



# UNSTOPPABLE

2020  
ANNUAL  
REPORT



# 2020 ... A YEAR UNLIKE ANY IN RECENT MEMORY

The COVID-19 pandemic could have stopped The Leukemia & Lymphoma Society (LLS) in our tracks. But as leaders in the fight to cure blood cancers, we recognized the need to forge ahead with our mission.

In spite of the challenges we faced, we made great progress. We sustained our momentum in research, patient support, and advocacy.

We tackled COVID-19 head on. We promoted new avenues to diversity and inclusion. And we pressed ahead with exciting new initiatives.

We were, in a word,  
**UNSTOPPABLE.**

# UNSTOPPABLE IMPACT



Dear Friends,

At the end of 2019, our 70th year, all of us at The Leukemia & Lymphoma Society (LLS) were energized by our decades of success and eager to forge ahead with our mission. We never imagined the year that lay ahead.

When the global pandemic arrived in the United States in March 2020, LLS promptly realized that the remainder of the year would not be “business as usual.” We knew that blood cancer patients would likely be especially vulnerable to COVID-19. We were concerned how patients would manage not only their health, but the financial challenges of treatment, should they be economically compromised by the pandemic. We evaluated how we could safely conduct business and how COVID-19 would challenge our employees, volunteers, donors, researchers, healthcare professionals, and communities.

In the spirit of our founders, Rudolph and Antoinette Roesler de Villiers, and their relentless attempt to find cures for the 16-year-old son they lost to leukemia, we redoubled our efforts on behalf of the 1.3 million Americans living with—or in remission from—blood cancer.

Rather than succumb to the year’s challenges, we pledged to remain unstoppable.

**The pages that follow tell our 2020 story.  
You will learn how we...**

... **continued to support breakthrough research** in precision medicine and immunotherapy, including CAR-T cell therapy.

... **pivoted in real time** to conduct business safely and virtually.

... **mobilized to provide new patient education and support**—leveraging our online capabilities—to help families cope in this year of particular need.

... **forged ahead with bold advocacy efforts** at the national and state level to stand up for patients during the pandemic.

... **achieved impressive strides with our groundbreaking Children’s Initiative**, including the advancement of the milestone LLS PedAL clinical trial.

... **rallied our community around our commitment to diversity, equity, and inclusion** across every aspect of our organization and lifesaving work.

... **saluted our partners:** donors, scientists, physicians, other healthcare professionals, corporations, and volunteers who worked with us to keep our momentum going.

We are buoyed by our success during this challenging year and we’re thankful to all those who helped. For a listing of our incredible supporters please visit [www.LLS.org/AnnualReport](http://www.LLS.org/AnnualReport).

But we know the future holds more work for us as we aim to increase survival rates across all blood cancers and advance clinical trials for new and breakthrough treatments. We believe cancer is curable and with the continued help and generosity of our supporters, we pledge to always remain...**unstoppable**.

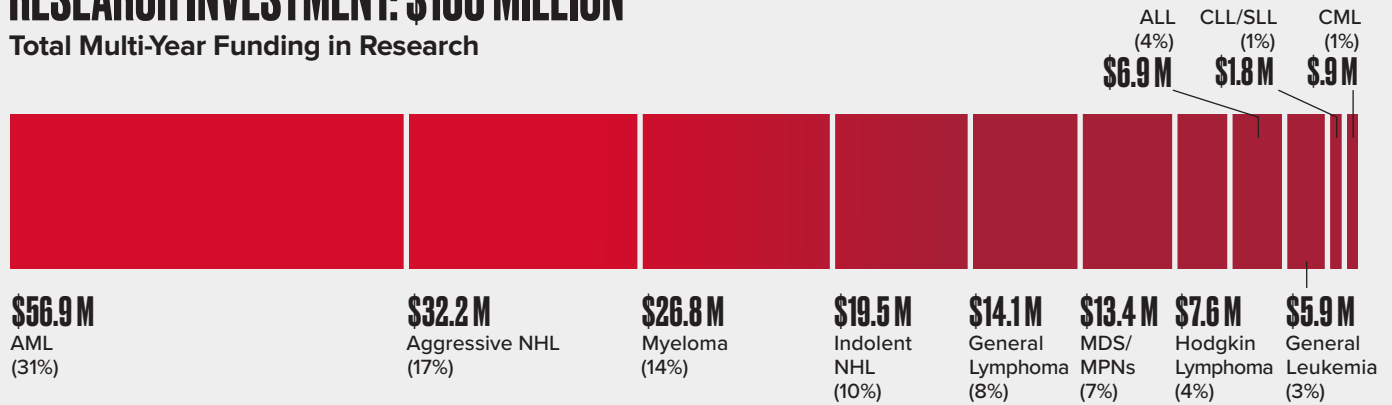
**Louis J. DeGennaro, PhD**  
President and Chief Executive Officer

**Jorge Benitez**  
Chair of the Board

# UNSTOPPABLE RESEARCH: OUR APPROACH

## RESEARCH INVESTMENT: \$186 MILLION

Total Multi-Year Funding in Research



At LLS, our mission begins with the word cure. We recognize that groundbreaking research will lead us toward the cures we seek. Through the decades, LLS support has been instrumental in the development of nearly every breakthrough in blood cancer treatment.

The 2020 COVID-19 pandemic threatened to divert attention and resources away from the pursuit of new treatments. Nevertheless, our longstanding commitment to scientific discovery remained intact as we drove forward groundbreaking approaches to treating blood cancers.

### Steadfast Support for Discovery

In 2020, LLS supported more than 190 active research grants and 20 Therapy Acceleration Program® (TAP) partnerships totaling \$186 million in multi-year funding. We dedicated \$27.6 million to support scientific grants to researchers across nine countries at the world's most prestigious research institutions, making us the largest nonprofit funder of blood cancer research.

Thanks to unrelenting donor contributions, LLS was able to continue our support of the world's most trailblazing scientific investigators. We remained focused on exciting breakthroughs, including precision medicine, immunotherapy, and the relationship between mutations and blood cancers.

### Bold Funding Strategies for Clinical Development

Through our Therapy Acceleration Program (TAP), we continued to partner with biotechnology companies and academic institutions to accelerate the development of promising novel therapies. Using the principles of biomedical venture philanthropy, TAP focuses on first-in-class innovations, usually in early stage clinical development, from biotechnology companies or academic centers. Ideas that show initial promise are often further developed by major pharmaceutical firms. Financial returns from successful investments then funnel back to LLS, to be used to support future efforts.

The LLS staff, working closely with blood cancer experts, has amassed an impressive track record in carefully selecting opportunities that are poised for clinical success and substantial impact. Since its inception in 2007, the TAP program has developed a rich pipeline of over 60 therapies. FDA-approved agents initially backed by TAP include: Celator's CPX-351 (Vyxeos®), Kite Pharma's axicabtagene ciloleucel (Yescarta®), and Stemline Therapeutics's tagraxofusp-erzs (Elzonris®).

At the end of 2020, more than 20 TAP-supported therapies were in active development—the majority in clinical trials, including five late-stage studies that will hopefully lead to near-term new drug approvals.





# UNSTOPPABLE LLS SUPPORT THROUGH THE YEARS



## SINCE 1949

Contributed more than **\$1.3 billion** to cancer research



## IN 2020

Helped advance **14** of the **17** blood cancer treatment options approved by the U.S. Food and Drug Administration



## SINCE 2017

Supported more than **85%** of FDA-approved blood cancer treatments

# UNSTOPPABLE RESEARCH: PROGRESS BY DISEASE STATE



“LLS is where it is today because it has groomed a remarkable generation of scientists and physician scientists who have led the extraordinary advances in treatment of hematologic malignancies.”

— Gary Gilliland, MD, PhD, President and Director Emeritus,  
Fred Hutchison Comprehensive Cancer Center

## Unrelenting Progress Across the Blood Cancer Landscape

At LLS, we have staked out broad territory to explore. We seek solutions for all blood cancers—prevalent and rare. Despite unforeseen circumstances, we pressed on with our quest in 2020. We formed new research partnerships and witnessed additional drug approvals made possible by our support.

Our efforts were unstoppable as we pursued advancements in:

### Immunotherapy

Our longstanding commitment to immunotherapy—the harnessing of the immune system to fight cancer—progressed as we continued to fund the development of less toxic therapies with fewer side effects.

Currently, we support an active multi-year funding portfolio of over \$40 million to investigate a variety of novel immunotherapy approaches. CAR T-cell immunotherapy, which infuses immune (T) cells with cancer-attacking “chimeric antigen receptors” (CARs), shows game-changing promise. Long-lasting remissions, perhaps even cures, have been seen in a range of blood cancers, including approximately 80% of pediatric acute lymphoblastic leukemia (ALL)

cases and 50% of highly lethal adult lymphomas, in patients who had previously not responded to multiple rounds of conventional therapies. Next up is the expansion of the efficacy, application, and accessibility of this groundbreaking therapy.

### Leukemia

With our continued investment in leukemia research, we are paving the way toward cures for all forms of this disease. Nearly one third (31%) of this funding was earmarked for AML efforts. In addition, we continued to advance our Beat AML® Master Clinical Trial. Established in 2016, this collaborative project leverages advancements in genomics and precision medicine to identify patients’ cancer-driving genetic mutations and deliver gentler, targeted treatment in place of toxic chemotherapies. At the end of 2020, the groundbreaking Beat AML trial had enrolled 1,000 patients.

### Lymphoma

We continued to pursue and advance promising new treatments for lymphoma patients. A recent significant advance was the approval of brexucabtagene autoleucl (Tecartus™), the first CAR T-cell therapy approved for patients with mantle cell lymphoma (MCL). This was one of six new treatment options approved by the FDA in 2020 for patients with lymphoma.

## A YEAR OF UNSTOPPABLE THERAPEUTIC GAINS

FDA-Approvals  
in 2020

### MARCH

\***isatuximab (Sarclisa®)**: with pomalidomide and dexamethasone for adults with myeloma who have received at least two prior therapies.

### APRIL

\***ibrutinib (Imbruvica®) and rituximab (Rituxan®)**: frontline for adult patients with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL).

\***luspatercept-aamt (Reblozyl®)**: for second-line treatment of anemia in adult patients with MDS.

### MAY

\***daratumumab and hyaluronidase-fihj (Darzalex Faspro™)**: subcutaneous form for adults with newly diagnosed or R/R myeloma.

### JUNE

\***gemtuzumab ozogamicin (Mylotarg™)**: for children newly diagnosed with AML who have the CD33 protein.

\***tazemetostat (Tazverik™)**: for adults with R/R follicular lymphoma (FL) who have an EZH2 mutation and have received at least two prior therapies, or who have no satisfactory treatment options.

\***selinexor (Xpovio®)**: for adults with diffuse large B-cell lymphoma (DLBCL) who have received at least two prior therapies.



## Multiple Myeloma

In 2020, our funding furthered LLS's role as a leading funder of visionary myeloma research. Four new treatment options we supported obtained FDA approval last year. Moving forward, we will continue backing expansion of the use of CAR T-cell immunotherapy in myeloma by exploring ways to "supercharge" the body's immune system to attack BCMA (B-cell maturation antigen) and CD38-expressing myeloma cells, key proteins in this disease. LLS is also supporting the development of new therapies to prevent pre-myeloma conditions from advancing to myeloma.

## Myelodysplastic Syndromes (MDS)

Last year, LLS funded MDS research worldwide, aiming to tackle this blood disorder and find therapies that can stop its potential progression to AML. While LLS is supporting the development of new treatments for MDS, it is clear that the underpinnings of this disease are unique and complex. Therefore, LLS continues to invest in a deeper foundational understanding of MDS. We are confident that this strategy, which has paid off for many other blood cancers, will yield new therapeutics in the near future.

Our TAP venture philanthropy partnership with Forty-Seven (later acquired by Gilead Sciences) helped advance magrolimab, a completely novel therapeutic to control MDS. In 2020, promising data led the FDA to grant breakthrough status to fast-track approval of this potential MDS treatment.

## Myeloproliferative Neoplasms (MPN)

Throughout 2020, LLS collaborated with the MPN Research Foundation to develop therapies for polycythemia vera (PV), essential thrombocythemia (ET) and myelofibrosis (MF)—the group of blood cancers collectively known as myeloproliferative neoplasms.

These trailblazing investigators and their work represent just a sampling of our unstoppable support ...



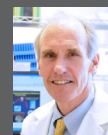
**Soheil Meshinchi, MD, PhD**  
*Fred Hutchinson Cancer Research Center*

Developing novel immunotherapeutic strategies in infants with high risk AML



**Irene Ghobrial, MD**  
*Dana-Farber Cancer Institute*

Spearheading leading-edge myeloma research including prevention of recurrence after treatment



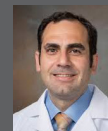
**Carl June, MD**  
*Perelman School Of Medicine, The University of Pennsylvania*

Continuing groundbreaking efforts in CAR T-cell immunotherapy



**Helen Heslop, MD**  
*DSC Baylor College of Medicine*

Furthering the application of CAR T-cell therapy to "off the shelf" versus personally engineered T-cells



**Amer Zeidan, MBBS**  
*Yale University*

Exploring durable control of chronic myeloid leukemia (CML) without ongoing therapy



**Maraget Shipp, MD**  
*Dana-Farber Cancer Institute*

Exploring molecularly-targeted therapies for an aggressive lymphoma as well as novel immunological approaches for Hodgkin Lymphoma

## JULY

**decitabine and cedazuridine (Inqovi®)**: an oral combination for adults with myelodysplastic syndromes (MDS).

\***brexucabtagene autoleucel (Tecartus™)**: the first CAR T-cell therapy for patients with mantle cell lymphoma (MCL).

**tafasitamab-cxix (Monjuvi®)**: combined with lenalidomide for R/R DLBCL.

## AUGUST

**belantamab mafodotin-blmf (Blenrep®)**: for adults with relapsed or refractory (R/R) multiple myeloma.

\***daratumumab (Darzalex®) with carfilzomib (Kyprolis®) and dexamethasone**: for adults with R/R myeloma.

## SEPTEMBER

\***CC-486 (Onureg®)**: as maintenance treatment of adult patients in remission from acute myeloid leukemia (AML).

## OCTOBER

\***pembrolizumab (Keytruda®)**: for adults and some children with R/R classical Hodgkin lymphoma (cHL).

\***venetoclax (Venclexta®)**: in combination with azacitidine, decitabine or low-dose cytarabine to treat certain patients with newly diagnosed AML.

## DECEMBER

\***selinexor (Xpovio®)**: for adults with multiple myeloma who have had at least one prior type of treatment.

\***ponatinib (Iclusig®)**: for adult patients with chronic-phase (CP) CML with resistance or intolerance to at least two prior kinase inhibitors.

# UNSTOPPABLE SUPPORT FOR PATIENTS AND FAMILIES



“I encourage fellow patients to take advantage of the many free support services offered by LLS. The more involved you are, the less alone you feel.”

— **Sonia Su, LLS volunteer, lymphoma survivor, and recipient of LLS-funded CAR T-cell immunotherapy**

At LLS, our purpose is two-fold: uncovering cures for blood cancers and improving quality-of-life for patients and families. The pandemic reshaped cancer for patients and families—juxtaposing dual crises: COVID-19 and cancer. We recognized that immunocompromised blood cancer patients would be particularly vulnerable to COVID-19 infection and its impact, and we ramped up our support, offering multiple forms of help, including...

## ...Providing a Financial Lifeline When Needed Most

Whether navigating lost income or paying more for grocery deliveries, many patients and caregivers experienced heightened uncertainty and financial concerns during the pandemic. Less than three weeks after the national emergency was declared, LLS took swift action to launch our COVID-19 Patient Financial Aid Program. One of the first to open during this crisis, we rallied our corporate and pharmaceutical partners to provide immediate financial relief to patients. Thanks to their generosity, LLS awarded a **\$250 one-time grant to over 19,300 blood cancer patients** experiencing pandemic-related economic hardship. This helped patients offset non-medical expenses such as rent, mortgage, utilities, and food.

We also worked diligently to ensure other LLS programs could continue to provide critical financial assistance to patients. Our Urgent Need Program, in partnership with Moppie’s Love, provided families of children and young adults in acute financial need with

a **\$500 grant**. In June, we expanded the Urgent Need Program, with the help of Charlie’s Fund, to support adults in acute financial need. In total, the Urgent Need Program provided **assistance to over 3,650 patients**. Moreover, our ongoing Susan Lang Pay-It-Forward Patient Travel Assistance Program continued to provide **assistance to over 5,300 patients with a \$500 grant** for treatment-related transportation and lodging costs. LLS’s Patient Aid Program provided a one-time stipend of **\$100 to 17,222 patients**, providing **more than \$1.7 million in assistance**. In total, LLS provided **\$142 million in financial assistance**.

## ...Amplifying Guidance, Knowledge, and Connections

COVID-19 resulted in new challenges and uncertainty for blood cancer patients and caregivers. Worries about heightened risk of viral infection, possible disruptions in clinical trials, treatment logistics, and isolation and stress were among the concerns that arose. Patients turned to LLS for support in record numbers.

- **LLS Information Specialists** – Our highly trained oncology professionals received a spike in inquiries in spring 2020, boosted by COVID-related questions. As always, patients and their families had access to free, one-on-one support—without having to leave home—including personalized guidance on treatment issues and financial and social challenges. Referrals to LLS’s registered dietitian for individual nutritional counseling were also available.



# BY THE NUMBERS — 2020



LLS PROVIDED A TOTAL OF  
**\$142 MILLION**  
IN FINANCIAL ASSISTANCE

#### Co-Pay Assistance Program

\$131 million+ supporting 22,253 patients

#### COVID-19 Patient Financial Aid Program

\$4.8 million+ to 19,338 patients

#### Susan Lang Pay-It-Forward Patient Travel Assistance Program

\$2.7 million in travel support  
to 5,335 patients

#### Urgent Need Program

\$2 million to 3,650 patients

#### Patient Aid Program

\$1.7 million to 17,222 patients



LLS INFORMATION SPECIALISTS  
RESPONDED TO **25,000** INQUIRIES  
FROM PATIENTS AND CAREGIVERS

26% increase over last year



CLINICAL TRIAL SUPPORT CENTER  
PLACED **21%** OF PATIENTS  
INTO A CLINICAL TRIAL

Significantly higher than national  
average enrollment rate of 5-8%

Provided nearly **800** patients with in-depth  
clinical trial navigation and support

**579** first time contacts—  
31% increase over last year

- **The nurse navigators in our Clinical Trial Support Center (CTSC)** continued to help patients connect to clinical trials. In January 2020, in collaboration with the American Society of Hematology (ASH), LLS launched a new direct referral portal on the ASH website for member physicians, providing an efficient way to refer their patients to our CTSC. From curating a list of most appropriate trial options to helping overcome barriers to enrollment, CTSC Nurse Navigators supported patients and caregivers every step of the way.

Pandemic-related isolation underscored the importance of patient connections. Our **Patti Robinson Kaufmann First Connection Program** matched more than 1,700 trained volunteers with patients and caregivers facing the same disease. In addition, **LLS Community**, our online social network, grew to over 16,500 members strong.

As the world pivoted to virtual communications, so did we, offering:

- **podcasts** delivering “need to know” updates with more than 75,000 listens.
- **virtual Blood Cancer Conferences** run by teams of experts.
- weekly, professionally moderated **online chats** including “Feeling Good Fridays,” addressing pandemic-related isolation and concerns for patients and caregivers.
- **webcasts and blogs** addressing the medical and financial impact of COVID-19.

## ... Reducing Disparities in Healthcare

In a year that brought racial injustice to the forefront, we began to develop efforts that will continue to address the gaps in cancer outcomes and healthcare that disproportionately impact minority and rural communities and other underserved populations. We worked hard to break down barriers to care with multifaceted programs, including:

- **Myeloma Link**, our education and outreach program, is designed to improve cancer care in Black communities. The incidence of myeloma is twice as high among Black Americans as among white Americans, and Black patients are less likely to have access to timely, optimal treatment and care.
- **“Equity in Access,” a research program** under development, that will advance study of the underlying causes of inequitable access to care and identify policies, strategies, and interventions to effect change.



“We are forever grateful that LLS was there for us during a time when we needed support most. From keeping us informed through their free, informative

webinars to helping us pay for essentials like groceries, LLS was a huge source of support for us.”

— **David and Kay LaFrance, COVID-19 Patient Financial Aid Program recipients**

## UNSTOPPABLE PATIENT ADVOCACY



Diagnosed with chronic myeloid leukemia at age 22, Amanda Steffy might have seemed like an unlikely LLS advocate. “I didn’t know anything about advocacy... lawmaking or government, other than what you learn in high school,” she said. “But LLS said I should come and share my story.” As a result, Amanda got involved in fundraising efforts, then expanded her influence through advocacy. Along with 1,100 volunteer advocates around the country, Amanda participated in LLS’s Virtual Day of Action in May, helping to send letters to members of Congress and share Facebook posts, highlighting the need for lawmakers to take swift action to protect patients during COVID-19. We are grateful to Amanda, and others like her, for heeding our call to action.

### Important Victories...More to Come

The LLS Office of Public Policy, working alongside thousands of advocacy volunteers, has long been on the front lines of policy change at both the state and federal levels. We are unwavering in our commitment to advancing laws and regulations that accelerate the development of new therapies and break down barriers to care. In 2020, we were nimble, driven, and successful.

### Pivoting in the Face of a Pandemic

When COVID-19 arrived, rather than slow down, we ramped up efforts to protect patients.

We are proud that LLS was among the first patient organizations to organize a federal policy response to the pandemic, achieving important wins for blood cancer patients nationwide. Beginning in March—and continuing throughout 2020—we spearheaded outreach to federal and state leaders, along with more than two dozen patient organizations, urging lawmakers to take steps to protect patients during the pandemic. These included expansion of no-cost COVID-19 testing, increased federal support for the Medicaid program, and extension of availability of telemedicine to promote social distancing.

The pandemic caused us to pivot to a whole new way of doing business. In-person meetings between our staff, blood cancer advocates and lawmakers—once our mainstay—immediately shifted to a virtual format. In May, we conducted digital meetings with more than 100 Congressional offices in a single day and launched our first “Virtual Day of Action” during which advocates sent thousands of letters to federal lawmakers urging them to stand up for patients during the pandemic.

### Continuing to Improve Treatments and Coverage

As we pursued our COVID-19 efforts, we also stayed the course with other longtime priorities. In early 2020, patients and advocates celebrated a **\$1.25 billion increase in funding for groundbreaking medical research** at the National Institutes of Health, including critical funding dedicated to pediatric cancer programs. And in November, California **voters approved \$5.5 billion of funding** for medical research, which we backed based on its potential to support new treatments.

LLS knows that new treatments only benefit patients when they are affordable. After years of working toward greater access for cutting edge CAR-T treatment, we secured an important triumph in 2020, increasing Medicare payments for hospitals providing this treatment, ensuring enhanced patient availability without long-distance travel.

We also continued our work towards protecting Medicaid as an option for both low-income and disabled patients.





“People notice that I want to help do as much as I can to solve issues,” said Wanda Pearson, a multiple myeloma patient since 2007, and a volunteer advocacy leader in North Carolina.

Wanda, who works for the American Red Cross, believes LLS picked up on her tenacity when tapping her for this prominent volunteer role in 2018. Her duties included organizing and leading meetings with other advocates and sharing her story with lawmakers at both the state and federal level. She urged elected leaders to ensure coverage for pre-existing conditions, restrict “junk” insurance plans that often fail to cover patients, and protect patients from surprise medical bills.

In 2019, Wanda visited Washington, D.C., along with other advocates, to meet with members of Congress. The pandemic caused her advocacy to go virtual in 2020, with letters and targeted phone calls replacing in-person meetings. In 2020, she took on a new role with LLS, serving as a volunteer on a new committee of advocates focused on promoting diversity and inclusion.

The summer brought important victories in Oklahoma and Missouri, as voters there approved measures to expand Medicaid eligibility. LLS mobilized volunteer advocates in both states through emails, text messages, and social media posts, urging them to vote to expand Medicaid and directing them towards information on how to register to vote and cast their ballots—efforts complicated by the pandemic. Our work in these states will **help bring healthcare access to an additional 430,000 people.**

As we worked to bring about new coverage, we also sought to protect patients from substandard plans and risky products that resemble insurance but often fail to provide coverage when needed most. We published a groundbreaking study of “short-term” health coverage, a type of “junk” insurance that frequently discriminates against cancer patients and leaves them vulnerable to massive bills. We saw significant victories in New Mexico and Virginia, which have now restricted availability of some forms of “junk” health insurance.

## Landmark Federal Law

Congress’s 2020 year-end spending bill included a ban on surprise medical bills, which occur when out-of-network healthcare is provided to patients at in-network facilities. The topic was a focus of intense LLS lobbying and advocacy throughout 2020. Moving forward, we are pleased that patients will be protected from devastating medical expenses due to unexpected billing by out-of-network providers.

Congress also required all states to cover costs associated with routine care provided to Medicaid patients while enrolled in a clinical trial. This reform will help improve access to trials for the 75 million Americans who receive care through Medicaid and help ensure those participating in trials are more representative of the entire blood cancer patient population.

## Striving for Affordable Treatments

LLS also sustained the pursuit of enhanced access to affordable drugs. In 2020, our six-year leadership of a coalition supporting caps on out-of-pocket drug costs paid off as New Jersey enacted a law requiring that insurers offer plans with these caps. In Washington state, LLS worked closely with coalition partners to successfully advance regulations that protect patients from high out-of-pocket costs through new standard benefit design plans.

And in New Hampshire, LLS and our partners successfully persuaded the legislature to preserve laws that prevent cancer patients receiving oral treatments from paying more for their drugs than patients undergoing intravenous cancer therapies.

## Looking Ahead...

LLS continues to develop innovative ways to advocate on behalf of patients. Knowing that the first 100 days of a presidential and congressional term are a key period for initiating major reforms, in 2020, for the first time, we began mobilizing patient organizations in advance of a presidential election. **This “100 Days Agenda” initiative united the power of 33 patient organizations, representing millions of people with pre-existing conditions.** This effort prepared us to hit the ground running in 2021 to promptly begin pursuing adequate, affordable health coverage with the new administration and Congress, as well as with policymakers at the state level.



## UNSTOPPABLE CHILDREN'S INITIATIVE

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

— Gwen Nichols, MD, LLS Chief Medical Officer

### A New Era In Pediatric Blood Cancer Treatment And Care

As an organization founded by parents who lost a son to leukemia, LLS has always placed great importance on conquering childhood blood cancers. Throughout 2020, we sustained our quest to uncover targeted treatments designed expressly for younger patients, ever-aiming for improved survival rates and safer long-term outcomes. With the pandemic impacting families’ lives, we continued to optimize our free education and support and worked to break down barriers that stand between patients and the care they need.

### LLS Children’s Initiative — Striving to raise \$100 Million to find cures

LLS made important strides in 2020 as the leader of this unprecedented, global collaboration, aimed at reimagining pediatric blood cancer care by taking on children’s cancer from every direction.

#### An Expanded Science Agenda

##### • Advances in Child-Focused Research

This year, we supported **32 pediatric research grants**, totaling nearly **\$14 million in multi-year funding**. We prioritized exploration of the unique molecular mechanisms and mutations involved in childhood blood cancers to learn how precision medicine and genomics can deliver safer, targeted, custom-designed therapies and cures. Our more than 20-year

investment in CAR T-cell immunotherapy continues to make an impact for children and young adults with ALL. With LLS support, researchers are now working to enhance efficacy of this approach, while also studying other emerging technologies. Additionally, we continued our commitment to support research into long-term treatment effects.

#### A 360° Research Approach: A Sampling Of Key 2020 Grants

| AREA OF FOCUS                                       | RESEARCHERS   |
|---|---|
| <b>Long-Term Side Effects</b>                       | Kasey Leger, MD, Seattle Children’s Hospital  |
| <b>Immunotherapy – Including CAR T-Cell Therapy</b> | Terry Fry, MD, University of Colorado; Soheil Meshinchi, MD, Fred Hutchinson Cancer Research Center; Ryotaro Nakamura, MD, City of Hope |
| <b>Personalized Antibody Treatments</b>             | Jatinder Lamba, PhD, University of Florida  |
| <b>High-Risk Acute Leukemias</b>                    | Robert Albergo Gallego, MD, Columbia University; Iannis Aifantis, MD, NYU Langone Health  |
| • T-Cell Acute Lymphoblastic Leukemia               | Charles Mullighan, MSc, MD, St. Jude Children’s Research Hospital   |
| • Crlf2-Rearrangement In ALL                        |   |
| <b>Hodgkin Lymphoma Treatment</b>                   | Davide Rossi, MD, PhD, Foundation for the Institute of Oncology Research in Switzerland   |

- **A Monumental Worldwide Clinical Trial: LLS Pediatric Acute Leukemia (PedAL)**

LLS continued to lead the planning of the first global precision medicine clinical trial for children with relapsed acute leukemia. This revolutionary effort—in partnership with the Children’s Oncology Group, the U.S. Food and Drug Administration (FDA) and the European Medicines Agency (EMA), among others—leverages precision medicine experience gained from our Beat AML Master Clinical Trial. **Multiple targeted therapies will be tested simultaneously at 200 worldwide sites**, with the goal of matching patients to precision treatment based on their unique tumor biology.

- **Data Sharing to Accelerate Cures**

To expedite discovery and enhanced clinical outcomes, LLS continued to spearhead efforts to standardize data collection and facilitate comparison and analysis across institutions and countries. Working with data science pioneers, we are establishing a Data Commons, or cloud-based resource for integration and alignment of historical and new research data, including pediatric genomic and health history information. The LLS PedAL study will put data sharing into practice, translating global data into a common language, accessible to researchers and practitioners worldwide.

### Increased Patient Support

In 2020, LLS worked to expand our free education and support services for children and their families. We produced an extensive array of enhanced educational materials for parents, children, healthcare professionals, and educators, including new workbooks, apps, blogs, and podcasts. For example, our Staying Connected online continuing education program is designed to help K-12 and college personnel, as well as parents, improve patients’ learning experience during and after treatment. We also **expanded our financial assistance to help families cope with the economic burden of cancer treatment during the COVID-19 pandemic.**

### Advocacy

As a leader in pediatric advocacy, and co-chair of the Policy Committee of the Alliance for Childhood Cancer, LLS drives forward critical policies to benefit children with cancer. We helped advance the Research to Accelerate Cures and Equity (RACE) for Children Act, which went into effect in August 2020 and requires that drugs being tested for adult cancers also be evaluated in children if indicated. We also continued our work to ensure ongoing funding for the Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act, the **most comprehensive childhood cancer legislation ever introduced**, which was enacted with LLS support. In 2020, we helped ensure full funding for both the STAR Act and the NIH’s Childhood Cancer Data Initiative. Additionally, we pressed on at the federal and state level, to strengthen and expand Medicaid and the Children’s Health Insurance Program (CHIP), which together provide health coverage to half of our nation’s children.



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In December 2017, while 36 weeks pregnant with twins, Lauren Palmer was told that her 2-and-a-half-year-old son Jennings had acute myeloid leukemia (AML), with a 50/50 chance of survival. Treatment included four rounds of chemotherapy, regular blood and platelet transfusions, and a bone marrow transplant with his big sister Caroline as his donor.

Jennings was in remission for 2 and a half years before relapsing in November 2020 and is currently in treatment. LLS continues to fight hard to advance AML therapies and increase survival rates for children like Jennings. We want to fulfill the dream of his mom Lauren: that families facing Jennings’ diagnosis will soon be told, “We’ve made progress: your child has a good chance of survival.”



## UNSTOPPABLE SUPPORT FOR THE MISSION

While COVID-19 stopped much of the world in its tracks in 2020, there was no pause button for cancer. From the pandemic's outset, LLS continued moving forward, despite facing business disruptions. The support of our volunteers, donors, corporate partners, and employees became more important than ever. From coast to coast, our supporters stepped up to raise significant funds for our mission and make a difference in the lives of patients and families. We thank all those who helped further our mission during these unprecedented circumstances.



### Richard Pentz

Like so many dedicated LLS volunteers, Richard Pentz's personal connection to blood cancer drew him to the cause. Six years ago, his mother lost her battle with acute myeloid leukemia. After supporting his friend Adam Jones at the LLS Indianapolis Man & Woman of the Year Grand Finale in 2018, Richard knew the time had come to tell his story. As a candidate for our 2020 Man & Woman of the Year philanthropic competition, Richard drew upon his sales and relationship management experience to recruit friends, family, and neighbors to share their stories, too. "I wanted my campaign to be bigger than my story because I believe we're better together," he said. Richard's Team Echo, which relied on social media and other innovative fundraising tactics, broke an LLS fundraising record for Indiana, pulling in nearly \$519,000. As a result, Richard earned the coveted title 2020 National Man of the Year. Today, Richard works with 2021 candidates and serves on the local Board for the Michigan-Indiana Region, vowing to achieve "a world without cancer."



### Tina Swallow

The fight against cancer has been in Tina Swallow's blood since her son Beau was diagnosed with stage IV Ewing's Sarcoma when he was 12 years old. Happily, after a series of grueling treatments and several years of watching and waiting, Beau showed no evidence of disease. Tina, a northern Virginia resident and 21-year Navy veteran, used skills from her work as a sales director in the tech industry to fundraise in honor of Beau's survival. In 2020, nominated as a candidate for Man & Woman of the Year, Tina relied on colleagues, family, and friends to help her succeed with her multi-faceted Team Bridge to a Cure campaign. Her efforts included continuing the tech community's "Corporate Olympics," held virtually this year. She also rallied her workplace to support our mission through a silent auction and a 600-participant Fund the Fight virtual gathering where executives shared their cancer stories. All told, Tina raised nearly \$468,000 for LLS, earning her the 2020 National Woman of the Year title.





## Brandon Abernathy

“You don’t need a personal connection to support those who need it the most,” said long-time LLS Atlanta area volunteer leader Brandon Abernathy. Along with his wife, Mallory, Brandon, an engineer by training, has dedicated thousands of hours running and climbing on behalf of LLS, which he considers “one of the most authentic, genuine philanthropic organizations.” From his first volunteer leadership role as captain of the Georgia Tech Chapter of Team in Training to being named runner-up for Man & Woman of the Year in 2018, Brandon has proven to be a significant fundraising force. In 2020, determined to continue helping patients, Brandon rallied a team of volunteers over Zoom, and encouraged them to “lean in more than ever.” Their socially distanced outdoor climb in the Georgia Mountains made for an “unforgettable Climb Day experience” that raised more than \$3,000 in just over 2.5 hours—contributing to a first place team title at the Big Virtual Climb event.



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“Since our daughter Abigail’s diagnosis and successful treatment for ALL, our family has been actively supporting The Leukemia & Lymphoma Society, first through the Man & Woman of the Year program and later through Beat AML. We have been so impressed with LLS’s strong commitment to patients through support, advocacy, and research. Research from LLS has been crucial to moving forward with new cures. We are thrilled that LLS has taken a serious position in the fight against children’s blood cancers through launching the LLS Children’s Initiative. Abigail’s remission anniversary is a date we celebrate each year, and we support the Children’s Initiative so that many other families can do the same.”

— The Boldt Family, Indiana



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“Since 2004, as a lymphoma survivor and spouse, we have proudly supported LLS in its comprehensive approach to blood cancer, including basic research, novel therapy adoption, patient support, and legislative advocacy.”

— Jerry & Lois Rosenblum, California





## Neelam Shah & Naggena Ohri

Maryland high school students Neelam Shah and Naggena Ohri got early insight into blood cancer by witnessing its impact on others. Inspired by the role LLS played in helping Neelam's father and aunt and Naggena's classmate as they beat cancer, the teens sprang into action to make an impact. After starting with Light The Night walks, in 2018, the duo participated in a Students of the Year campaign run by Neelam's brother, helping to found the first annual Team Fly4aCure Kite Festival. In 2019, they supported Team Finish the Fight and hosted their own Kite Festival, raising money for LLS's mission, including the Children's Initiative. In 2020, as Students of the Year candidates, they raised nearly \$450,000—an all-time high—earning the national title. Their campaign centered on "Rhythm 2020," a multicultural music and dance showcase (held pre-pandemic) that attracted more than 200 performers and 800 attendees. Neelam and Naggena plan to maintain their philanthropic momentum by volunteering with LLS's 2021 Students of the Year Leadership Team.

## UNSTOPPABLE PARTNERS

Many thanks to the following companies who stood by our side in a challenging year, never wavering in their commitment to LLS goals.

|                            |  |
|----------------------------|--|
| Amgen                      | Pfizer   |
| AstraZeneca                | Pharmacyclics,<br>An AbbVie Company<br>& Janssen Biotech |
| Burlington                 |  |
| Bristol Myers<br>Squibb    | Subaru of<br>America, Inc.                               |
| Celgene                    | Takeda Oncology  |
| Genentech Inc.<br>& Biogen | United Food and<br>Commercial Workers                    |
| Gilead Sciences            | The Wawa<br>Foundation                                   |
| Incyte                     |  |
| Jazz Pharmaceuticals       | Walgreens  |



## Elizabeth Matthews

As an LLS Northern California Region Campaign Development Manager, Elizabeth Matthews has always admired LLS's "big, bold, trendsetting fundraising." Her work on LLS's Hero Squad, an in-school fundraising and educational program, was tested when the pandemic forced many students to learn at home. Thanks to the dedicated, coordinated efforts of teams across LLS, Hero Squad reimaged its popular LLS STEM+ Curriculum to facilitate remote learning on a new digital platform. Soon, Elizabeth began hosting Hero Squad lessons on Facebook Live. Under the "stage name" Miss Elizabeth, she drew on her performance background to create engaging, interactive science presentations. She called the results "the best show I could produce from my living room," and praised the ability of LLS to "pivot, adapt, and always keep our donors and patients in the center of why we do what we do."



“In October 2014, my brother Ted was diagnosed with stage two, non-Hodgkin lymphoma. In April 2015, he passed away, not from the cancer but from a toxic reaction to the chemotherapy. My sister Cathy felt very strongly

that no family should have to endure what we had, losing a brother to cancer and ultimately the cancer treatment itself, the chemotherapy. She became involved in the Portland LLS chapter to help others. From an evening in the backyard with some amazing women sipping wine, visiting, and brainstorming, the idea of the Cancer Cure Council (C3) initiative was born. Unfortunately, Cathy was diagnosed with triple-negative breast cancer in August 2018 and passed away in August 2019. During her own battle against cancer, she never stopped helping others including rallying the troops to support LLS. It is for this reason in honor of my brother and sister, and all of those who have fought against cancer, that we continue to support LLS and the wide scope and wonderful work that they are doing to end cancer. I am proud to be a supporter of the LLS C3 initiative and we encourage anyone to support this amazing organization to help end cancer.”

— The Joseph and Catherine Johnson Family Foundation



“I was diagnosed with CLL in 2012, and I’m on a drug now that was funded by LLS and approved last year for CLL. LLS is one of my family’s top priorities. All of my kids have done Team In Training races with me. My son

has run the New York marathon twice, and he has had countless parties for LLS. All of these events have made it easier for me to talk to my kids about my cancer. I feel like at LLS we are standing on the shoulders of giants. The advances we are supporting today are building on the advances LLS has made possible in the past—we have our hands in everything that is cutting edge. I really do believe that LLS is going to find the cures for leukemias and other cancers.”

— Lynne O’Brien, LLS Board of Directors member, co-founder Women Curing Cancer



## Amanda Salas

Amanda Salas wasted no time assuming an LLS volunteer leadership role. While undergoing treatment for her recently diagnosed non-Hodgkin lymphoma in June 2019, she formed a Light The Night team—Amanda’s Army—that raised more than \$50,000. Since then, she has heightened awareness of LLS by sharing her survivorship story with the media and with attendees at the 2019 Los Angeles Light The Night event. The pandemic did not quash her passion for making a difference. In March, Amanda—a popular entertainment news anchor on FOX’s “Good Day LA” morning show—followed doctors’ advice and began broadcasting live from her home. In June, she joined the local Board serving the LLS Greater Los Angeles Region. She also served as the Executive Challenge Chair for the 2020 Los Angeles Light The Night virtual event, which raised a record-breaking \$400,000. And in September, Amanda leveraged her local celebrity and social media platforms to drive critical support for LLS during Blood Cancer Awareness Month.

## UNSTOPPABLE VOLUNTEERS

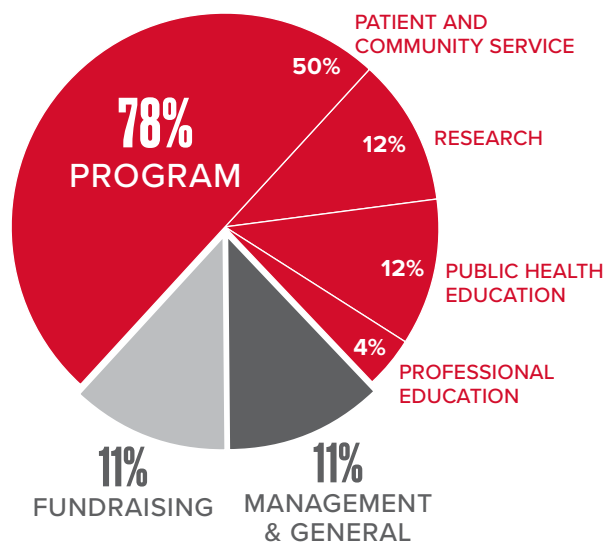
LLS extends a sincere thank you to all of our dedicated volunteers who passionately give their time and talents to help make LLS’s lifesaving work possible. Whether raising critical funds, advocating for lifesaving policies, providing support to those impacted by cancer, or building critical capacity, our volunteers always make a tremendous impact on blood cancer cures.



# FINANCIALS

Your support is invested wisely.

In fiscal year 2020, LLS raised \$486.9 million to support our mission and operations. We spent \$318.1 million or 78% 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, 2020 (USD Thousands)

### Revenue

|                                  |            |
|----------------------------------|------------|
| Campaign contributions           | \$ 268,455 |
| Less: direct donor benefit costs | (19,931)   |

|                                   |                   |
|-----------------------------------|-------------------|
| <b>Net campaign contributions</b> | <b>\$ 248,524</b> |
|-----------------------------------|-------------------|

|                                  |            |
|----------------------------------|------------|
| Co-Pay contributions             | \$ 176,100 |
| Royalties and other income       | 54,868     |
| Net interest and dividend income | 7,359      |

|                      |                   |
|----------------------|-------------------|
| <b>Total revenue</b> | <b>\$ 486,851</b> |
|----------------------|-------------------|

### Expenses

|                               |           |
|-------------------------------|-----------|
| Research                      | \$ 50,440 |
| Patient and community service | 203,547   |
| Public health education       | 48,089    |
| Professional education        | 16,011    |

|                               |                   |
|-------------------------------|-------------------|
| <b>Total program services</b> | <b>\$ 318,087</b> |
|-------------------------------|-------------------|

|                        |           |
|------------------------|-----------|
| Management and general | \$ 43,757 |
| Fundraising            | 46,643    |

|                       |                   |
|-----------------------|-------------------|
| <b>Total expenses</b> | <b>\$ 408,487</b> |
|-----------------------|-------------------|

|   |          |
|---|----------|
| Foreign currency loss                     | \$ (304) |
| Net Increase in fair value of investments | 21,402   |

|                             |                  |
|-----------------------------|------------------|
| <b>Change in net assets</b> | <b>\$ 99,462</b> |
|-----------------------------|------------------|

## CONSOLIDATED BALANCE SHEET

As of June 30, 2020 (USD Thousands)

### Assets

|  |           |
|--|-----------|
| Cash and cash equivalents                | \$ 32,345 |
| Prepaid expenses and other assets        | 3,933     |
| Contributions and other receivables, net | 24,493    |
| Investments                              | 520,898   |
| Fixed assets, net                        | 9,510     |

|                     |                   |
|---------------------|-------------------|
| <b>Total assets</b> | <b>\$ 591,179</b> |
|---------------------|-------------------|

### Liabilities

|                                       |           |
|---------------------------------------|-----------|
| Accounts payable and accrued expenses | \$ 19,672 |
| Deferred revenue                      | 13,076    |
| Awards and grants payable             | 35,490    |
| Co-Pay assistance payable             | 145,390   |
| Other long-term liabilities           | 4,020     |

|                          |                   |
|--------------------------|-------------------|
| <b>Total liabilities</b> | <b>\$ 217,648</b> |
|--------------------------|-------------------|

### Net assets

|                           |            |
|---------------------------|------------|
| Without donor restriction | \$ 255,343 |
| With donor restriction    | 118,188    |

|                         |                   |
|-------------------------|-------------------|
| <b>Total net assets</b> | <b>\$ 373,531</b> |
|-------------------------|-------------------|

|   |                   |
|---|-------------------|
| <b>Total liabilities and net assets</b> | <b>\$ 591,179</b> |
|---|-------------------|

## UNSTOPPABLE

## COMMITMENT TO DIVERSITY, EQUITY &amp; INCLUSION



## Curing Blood Cancer Needs Every One of Us

**At the Leukemia & Lymphoma Society (LLS), advocacy is in our blood. We are a vibrant community of researchers, volunteers, philanthropists, advocates, healthcare professionals, and nonprofit leaders. Each day, we fight to find cures for blood cancers and help every patient access the care they need to survive and thrive. We believe our individual backgrounds, identities, abilities, and experiences are our greatest sources of creativity and innovation as we work together to create a more equitable world without blood cancer.**

We stand for equal treatment, equal opportunities, and equal rights for Black, Indigenous, and People of Color (BIPOC), people with disabilities, Hispanics and Latinx, members of the LGBTQIA+ community, veterans, women, and other underrepresented groups.

Together, we are working tirelessly to create pathways for equity for our staff, our volunteers, and our communities, while driving forward change that honors our mission and stands against systemic racism and injustice in all its forms. We are determined to break down barriers and address the needs of underserved populations. To date, we have pioneered advances in treatment that stem from a diverse ecosystem. By bringing together different perspectives, backgrounds, and thinking, we are fueling innovative breakthroughs that are a life force for blood cancer patients and their families who deserve to receive the best care and support possible.

At LLS, it is important that our teams reflect the communities we serve. We are dedicated to fostering an inclusive workplace where everyone feels welcome, seen, and heard. We grow stronger when we embrace and learn from our differences. At the same time, we recognize that our shared identities unite us, creating a sense of belonging.

We believe in continuous improvement, and we know we have more to do. As the global leader in the fight to end blood cancers, finding cures for all people impacted by these diseases is in our DNA. We will continue to educate ourselves, engage in difficult conversations, and hold ourselves and each other accountable.

Because curing blood cancer needs every one of us.

HIGHLIGHTS  
OF OUR WORK

## REACHED

nearly 7,400 patients and caregivers in 13 cities through Myeloma Link, our education and outreach program designed to improve cancer care in Black communities

## JOINED

more than 1,600 organizations in signing the CEO Action for Diversity & Inclusion™, the largest CEO-driven business commitment to advance diversity and inclusion

## LAUNCHING

10 Employee Resource Groups with 550 employees—more than half of LLS staff—planning to participate in one or more groups

## CULTIVATED

awareness and understanding through book clubs, regional roundtables, town halls, and a 21-day interactive learning journey



**BEATING  
CANCER  
IS IN  
OUR BLOOD.<sup>®</sup>**

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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](http://www.LLS.org).