SPECIAL BEAT AML ISSUE

HIGHLIGHTS



NEWS IN THE FIGHT FOR CURES

FALL 2019

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

Supporters' Corner

A lifelong athlete, John Kellenyi signed up for his first endurance event with LLS's Team In Training in 1999 as a way to give new meaning to his running "by supporting a very good cause," he recalled later.

Little did John know the Marine Corps Marathon would take him on a two-decades-long journey as one of LLS's most dedicated volunteers.

A successful hedge fund manager and Wall Street analyst before retiring at 55, John dove into his second career. "I work for LLS now," John told his family. "He gave generously of what he called The Three T's—time, talent and treasury," said daughter Cristina Kellenyi.

John served on many LLS committees at local and national levels. As a long-time board member and chapter president, he significantly helped drive the

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LLS Reaches Historic Fundraising Milestone with Beat AML

Reaching another major milestone with Beat AML, The Leukemia & Lymphoma Society (LLS) has met its fundraising target of \$125 million in philanthropic support for the groundbreaking initiative. This is a major achievement for LLS and our supporters, and another "first" for Beat AML.

Launched three years ago, Beat AML is an ambitious, collaborative attack on acute myeloid leukemia (AML), a deadly blood cancer that has defied medical science. Until now.

Beat AML was the first master clinical trial sponsored by a voluntary health organization. Likewise, the fundraising campaign to support it was the first major capital campaign ever launched by LLS, and it has been the largest and most successful campaign in LLS's 70-year history.

"We are very proud of the incredible generosity of our supporters and what has been accomplished with Beat AML," said Louis J. DeGennaro, PhD, President and CEO of LLS. "Instead of running a trial to move a drug forward, we are running the Beat AML Master Clinical Trial to move treatment forward. That is patient-centered research, and it is working."

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▲ The Beat AML Master Clinical Trial team, including Master Clinical Trial lead investigators John C. Byrd, MD, Brian Druker, MD, and Ross L. Levine, MD; LLS's Amy Burd, PhD, and Gwen Nichols, MD; and the entire national research team.

Supporters' Corner

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success of the New Jersey Chapter. In 2016, he became vice chair of Beat AML, a position he was passionate about. "The campaign would not have been the same without John," said Michael Copley, National Chair. "He was the most amazing fundraiser, friend and human being."

"John took tremendous pride in knowing what he did furthered the LLS mission by improving and saving lives of patients," said his wife, Teresita Blake Kellenyi. "He even learned to swim in order to participate as a member of the New York Ironman Triathlon LLS team."

John is the highest-ever individual fundraiser for Team In Training. More than \$19 million raised across all campaigns for LLS can be attributed to John's efforts and personal generosity—more than any other volunteer in LLS history.

In 2017, shortly before losing his own battle to cancer, John received LLS's prestigious Spiral of Life award. Cristina recalled, "My dad never stopped asking 'What's next?', 'What more can I do?', 'How can I get others involved?'"



John Kellenyi at right with friend and Beat AML Campaign Chair, Michael Copley



"I am extremely happy with my investment in the Beat AML initiative. As a survivor who witnessed others with less successful outcomes, I understand the need to advance AML treatment. The Beat AML effort is revolutionizing the advancement of AML treatment through a LLS coordinated process that is yielding results at a much faster pace than experienced in the past. I am thankful for LLS's creative thinking to curing blood cancers."

- Jeffrey Sachs, Duluth, Georgia



"I've been a supporter of LLS since 2005, the year I lost my husband and my children lost their father to AML. My greatest hope is that others will never have to experience the loss we have as a result of this aggressive cancer. Beat AML is absolutely critical to push the boundaries of research, care and treatment for those facing this diagnosis, in addition to other rare blood cancers, and ultimately save

more lives. My support of LLS is to both honor my husband and my children's father, and to also stand proudly with LLS to create change and improve the lives of those with AML as we strive for the ultimate dream—a cure. Please join us in this fight to Beat AML."

- Andrea Reid, San Francisco, California



"I've been supporting LLS for over ten years, and continue to be amazed at their commitment, dedication, and success in tackling blood cancers. The Beat AML campaign was particularly important to me, as AML has been and remains among the deadliest blood cancers for the last forty years. It was almost forty years ago that I lost my father to AML—he was forty-seven, and I was sixteen. Through my support of the Beat AML effort, I'm proud to contribute to the LLS mission so that no fathers, sons, or families have to face such a tragedy. With a focus

on precision medicine, along with their ability to bring together research, analytics, medical expertise, and pharmaceutical partners, LLS is well positioned to do for AML what it has already done for other forms of blood cancer."

- Steven Lieblich, Bonita Springs, Florida



"We support the Beat AML campaign so that my success story will be the rule, not the exception."

- Gayle Helman, Scarsdale, New York



"Our work with LLS began in 2015 when Kelly ran for LLS Woman of the Year. We continued our support with two additional candidates and then Tom ran for LLS Man of the Year in 2018. We nominated a friend for Student of the

Year in 2019 and now are targeting our focus towards the Beat AML campaign. Our son, Michael passed away in 2008 from AML and our goal is to support better treatment and results through the work of LLS and the Beat AML initiative. We want people that are diagnosed with AML to know that there is hope!"

Kelly Treinen, The Michael Treinen Foundation,
 Noblesville, Indiana



"After losing our beloved son and brother Robert Lyon to AML in 2007 we dedicated our family foundation to

supporting AML research to ensure that those facing the same diagnosis have far better odds at beating the disease. With the Beat AML initiative in full swing, the Lyon Family Foundation is even more focused on disrupting the current trajectory for these patients and seeing treatment change at a really rapid rate!"

- Lyon Family, Chicago, Illinois



"My son Doug is the one that started supporting LLS. A friend was running the Boston Marathon and he supported her efforts in the race. Doug unfortunately had the diagnosis of AML and despite all efforts succumbed to this terrible illness within

one year of his diagnosis. My husband, Arthur, continued fundraising once Doug had passed away and did everything imaginable to maximize his efforts to support such a wonderful mission. Our hope is that the success achieved by LLS to cure this disease will translate into cures for other serious illnesses as well."

Lois Kroll (shown above with her son Doug),
 Briarcliff Manor, New York

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Testing multiple drugs at multiple medical institutions simultaneously, the Beat AML trial design gives more choices to patients and ensures a more efficient clinical trial process. All patients in the Beat AML trial are given an experimental treatment option, versus the traditional design of "one trial, one therapeutic option."

While the fundraising campaign to support the Beat AML initiative has reached its target, the fight to end AML continues at full force. LLS will continue its offensive against AML until the disease is no longer a threat.

Louis J. DeGennaro, PhD, LLS President and CEO

Another milestone is the validation—for the very first time – that genetic screening can be successfully incorporated into treatment for a highly aggressive disease. Using genomic technology physicians can identify the genetic mutations of AML patients and make a treatment decision in an unprecedented seven days. This game-changing advance has implications beyond AML, opening up new opportunities for highly precise and personalized precision medicine.

LLS's battle with AML is far from over. "While the fundraising campaign to support the Beat AML initiative has reached its target, the fight to end AML continues at full force," added Dr. DeGennaro. "LLS will continue its offensive against AML until the disease is no longer a threat."

The Beat AML trial continues to enroll patients at centers across the country, with more medical centers to join in the months ahead. At the same time, LLS will continue to allocate approximately one-third of its annual research budget to science devoted to defeating the disease.

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The Beat Goes On

LLS will battle AML until the disease is overcome.

These are some of the ways LLS and its supporters will continue to drive advances in treatment for patients.

- Having already surpassed the original goal of enrolling 500 patients to the Beat AML trial, LLS is now targeting a total enrollment of 2,000 patients over the course of four years.
- LLS applied to the FDA to lower the enrollment age to 18 for two Beat AML trial arms that target molecular mutations that are prevalent in younger patients.
- In 2020 LLS will open a trial for myelodysplastic syndromes, disorders that often progress to AML.
 The study will run at the current sites and will be

- open to newly diagnosed patients 18 years of age and older.
- LLS will be among the first to test "novel-novel" drug combinations for AML, bringing together two new drugs from two different companies. Several other combination studies are in development.
- A biobank of samples from the Beat AML trial will be made available to researchers to study AML progression and drug resistance.
- Applying the expertise of Beat AML, LLS launched The LLS Children's Initiative, including a pediatric master clinical trial for acute leukemia, which will test multiple therapies at as many as 200 clinical sites globally.



To reach an Information Specialist, call **800.955.4572** • Visit our online community at **IIs.org/community**To learn about giving to LLS, call **(914) 821-8825** • To include LLS in your estate plans, email **legacy@lls.org** or call **(914) 261-0171**

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 LLS.org.