velcade®),<br>cyclophosphamide, and<br>dexamethasone         belumosudil (Rezurock <sup>™</sup> ) |

\*Denotes LLS support \*DLBCL, Burkitt or Burkitt-like lymphoma

## EXPANDING THE POSSIBLE: PATIENT AND FAMILY SUPPORT

# **360-DEGREE APPROACH Addresses ever-evolving needs**



We strive to make sure we have a program that will assist patients with every type of out-of-pocket cost they have. Financial assistance is a 360-degree approach to expanding the possible for patients to access the care they need."

– Anne Gutch, LLS Senior VP, Mission Operations and Patient Financial Assistance

At LLS, we recognize the financial and emotional impact of a cancer diagnosis and strive to help ease these burdens. We offer a wide variety of programs to provide patients, families, and caregivers the resources they need to better afford—and understand—available options for treatment and support.

#### **Financial Assistance**

Our financial assistance programs aim to lessen the economic toll on patients and families to help patients afford life-saving treatments. To counter continually rising drug prices and the ongoing financial impact of COVID-19, we **provided more than 42,000 patients with over \$241M in total grants, a 70% increase over last year**. The lion's share—more than \$234 million—supported patients' insurance premiums and treatment-related co-pay and co-insurance out of pocket costs through our **Co-Pay Assistance Program**. The remainder of our support dollars funded other signature LLS financial assistance programs:

- Urgent Need Program: In partnership with Moppie's Love and Charlie's Fund, we provided a \$500 grant to more than 7,800 patients and families in acute financial need for non-medical living expenses—including rent, utilities and food.
- Susan Lang Pay-It-Forward Patient Travel Assistance Program: We awarded a \$500 grant to nearly 5,000 patients for treatment-related transportation and lodging costs.

- Susan Lang Pre CAR T-cell Therapy Travel Assistance Program: LLS provided more than 200 grants, each \$2,500, for treatment-related transportation and lodging costs for patients who are being evaluated to receive CAR T-cell therapy as either standard treatment or a clinical trial.
- LLS's Patient Financial Aid Program: We provided a one-time stipend of \$100 to more than 2,500 patients to help offset non-medical expenses.

New in 2021 was the introduction of our **Scholarship for Blood Cancer Survivors** providing up to \$7,500 in tuition support for patients diagnosed before age 25, who are U.S. citizens or permanent residents pursuing virtual or in-person, vocational, 2 year or 4 year post-secondary education.

In keeping with our commitment to diversity, equity, and inclusion, LLS recognizes that need exists throughout all geographic regions and within all patient populations, including those traditionally underrepresented. In 2021, financial assistance was provided to patients who resided in 55% of all U.S. counties and 51% of the counties across the U.S. with the highest poverty rates.<sup>\*</sup>

## FINANCIAL LIFELINES DURING UNPRECEDENTED TIMES

TOTAL 2021 FINANCIAL ASSISTANCE **\$241M TO 42,000+ PATIENTS** 

**Co-Pay Assistance Program** \$234M to 27,000+ patients

Urgent Need Program \$3.9M to 7,834 patients

Susan Lang Pay-It-Forward Patient Travel Assistance Program \$2.9M to 4,958 patients

Patient Financial Aid Program \$253K to 2,535 patients

| EXPANDING THE POSSIBLE<br>THROUGH FINANCIAL ASSISTANCE |     |
|--|-----|
| Race, as Identified by Patient*                        |     |
| White  | 64% |
| Black/African American                                 | 23% |
| Hispanic/Latino  | 12% |
| Asian  | 2%  |
| American Indian  | 1%  |

\*Excludes Co-Pay recipients.

#### **Education & Services**

At LLS, we believe knowledge is power. As always, we offered our informational programs in virtual formats, continuing to provide vitally needed education and emotional support for those impacted by blood cancer, as we addressed...

#### ...Ongoing Pandemic Concerns

Trained oncology Information Specialists in our Information Resource Center (IRC) were available to answer pandemicrelated and other questions. **More than 26,000 interactions between the IRC and patients and caregivers took place, with average call lengths up 30% over 2020.** 

#### ...Facilitating Clinical Trial Access

The **LLS Clinical Trial Support Center** (CTSC) grew throughout the year as we increased our bi-lingual and pediatric expertise among the CTSC nurse navigators, and continued to expand the possibility of positive outcomes for patients by matching them to suitable clinical trials. Our nurse navigators assisted 1,019 patients (up 31% from 2020). Of the 759 new patients assisted (up 31% from last year), 21% entered a trial.

We were honored that a CTSC-team-authored article, Overcoming Barriers to Clinical Trial Participation: Outcomes of a National Clinical Trial Matching and Navigation Service for Patients with a Blood Cancer, was published in the "Journal of Clinical Oncology, Oncology Practice" in May.

#### ...Outreach to Underserved Groups

We augmented efforts to expand access to LLS services and resources by bolstering relations with community groups and leaders, notably in the African American and Latino communities, and increased our number of bilingual volunteers. We also increased accessibility of our education programs to rural patients and families via our virtual offerings. Moreover, we expanded partnerships with affinity groups including: the Coalition of 100 Black Women, The Mexican Consulate's Ventanilla de Salud program, and Promotores (Vision y Compromiso).

The LLS **Myeloma Link** program, launched in 2017, continued to gain traction. We improved understanding of treatment options by providing important information to African Americans, who are twice as likely to be diagnosed with multiple myeloma as Caucasian Americans. In 2021, LLS reached approximately 10,448 people through more than 72 Myeloma Link education and outreach activities in 13 cities.

#### ... Education and Patient Connections

Our **virtual education programs** provided both patients and families, as well as health care professionals, access to content including blood cancer conferences, local education programs, national webinars, videos, lectures, and podcasts.

LLS's highly viewed website continues to provide the most up to date blood cancer information including access to blogs, booklets, workbooks, fact sheets and more. In addition, nearly 1,000 cancer patients were provided with personalized nutrition consultations by LLS's registered dietitian.

Our Patient & Community Outreach team continued to bring patients together via online local support groups and chats. The **Patti Robinson Kaufmann First Connection® Program** matched nearly 1,800 patients (up 5% from 2020) with trained volunteers facing the same disease, helping to avert pandemic-related isolation. In addition, membership in **LLS Community**—our online social network—increased 23% over 2020.

# EDUCATING AND CONNECTING PATIENTS AND FAMILIES

#### LLS INFORMATION **RESOURCE CENTER**

## MORE THAN

SPECIALIST-PATIENT INTERACTIONS.

AVERAGE CALL LENGTHS UP 30% OVER 2020

#### CLINICAL TRIAL SUPPORT CENTER

**INCREASE OVER LAST YEAR** PROVIDING PATIENTS WITH IN-DEPTH CLINICAL TRIAL NAVIGATION AND SUPPORT

OF FIRST TIME CONTACTS ENTERED A TRIAL

## INCREASE OVER LAST YEAR OF FIRST TIME CONTACTS

PATIENT AND PROFESSIONAL **EDUCATION/SERVICES** 

## 453110

BOOKLETS AND FACT SHEETS DOWNLOADED OR ORDERED IN HARD COPY

## 139.943

VIRTUAL LECTURE AND ARCHIVED PROGRAM VIEWS

## 48.995

PATIENT VIDEO VIEWS

PATIENT AND PROFESSIONAL PODCAST DOWNLOADS

## **MAKING A DIFFERENCE IN PATIENTS' LIVES**



#### **LLS** has helped financially, easing my mind. I am extremely grateful to LLS, my partner and guardian angel, on this unexpected journey"

— Laurel, multiple myeloma patient



#### **II** The people at LLS helped guide me towards resources available to me. Their generosity did so much to boost my morale and give me one less thing to worry about."

— Michael, leukemia patient



#### **LLS** has provided me and my family with much needed financial support in the form of travel, copay, grants and educational information. I am grateful to the LLS staff for their professionalism, patience and compassion."

- Angela, multiple myeloma patient



**L** Even having health insurance does not guarantee you'll be able to afford treatment... LLS helped us financially with some of our out-ofpocket costs. We are grateful for all the support and assistance we have obtained."

- Gregory, multiple myeloma patient



I have been in contact with social workers and clinical trial navigators at LLS and can hardly believe how accessible, knowledgeable, helpful, and genuinely caring they have been. The expertise at LLS has saved me hours of research and countless sleepless nights!"

- Julie, lymphoma patient



# EXPANDING THE POSSIBLE:

## WORKING TOWARDS ACCESSIBLE TREATMENTS FOR ALL



## GEORGIA SURVIVOR AND ADVOCATE

For former nurse Valerie Taylor, the need to ensure access to cancer treatment hits close to home. Diagnosed with AML in April 2018, Valerie was denied Medicaid coverage for crucial therapies, including a stem cell transplant. Valerie lives in Georgia, one of 12 states that has chosen not to extend Medicaid to people who need it. "I was going to die, not because there wasn't a treatment, but because I couldn't afford it," Valerie recalled. A "maverick" who "never took no for an answer," she frequently meets with her members of Congress to share her story, build relationships, and advocate for more affordable care and access to treatment.

At LLS, we strive for a world where cancer care is no longer prohibitively expensive for anyone and is available to all, regardless of background, income, or insurance status. Our Office of Public Policy—together with a cadre of dedicated volunteer advocates—serves as a voice for blood cancer patients, providing policymakers with the information and inspiration they need to improve access to health coverage and treatments.

In 2021, we worked harder than ever to expand possibilities for patients, focusing on...

#### Improving Health Insurance Affordability

In 2021, LLS helped improve the affordability of health insurance through a new federal law that **reduces or eliminates premiums for millions** of people who purchase insurance through HealthCare.gov.

In June, the U.S. Supreme Court **dismissed a challenge to the Affordable Care Act (ACA)**, thereby preserving protections blood cancer patients rely upon. LLS and other patient organizations played a key role in this ruling, joining "friend of the court" briefs that communicated to the courts, journalists, and lawmakers the importance of ACA protections for those with pre-existing conditions.

We helped to secure the federal funding that has allowed Medicaid to remain available to patients throughout the economic downturn. At the state level, we continued to work in Missouri and Oklahoma to **support implementation** of voter-approved Medicaid expansions, which will extend coverage to an estimated 450,000 people. We also worked with patient organizations and advocates across the country to advance legislation that would ensure access to affordable healthcare for more than 2 million low-income residents in 12 states that have not expanded Medicaid.

#### Easing the Burden of Out-of-Pocket Drug Costs

LLS continued to play a pivotal role as a leader in the fight to cap **Medicare patients' drug costs and allow patients to spread those costs—which can exceed \$10,000 annually throughout the year, making them more manageable**. In 2021, we met with more than 100 members of Congress and ran a digital media campaign seen by more than 3.6 million people emphasizing the need for these policies.

We helped pass a new Illinois law ensuring that **patients can** select a health plan with affordable, predictable drug co-pays, and continued to advocate for similar policies in other states.

#### Protecting Blood Cancer Patients Throughout the Pandemic

Along with allied organizations, we helped advocate for crucial

measures in the stimulus package signed in March 2021. Included were: improved U.S. capacity for vaccine distribution; expanded sick leave; and greater funding for COVID tests, contact tracing, and personal protective equipment (PPE).

We closely monitored the Biden Administration's COVID-19 vaccine rollout and communicated to the Centers for Disease Control (CDC) the importance of immunocompromised patients having access to vaccination. We also supported vaccine requirements to help reduce risks to vulnerable blood cancer patients.

#### Making Progress Towards Health Equity

In 2021, LLS continued our support for policies that will promote health equity for all blood cancer patients. Along with our advocacy partners, we implemented the CLINICAL TREATMENT ACT requiring **Medicaid to cover care received during a clinical trial**, thereby increasing trial access for more than 41 million people, including members of racial and ethnic minority groups. We also carried forth our efforts to advance legislation to increase trial access for currently underrepresented populations.

LLS launched its new **Equity in Access Research Program**, a collaboration between the Office of Public Policy and the LLS Education & Services Department that will fund health services research. The initial focus will be on improving our understanding of how insurance status and type impacts access to care for blood cancer patients and survivors.

On the state level, we supported first-of-its-kind legislation in Oregon that improves collection of patients' demographic information, enabling a **data-driven approach to addressing health disparities**. And in Texas, we successfully advocated for a bill that **creates a bone marrow recruitment program to increase the number of registered donors—particularly currently underrepresented people of color**.

#### Protecting Patients From Unscrupulous Practices

In 2021, we are proud to have led a coalition of more than 30 patient organizations that produced a **groundbreaking report detailing the proliferation of junk insurance**—plans that leave patients vulnerable to enormous medical debt and discriminate against patients with a history of cancer. Our advocacy campaigns in Kansas and Virginia resulted in key gubernatorial vetoes of bills that would have expanded the availability of these policies.

LLS also played a critical role advocating for patients as regulators wrote the rules that will guide implementation of the **first federal law prohibiting "surprise" medical bills**—a problem in 1 in 6 in-patient hospitalizations.



### oregon advocate ANDREA SANCHEZ

Andrea Sanchez's mother, a nurse, never lost her passion for helping others, even as she faced multiple myeloma. Looking to continue this tradition after losing her mother in 2017, Andrea connected with LLS, and an advocate was born. Andrea said her awareness of many "tragic and devastating" situations where patients struggle to afford their treatments continues to fuel her motivation to "draw attention to issues, raise awareness, and make a difference."

## Legal Advocacy, A Powerful Tool for Policy Change

In 2021, LLS expanded its use of legal advocacy to ensure that the judiciary understands how its decisions impact access to care for blood cancer patients. This included the organization's first-ever brief filed with the U.S. Supreme Court, arguing against policies that threatened to block patients from accessing Medicaid.

2021 ADVOCACY

BY THE NUMBERS **30,000** ACTIVE ONLINE VOLUNTEER ADVOCATES

21 STATES WHERE VOLUNTEER ADVOCATE COMMITTEES OPERATE 56.161

LETTERS TO 834 STATE AND FEDERAL LAWMAKERS 241 ADVOCATE MEETINGS WITH MEMBERS OF CONGRESS

## EXPANDING THE POSSIBLE: THE LLS CHILDREN'S INITIATIVE

# BREAKTHROUGH PROGRAMS Brighten Outlook for Long-Term Success



Advancing research in pediatric cancer and improving quality-of-life for childhood cancer survivors are at the core of LLS's mission. What differentiates LLS is we can impact patients and families from different angles with our comprehensive approach.

-Gwen L. Nichols, MD, LLS Chief Medical Officer

With the promise of a full lifetime ahead, children, teens, and young adults have a great deal to gain from our efforts to "expand the possible." That is why LLS has made a five-year investment of more than \$100 million to fund the LLS Children's Initiative, a groundbreaking global collaborative effort to accelerate pediatric, adolescent, and young adult blood cancer research and reimagine the standard of care. We aim to improve survival for all childhood blood cancers, and develop safer, less toxic cancer therapies to spare survivors a lifetime of treatment-related health issues. Our hope is to provide our youngest patients with the chance to thrive in survivorship.

In 2021, our comprehensive Children's Initiative included the following efforts:

## Intensified Commitment to Breakthrough Research

As a parent-founded organization, the mission to discover cures for childhood blood cancers is embedded in the very DNA of LLS. Techniques including genomic sequencing and precision medicine, along with advances in clinical trial design and data collection, are taking us to the next frontier: replacement of the "one size fits all" approach with safer, highly effective, customized treatments to increase survival across the childhood cancer landscape.

To expedite new discoveries, we have nearly tripled our pediatric-focused multi-year grants since the Children's Initiative's inception, from \$11M in 2018 to **\$30.5M in 2021**. Moreover, grants totaling \$52M have been planned through

2027. Approximately **30 LLS-funded research projects focused on childhood blood cancers** were underway in 2021. Areas of exploration included:

- expansion of immunotherapy techniques to pediatric patients
- detection of post-treatment cancer cells that can lead to relapse
- · identification of patients most likely to respond to therapy
- discovery of new approaches for high-risk patients resistant to available therapies
- addressing long-term treatment effects including cardiotoxicity

#### 2021 NEW FDA PEDIATRIC APPROVALS

Five significant 2021 FDA approvals further expanded possibilities for pediatric patients:

| Pediatric Acute Myeloid<br>Leukemia (AML)                          | daunorubicin and cytarabine<br>(Vyxeos®)*                         |
|--|---|
| Acute Lymphoblastic<br>Leukemia (ALL)                              | asparaginase erwinia chrysanthemi<br>(recombinant)-rywn (Rylaze™) |
| Pediatric ALK-Positive<br>Anaplastic Large Cell<br>Lymphoma (ALCL) | crizotinib (XALKORI®)   |
| Pediatric lymphomas <sup>+</sup>                                   | rituximab (Rituxan®) with chemotherapy                            |
| Pediatric Mature B-cell<br>acute leukemia                          | rituximab (Rituxan®) with chemotherapy                            |

\*LLS supported original adult indication \*DLBCL, Burkitt or Burkitt-like lymphoma

#### A Sampling of 2021 CI Research Grants



Therese Vu, PhD University of Colorado, Anschutz Medical Campus

Understanding novel protein interactions to improve targeted treatments for T-ALL



#### Alexandra Stevens, MD Baylor College of Medicine Patient-derived xenograft models

and drug testing in pediatric AML



Jeffrey Magee, PhD, MD Washington University School of Medicine

Neonatal origins of pediatric AML



#### Clara Reglero, PhD Columbia University Medical Center Chemotherapy resistance in relapsed leukemia



#### Soheil Meshinchi, PhD, MD Fred Hutchinson Cancer Research Center Immunotherapeutic targeting in AML in infants and children



#### Sarah Tasian, MD The Children's Hospital of Philadelphia

Precision medicine and immunotherapy for high-risk childhood leukemias

#### New Resources for Families

As part of our patient-focused approach, we continued to add new pediatric educational and supportive resources for families. LLS Coloring for Kids,<sup>™</sup> our free mobile app gained traction in 2021. This tool offers educational activities that explain blood cancer and treatments. In March 2021, the Wiskurs Emotion Flipbook was released, providing illustrations allowing children to express their mood. In addition, both of our AML and ALL educational booklets were updated, with content focused on children and teens.

In an effort to further expand our services, we set big goals for the next five years, including:

- reaching more than 11,000 pediatric patients through outreach, support, and education
- awarding 200 scholarships to blood cancer survivors
- assisting at least 9,000 pediatric patients with our Urgent Need program (See page 6)

#### Sustained Pediatric Advocacy Efforts

The LLS Office of Public Policy serves as a leading national voice advocating for all blood cancer patients. We are proud to serve on the steering committee for the Alliance for Childhood Cancer as co-leader of its policy committee. In 2021, LLS advocated for ongoing funding of the Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act, the most comprehensive childhood cancer legislation ever, and prepared for the next iteration of the landmark bill set for introduction in 2022. Our efforts also helped secure \$80M to fund childhood cancer research programs at the National Institutes of Health, to bring us closer to less toxic, more effective pediatric cancer treatments.

Through grassroots advocacy and lobbying, we increased Congressional support for the Accelerating Kids' Access to Care Act, which will reduce delays for out-of-state treatments. We also began developing a new volunteer-led national Pediatric Advocacy Committee, to ensure that families affected by pediatric cancer have the opportunity to inspire policymakers to create change.

## WORLDWIDE PEDAL TRIAL Breaking New Ground In Customized Treatment

Thanks to advances in genetic sequencing and data sharing, the promise of individualized treatment for children with relapsed acute leukemia (AL) is becoming reality. Big progress was made in 2021, as LLS continued to align with trial partners and sponsors to prepare for **LLS PedAL**, the first integrated global master clinical trial to test new precision medicine therapies and match patients to treatment based on their unique tumor biology.

PedAL will utilize two LLS-supported breakthroughs in data gathering. The **GEARBOx** database (Genomic Eligibility Algorithm at Relapse for Better Outcomes) will help practitioners match patients with relapsed disease to appropriate available clinical trials. And the **Data Commons** platform will allow consolidation of information from multiple institutions into a single data set to ensure consistency in analysis and reporting.

Trial screening is expected to begin early in 2022, followed by patient enrollment in more than 200 U.S. sites, with Europe, Australia and New Zealand, and Canada coming onboard soon afterwards. Widespread availability of trial locations will ensure a critical mass of patients, including participants from previously underserved populations.

## SUPPORTING PEDIATRIC PATIENTS AND FAMILIES

#### LLS INFORMATION RESOURCE CENTER

## 76%

OF IRC SPECIALIST INTERACTIONS WERE WITH FIRST-TIME PATIENTS

#### CLINICAL TRIAL SUPPORT CENTER

### +123%

INCREASE OVER LAST YEAR PROVIDING PATIENTS WITH IN-DEPTH CLINICAL TRIAL NAVIGATION AND SUPPORT

#### PATIENT AND PROFESSIONAL EDUCATION/SERVICES

## 40,863

CHILDHOOD AND YOUNG ADULT WEBPAGE VIEWS

## 16,605

BOOKLETS/MATERIALS ORDERED OR DOWNLOADED

## 10,003

VIRTUAL LECTURE OR ARCHIVED PROGRAM VIEWS

## 8,144

PODCAST ENGAGEMENTS-THE BLOODLINE WITH LLS AND TREATING BLOOD CANCERS

### **3,026** VIDEO VIEWS

\*Approximately 5% of households served had a pediatric patient age 19 or younger



## IMMUNOTHERAPY DELIVERS LIFE-SAVING SUCCESS

Jude of Tucson, AZ began his cancer journey at 18 months old. A diagnosis of ALL led to four cycles of intense chemotherapy over two years. After recovering from a stem cell transplant, Jude relapsed a second time. A groundbreaking clinical trial in CAR T-cell therapy at Seattle Children's Hospital represented a promising new lifeline as scientists modified Jude's own cells to fight his leukemia. This treatment worked, but his cancer returned, and two additional clinical trials followed. His family returned to Banner-UMC in Tucson to try a new immunotherapy drug. It was successful, making Jude eligible for a second bone marrow transplant. Despite some lingering side effects, including joint stiffness and partial hearing loss, Jude is now happy, curious—and cancer-free. "Jude is alive today only because of recent advances in cancer immunotherapy," said his mother, Barbara.



To date, progress in evaluating new drugs which are essential to improve cure and reduce long-term toxicity has been hampered by lack

of coordination, small numbers, and lack of prioritization. The Children's Initiative provides a critical framework for new drugs for AML to be evaluated efficiently in North America and Europe. The impact of this program extends much further than pediatric AML and is a paradigm for other childhood malignancies, both leukemias and solid tumors."

 ADJ Pearson, Retired Professor of Pediatric Oncology, Institute of Cancer Research, Royal Marsden Hospital

## EXPANDING THE POSSIBLE: PARTNERSHIPS

## RECORD-SETTING EFFORTS CATAPULT OUR MISSION TO NEW HEIGHTS

LLS is always grateful to the thousands of volunteers, donors, corporate partners, and employees that join forces with us to advance our mission. In 2021, as COVID-19 obstacles remained in place, the steadfast loyalty of our supporters meant more to us than ever. Despite the unusual business and fundraising circumstances prompted by the pandemic, our partners turned the seemingly impossible to possible—managing to raise record-setting amounts of money for our cause...even without holding a single in-person event for the entire fiscal year.

As we transition back to in-person fundraising events, we have set the stage to grow a more diverse LLS volunteer community with even more activities and opportunities for partner engagement.

## **EXTRAORDINARY VOLUNTEERS PRODUCED WINNING RESULTS**



#### Josh Sussberg: National Man of the Year

Scarsdale, NY, attorney Josh Sussberg has had first-hand knowledge of the devastation of cancer since his diagnosis of T-cell lymphoblastic lymphoma in 2016. Eight months of intense chemotherapy, followed by three years of a daily "maintenance" chemo regime have left him cancer-free. "I would not be here today without medical advances made possible by research and programs funded by organizations like LLS," Josh said. Yet, he is hoping for more, envisioning a day when 100% cure rates are the norm and cancer is merely a "speed bump." As a 2021 LLS Man of the Year candidate, Josh kicked his fundraising efforts into high gear, **raising a record-breaking \$1.75M for LLS's mission**.



#### Julia Lauria: National Woman of the Year

When nominated to compete for Woman of the Year, Atlanta marketing executive Julia Lauria went "all in." Inspired by the plight of several friends who were touched by cancer, Julia made it her mission to make a difference. With a goal of bringing equality and diversity to the cancer arena, she formed a groundbreaking campaign team that included professional athletes, cancer survivors, and relatives and friends of cancer patients. **Their winning effort raised more than \$538K for LLS.** "No matter where you're from or what you believe in, we all know somebody whose world was turned upside-down by cancer," Julia stated.



#### Aaron Steele Logan: Students of the Year Participant

Charlotte, NC, teen Aaron Steele Logan likes to quote a line from Spiderman: "With great power comes great responsibility." Dubbed by those who know him as a "natural influencer" and "all-around amazing young man," Aaron seized the opportunity to put his favorite quote into action when a former high school counselor nominated him to participate in LLS' 2021 national Students of the Year campaign. Fueled by his desire to increase awareness of blood cancer's impact and the need to support cutting-edge research, Aaron formed Team LLSteele. "LLS has empowered me with a tremendous opportunity to reach others, and now I feel it's my responsibility to make a real difference in their lives," he said. "I want to inspire others to join the fight to find a cure."

## LLS RAISED THE FUNDRAISING BAR

ACHIEVEMENTS INCLUDE:

Campaigns over-performed expectations by 28%, raising more than \$167M

Advancement colleagues connected with donors in new ways, raising \$42.9M

"Of the Year" mobilized community leaders and next-generation philanthropists to new revenue heights – with top fundraiser **raising more than \$1M** 

Light The Night was recognized as a **top-five peer-to-peer fundraising program** in North America

Team In Training launched the Virtual Resilience Challenge, raising more than \$1M. Business Development and Direct to Constituent outperformed goals by 33% raising more than \$56M.

## **2021 VOLUNTEER CAMPAIGN HONOR ROLL**

Light The Night: Heath Melton, The Woodlands, TX, raised \$264K+

**Team in Training:** James Lau, Los Altos, CA, raised \$118K+

National Man of the Year: Josh Sussberg, Scarsdale, NY, raised \$1.75M

National Woman of the Year: Julia Lauria, Atlanta, GA, raised \$538K

National Man of the Year Runner-up: Bryan Thomas, Washington, DC, raised \$1.25M+

National Woman of the Year Runner-up: Denise Hartmann, Charlotte, NC, raised \$482K+

National "All Star" Man of the Year: Stephen Collins, San Antonio, TX, raised \$2.26M+ The highest amount by any candidate in the campaign's history

National "All Star" Woman of the Year: Dianne Callahan, Highland, CA, raised \$150K+

National 2021 Students of the Year winners: Team NewGen, Charlie Farrell, 16; Isabelle Ashley, 16; William Ashley, 16, The Branson School, Ross, CA, raised \$660K

#### The 2021 National Students of the Year runners-up:

Team CUREsaders, Kaeden Koons-Perdikis, 16; Ella Song, 17; Calla O'Neil, 18, Georgetown Visitation Preparatory School & Whittle School and Studios, Washington D.C., raised \$546K



## Brett Jenkins: Light The Night Fundraiser and LLS Regional Board Member

For Brett Jenkins, blood cancer is an integral part of his personal story. In 2010, Brett's older sister, Dawn Marie Jenkins, was diagnosed with a rare form of AML. Despite having an initially promising bone marrow transplant, Dawn passed away in 2011 at age 44. The following year, Brett and his wife began hosting an annual fundraiser at their home, doing what they could to help raise funds for LLS. Fast-forward to 2016, when Brett discovered the eerie coincidence that his childhood best friend, Jamie Crowley, was battling the same leukemia. Like Dawn, Jaime had a successful bone marrow transplant and went into remission, only to lose his cancer battle, in 2018. In this, his 11th year of fundraising, Brett raised \$40,245 for his participation in LLS' Light The Night campaign in his hometown of Portland, OR. Spurred on by personal tragedies, his fundraising credo calls for "no excuses" and "not settling for not achieving goals." Brett adds, "we must continue to challenge ourselves and figure out how to make lemonade."



#### Nicholas Santaniello: Big Climb Participant

Covid 19 has made every cancer diagnosis even more frightening and isolating. That was Nick Santaniello's story after he developed great difficulty swallowing and his tele-medicine doctor urged him to go to the ER, immediately. Nick was diagnosed with non-Hodgkin lymphoma and underwent six rounds of chemotherapy over seven months before achieving remission. After LLS helped him deal with the physical and emotional challenges of his survivorship, Nick found an opportunity to give back by getting more involved with LLS and Big Climb. "Last year, I was the local Boston Honored Hero and this year, I have gotten even more involved by taking on the role of Climb Chair and participating in the LLS National Patient Registry," Nick said. He considers beating non-Hodgkin lymphoma his biggest challenge and "I wake up every day thankful for everyone who helped me win this fight."



#### Brian Kozera: Team In Training Endurance Challenge Participant

At age 36, Philadelphia-area resident and triathlete Brian Kozera received an unexpected cancer diagnosis—from his hernia surgeon. After 16 rounds of chemotherapy for what turned out to be Stage IV lymphocyte depleted Hodgkin lymphoma, followed by a bone marrow transplant, Brian began dreaming of a return to competitive sports—as an Ironman. Working out on a stationary bicycle he installed in his hospital room, Brian began training. Six months later, in 2016, his first goal was met: completion of the Philadelphia marathon. Several international Ironman competitions followed, leading to his dream of representing LLS in the Ironman World Championship in Kona, Hawaii. Kona may have been pushed back to 2022, but Brian hasn't slowed down his support of LLS. He has raised more than \$52,000 and is still pushing for more life-saving funds. This married police officer, and father of three girls (one battling a rare neurological disease) calls himself a "cancer thriver" and believes that he is proof that "anything is possible."

## **DONORS DISPLAYED UNCEASING GENEROSITY**



The Borstein Family Foundation is excited to partner with LLS and Dr. Arash Alizadeh at Stanford University in its groundbreaking research. We supported the *Refining Molecular Risk Prediction & Individualized Lymphoma Therapy Using Circulating Tumor DNA* research program, as this form of liquid biopsy represents a unique way to measure the efficacy and potential long-term success of existing or proposed patient treatment. We are grateful that LLS introduced us to this program, as it furthers our mission to support innovative medical research for a cause that we care deeply about. The link that LLS provides between researchers, institutions, foundations such as ours, and patients is of vital importance."

- Borstein Family Foundation, California



As parents, Amelia and I know the instinct to do whatever it takes to help our children. When we learned about what LLS is doing through the LLS Children's Initiative, we were so moved. We imagined what it would be like to be told our children were sick and that there were no treatments that could help them, and then what it would be like to be a part of transforming treatment and care for children. There is nothing more important than investing in the lives of our children, and we're eager to see how this investment pays off in better treatments and lives saved."



We are so inspired by LLS's work—by the support offered to families, by the partnership with researchers who are working so hard to fight AML, and by the volunteers who are so passionate about the mission. It's all so impactful. We established the Bobby Zahurak Pediatric AML Research and Patient Support Fund in honor of our cousin. Bobby was a wonderful, handsome, and bright young man, full of promise and driven to make a difference. He was a positive force in the lives of those around him, and will always be loved and remembered—especially now through LLS."

- Jeanne and John Hubbard, PhD, FCP, Pennsylvania



Lauren was almost two when she was diagnosed with T-cell ALL. We had amazing, gifted doctors who had never treated a child so young with her disease; there was no research study for her to participate in; and she had to move more than 3,000 miles away from home to find a hospital that had done a transplant on a child her age. Children get cancer too. And even though they're stronger than we'd imagine and more resilient than you could ever believe, when they survive, we don't know how it will affect the rest of their lives. We had to rely on doctors who had to tell us 'I don't know.' Our commitment to LLS is to help ensure families in the future won't have to."

-Moore Family, Florida



Having lost both of my parents to leukemia, the LLS BEAT AML Initiative showed me that progress is possible through focused collaboration. When the IMPACT Program at Mayo Clinic rolled out, we saw an opportunity for a different kind of progress—combating healthcare disparities amidst a pivotal year for racial equity. Our company is honored to partner with LLS to bring world class medicine to underserved patients. LLS has the ability to collaborate and innovate like I've never seen before, so investing in their work is an easy decision."

## **A SINCERE THANK YOU**

As always, LLS sincerely thanks all of our dedicated volunteers and donors who help make our lifesaving work possible. Whether raising critical funds, advocating for lifesaving policies, providing support to those impacted by cancer, or building critical capacity, our volunteers and supporters are invaluable as we continue to advance the LLS mission.

– William Rahr, Minnesota

## CORPORATE PARTNERS Aligned with our mission

Many thanks to these companies who held steadfast in their commitment to LLS:

AbbVie Amgen AstraZeneca Bristol Myers Squibb Burlington Genentech Inc. & Biogen Gilead Sciences GlaxoSmithKline Janssen Biotech Jazz Pharmaceuticals Kirkland & Ellis LLP

#### Pfizer

Pharmacyclics, An AbbVie Company & Janssen Biotech

Subaru of America

Sylvester Comprehensive Cancer Center

Takeda Oncology

**The Wawa Foundation** 

United Food and Commercial Workers

Walgreens

World Wide Technology

World Wrestling Entertainment, Inc.



🔓 In my experience, it's good business to take services to rural and remote areas. That is exactly what LLS is doing with the IMPACT program-taking clinical trials to the underserved. But this initiative is more than good business, it's the right thing to do. I firmly believe that your zip code

should not determine the level of care that you receive after being diagnosed with blood cancer. Families who live far from any major medical centers that specialize in blood cancer treatments may not know about clinical trials available to them, or be able to afford the travel, time away from work, or the experimental treatment itself. By giving to LLS's IMPACT program, I hope to help change this. I am thrilled to be a part of this one-of-a-kind initiative and look forward to better access and outcomes for patients."

– Cal Turner, Tennessee

# EXPANDING THE POSSIBLE:

#### Your support is invested wisely.

In fiscal year 2021, LLS raised \$484 million to support our mission and operations. We spent \$274.7 million or 74% of our expenses on specific programs designed to find new treatments for blood cancers, provide financial assistance to blood cancer patients, break down barriers to care, and improve the lives of patients and their families.



#### **CONSOLIDATED STATEMENT OF ACTIVITIES** For the year ended June 30, 2021 (USD Thousands)

| R | ev  | e | าน | е |
|---|-----|---|----|---|
|   | C v | e | iu | e |

| Campaign contributions                    | \$<br>260,922 |
|---|---------------|
| Less: direct donor benefit costs          | (5,868)       |
| Net campaign contributions                | \$<br>255,054 |
| Co-Pay contributions                      | \$<br>184,417 |
| Royalties and other income                | 40,308        |
| Net interest and dividend income          | 4,165         |
| Total revenue                             | \$<br>483,944 |
| Operating Expenses                        |               |
| Program Services                          |               |
| Research                                  | \$<br>65,402  |
| Patient and Community Service             | 171,939       |
| Public Health Education                   | 26,994        |
| Professional Education                    | 10,366        |
| Total Program Services                    | \$<br>274,701 |
| Supporting Services                       |               |
| Management and general                    | \$<br>46,495  |
| Fundraising                               | 50,399        |
| Total Supporting Services                 | \$<br>96,894  |
| Total operating expenses                  | \$<br>371,595 |
| Foreign currency loss                     | \$<br>901     |
| Net Increase in fair value of investments | 38,208        |
| Change in net assets                      | \$<br>151,458 |

#### **CONSOLIDATED BALANCE SHEET** As of June 30, 2021 (USD Thousands)

| Assets                                   |    |         |
|--|----|---------|
| Cash and cash equivalents                | \$ | 19,473  |
| Prepaid expenses and other assets        |    | 3,891   |
| Contributions and other receivables, net |    | 18,786  |
| Investments                              |    | 708,071 |
| Fixed assets, net                        |    | 11,128  |
| Total assets                             | \$ | 761,350 |
|  |    |         |
| Liabilities                              |    |         |
| Accounts payable and accrued expenses    | \$ | 29,938  |
| Deferred revenue                         |    | 13,134  |
| Awards and grants payable                |    | 36,704  |
| Co-Pay assistance payable                |    | 152,050 |
| Other long-term liabilities              |    | 4,534   |
| Total liabilities                        | \$ | 236,361 |
| Net assets                               |    |         |
| Without donor restriction                | \$ | 220.806 |
|  | ⊅  | 339,806 |
| With donor restriction                   |    | 185,183 |
| Total net assets                         | \$ | 524,989 |
| Total liabilities and net assets         | \$ | 761,350 |

Please visit **www.LLS.org/AnnualReport** to read our full Fiscal Year 2021 Annual Report, including financials and acknowledgments.



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The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at **www.LLS.org**.

