

HIGHLIGHTS



NEWS IN THE FIGHT FOR CURES

WINTER 2019

At The Leukemia & Lymphoma Society (LLS), generous donors and volunteers make lifesaving advances possible.

Supporters' Corner

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We became interested in medical research a long time ago, inspired by our brother-in-law, who had lymphoma, as well as other family. Cancer in the '60s was a death knell. You simply asked, “How long do I have?”

LLS is the place to be. There are so many good things happening. A great deal of progress has been made, but for some types of blood cancer, there is much work still to be done.

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Myeloma Link Expands to Eight Cities

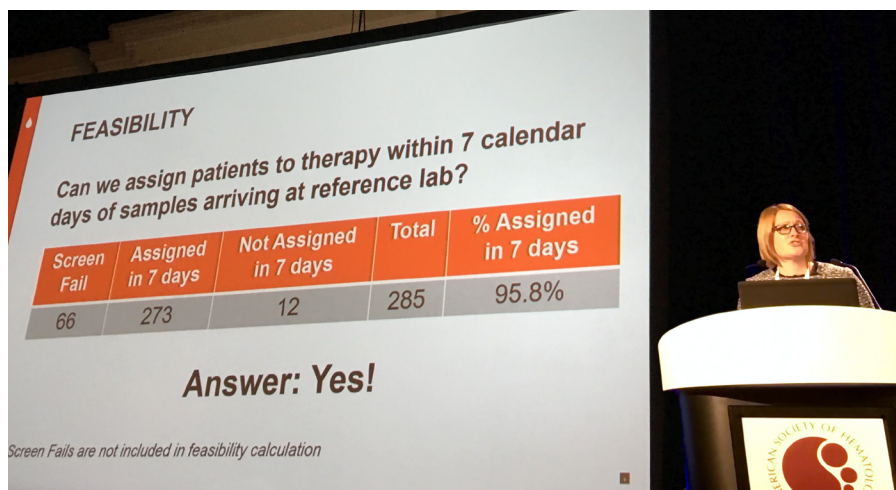
LLS continues to get the word out about myeloma. Following its successful 18-month pilot program in two cities, Myeloma Link, the initiative to build awareness of myeloma in African American communities, has expanded to eight cities across the country.

As of October 2018, the multifaceted community-outreach initiative is now operating in St. Louis, Missouri; Houston, Texas; Baltimore, Maryland; Detroit, Michigan; and Oakland, California, in addition to continuing in the

original pilot cities of Washington, D.C., and Atlanta, Georgia.

“We are proud to be able to connect even more people to the information and resources they need to learn about myeloma and gain access to state-of-the-art care,” says Elisa Weiss, LLS’s senior vice president of patient access and outcomes. “Our community partners, LLS volunteers, and staff are doing a tremendous job.”

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▲ Shown above at the annual meeting of the American Society of Hematology, Amy Burd, PhD, vice president of research strategy, presented the first findings from the breakthrough Beat AML Master Clinical Trial.

Supporters' Corner

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For example, we weren't aware of the extent to which children are affected by leukemia and lymphoma, and we are pleased to support the LLS Children's Initiative to advance pediatric research.

Last year, we were honored that the LLS Illinois Chapter chose to create and present us with the Paul & Joan Rubschlager Philanthropist of the Year Award. They now plan to award it annually.

We are both lucky cancer survivors. That couldn't have happened if someone hadn't funded research long before we did. We don't know who they were, but we say, "Thank you very much." We want to pass that on. Hopefully, lives in the future will be saved by something that we've done.



Paul and Joan Rubschlager
Chicago, Illinois

Expanded Financial Assistance for Patients

In keeping with our commitment to support patients and families, LLS has launched two new programs to help blood cancer patients cope with the financial burden of treatment.

Launched in September 2018, the ***Urgent Need Program***, established in partnership with Moppie's Love, helps pediatric and young adult blood cancer patients, as well as adult blood cancer patients enrolled in clinical trials, who have acute financial need. The program provides a \$500 grant to assist with nonmedical expenses, including utilities, rent or mortgage, food, lodging, dental care, childcare, eldercare, and other essentials.

Opened in November 2018, the ***Patient Aid Program*** provides financial assistance to blood cancer patients in active treatment. Eligible patients receive a \$100 stipend. In addition to much-needed financial assistance, the program enables LLS to build relationships with patients and health care providers.

Together, these initiatives complement LLS's other financial assistance programs to help patients overcome obstacles, enabling them to access the best, most timely treatment. These programs are provided through LLS national and chapter offices in the United States and are available to U.S. citizens and permanent residents residing in the U.S. To find out more about LLS's financial assistance programs, call (800) 955-4572 to speak with an Information Specialist, or visit <http://www.lls.org/support/information-specialists>.



Four-year-old Mikah, who is battling acute lymphoblastic leukemia, and his family are among those receiving critical financial support through the Urgent Need Program.

To support research in the area of greatest interest to you, contact us at 1-888-773-9958.

Myeloma Link Expands to Eight Cities

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The need is urgent. In 2019, more than 32,000 people will be diagnosed with myeloma, an often debilitating and painful disease. It is the most common blood cancer in African Americans, affecting this population twice as much as Caucasian Americans. Furthermore, African Americans are less likely to receive the newest treatments, and are more likely to experience treatment and transplant delays.

To address these disparities, LLS created Myeloma Link in 2017. Among the goals: educate African American communities about myeloma, empower patients to seek out novel treatments, and help patients access the extensive free resources provided by LLS.

To achieve these goals, LLS has joined forces with partners within African American communities, such as churches, senior centers and community health centers. Myeloma Link has expanded to provide education and awareness outreach in health care settings in an effort to reach more patients, especially those newly diagnosed. There is a concerted effort to make connections with primary care providers to educate them about myeloma and how LLS can support them and their patients.

To advance the patient- and professional-education programs, LLS has partnered with renowned health care organizations. They

“ This year, more than 32,000 people will be diagnosed with myeloma. African Americans are diagnosed at twice the rate of Caucasian Americans and experience significant disparities in access to care. The need for this community awareness and education is urgent.”

— Elisa Weiss, Senior Vice President, Patient Access and Outcomes

include the Sidney Kimmel Cancer Center, Philadelphia; the Black Nurses Association, Detroit Chapter; Beaumont Health, Michigan’s largest health care system; Kaiser Permanente, Oakland; Southeast Regional Clinicians Network, Atlanta; MD Anderson Cancer Center, Houston; and Unity Health Care, D.C.’s largest network of community health centers.

By all accounts, the outreach is working.

During the 18-month pilot program, more than 4,000 people in D.C. and Atlanta attended Myeloma Community Awareness programs and Myeloma Sundays, which are held in churches with

predominately African American congregations. An additional 3,000 people participated in such events after the program expanded to another six cities in October 2018.



Tracy Orwig, Director of Patient Access in Washington DC and Maryland, is joined by nurses from the health ministry and leaders of the congregation at a Myeloma Link event at Bethel AME Methodist Episcopal Church in Baltimore, MD.

ASH Update: LLS Releases the First Results of Beat AML Master Clinical Trial

LLS reached another significant milestone at the 2018 American Society of Hematology (ASH) Annual Meeting, a major conference attended by more than 30,000 researchers and physicians from around the world. Amy Burd, PhD, LLS's vice president of research strategy, presented the first formal results of the Beat AML Master Clinical Trial to more than 2,000 world-class scientists, demonstrating that the trial had met its primary proof point.

"The trial uses genomic technology to identify the patient's type of AML so they can get a targeted therapy to treat their disease," Burd said. "Within an unprecedented seven days, we have successfully identified the subtype of AML and assigned a novel

targeted therapy to more than 95 percent of patients who entered into our trial," she added.

The study has been open for two years and has 11 different study arms open at 13 centers, with nearly 500 patients now enrolled.

Response from the research community was enthusiastic. Burd's scientific abstract for the presentation, as well as another abstract on the Beat AML study, were selected for the "**Best of ASH**," a significant honor for LLS because these abstracts are featured in the publication *Highlights of ASH* and are presented throughout the year at ASH satellite meetings around the country.