

# Highlights



NEWS IN THE FIGHT FOR CURES

SPRING / SUMMER 2018

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

## Supporter's Corner

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**When I was young, my aunt, one of my favorite people, succumbed to lymphoma.** A few years ago, another family member was also diagnosed with the disease. As I was trying to find information, I learned about LLS. It is so different from any organization I have ever been involved with or supported.

The quality of LLS communications drew me in and kept me in—first to help a close relative, then to help others. As a clinical

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## Helping Patients Help Each Other

There are an estimated 1,300,000 people in the United States living with or in remission from blood cancer. Each patient's journey is filled with life-changing experiences, some unique and others common. Sharing those experiences is a powerful way to overcome isolation and advance understanding of both the immediate and long-term impact of cancer and its treatment. These are the goals of the LLS Community.

An online patient forum where patients and caregivers share real world experiences and contribute to vital research, the LLS Community was launched in 2016 to leverage digital technology to improve treatments and outcomes.

Connecting patients with one another and with the research process, the LLS Community

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[www.lls.org/community](http://www.lls.org/community)

**8,087**

Community users

**44,605**

Community comments

▲ **The LLS Community is accelerating research and improving the lives of patients and caregivers by empowering them to seek answers, share wisdom, and drive change. Be a part of this life-changing group at [www.lls.org/community](http://www.lls.org/community).**

## Supporter's Corner

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counselor and an educator, I am involved with end-of-life and bereavement issues. People with cancer are often frightened, unsure what can be done, concerned about the time they may have left. Many try not to disclose their disease.

LLS has an Information Resource Center people can call and get support that is personal, meaningful and authentic. Just knowing LLS is there can give them hope.

I am excited about the research going on through LLS. Giving to this outstanding organization is a way for those of us who cannot be a cancer researcher or someone's regular caregiver to make a difference. For me, giving is not just about tangible things. It is about what we want to do with our lives.

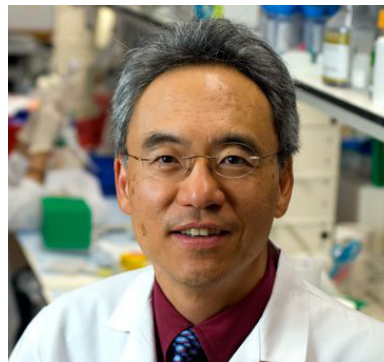


**Evelyn Bata, PhD**  
Chevy Chase, MD

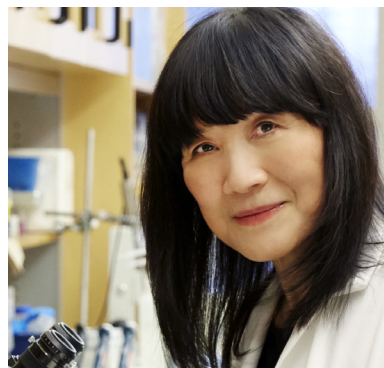
# Two Major Grants Target MCL

**LLS and our donors are partnering in innovative science to bring hope to patients with mantle cell lymphoma.**

LLS is taking on mantle cell lymphoma (MCL), a relatively rare and typically aggressive form of non-Hodgkin lymphoma (NHL). Thus far in 2018, two major grants have been awarded for novel approaches to improve treatment for this disease, which is usually diagnosed at a later stage and has a median survival of only two to five years. These grants are made possible by donors and volunteers, and major funders the Rising Tide Foundation, Sarah Cannon, Snowdome, and the Babich Family Foundation.



A grant awarded to **Larry Kwak, MD, PhD**, of City of Hope, supports three concurrent projects to develop immunotherapeutic approaches to improve treatment and outcomes for patients with MCL. Testing novel immunotherapy agents against MCL, including several manufactured on the City of Hope campus, the research includes a unique tumor-specific antibody therapy and a CAR T-cell combination therapy. The therapies will recognize specific molecules on the surface of MCL tumor cells to improve the targeting of treatments, reducing the side effects that are a result of collateral damage to normal cells.



**Selina Chen-Kiang, PhD**, of Cornell University's Weill Cornell Medical College, is leading three projects aimed at developing novel molecularly-targeted therapeutics for MCL, as well as overcoming the development of drug resistance in MCL, which limits treatment options and allows the cancer to grow rapidly, essentially making it incurable. By defining the molecular mechanisms behind drug resistance in MCL and developing strategies that overcome it, Dr. Chen-Kiang seeks to develop novel therapies that are effective, well tolerated, and durable and can be individualized for patient treatment.

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

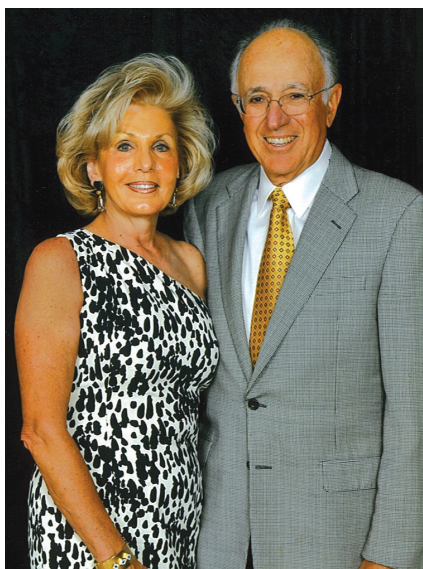
# Helping Patients Help Each Other

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accelerates access to valuable information and resources and enables patients to provide information about their unmet needs, shedding light on potential new paths for better care and improved treatments. Content supports and engages patients, caregivers, and professionals via articles and blogs, group discussions, polling, and other timely news on blood cancer.

## Making connections . . . and finding answers

After losing their son, Michael, to the intense long-term side effects of his leukemia treatment, Bernard Garil a longtime LLS Board of Directors member and his wife, Ethel, were determined to close a major gap



▲ Bernard and Ethel Garil wanted to make a difference in the lives of patients and survivors by creating a centralized resource that would help patients and caregivers get and give advice, support, and information, as well as create a platform for research into immediate and long-term effects of blood cancer and its treatment. Visit [www.lls.org/community](http://www.lls.org/community) to learn more and to join.

**“Knowledge and information are power.”**

—Bernard and Ethel Garil

**The Garils’ vision and kindness have had a profound impact: The LLS Community grew to 6,000 members in its first year and has now surpassed 8,000 members.**

in care and research: There were no integrated systems to track outcomes and the health of patients and survivors. They turned to LLS to help build that valuable resource.

It was their vision and generosity that led to the first stage of this endeavor—the LLS Community—gathering vital information from a large pool of people affected by blood cancers. Collecting the shared and unique experiences of patients will help researchers understand the true impact of treatment over time, enabling them to identify unanticipated concerns or effects and develop improved therapies and interventions.

The next phase will be a registry, to be launched in June 2018, to which electronic health records from the institutions involved in a member’s care can be uploaded, creating a data set of health records that can be studied for patterns and

outcome implications. The initial studies will be related to real world care and outcomes regarding Chronic Lymphocytic Leukemia and Waldenstrom’s Macroglobulinemia.

## How does LLS Community help?

### Offering Support

Personalized, accurate and up-to-date information, education, and resources to support you.

### Sharing Information

See what other people affected by blood cancers are talking about and share experiences.

### Impacting Research

Contribute to surveys and research. LLS Community relies on your experiences and insights to drive program development and research studies.

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## A Win-Win Partnership

Wanting to help blood cancer patients access innovative new therapies, the American Society of Hematologists (ASH) turned to LLS, a trusted leader in expert patient support. In a six-month pilot program launched in January 2018, ASH and LLS are collaborating to help their member physicians guide patients to the most appropriate clinical trials for their specific malignancies.

The pilot connects eight geographically diverse clinical centers and 53 physicians to the clinical trial navigation of the Clinical Trial Support Center (CTSC):

- Illinois CancerCare, Peoria, IL
- Northwell Health, Lake Success, NY
- Stanford University, Stanford, CA
- Sunnybrook Health Sciences Centre, Toronto, ON

- Swedish Cancer Institute, Seattle, WA
- University of Oklahoma, Oklahoma City, OK
- Winship Cancer Institute, Atlanta, GA

For patients interested in finding a clinical trial, LLS's unique, highly personalized CTSC leads the industry in providing one-on-one guidance from registered nurses who specialize in blood cancer. By connecting physicians to this expertise, we help more patients access new treatments.

The pilot is expected to reduce the burden on physicians to identify appropriate trials for their patients, and it will advance LLS's mission to support as many blood cancer patients as possible. Running through June 2018, the results of the pilot will be evaluated and presented in September 2018.