

# PULSE

## A PIONEERING SPIRIT

Dr. Eduardo Sotomayor is embarking on a new and exciting challenge in his career that will combine his pioneering work in cancer immunology and dedication to providing quality cancer care for all patients.

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## PULSE

### A Publication for Friends of the Lymphoma Research Foundation

LYMPHOMA  
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*Pulse* is a publication of the Lymphoma Research Foundation, providing the latest updates on the Foundation and its focus on lymphoma research, awareness, and education.

The Lymphoma Research Foundation is devoted to funding innovative lymphoma research and serving the lymphoma community through a comprehensive series of education programs, outreach initiatives, and patient services.

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#### CONTACT US

**National Headquarters**  
Wall Street Plaza  
88 Pine Street, Suite 2400  
New York, NY 10005

Tel: 212 349 2910  
lymphoma.org

**LRF Helpline**  
800 500 9976  
helpline@lymphoma.org

**Contact the Editor**  
For more information or to share comments, please email  
editor@lymphoma.org.

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The Lymphoma Research Foundation (LRF) understands that a diagnosis of lymphoma may bring about many different emotions and that everyone's journey is personal.

LRF's *Living with Lymphoma* podcast is here to help the lymphoma community better understand how to cope with the unique circumstances that a diagnosis of lymphoma presents.

Listen in as experts and patients discuss psychosocial topics related to a diagnosis with lymphoma and other forms of cancer. Join Victor Gonzalez and Izumi Nakano from the Foundation's Helpline as they explore various survivorship topics.

Visit [lymphoma.org/podcast](https://lymphoma.org/podcast) to listen and subscribe to upcoming episodes.

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# 2021 LRF ANNUAL GALA

Thank you to the generous sponsors and supporters listed below and to our many other donors who helped to contribute to the success of the 2021 Annual Gala, which helped to raise more than **\$790,000** to support the Lymphoma Research Foundation's (LRF) mission of eradicating lymphoma and serving those touched by the disease.

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LRF is delighted to announce the 2022, Annual Gala taking place Thursday, September 29, 2022 at the Ziegfeld Ballroom in New York City.

If you are interested in pledging your 2022 support early or would like to be added to our list to be the first to hear about our event details, please reach out to **Rebecca Rausch, Associate Director of Distinguished Events**, at [rrausch@lymphoma.org](mailto:rrausch@lymphoma.org)



# FROM THE CEO

**What distinguishes the Lymphoma Research Foundation (LRF) from other groups is our depth and commitment to finding cures for lymphoma.**

We give our scientists the freedom and security to develop new approaches to understanding, diagnosing, treating, and surviving lymphoma. They are pioneers exploring the frontier of the field, working toward breakthroughs that bring us closer to our mission to eradicate lymphoma and serve those touched by this disease.

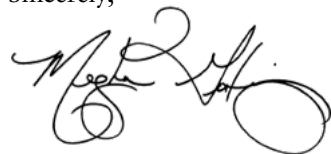
We profile one of these pioneers in this issue of *Pulse*: world-renowned cancer immunologist and lymphoma expert Eduardo Sotomayor, MD of Tampa General Hospital. Dr. Sotomayor, a member of the Foundation's prestigious Scientific Advisory Board (SAB), has led the way in furthering our understanding of harnessing the immune system to fight cancer and developing novel targeted therapies for the treatment of lymphoma. He also expanded our understanding of rare lymphoma subtypes like mantle cell lymphoma (MCL), by advancing research intended to improve patient outcomes. It is no surprise then that Dr. Sotomayor was recently elected Chair of the Foundation's Mantle Cell Lymphoma Consortium, which convenes thought leaders from around the world to collaborate and share research findings with the goal of accelerating the field and scientific breakthroughs.

In this issue, you will also read an inspiring story about Shelia, a cutaneous T-cell lymphoma survivor who credits where she is today to the encouragement she received from the lymphoma community and research advancements focused on her rare lymphoma. Support and research can have a profound impact on one's healing, and we are proud to have played a part in her journey.

You will also read about the Foundation's impact in this issue's updates from the American Society of Hematology Annual Meeting & Exposition, the world's premier event in malignant hematology. Lymphoma Research Foundation grantees and SAB members presented pivotal data that will inform the development and adoption of new therapies across the spectrum of lymphoma subtypes. Many of these studies will be highlighted during LRF patient education programs throughout 2022.

I wish to thank you for the important role that you play in this critical work. Your support, coupled with the expertise of our SAB and the dedication of our research grantees, make such scientific discoveries possible. Together, we are on a path to find cures and eradicate this disease forever.

Sincerely,



Meghan Gutierrez  
*Chief Executive Officer*



# PHILANTHROPY IN ACTION



## **NAPERVILLE WALK RAISES MORE THAN \$50,000**

On July 30, 2021, the Naperville Park District in Naperville, Ill., held a special dedication ceremony and Walk in honor of the late Chuck Papanos. For 20 years, Papanos served the park district as the Parks North/Riverwalk Manager. He was known as the “quiet hero” behind many city events and remembered for his hard work and outstanding leadership to help make the community’s Riverwalk a place of beauty for everyone to enjoy. The event’s success was made possible by friends, family, and colleagues who were determined to pay it forward and honor Papanos’ motto that “doing nothing is not an option.”



## **STONE STRONG NEIGHBORHOOD WALK FOR LYMPHOMA RAISES \$12,250**

Max Stone was a student at the University of Massachusetts Amherst and a beloved brother at the Alpha Epsilon Pi Fraternity. He was cherished both at school and in his hometown of Dartmouth, Mass., because of his compassionate qualities. He was diagnosed with non-Hodgkin B-cell lymphoma and during his treatment, he stayed positive and looked out for others. Stone had a fierce determination and never gave up even when he was met with challenges. The UMass and greater Amherst community came together for a Neighborhood Walk to honor Stone’s memory. Stone stood for helping others, and this event allowed for those close to him to continue helping the community in his honor.



### **STORMS AGAINST LYMPHOMA FUNDRAISER RAISES MORE THAN \$100,000**

On October 16, 2021, CEO of Aspire General Insurance Byron Storms held an event to raise funds for LRF after his close friends Andy and Dylan were diagnosed with lymphoma. Over 200 guests attended this event, and there was ample entertainment. There was live music, a photographer, food, and more. There were also over a dozen classic cars and 20 custom Harley-Davidsons at the event. All the entertainment not only made this a special event, but it also helped to gather the community together in the fight against lymphoma. The fundraiser exceeded its goal, and it was both an exciting and meaningful event.



## **START A FACEBOOK FUNDRAISER**

**It's easy to rally your community and start a Facebook Fundraiser in support of the Lymphoma Research Foundation (LRF).**

### **STEP**

# **1**

Visit LRF's Facebook page at [facebook.com/lymphomacommunity](https://facebook.com/lymphomacommunity) and click the "create a fundraiser" button.

### **STEP**

# **2**

Name your campaign, select your goal amount and end date, and let your friends know why you're fundraising for LRF.

### **STEP**

# **3**

Share your fundraising campaign with friends, family, and your community on Facebook.



### **Join Team LRF Today**

Raise awareness and funds to support LRF's mission to eradicate lymphoma and serve those touched by this disease.



# SHOWING YOUR LOVE MAKES AN IMMEDIATE IMPACT

Each February, the Lymphoma Research Foundation (LRF) shows its love for lymphoma patients in a special way. Throughout the month, LRF's Show Your Love campaign raises money to help fund its Patient Aid Grant Program, which provides financial assistance to lymphoma patients in active treatment. Each grant makes a meaningful difference in the life of someone with lymphoma.

Treating lymphoma can come with a significant financial burden that not all are able to pay. Many requests for financial assistance come from patients and caregivers who are struggling to cover health insurance copays, medical bills, transportation to and from treatment, and other expenses related to their cancer care. "It is critical that we focus on health equity and provide these grants so that more patients have access to quality cancer care," says Micah Banner, Senior Director of Development at LRF. "Our Show Your Love campaign has been a great success and each year, as support for the campaign grows, we are able to help more patients and address the disparities in access to care."

This year, the Show Your Love campaign is more important than ever. Because of the ongoing effects of the COVID-19 pandemic, requests for financial assistance are growing. In addition, novel therapies are emerging that require indefinite courses of treatment, increasing the financial burden on some patients. "LRF's Patient Aid Grant Program can provide not only necessary financial assistance, but also a sense of comfort in knowing that they are not alone," says Izumi Nakano, Associate Director of Support Services at LRF. "In addition to supporting patients and caregivers through financial aid and referrals, we also provide additional resources regarding health insurance and employee rights."

**"LRF's Patient Aid Grant Program can provide not only necessary financial assistance, but also a sense of comfort in knowing that they are not alone."**



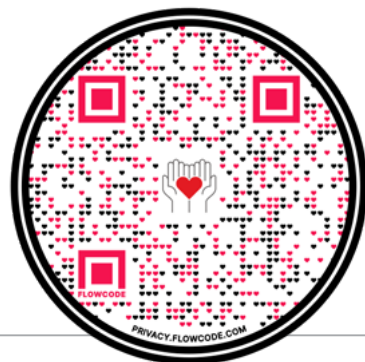
## DONATIONS MAKE AN IMMEDIATE IMPACT

LRF's Patient Aid Grant Program is 100 percent funded by individual donors and is critical to ensuring patients receive assistance when they need it most. Many donors to the Show Your Love campaign are members of the lymphoma community—including lymphoma patients, survivors, and caregivers—who choose to make an immediate impact on someone's life.

"Our donors are truly dedicated, not only to our mission, but also to uplifting and supporting fellow members of the lymphoma community in their time of need," says Banner. "We are so heartened by their support for this campaign each year."

This year, a generous LRF donor has pledged to match all donations to our Show Your Love campaign, up to \$30,000, meaning every gift we receive will have twice the impact on supporting lymphoma patients.

To support LRF's Patient Aid Grant Program and show your love to lymphoma patients in need, please visit [lymphoma.org/showyourlove](https://lymphoma.org/showyourlove). 📍



Join Us for a Virtual

# Lymphoma **ROUNDS** Program



The Lymphoma Rounds program provides a virtual forum for practicing physicians from academic and community medical centers to meet on a regular basis and address issues specific to the diagnosis and treatment of their lymphoma patients.

Physicians network, share best practices, and learn the latest information on new therapies and advances in the management of lymphoma through interactive case studies presented by lymphoma experts.

Register for an upcoming Lymphoma Rounds program at [lymphoma.org/hcpeducation/](https://lymphoma.org/hcpeducation/)

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# 2022 PUBLIC POLICY AGENDA

The Lymphoma Research Foundation (LRF) is proud to be a national thought leader and advocate for policies and legislation that will improve the lives of people with lymphoma and chronic lymphocytic leukemia (CLL). The Lymphoma Research Foundation leads efforts to ensure the needs and perspectives of the lymphoma community are considered and integrated into public policy at the federal level.

The 2022 Public Policy Agenda outlines LRF's policy priorities for the year ahead and will direct the efforts of thousands of patient and caregiver advocates across the United States. This year, LRF will prioritize federal funding for lymphoma research and education, to ensure patient access to high quality cancer care.



## Supporting Lymphoma Research

The Lymphoma Research Foundation supports increasing federal investment in lymphoma research and funding for agencies like the U.S. Food and Drug Administration so that new lymphoma treatments can become available to patients faster. These efforts include:

- Increased funding for the National Institutes of Health (NIH) and the National Cancer Institute, including research intended to better understand the impact of the COVID-19 pandemic on people with blood cancer.
- Greater support for the nation's clinical trials enterprise and improvements to infrastructure, including efficiencies to the clinical trial development process, with a focus on patient-centered outcomes and health equity.
- Continued support for the Food and Drug Administration, including the Oncology Center of Excellence, to ensure efficient review of new cancer therapies and integration of the patient voice in drug development and review activities.
- Increased support for research and regulations that aid in the development of new therapies for rare lymphoma subtypes and underserved patient populations.
- Increased support for research activity to understand the needs of underserved patient populations, including those with cancer and those who are cancer survivors.

## Supporting Access to Quality Cancer Care

The Lymphoma Research Foundation endorses legislation and regulations which seek to increase access to comprehensive lymphoma treatment and cancer survivorship care, including:

- Public policies that ensure access to adequate and affordable health insurance coverage for people with lymphoma and protect access to quality cancer care, as well as maintaining coverage for pre-existing conditions.

- Payment and delivery reform efforts that assist health care providers in improving the quality of cancer care in all communities in the United States.
- A health care system that collects real world data to support access to therapies and quality improvement.
- Coverage standards in public and private health insurance systems to protect access to all approved anticancer regimens including, but not limited to oral and intravenous drugs, injections, cellular and gene therapy, surgery, radiation and transplantation.
- Implementation of policies which support the development of new therapies and clinical trials for rare diseases and policies which assist and encourage patient participation.
- Revision of clinical trial enrollment criteria to encourage more diversity among trial enrollees, accompanied by outreach and education efforts to increase trial enrollment among the elderly, rural residents, and ethnic and racial minorities.

## Supporting Lymphoma Survivors

The Lymphoma Research Foundation endorses legislation which recognizes the increased number of cancer survivors in the United States and the needs of people living with and after a lymphoma diagnosis. These efforts include:

- Legislation which protects access to quality health insurance for anyone with a preexisting condition.
- Health care payment and delivery reforms that will incentivize delivery of quality survivorship care for patients across the cancer care continuum. Among these reforms are education and provider reimbursement for cancer care planning to improve planning services for all people with lymphoma.
- Policies that would increase funding for cancer survivorship research and the study of treatment-related side effects. ○

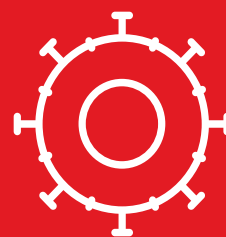


## BECOME AN LRF ADVOCATE

When you register to become an LRF advocate, you will support the Foundation's public policy agenda and join a network of more than 5,000 Americans who want to make certain the voice of the lymphoma community is heard. Visit [lymphoma.org/advocacy](https://lymphoma.org/advocacy) to become an Advocate today.

# A PIONEERING SPIRIT

Lymphoma Research Foundation (LRF) grantee and Scientific Advisory Board (SAB) member Eduardo M. Sotomayor, MD was recently named director of Tampa General Hospital's newly established Cancer Institute. This appointment marks a new and exciting challenge for the world-renowned lymphoma expert—combining his pioneering work in cancer immunology and immunotherapy with his dedication to providing quality cancer care for all patients—in hopes of finding cures for lymphoma.





## Riding the Waves to His Passion

Dr. Sotomayor lives and works in Tampa, Fla., on the shores of the Gulf of Mexico. The Gulf's steady waves are very familiar and remind him of his childhood swimming the Pacific Ocean in his hometown of Puerto San Juan de Marcona, Peru. "My life has always been associated with the ocean and the coast, and it has defined my easygoing personality," says Dr. Sotomayor. "There is something about living by the sea that makes you enjoy life and have fewer worries."

But life, like water, does not always flow smoothly. While playing in his parents' kitchen when he was 5 years old, boiling water spilled on his face, arm, and leg and left him badly burned. However, life sometimes reveals opportunity in misfortune.

"I spent three months in the hospital, and at that age, the doctors and nurses talk to you, and they make you laugh," he recalls. "I thought, 'This is very interesting. I like these guys.' Pediatricians are a special group of people and play an important role in a child's healing. I'll always remember how they helped and inspired me."

Later, an uncle studying medicine in Lima, Peru, visited his family and enthralled him with his stories about becoming a doctor. Those experiences helped Dr. Sotomayor find his calling: becoming a doctor. He attended medical school at Federico Villarreal National University School of Medicine in Lima, performed his residency at Jackson Memorial Medical Center with the University of Miami School of Medicine in Florida, and completed his fellowship in hematology/oncology at Johns Hopkins University School of Medicine in Baltimore, Md.

During his time at Federico Villarreal National University, Dr. Sotomayor's interest in the immune system was piqued by a former student, Francisco La Rosa, who migrated to the United States to perform immunology research and often returned to Federico Villarreal to teach medical students. The burgeoning field of tumor immunology grabbed his attention.

"He talked about the immune system and how it needs to be tightly controlled," Dr. Sotomayor recalls. "He said one of the functions of the immune system is to fight infection, and there was emerging evidence that the immune system could one day fight cancer. Very few researchers were focusing on tumor immunology—it was a new frontier."

From there, Dr. Sotomayor embarked on a journey to confront challenges few have explored and sought to answer the most challenging questions in medical science.

## Investigations on the Battlefield

In 1988, Dr. Sotomayor began working in tumor immunology with Dr. Diana Lopez at the University of Miami Miller School of Medicine. At that time, he recalls tumor immunology was not an established study or common area of research focus.

"We were considered dreamers but without a future in oncology, because of the prevalent skepticism at that time towards the emerging field of tumor immunology. But today, tumor immunology has proven successful, and there are effective immunotherapies to treat almost every type of cancer," he says. "Having committed my life to research and understanding this new treatment modality, I can tell you that we are just seeing the tip of the iceberg."

From Miami, Dr. Sotomayor headed north to Baltimore to become an oncology fellow at Johns Hopkins and further pursue tumor immunology. In his first year, he learned to treat cancer patients, cultivating a sense of compassion. In his second and third years, he conducted research and was assigned to study lymphoma and its interaction with the immune system. There, his passion for both researching cures and treating lymphoma began.

"I've found that to be an efficient clinical investigator or physician-scientist, you should continue to treat patients," says Dr. Sotomayor. "As a clinician, you can recognize early if treatment is or isn't working or if there are side effects. You can take these observations and apply them to your lab to further investigate."

**"We were considered dreamers in the field. But today, tumor immunology has proven successful, and there are effective immunotherapies to treat various cancers."**



*Continued on the next page*



Dr. Sotomayor's research involves investigating what he calls a *battlefield*. He describes the T-cells of the immune system and tumor (cancer) cells as two armies fighting a war within the lymph nodes. While studying this internal fight, he and his team were among the first researchers to show in an experimental model of lymphoma that the tumor cells can control the T-cells and order them not to attack.

"They reach a peace agreement, so the tumor cells say, 'Do not attack me,' and the T-cell will say, 'Let's live together.' But they are going to try to cheat each other," he says. "It's a constant dynamic, and at some point, one is going to win."

His research delves deeply into understanding this interaction on a cellular and molecular level, the role the lymphoma microenvironment plays in this interaction, and what strategies each *opponent* uses on the battlefield. Through this hyperfocused research, Dr. Sotomayor has made great strides and contributions regarding how molecular mechanisms, signaling pathways, epigenetics, and the lymphoma microenvironment influence immune responses against lymphomas.

### A FOCUS ON RARE LYMPHOMA

Just like he was drawn to the challenge of the emerging field of tumor immunology, Dr. Sotomayor has focused much of his research on mantle cell lymphoma (MCL), an aggressive and rare form of non-Hodgkin lymphoma.

Patients with MCL are typically diagnosed at a later stage of the disease and represent only six percent of all non-Hodgkin lymphomas, making them a historically understudied and underserved population.

"We now have several novel targeted therapies for MCL, including chimeric antigen receptor therapy, also known as CAR T cell therapy," he says. "Significant advances have been made studying mantle cell lymphoma, and it is a great focus of mine."

Dr. Sotomayor believes that LRF has profoundly impacted his research and researchers' overall understanding of MCL. In 2004, he received a Mantle Cell Lymphoma grant through LRF's Mantle Cell Lymphoma Initiative—a research endeavor focusing on funding MCL research and accelerating developments in the understanding and treatment of MCL—to conduct the first vaccine trial for the disease.

"Outside of the National Cancer Institute (NCI), most of the advances in mantle cell lymphoma are made by researchers funded by LRF," says Dr. Sotomayor. "I think it is fair to say they have changed the history of new formulation and treatment, and I would say a significant portion of the advances in lymphoma are because of LRF, period."

Furthering his impact on MCL research and patient care, Dr. Sotomayor became a member of LRF's Mantle Cell Lymphoma Consortium (MCLC) in 2005, joined the Executive Committee in 2015, and was elected Chair in 2021. The MCLC is comprised of 37 international laboratory and clinical scientists whose research is focused on MCL. Members of the MCLC convene biennially for a global scientific workshop to discuss the latest research findings, foster collaboration within the MCL research community, and create new directions for research, all to improve the diagnosis and treatment for this disease. As Chair of the MCLC, Dr. Sotomayor hopes to bring together the brightest minds from all different areas of study to provide fresh perspectives to the study of MCL and advance LRF's MCL Initiative.

"There are brilliant scientists within the consortium who are all dedicated and have the potential to make a great impact," says Dr. Sotomayor. "I am looking forward to working with them over the next two years to help move the research needle forward and advance our understanding of this disease."



"Outside of the National Cancer Institute (NCI), most of the advances in mantle cell lymphoma are made by researchers funded by LRF...and I would say a significant portion of the advances in lymphoma are because of LRF, period."





### AN EVER-GROWING RELATIONSHIP WITH LRF

In addition to the MCL grant, Dr. Sotomayor received two other LRF research grants, including a Postdoctoral Fellowship and a Junior Faculty award. He feels LRF's impact on research and advancing cures cannot be understated, and the Foundation is one of the leading funders of lymphoma research. With a more significant investment in research, Dr. Sotomayor believes there are significant opportunities to find cures.

"There are talented scientists all over the world, but they need support," says Dr. Sotomayor. "The first grant I received from LRF kick-started my career and allowed me to put in long hours to develop and establish my place as a researcher and successfully compete for federal NIH/NCI grants."

Dr. Sotomayor sees the impact of LRF's grant program beyond funding research.

"It's the message it sends—the Foundation believes in you, even if you think you have the craziest idea," he says. "LRF's incredible Scientific Advisory Board views that crazy idea as a potential breakthrough or discovery. It motivates and excites researchers and keeps them in the field. The more LRF can fund, the more we can advance."

### A NEW FRONTIER


In his new role as director of Tampa General Hospital's Cancer Institute, Dr. Sotomayor aims to bring in new voices, recruit the best and brightest scientists, including those beyond the oncology field (i.e., engineers, physicists, and chemists, among others) to conduct advanced

research, and provide the next breakthroughs in cancer care leading to the best care of cancer patients.

"I will define Tampa General Hospital's Cancer Institute as innovative, compassionate, and collaborative—we care, and we want to have an impact in our community," he says. "Our priority is to use the latest research and therapies to provide the best care to patients in Florida and beyond, with special emphasis in breaking the barriers to access to cancer care."

One of his priorities will be advancing the understanding of the biology of hematologic malignancies through new diagnostic tools like biomarker testing. Next-generation sequencing is helping scientists and clinicians to identify mutations (abnormalities) in tumor cells. Next-generation sequencing can also help identify these mutations in people with diseases other than cancer, like heart disease—an emerging field of study called clonal hematopoiesis of indeterminate prognosis (CHIP). Sotomayor hopes to further understand the connection between these diseases and cancer. He is developing a partnership with cardiologists at the USF Health Morsani College of Medicine to bring together oncologists and cardiologists to research these abnormalities.

"This will help identify the next big question in cancer and how disciplines beyond oncology working side by side with us would provide answers to that question," he says.

At the forefront of Dr. Sotomayor's work will always be his MCL research and his drive to ensure Tampa General Hospital continues to care for its diverse community on the Gulf, where the water reminds him of the birthplace of his pioneering spirit—home. 



# 2021 AMERICAN SOCIETY OF HEMATOLOGY MEETING UPDATES

The Lymphoma Research Foundation (LRF) returned to the American Society of Hematology (ASH) Annual Meeting and Exposition, with more than 70 LRF-affiliated scientists, including past and present members of LRF's world-leading Scientific Advisory Board (SAB) and grantees, presenting abstracts at the conference.

Widely regarded as the premier event in malignant and non-malignant hematology, the ASH Meeting provides a critical forum for leading hematologists/oncologists to present their findings to over 20,000 of their peers. Among the distinguished scientists attending, more than 40 percent of LRF Scholars—participants in LRF's Lymphoma Scientific Mentoring Program (LSRMP)—presented at the 2021 ASH Annual Meeting.

In addition to LRF's representation through presentations, more than 50 percent of LRF grantees (including 94 percent of LRF Scholars) were authors on abstracts selected for the annual meeting. LRF is also represented across more than 700 abstracts through grantees, *Lymphoma Rounds* Steering Committee members, Mantle Cell Lymphoma (MCL) Consortium members, and current and past SAB members.

The 2021 ASH Annual Meeting also featured 20 abstracts and presentations stemming from LRF-funded research and 25 COVID-19-related research studies authored by LRF-affiliated scientists.

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**"The Lymphoma Research Foundation's commitment to advancing the field of lymphoma research through its investment in the most promising lymphoma research is highlighted through its breadth of research at ASH," says Sonali M. Smith, MD, FASCO, Chair of the LRF Scientific Advisory Board. "LRF continues to work with the best scientists in the field and invest in the research projects that have the greatest potential to impact and improve the treatment and understanding of lymphoma."**

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LRF was represented across

**729**  
abstracts







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**Brad S. Kahl, MD**  
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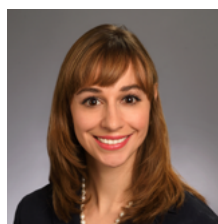
### Long-Term Follow-Up Reveals Superiority of Maintenance Rituximab Therapy Over Retreatment Strategy in Low Tumor Burden Follicular Lymphoma

In a long-term follow-up of the RESORT study, maintenance rituximab (Rituxan) delayed time to first cytotoxic therapy (a substance that kills cells, including cancer cells. These agents may stop cancer cells from dividing and growing and may cause tumors to shrink in size.) and improved response duration compared with a retreatment approach in low tumor burden follicular lymphoma (FL), according to study results presented by LRF Scientific Advisory Board (SAB) member Brad S. Kahl, MD, of the Washington University School of Medicine.

In the original RESORT study, 289 patients with untreated, low tumor burden FL who responded to an initial four doses of weekly rituximab therapy were randomized to receive maintenance therapy (a single dose every three months) or retreatment rituximab (four doses weekly at each disease progression) until treatment failure, defined as progression within six months of the last dose of rituximab, no response to rituximab retreatment, initiation of alternative therapy, or inability to complete protocol therapy. After a median 3.8 years of follow-up, time to treatment failure was similar in both groups.

However, researchers observed that after seven years, 83 percent of patients in the maintenance rituximab group had not been treated with a first cytotoxic therapy, compared with 63 percent of patients in the retreatment group. At 10 years, 66 percent of patients in the maintenance group and 30 percent of patients in the retreatment group remained in their first remission. The median response rate in the rituximab retreatment group was 3.25 years. No difference was observed in overall survival. Researchers noted that both dosing strategies delayed time to first cytotoxic therapy compared with the historical three-year benchmark for a “watch and wait” (active surveillance) approach.

*This study also included contributions from LRF SAB member and Past-Chair, Thomas M. Habermann, MD of Mayo Clinic Rochester; LRF Mantle Cell Lymphoma Consortium (MCLC) member Timothy S. Fenske, MD of Medical College of Wisconsin; and LRF Philadelphia Lymphoma Rounds Steering Committee member Stephen J. Schuster, MD of Hospital of the University of Pennsylvania.*



.....  
**Pamela B. Allen, MD**  
 .....

### No Difference in Survival Among Black Patients with Cutaneous T-Cell Lymphomas in Multicenter Analysis

Large registry studies in the United States have revealed lower rates of survival and a propensity for high-risk features in Black patients with mycosis fungoides and Sézary syndrome compared with other races and ethnicities. Lymphoma Research Foundation grantee Pamela B. Allen, MD of Winship Cancer Institute at Emory University presented the results of a retrospective review, funded in part by LRF, which aimed to determine drivers of disparities in cutaneous T-cell lymphoma (CTCL) outcomes.

Outcomes from 417 patients across six academic institutions serving high numbers of Black patients were reviewed. Nearly half of patients included in the analysis were Black; most of the rest of the population were White. The majority of patients (87.8 percent) had been diagnosed with mycosis fungoides, and 11.3 percent were diagnosed with Sézary syndrome; four patients were classified as “other.”

Compared with non-Black patients, Black patients had higher rates of lymphadenopathy (swelling of lymph nodes), higher rates of bacteremia (presence of bacteria in blood), and longer delays from the onset of symptoms to diagnosis (1.2 years vs. 2.0 years, respectively). Among these features, bacteremia was the only one found to be associated with inferior survival. Other features associated with inferior survival, including disease stage at diagnosis, were not significantly different between Black and non-Black patients.

In this population, race was not found to be associated with survival in mycosis fungoides or Sézary syndrome. The median survival was 10.5 years for Black patients and 10.9 years for non-Black patients. Researchers suggested that these results may be different from those reported by previous studies given the access to academic treatment centers and/or high rates of insurance coverage among Black patients in the population studied.

*This study also included contributions from LRF grantee Brian Greenwell, MD of Medical University of South Carolina.*

*Continued on the next page*



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**Alex F. Herrera, MD**  
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### **Pembrolizumab Plus HDAC Inhibition Exhibits High Response Rates for Hodgkin Lymphoma in Early Study**

Response rates to pembrolizumab (Keytruda) plus vorinostat (Zolinza), a histone deacetylase (HDAC) inhibitor, were high in anti-PD1 naïve/sensitivity relapsed/refractory Hodgkin lymphoma (HL), according to a study funded in part by LRF and presented by LRF grantee Alex F. Herrera, MD, of City of Hope.

Complete response rates to PD1 blockade are low, and treatment options for patients who progress are limited. In preclinical models, the addition of an HDAC inhibitor improves the antitumor activity of PD1 blockade. Researchers therefore sought to determine whether pembrolizumab plus vorinostat improved response rates in relapsed/refractory HL in an early, phase 1 study. The study included 32 patients, of which 56 percent were PD1 refractory.

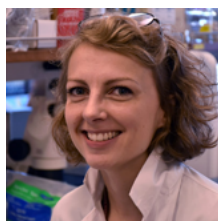
Nearly three-quarters of patients responded to pembrolizumab plus vorinostat treatment in the study, and one-third experienced a complete response. Response rates were lower among those who were refractory to PD1 blockade (56 percent) than anti-PD1 naïve/sensitive patients (93 percent), but six out of 10 refractory patients with PD1 blockade as their most recent therapy still experienced some response to treatment. The median duration of response was 14 months in all patients, and the one-year overall survival rate was 93 percent.

Researchers also noted that pembrolizumab plus vorinostat is in early phase studies in patients with diffuse B-cell lymphoma (DLBCL) and follicular lymphoma (FL).

*This study also included contributions from LRF grantee and LRF Mantle Cell Lymphoma Consortium (MCLC) member Stephen J. Forman, MD of City of Hope; LRF grantee Leslie Popplewell, MD, FACP of City of Hope; LRF MCLC member Elizabeth Budde, MD of City of Hope; and past Scientific Advisory Board (SAB) members Larry W. Kwak, MD, PhD and Steven T. Rosen, MD of City of Hope.*



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**Ari Melnick, MD**  
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**Coraline Mlynarczyk, PhD**  
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### **BTG1 Mutation Is Associated with Aggressive Lymphomagenesis in Human and Animal Models of Diffuse Large B-Cell Lymphoma**

A recurrent mutation in BTG1 is associated with a “super-competitive” B-cell phenotype in both mice and humans and may promote the development of aggressive diffuse large B-cell lymphoma (DLBCL), according to research, funded in part by LRF, presented by LRF grantee Coraline Mlynarczyk, PhD, of Weill Cornell Medicine.

Using genetic covariate analysis, a team of researchers led by LRF grantee and Scientific Advisory Board (SAB) member Ari Melnick, MD, of Weill Cornell Medicine identified mutations in the BTG1 gene as a common genetic driver of DLBCL. When the most frequent of these mutations, Q36H, was engineering into a mouse model, germinal center B-cells exhibited a significant competitive advantage over wildtype cells, virtually overtaking germinal B-cell populations. A similar fitness advantage was observed in B-cells taken from patients with BTG1 mutations.

Using RNA sequencing experiments in mutant and wildtype mouse and human B-cell lines, the Q36H mutation in BTG1 was found to be associated with upregulation of Myc target genes. This activity was determined to be the result of disruption of Myc translational regulation, which resulted in increased Myc protein synthesis. In germinal B-cells, Myc induction corresponds with cell cycle progression, and BTG1 mutation was found to be associated with faster progression through the cell cycle.



**50%**  
of LRF grantees  
authored abstracts

In a mouse model of DLBCL, mice with the Q36H BTG1 mutation exhibited earlier onset of lymphoma, dysplastic B-cell infiltration into non-lymphoid organs, and shorter survival relative to non-BTG1 mutant mice. These results were similar to what was observed in human patients with activated B-cell-like DLBCL, in which BTG1 mutations were associated with worse clinical outcomes and reduced overall survival.

The authors concluded that mutations in BTG1 result in a “super-competitive” B-cell phenotype, in which enhanced Myc induction accelerates germinal B cell dynamics and confers a fitness advantage over healthy B cells, potentially leading to the formation of aggressive lymphomas.

*This study also included contributions from LRF grantee and SAB member David Scott, MBChB, PhD, FRCPC of BC Cancer, Vancouver; LRF grantee Hannah M. Isles, MD of Weill Cornell Medicine; and New York Lymphoma Rounds Steering Committee member Amy Chadburn, MD of Weill Cornell Medicine.*



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**Lisa Rimsza, MD**  
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**Allison C. Rosenthal, DO**  
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### High MCL35 Score Is Predictive of Poor Survival in Older Patients with Mantle Cell Lymphoma Treated with Bendamustine-Rituximab

A variety of risk stratification tools are available to help guide treatment decision making in newly diagnosed mantle cell lymphoma (MCL) but are infrequently used. In a study funded in part by LRF and led by LRF Scientific Advisory Board (SAB) and Mantle Cell Lymphoma Consortium (MCLC) member Lisa M. Rimsza, MD, of Mayo Clinic, Phoenix, researchers examined the prognostic value of the MCL35 assay in older patients (aged 65-93) with MCL who were treated with frontline bendamustine (Treanda) plus rituximab (Rituxan).

The MCL35 assay was performed on 119 archived tissues samples across multiple treatment sites. The results of the MCL35 assay, presented by LRF grantee Allison C. Rosenthal, DO, of Mayo Clinic, Phoenix, were used to stratify patients into three risk groups: low (51 patients), standard (39 patients), and high risk (29 patients).

After a median 33.4 months of follow up, 82 patients were alive and 35 had died. Overall survival rates were significantly lower in the high-risk group compared with the low-risk group. Twelve out of 18 cases with blastic/pleomorphic morphology, which was associated with worse survival than classic MCL, were observed in the high-risk MCL35 group. No difference in survival was observed between the standard- and low-risk groups.

Other risk assessment measures, including high s-MIPI and positive p53 immunohistochemistry status, were also found to be associated with reduced survival rates.

The researchers noted that further validation of the MCL35 assay in a larger sample size is planned, but added that preliminary results suggest that the MCL35 assay may be useful in combination with other risk assessment tools to help guide risk-based treatment stratification, particularly in clinical trials.

*This study also included contributions from LRF grantees and SAB members Thomas M. Habermann, MD of Mayo Clinic, Rochester and David Scott, MBChB, PhD, FRCPC of BC Cancer, Vancouver; LRF grantee and Mantle Cell Lymphoma Consortium (MCLC) member Elias Campo of Hospital Clinic University of Barcelona; and LRF grantee Jonathan Cohen, MD, MS of Winship Cancer Institute at Emory University.*



**41%**

of LRF Scholars presented abstracts

**91%**

of LRF's Scientific Advisory Board (SAB) members were involved in abstracts



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**Jacob Soumerai, MD**  
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**Andrew D. Zelenetz, MD, PhD**  
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### **Minimal Residual Disease Kinetics Identified as a Predictor of Zanubrutinib-Obinutuzumab-Venetoclax Treatment Response in CLL**

Minimal residual disease (MRD) kinetics were found to be predictive of achievement and durability of undetectable MRD with zanubrutinib-obinutuzumab-venetoclax (BOVen) treatment in patients with chronic lymphocytic leukemia (CLL), according to trial results presented by LRF grantee Jacob D. Soumerai, MD of Massachusetts General Hospital Cancer Center.

In a multicenter, phase 2 trial funded in part by LRF and led by LRF Scientific Advisory Board (SAB) Immediate Past-Chair and current member Andrew D. Zelenetz, MD, PhD of Memorial Sloan Kettering Cancer Center, patients with previously untreated CLL received BOVen in 28-day cycles for eight to 24 cycles, until undetectable MRD in peripheral blood and bone marrow was achieved.

At a median 26 months of follow up, 33 out of 37 patients achieved undetectable MRD in peripheral blood. Undetectable MRD in bone marrow was observed in 33 patients at a median eight months, all of which discontinued treatment after a median 10 months. These results demonstrated a frequent and durable achievement of undetectable MRD in patients with CLL with BOVen treatment.

Additionally, a  $\geq 400$ -fold reduction in peripheral blood MRD was found to be highly predictive of undetectable MRD in bone marrow within eight months. The median duration of treatment was consequently shorter in patients who achieved this metric (eight months vs 13 months for those who did not). However, researchers found that despite a shorter treatment duration, these patients experienced longer MRD failure-free survival.

The researchers suggested that further studies are needed to determine the utility of MRD kinetics as a biomarker to predict BOVen treatment duration.

*This study also included contributions from LRF grantees Connie Batlevi, MD, PhD, and Anita Kumar, MD and Lia Palomba, MD of Memorial Sloan Kettering Cancer Center; LRF grantee P. Conner Johnson, MD of Massachusetts General Hospital Center; New England Lymphoma Rounds Steering Committee members Jeremy Abramson, MD and Jeffrey Barnes, MD, PhD of Massachusetts General Hospital Cancer Center; and New York Lymphoma Rounds Steering Committee member Anthony Mato, MD of Memorial Sloan Kettering Cancer Center.*



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**Christopher R. Flowers, MD, MSc**  
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### **Polatuzumab Vedotin Reduces Risk for Disease Progression in Previously Untreated Diffuse Large B-Cell Lymphoma**

The current standard of care for newly diagnosed diffuse large B-cell lymphoma (DLBCL), R-CHOP (rituximab [Rituxan], cyclophosphamide [Cytosan], doxorubicin [Adriamycin], vincristine [Oncovin], and prednisone) is not effective for all patients, such that 40 percent of patients remain uncured.

In the phase III POLARIX study, a team of investigators led by LRF Scientific Advisory Board (SAB) member Christopher R. Flowers, MD, MSc of the University of Texas MD Anderson Cancer Center compared the efficacy of standard R-CHOP with that of a modified drug regimen, in which vincristine was replaced with the antibody-drug conjugate polatuzumab vedotin (pola-R-CHP). A total of 879 patients with intermediate- to high-risk diffuse large B-cell lymphoma were included in the trial.

The investigators observed that after 28.2 months of follow up, patients who received pola-R-CHP had a 27 percent lower risk for disease progression, relapse, or death compared with those who received standard R-CHOP. The two-year progression-free survival rates were 76.7 percent among those treated with pola-R-CHP and 70.2 percent among R-CHOP-treated patients. Overall survival rates between groups were not significantly different.

While complete response rates were similar between groups, fewer patients in the pola-R-CHP-treated group received subsequent anti-lymphoma therapy (23 percent) than in the R-CHOP-treated group (30 percent), investigators noted that disease-free survival rates suggested patients treated with pola-R-CHP experienced more durable responses than those treated with R-CHOP.

The results of the POLARIX trial were published in the New England Journal of Medicine on December 14, 2021.

*This study also included contributions from LRF grantee and SAB member Jonathan W. Freidberg, MD of Wilmot Cancer Institute, University of Rochester; LRF SAB member Laurie Sehn, MD of BC Cancer Centre for Lymphoid Cancer; and LRF grantee Neha Mehta-Shah, MD of Washington University in St. Louis.*

### **Pivotal Data on CAR T Cell Therapy and Emerging Construct Presented at ASH**

Investigation into the use of chimeric antigen receptor (CAR) T cell therapies has expanded rapidly in recent years, including for hematologic malignancies. Results from several key studies were presented at the 2021 Annual ASH Meeting, which demonstrated the use of these emerging therapies in multiple lines of therapy, new disease states, and using novel constructs to enhance responses.

Among these were results from the ZUMA trials, including long-term survival data from the original phase III ZUMA-1 trial examining the use of axicabtagene ciloleucel (axi-cel) in adults with refractory large B-cell lymphoma after two or more lines of prior therapy. Investigators reported that at five years, the overall survival rate among patients treated with axi-cel was 42.6 percent. Additionally, among those alive at five years, 92 percent needed no additional anti-cancer treatments since their first infusion of axi-cel, suggestive of a potential cure for these patients.

Results from the phase III ZUMA-7 trial supplemented those observed with ZUMA-1, demonstrating the efficacy of axi-cel relative to standard of care (high-dose therapy with autologous stem cell transplant) in relapsed/refractory large B-cell lymphoma in the second-line treatment setting. In this trial, 2.5-times as many patients in the axi-cel-treated group were alive after over two years of follow up than in the standard of care group, and median event-free survival was over 4-times greater for axi-cel-treated patients (8.3 months) than for the standard of care group (2.0 months).

Similar results were observed in the TRANSFORM trial, which also examined the efficacy of a novel CAR T cell therapy (lisocabtagene maraleucel; liso-cel) as second-line treatment for patients with relapsed/refractory large B-cell lymphoma. In this trial, the median event-free survival for liso-cel-treated patients with 10.1 months, compared with 2.3 months for the standard of care group. Progression-free survival and complete response rates were also higher for patients who received liso-cel compared with those who received standard of care.

Results from the phase II ZUMA-12 study suggest that CAR T cell therapies may also benefit patients with high-risk large B-cell lymphoma even earlier in disease. In this study, 89 percent of newly diagnosed patients who received a single dose of axi-cel achieved a response, including 78 percent who achieved a complete response at a median 15.9 months of follow-up. Collectively, these results suggest that patients across the spectrum of large B-cell lymphoma may benefit from CAR T cell therapies.

Emerging results from other disease states were also reported. In the phase 2 ZUMA-5 trial, the overall response rate among patients with relapsed/refractory indolent non-Hodgkin lymphoma who received axi-cel was 92 percent, with a complete response rate of 75 percent.

In addition to existing CAR T cell constructs, early results using a novel CAR T cell construction platform were also described, which simplifies and shortens manufacturing and preserves naïve and stem cell memory T cells. Using a novel construct developed using this system (YTB323), investigators observed overall and complete response rates of 75 percent in patients with relapsed/refractory diffuse large B-cell lymphoma (DLBCL) in a phase I study, and expect to see enhanced durability of responses with longer follow up. ○

## **WATCH: UPDATES FROM THE 2021 AMERICAN SOCIETY OF HEMATOLOGY ANNUAL MEETING WEBINAR**

Learn more about pivotal lymphoma research presented at the 2021 American Society of Hematology (ASH) Annual Meeting from Brad Kahl, MD of Washington University School of Medicine in St. Louis and Deborah Stephens, DO of the Huntsman Cancer Institute, University of Utah. **View the 2021 ASH webinar on demand at [lymphoma.org/webinars](https://lymphoma.org/webinars)**

## WHERE ARE THEY NOW?

# ANITA KUMAR, MD



Dr. Anita Kumar is a medical oncologist at Memorial Sloan Kettering Cancer Center (MSK) and Regional Care Network Medical Site Director at MSK Basking Ridge, N.J.

### When did you become interested in the study of lymphoma?

I did my internal medicine training at the Brigham and Women's Hospital in Boston, initially thinking I wanted to pursue a career in cardiology. The two biggest programs there were cardiology and oncology. I started my intern year on the oncology service with Dr. Ann LaCasce, who is a lymphoma specialist at the Dana-Farber Cancer Institute and Chair-Elect of the Lymphoma Research Foundation's Scientific Advisory Board (SAB). She was such an inspiring teacher, mentor, and clinician—a compassionate doctor who cared deeply for all of the patients and a talented teacher in the field of hematologic malignancies. I feel so lucky I met her earlier in my career and benefited from her guidance. She remains an important role model to me and is definitely one of the biggest reasons I decided to study lymphoma.

I conducted a subsequent research project with Dr. LaCasce and Dr. Gregory Abel at Dana-Farber, looking at central nervous system (CNS) prophylaxis in diffuse large B cell lymphoma (DLBCL) using the National Comprehensive Cancer Network (NCCN) database. Because of that research, I was mentored by Dr. Craig Moskowitz, a lymphoma specialist and leading investigator in the field of Hodgkin lymphoma (HL), when I began my fellowship at Memorial Sloan Kettering Cancer Center (MSK). Dr. Moskowitz is also a past member of the LRF SAB and current member of the LRF Mantle Cell Lymphoma Consortium (MCLC). Similarly, he was a wonderful role model—such a caring physician, an inspiring clinical researcher, and a talented mentor who really believed in the success of his mentees, supporting our development and celebrating our successes.

I also enjoyed seeing lymphoma patients. Of course, the disease biology is interesting. It's clinically and biologically heterogeneous; there are many different subtypes of lymphoma. It can be curable. It can also be manageable over the course of a lifetime. When I started my career about 10 years ago, there were a number of new therapies being developed. And since then, there's been an explosion in terms of the research and the advances in the field.

### At what point in your career did you receive funding from LRF? What kind of grant did you receive?

I first received funding from the LRF Lymphoma Scientific Research Mentoring Program (LSRMP). That was a great program during my fellowship at MSK, where I submitted a project I'd been working on with Dr. Moskowitz for



a novel treatment program of brentuximab vedotin (Adcetris) and AVD (doxorubicin [Adriamycin], vinblastine [Velban], and dacarbazine) chemotherapy for early-stage, unfavorable-risk HL patients. My time in the LSRMP was tremendous. The Scholar class came together for a week-long intensive workshop with incredible mentors across the field of lymphoma from many different institutions. I received specific feedback on my LRF research project, which was valuable because I was writing the protocol and designing the clinical trial. But there was also a curriculum that offered general advice about how to build a successful career in the field of lymphoma. I remember many leaders in the field gave such great talks about how to support a research program, how to receive funding, and how to publish successfully in top peer-reviewed journals. I found that advice and mentorship so valuable.

### **What were you hoping to achieve with your LRF research grant?**

My LRF research grant studied a novel combination of an antibody drug conjugate for brentuximab vedotin that targeted CD30 and is linked to monomethyl auristatin E (MMAE), in conjunction with a standard AVD chemotherapy. The purpose of using this combination was to see whether we could potentially reduce or limit the extent of radiation required for patients who presented with bulky mediastinal early-stage HL to limit the long-term side effects of treatment.

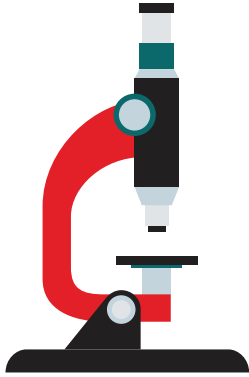
### **Was the grant funding you received from LRF vital to advancing your career in studying the disease and treating people with lymphoma?**

Absolutely! The Lymphoma Research Foundation has been such a tremendous support during my career. I feel so grateful to LRF for the way in which it helped introduce me to important leaders in the field to gain helpful advice and guidance about how to develop a successful academic or research career. That began in the LSRMP. But I was also fortunate to receive an additional grant from LRF, a clinical career development award (CDA) for a clinical trial studying ibrutinib (Imbruvica) in T-cell lymphoma.

The treatment was not successful in the sense that we did not further develop the use of ibrutinib in T-cell lymphoma because it did not have a high level of activity in that disease. But we did learn that ibrutinib alone is not a viable option to treat the disease. Nevertheless, garnering that research support and being a part of the LRF community has been tremendously valuable in terms of learning how to successfully write a grant and design and execute a clinical trial. In addition, through LRF I've learned how to successfully write up the results from a study, even if they're negative results, and what you can learn from a study that can help you gain new insights into developing a better treatment. And then how do you also collaborate with others, not only for ongoing mentorship, but also for collaboration, for correlative science and for multicenter efforts? All of those things I've taken away from my funding and support from the LRF have been tremendously valuable.



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**“[The Lymphoma Research Foundation] helps advance life-saving research, helping fund crucial clinical trials and research endeavors that have contributed to many FDA approvals and advancement in the field.”**

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**How has your LSRMP and CDA research impacted the work you do today?**

Although I've shifted from HL and T-cell lymphomas, the support I received from LRF through my participation in the LSRMP and CDA helped to set the stage in my work in mantle cell lymphoma (MCL), where I currently lead the Mantle Cell Lymphoma Research Program at MSK. Many of the principles and themes I learned in the context of the LSRMP program and workshop and ongoing leadership and training, as well as the skills I developed, have helped build a strong foundation for developing a successful research career more broadly.

Recently, my LSRMP Scholar class got together again, and we continue to maintain those professional ties. I continue to get great advice from and continue to touch base with my mentors from the program. Being part of that broader lymphoma family across the country, and even beyond, has been so valuable. Many questions we can't answer alone at our own institutions, and many of the diseases we treat are rare diseases. So, we need those collaborations and that network. We need those connections to be able to answer the most important questions for our patients.

**Much progress has been made in the development of targeted therapies to treat lymphoma/chronic lymphocytic leukemia (CLL). Can you describe your work in the realm of targeted therapies? Why are these therapies important and why do they represent a new frontier in the treatment of lymphoma?**

The concept with targeted therapies is that each case of lymphoma is unique. And if we understand the disease biology and its molecular underpinnings, we can potentially design more individualized therapies that allow us to target the pathways or the mutations most critical for the survival of that lymphoma. For example, genomic profiling of many of our patients with lymphomas can help us understand the pattern of mutations in each specific patient. Then, we can try to use that information

to understand what's driving that cancer cell to grow and how we can target this at a molecular level.

And there have been a number of targeted therapies. For example, Bruton's tyrosine kinase (BTK) inhibitors have been an important treatment development in the field of lymphoma and CLL that have revolutionized the treatment for patients with MCL, because we understand there's chronic activation of the B cell receptor pathway and BTK sits within that pathway. Targeting that site can be very effective to treat MCL patients. Similarly, we continue to learn more about the mutational profiles and the molecular underpinnings of the different histologies and subsets within lymphoma to try to personalize therapy for our patients.

**How has your involvement with LRF evolved since receiving an early career grant?**

I continue to be involved with LRF in a variety of educational programs. The Foundation has great programming for our [MSK] patients in New Jersey and in New York. And as speaking faculty for their education programs, I've been able to help engage with other patients and their loved ones on topics like clinical trials and the basics of lymphoma. It's important to educate not only at a one-to-one level with our own patients, but also more broadly within the lymphoma community. LRF has also proven to be a wonderful leader in the scientific and academic clinical community. It hosts a number of different scientific workshops that allow us to get together as a scientific community and collaborate.

**Why is LRF's mission and focus on lymphoma-specific research and research programming so important? How would the lymphoma community be impacted if there was no LRF?**

The Lymphoma Research Foundation helps in so many different ways. It helps advance life-saving research, helping fund crucial clinical trials and research endeavors

that have contributed to many FDA approvals and advancement in the field. And it has contributed to supporting many of our research and clinical careers. It also serves as a vital source of education and counseling. It brings patients together who have similar experiences, so they can support each other. It also provides patients with actual resources, whether it's financial support or just connection, psychosocial support, or community. All of those dimensions are important.

It brings the lymphoma experts closer to individual patients. We know only a fraction of patients can receive their care in a medical or academic center. But LRF democratizes that type of expertise. So, you have many lymphoma experts who will come together for the "Ask the Doctor" patient education series, where patients living in smaller cities, towns, and communities can ask specific questions about new treatments and research in their disease area.

#### **What research or projects are you currently pursuing that you would like to share with our readers?**

One of the most important is the BOVen study, which is a combination of zanubrutinib (Brukinsa), obinutuzumab (Gazyva), and venetoclax (Venclexta), for high-risk MCL patients. We know patients with P53 mutant MCL do poorly with current chemo immunotherapy or standard chemo immunotherapy programs. This is a novel combination of targeted therapies, which we believe has strong biologic rationale for having a higher degree of activity in patients with high-risk MCL. And this is a clinical trial open here at MSK and at Mass General Hospital in Boston. It is a rare subset of an already rare disease, so we are trying to get the word out about this trial because we've seen exciting activity thus far. We believe it represents an unmet need within the field of MCL.



**"Having individualized treatment planning based on a strong understanding of a specific disease biology is the next frontier and what makes me really excited about the work we're doing in the field of lymphoma."**

#### **What are you most excited about in the field of lymphoma research today? Why?**

One of the things that makes me very excited, especially in the field of MCL research, is that we're moving away from a one-size-fits-all approach. There's an interest in learning as much as we can about a patient's individual disease profile, their specific biologic and clinical characteristics, so we can tailor our treatment programs based on a patient's disease biology and their clinical features. This way, patients have received treatments that have the highest likelihood of having excellent clinical activity, but also consider maintaining a patient's quality of life and minimizing toxicities. Just because we have a hammer, doesn't mean everyone needs to receive the same "hammer."

Having individualized treatment planning based on a strong understanding of a specific disease biology is the next frontier and what makes me really excited about the work we're doing in the field of lymphoma. ○

## **LATEST U.S. FOOD AND DRUG ADMINISTRATION (FDA) APPROVALS**

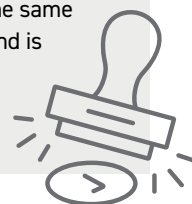
The U.S. Food and Drug Administration (FDA) is responsible for the approval of drugs, including biological products, for human use in the United States.

### **RITUXIMAB (RITUXAN)**

**December 2, 2021** — a monoclonal antibody approved in combination with chemotherapy for pediatric patients aged at least 6 months to 18 years with previously untreated, advanced staged, CD20-positive diffuse large B-cell lymphoma (DLBCL), Burkitt lymphoma (BL), and Burkitt-like lymphoma (BLL).

### **SPIKEVAX (MODERNA COVID-19 VACCINE)**

**January 31, 2022** — a COVID-19 vaccine approved for individuals 18 years of age and older. Spikevax has the same formulation as the EUA Moderna COVID-19 Vaccine and is administered as a primary series of two doses, one month apart.





# GANGSTAGOOD *Kitchen*

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"I did not know much about lymphoma at the time, but I knew enough to know that it meant cancer."

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# COOKING UP INSPIRATION THROUGH LYMPHOMA

There's never a convenient time for a lymphoma diagnosis. But for 53-year-old mother of two Shelia Johnson, the poor timing of her cutaneous T-Cell lymphoma (CTCL) diagnosis left her laughing to herself saying, "God, you've really got some jokes for me now!"

Joy and determination are a few of the ways the effervescent Kansas City, Mo., native and Gangsta Goodies Kitchen founder has handled and survived her CTCL, a rare form of lymphoma, since being diagnosed 10 years ago. But this chronic illness wasn't her life's first big challenge.

Johnson had a daughter when she was 16, which she credits for making her the strong and caring person she is today. She later had a second daughter, and Johnson and her daughters moved in with her mother. A year later, she and her daughters were back out on their own beginning a fulfilling new life.

Then, she noticed hives on her thighs and back—raised, irritating red spots that itched persistently. She made an appointment to see an allergist. After several tests, he recommended she seek a second opinion from a dermatologist, who tested her for "a rare skin disease." While waiting for skin biopsy results, he referred her to another dermatologist who had more experience with African American patients. The biopsy test came back negative, and the hives went away with topical steroids. Johnson moved

on, and her life returned to normal...until another breakout six years later.

She returned to her allergist, who thought she might be experiencing an issue related to her immune system and referred her back to her dermatologist. At the dermatologist, she noticed a note in her file that read, "this patient should be tested for CTCL every six months." She asked the doctor to clarify what CTCL stood for and was stunned to learn it meant cutaneous T-Cell lymphoma.

"I did not know much about lymphoma at the time, but I knew enough to know that it meant cancer," says Johnson.

Cutaneous T-cell lymphoma is a general term for T-cell lymphomas that primarily involve the skin. T-cell lymphomas account for 5 to 10 percent of all non-Hodgkin lymphomas (NHL) in the United States. Clinical studies indicate that African Americans may be more susceptible to CTCL, particularly African American women. Additionally, African American women are likely to have more aggressive forms of CTCL compared to the average CTCL patient.

Johnson was then referred to the head of dermatology at the KU Medical Center. The new doctor evaluated her skin, reviewed her previous medical records, and ordered a skin biopsy, a blood sample, and an MRI. The blood sample and MRI confirmed a CTCL diagnosis.

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“I had just gone back to school, the girls had recalibrated, I met new friends, I helped start a book club and wine club, and I was traveling,” says Johnson. “Life was moving on, then...BOOM! This diagnosis.”

Having recently lost her cousin Claudia Johnson to breast cancer, feelings of shock and fear set in quickly. And because CTCL affects the skin, which everyone can see, Johnson began to turn inward and avoid others.

“I’m a social butterfly who loves people, but I didn’t go out because of my skin... I felt like people could look at me and tell that there was something going on,” says Johnson. “I always felt like my skin was my best physical attribute. So then for something to attack my skin, the emotional part of me was like – I can’t cover this up, and people are going to be able to look at me and know that there’s something going on.”

Treatment started with phototherapy, a treatment that uses ultraviolet light to decrease inflammation in the skin. She got into what resembled a tanning booth three times a week for three months. Unfortunately, the phototherapy was not enough, and increasing T-cell counts were cause for concern, so doctors suggested additional treatment.

“This is when I became emotionally unglued,” Johnson said. “So far, I have been able to stay focused and keep my emotions in check. But this time I let the fear get the best of me, and I just cried.”

She began photopheresis therapy—a medical treatment that removes blood via a machine that isolates white blood cells and exposes them to medication and UV light before returning the blood to the patient. Her doctors began to see good results, and she got to work on handling the emotional weight of her journey to survivorship. She confided to her therapist her anxieties and worries about mortality.

“She said, ‘Well, Shelia, what age do you want to be before you transition?’,” Johnson says. “And I said ‘90.’ She said, ‘Well then... 90 it is!’ And I thought, ‘You know what, you’re right. This is not going to be it. I’m going to live to be a 90-year-old spunky woman!’”

And then something clicked.

“It transitioned me out of having this, ‘Am I going to die today? Am I going to die tomorrow? Am I going to die next week?’ mindset,” she continued. “Now, mind you, I was diagnosed with stage 1A and in the grand scheme of it, no, I wasn’t going to die tomorrow or the next day. But because of my experience with my cousin, I felt like ‘Oh my God, this is it.’ It took me a couple of years to really wrap my mind around the diagnosis, and how I was going to choose to live with it, how I was going to choose to have it impact my life.”

She had her epiphany: “You can decide it’s going to control you, or you can decide to control it.”

Initially, Johnson had two photopheresis treatments every other week. She changed her diet to include healthier options, including more fruits and vegetables, and continually got better. Her T-cell counts were eventually cut in half, and she began getting two treatments every eight weeks. Since CTCL is chronic, there is no cure. However, she received news from her doctor that starting November 2021, she will only need two treatments every 12 weeks because her CTCL is now indolent (slow growing).

“There’s no treatment that will just come in and wipe this out because remember, we’re talking about my T-cells and you can’t wipe out T-cells,” says Johnson. “I always say I’m living successfully with CTCL. There is no cure yet. So, treatments are just a part of my life.”

The Lymphoma Research Foundation (LRF) has also made a significant impact on her life and recovery. She became a member of LRF’s Ambassador Program, consisting of lymphoma survivors and caregivers who help raise awareness of lymphoma by connecting with others in the community and sharing their personal journeys with the disease.



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**“As an [LRF] Ambassador, I’ve learned that sharing my story makes a tremendous impact and is a unique way of addressing the immediate need of someone newly diagnosed—the need for hope.”**

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“As an Ambassador, I’ve learned that sharing my story makes a tremendous impact and is a unique way of addressing the immediate need of someone newly diagnosed—the need for hope,” says Johnson. “By connecting with patients, I can help calm some of their anxiety. Then, of course, I’ve learned a lot about research. The lymphoma that I have is so rare, yet it amazes me that the amount of research being done, due in part to LRF. The Foundation saves lives – it just does.”

Johnson further inspires others through her passion for cooking, which she inherited from her mother – a Louisiana native and nurse who had that state’s well-known gift for cooking delicious cuisine and sharing it with others.

“I have two brothers, and we always helped prepare meals, whether one of us was chopping or setting the kitchen table,” she says. “Even though my mother often worked 10- to 12-hour shifts, we always had a home-cooked meal. She used that time to not just feed us but to teach my brothers and me that we had to work together on a team, we are a family unit, and we are here to help each other. I learned who my mother was in that kitchen. She would talk about her childhood, her upbringing, and her first love. The heart of our home was definitely the kitchen and the kitchen table.”

With that same heart and generosity, Johnson was inspired to do something different with her life and pursue her dreams.

“After my diagnosis, I wondered, ‘What am I here for? What is this human experience all about?’” says Johnson. “I knew that I wasn’t going to go back into corporate America, but what else was I going to do? And I have always been the one in my group of friends who if I hosted something, my friends were like, ‘Oh my God, we know we’re in for a treat! What are you going to cook for us this time?’”


While earning her MBA from Rockhurst University, Johnson had a mentor who asked her to consider her ideal role after graduation and dream big.

“What would you do if you could just create it yourself, what would it be?” says Johnson. “That’s easy – I would invite people into my space, and I would feed them first. Then I’d connect them with information, resources, and tools to elevate the quality of their lives.”

That was the genesis for Gangsta Goodies Kitchen, where she began to show the world how to cook some of her favorite dishes on YouTube. Then, her daughters encouraged her to share more about her personal life, including her CTCL journey. Her YouTube channel has grown to include special guests who cook with her and share their stories and passions, with a focus on community service.

“And that’s what Gangsta Goodies does,” says Johnson. “I often invite guests who are doing amazing work in our community and it’s a great way of getting that information out. We cook together, we eat together, and then I get a chance to interview them.”

While her day job is serving as a social services director for a family-owned property management company, Johnson published three cookbooks, started a catering business, and is set to launch a line of products, including an all-natural kitchen cleaner called “Mrs. Jones.” Plans are also underway to debut a “Gangsta Style” line of products for the home and kitchen, including cutting boards, spice racks, table runners, place mats, and coasters.

With her CTCL now under control, her daughters thriving and a joy that radiates from her healthy, glowing skin, Johnson has a bright future—and perhaps a few good-natured jokes to tell after her 90th birthday. 

## **WATCH: CUTANEOUS T-CELL LYMPHOMA (CTCL) FACEBOOK LIVE**

In honor of Rare Disease Day (February 28), the Lymphoma Research Foundation (LRF) sits with lymphoma expert Lucia Seminario-Vidal, MD (Moffitt Cancer Center) and CTCL survivor Shelia Johnson to discuss the diagnosis and treatment of CTCL, the patient experience, and research coming down the pike. Watch on demand on LRF’s Facebook page at [facebook.com/lymphomacommunity](https://facebook.com/lymphomacommunity), and follow LRF for more updates, news, and events.

# SCIENTIFIC ADVISORY BOARD

The Lymphoma Research Foundation's volunteer Scientific Advisory Board, comprised of 45 world-renowned lymphoma experts, guides the Foundation's research activities, seeking out the most innovative and promising lymphoma research projects for support.

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## UPCOMING EVENTS

Show Your Love .....	<b>2.1-2.28</b>
World Cancer Day .....	<b>2.4</b>
National Lymphoma Rounds .....	<b>2.10</b>
Rare Disease Day .....	<b>2.28</b>
New York Lymphoma Rounds .....	<b>3.9</b>
Washington DC Lymphoma Rounds .....	<b>3.22</b>
San Francisco Lymphoma Rounds .....	<b>3.24</b>
Young Adult Cancer Awareness Week .....	<b>4.4-4.10</b>
Chicago Lymphoma Rounds .....	<b>4.13</b>
Los Angeles Lymphoma Rounds .....	<b>4.19</b>
Philadelphia Lymphoma Rounds .....	<b>5.10</b>
National Lymphoma Rounds .....	<b>5.12</b>
New England Lymphoma Rounds .....	<b>5.17</b>

Want to receive information about Lymphoma Research Foundation events happening in your area?  
Visit [lymphoma.org/emailsignup](https://lymphoma.org/emailsignup) to select your email preferences and stay up to date with the latest from the Foundation.





Wall Street Plaza  
88 Pine Street, Suite 2400  
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## Commit to your future impact today.

When you include the Lymphoma Research Foundation (LRF) in your estate plan, you are investing in the most promising research that has the greatest potential to dramatically improve the lives of those impacted by lymphoma.

Thank you for ensuring LRF can serve those touched by this disease well into the future and, ultimately, eradicate lymphoma.

To learn more, contact Kate LeBoeuf at **646 531 5184** or **[kleboeuf@lymphoma.org](mailto:kleboeuf@lymphoma.org)**, or visit **[lymphoma.org/legacy](https://lymphoma.org/legacy)**.

