



PULSE

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LYMPHOMA
RESEARCH • FOUNDATION

PULSE

A Publication for Friends of the Lymphoma Research Foundation

LYMPHOMA
RESEARCH • FOUNDATION

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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LYMPHOMA RESEARCH FOUNDATION'S YOUTUBE CHANNEL

The Lymphoma Research Foundation's YouTube channel offers a wide variety of educational videos to help the lymphoma community learn about lymphoma. These videos provide disease-specific information as well as education regarding diagnosis, treatment options, clinical trials, and other resources for people dealing with a lymphoma diagnosis.

Visit [YouTube.com/c/LymphomaResearch](https://www.youtube.com/c/LymphomaResearch) to watch and subscribe.

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Update on Lymphoma from the 2023 ASH Annual Meeting

The Lymphoma Research Foundation (LRF) hosts more than 50 free patient education programs each year to provide members of the lymphoma community with up-to-date information about lymphoma and treatment options. **These patient education programs include Ask the Doctor About Lymphoma, Lymphoma Workshops, Webinars, and the North American Educational Forum on Lymphoma** for people with lymphoma and their loved ones.

Whether you are newly diagnosed, want detailed information about your lymphoma subtype, are looking for ongoing support, or seeking help with long-term survivorship, LRF is here to help.

Visit **lymphoma.org/programs** to register and learn more.

FROM THE CEO

At the Lymphoma Research Foundation, our mission drives us toward a single goal: a world free of lymphoma. Our work toward this vision of the future is made possible by the commitment of an entire community – the leadership and guidance of our expert Scientific Advisory Board (SAB) members, the dedication of our grantees who are pushing the next generation of lymphoma research forward, the tireless voices of our advocates, and the support and compassion of those like you.

In this issue of *Pulse*, we profile Zachary Epstein-Peterson, MD from the Memorial Sloan Kettering Cancer Center. For Dr. Epstein-Peterson, his deep relationships with his patients are at the core of all that he does. These connections are why he's grateful for organizations like the Lymphoma Research Foundation that put lymphoma patients and the researchers working to find them new therapies and cures at the forefront.

We are also pleased to introduce you to the newest member of the Foundation's prestigious Scientific Advisory Board, Markus Müschen, MD, PhD Director of the Center of Molecular and Cellular Oncology at Yale University, whose expertise and leadership will steer the Foundation forward. This issue also highlights the challenges that cancer survivors can face, even after their time in active treatment is over, and the much-needed advocacy work being done to ensure that standards of care are improved upon at every point in a patient's lymphoma journey. I sat down with Congresswoman Debbie Wasserman Schultz to discuss the bipartisan Comprehensive Cancer Survivorship Act, her groundbreaking piece of legislation that would transform the field of survivorship research and healthcare.

Finally, finding moments of levity and joy amid a lymphoma diagnosis can feel difficult – but for Anthony Corrado, creating humorous TikToks that shared his journey with his audience provided a much-needed opportunity for laughter and support. In this issue's Story of Hope, Anthony shares how humor – along with the commitment of his Chicago Lymphoma Walk team, Tony's LymphOMIES, who raised over \$24,000 to support patients like him – has served as both an outlet during treatment and a way to connect with and inspire others.

As we approach this season of giving, I want to express my gratitude to you and thank you for your ongoing support as we work toward a brighter future for all those touched by this disease.

Sincerely yours,



Meghan Gutierrez
Chief Executive Officer



PHILANTHROPY IN ACTION



INAUGURAL LRF GIVING DAY RAISES OVER \$32,000

Each year, September 15 marks World Lymphoma Awareness Day, with a number of buildings and landmarks across the globe lighting up red to spread lymphoma awareness worldwide. This year, September 15 held even more special significance as we also marked the inaugural LRF Giving Day, a celebration of all that we make possible together and the work that we do in support of lymphoma patients and critical blood cancer research. Together, the lymphoma community raised over \$32,000 on LRF Giving Day 2023 to power the next generation of lymphoma research and to give hope to patients in need.



LRF ANNUAL GALA RAISES MORE THAN \$1M

Hope means something different to everyone: a promising new treatment, a breakthrough in research, a lifeline during a difficult moment, and the promise of brighter days ahead. The LRF Annual Gala this year celebrated these Stories of Hope from across the lymphoma community at the Ziegfeld Ballroom in New York City on September 28. This year's event honored Kara M. Kelly, MD, of Roswell Park Comprehensive Cancer Center, with the Distinguished Leadership Award and Genmab with the Corporate Leadership Award in recognition of their commitment to serving the lymphoma community and advancing cures. This year's event, which featured an exciting live auction, a rousing *Raise it For LRF* segment, and the inaugural Emerging Philanthropists After-Party, raised over \$1.1M in support of LRF's mission.



2023 LYMPHOMA RESEARCH RIDE RAISES MORE THAN \$105,000

Ninety riders took to the back roads of Montgomery County, Maryland, on Sunday, October 1 as they cycled to raise critical funds to power LRF's research programs. The event kicked off at the foot of Sugarloaf Mountain and featured both 25- and 50-mile rides through beautiful landscapes offering panoramic views. Afterward, cyclists toasted their successes at an after-party held at the historic Comus Inn, celebrating the more than \$105,000 they raised to fund the future of lymphoma research.

Did you know that LRF hosts and partners with endurance events like the Los Angeles Marathon, TD Five Boro Bike Tour, and the Disneyland Half Marathon so that you can train, challenge yourself, and fundraise to support LRF's mission? To learn more, visit lymphoma.org/endurance today.



ROUNDUP

The RoundUp app is a powerful new way to support LRF while you shop this holiday season. This service allows you to donate the “spare change” from credit card transactions made on any cards linked to your RoundUp account – effectively rounding up every transaction to the nearest whole dollar without any effort from you.

These small donations can make a major impact on the lymphoma community – consider using the RoundUp app, available through both Google Play and the Apple App Store, to support LRF while you shop!



ROUNDUP APP

**PEDALING TO
SUPPORT LRF'S
MISSION,**

1

MILE AT A TIME



Jim Baker cycles every day to stay in shape, clear his head, and do his best thinking. His passion for cycling is one he shared with his wife, Pia Samson, who was an avid cyclist in her own right. After Pia passed away from primary central nervous system (CNS) lymphoma in 2021, Jim found a whole new and deeper meaning in their shared hobby to support the Lymphoma Research Foundation (LRF).



Jim and Pia met in 2016 in Washington, D.C., through their jobs. The two quickly bonded over a love of cycling and cocktails, and a romance ensued. Jim recalls how they realized that they were “a perfect match for each other” from Day One. He was skilled in long-distance cycling, while Pia knew how to expertly navigate street cycling within the city. “We really clicked so well together. She was such a little bundle of fun and joy,” Jim says of Pia. “We were soul mates.”

Jim and Pia soon moved in together before moving to Virginia and later to California, where Jim’s two teenage sons reside. Pia worked for Jim’s technology company, and they loved traveling the world together. When the COVID-19 pandemic hit in March 2020, Jim decided to relocate the family to their rural farmhouse in England.

Taken Before Her Time

One evening that April, Pia was painting at the kitchen table while Jim was cooking, when she suddenly fell. “It was like she had had a stroke. She couldn’t move on her left side,” he says. A scan at the hospital revealed a “strange blur in her brain,” and she was ultimately diagnosed with CNS, an aggressive form of non-Hodgkin lymphoma.

With private UK hospitals reserved specifically for COVID patients at that time, Pia was transferred back to the U.S. for treatment. “Because it was COVID, it was very, very hard. No one could visit her. It was very isolating for her,” Jim says. He was finally able to get back into the States to join Pia that summer.

Pia made progress at first and went into remission in October 2020 before relapsing three months later.

This time, the lymphoma had spread. “She fought for her dignity and fought for her life,” Jim says, until she passed away peacefully on April 17, 2021 – almost exactly a year after she had first developed symptoms. “She was so strong,” Jim recalls.

Pia was only 44 years old when she succumbed to lymphoma. “We were expecting to have at least double that in our lives for the things that we wanted to do and the places that we wanted to go,” says Jim. “It was not her time,” he insists. “We didn’t have the longest time together, but she was the love of my life.”

Cycling for a Cure

While coping with such a devastating loss, Jim never wavered in his gratitude for the excellent care Pia received. “I was so grateful to the doctors, and nurses, and professionals who have made their careers out of looking after people who have this disease. I wanted to find any way I could of giving back to the community to support the work that they do,” he says.

LRF resonated with him most because of its focus on research and education. “To understand how this comes about in the first place, you have to go in at a certain level and tackle it at its root,” says Jim. “That’s how we will get to the crux of the matter the fastest,” he reasons, by investing in research to understand the disease, raise awareness, and, ultimately, save lives.

After contemplating how he could give back to the lymphoma community, he landed on the idea of organizing a fundraiser through a memorial bike ride across America. “I love cycling, Pia loved cycling, and I knew it would be a way to honor her memory while also raising money for a really good cause,” he explains.



Jim biked 3,150 miles along the Adventure Cycling Association's Southern Tier route in 35 days.

"If there is something that we can do after seeing this tragedy that's befallen us — contribute back and make a difference, make a change — I will do anything to support that."

In November 2021, Jim set out to raise \$10,000 over the following year. Thanks to his supportive network, he not only hit but exceeded that goal and raised \$11,125. Embarking on his journey from San Diego, California, on September 5, 2022, Jim biked 3,150 miles along the Adventure Cycling Association's Southern Tier route in 35 days. He ended his journey in St. Augustine, Florida, on October 15, 2022 – on the very beach where he and Pia's parents had scattered her ashes into the ocean just a year and a half earlier.

Jim describes how he felt Pia's presence on this epic journey and how it helped improve his overall well-being. "I was able to talk to her in my own way every day on that crossing," he says. "For me, it was this incredible catharsis because I didn't have an outlet for my grief, and I needed something to put my energy into. That bike ride really helped me get this pain out through just sheer sweat and activity."

Support Is a Two-Way Street

In hindsight, Jim now sees how there were early signs of Pia's lymphoma before she fell at the dinner table that night. "She was having difficulty grasping words, or she was repeating herself a little. I had no clue at the time," he says. "But now I look back. It's like, oh my gosh – yes. We have to become more aware."

Jim emphasizes how increased awareness can help others combat lymphoma. "It opened my eyes to so many things, and now I take a little more care of myself, and I advise other people to really check up," he says. "I am more aware now of how important it is to check your body physically."

In recognition of his fundraising efforts, LRF honored Jim as Rookie of the Year during its inaugural Fundraise Your Way Awards in March 2023. He is humbled by how this has brought him even closer to the organization. "I've still been coming to terms with grief, but I'm in a happier place than I was two years ago. It's things like this that help you get there. I've had as much support from LRF as I've given them," he says. "That gives me something to look forward to and something to say to keep going. Pia would want this. It's about bonding and supporting each other."

Planning to do another ride in the spring of 2024 from Canada to Mexico, Jim's ambition is to contribute to LRF annually in memory of Pia.

"Pia unfortunately was in the percentage of people who didn't recover," Jim acknowledges, but he hopes his contributions to LRF can help others have a different outcome. "That's what research into lymphoma is all about," he says. If a treatment doesn't work, he advises, "Don't despair. It could still work for others."

For Jim, giving back to LRF is all about helping to raise awareness of the disease that took Pia's life and affected him personally.

"If there is something that we can do after seeing this tragedy that's befallen us – contribute back and make a difference, make a change – I will do anything to support that." ○

FUNDRAISE YOUR WAY!



Fundraise Your Way is the Lymphoma Research Foundation's (LRF) community fundraising program—a way to turn an event into a fundraiser for lymphoma. Each year, thousands of volunteers across the country turn their talents and interests into unique fundraising events to support the LRF's mission of eradicating lymphoma and serving all those impacted by this blood cancer.

FUNDRAISERS CAN RANGE ANYWHERE FROM:

Facebook Fundraiser
Tribute Fundraiser

Bake Sale
Bike Ride

Fashion Show
Marathon

There's no limit to how you can fundraise and make an impact on the lymphoma community.

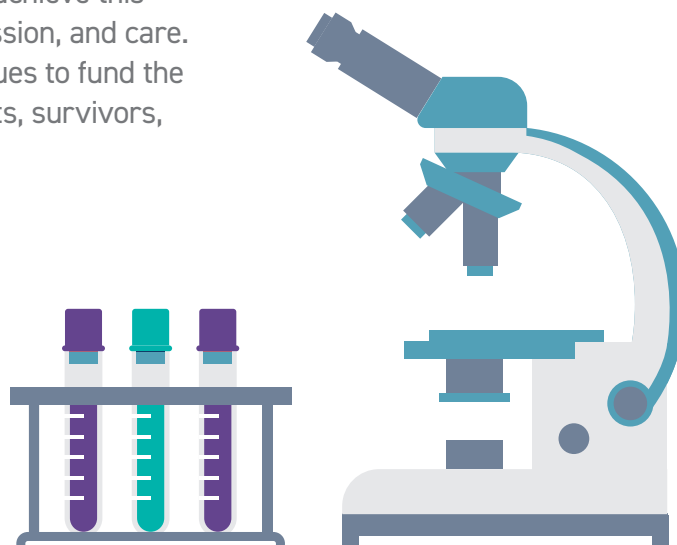
Visit lymphoma.org/fundraiseyourway to get started today!

HOW TO SUPPORT LRF



The Lymphoma Research Foundation's (LRF) mission is to eradicate lymphoma and serve those touched by this disease. We achieve this together — as one community — with confidence, compassion, and care. Supporting LRF helps ensure that the Foundation continues to fund the most innovative research and support lymphoma patients, survivors, and their loved ones when they need it most.

Gifts made to LRF are either classified as restricted or unrestricted donations. Both types help to further the Foundation's mission, with the major difference being that restricted funds are set aside, or designated, for a specific use. Unrestricted gifts allow Foundation and scientific leadership to support areas and programs with the greatest need.



EASY WAYS TO GIVE

One-Time
Donations

Recurring
Monthly Gifts

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LEGACY GIVING

Insurance
Beneficiary

IRA Beneficiary

Wills and Living
Trust Gifts

The LRF relies on the generous support of our community of dedicated donors to fill key innovation gaps that can change the future for everyone whose life has been affected by a lymphoma diagnosis.

FROM SCIENTIFIC DISCOVERY TO PATIENT ACCESS

1 Discovery



Innovation Gap:

Discovery is the scientific exploration to find therapies that may be able to treat or cure a disease. Only a fraction of the early-career research grants submitted to the NIH are funded, and there are few opportunities for investigators to collaborate with their peers.

LRF Solution: The Lymphoma Research Foundation (LRF) is committed to funding the most promising lymphoma researchers and advancing the understanding of the more than 100 different subtypes of lymphoma. LRF's disease specificity and hyperfocus on finding cures ensure the next generation of researchers dedicate their careers to studying lymphoma and world-leading lymphoma experts collaborate and accelerate the pace of scientific discovery.

3 Translational Research



Innovation Gap: Translational research facilitates the movement of laboratory discoveries to clinical application as well as the movement of clinical observations to the laboratory. "High risk/high reward" science, which is the hallmark of translational research, is almost never funded by traditional funding sources and proves difficult — if not impossible — to pursue mid-career or later.

LRF Solution: In 2021, LRF expanded its Lymphoma Scientific Research Mentoring Program (LSRMP) to foster and develop the next generation of laboratory and translational researchers and to bridge the gap between translational and clinical research. The goal of the LSRMP is to retain researchers in the field of lymphoma by providing mentoring and education programming and fostering research collaboration among expert faculty and grantees.

2 Basic Research



Innovation Gap: Basic research helps accelerate scientific discoveries by deepening our understanding of the biology of cancer and translating that knowledge into more effective, less toxic, and better-tolerated therapies. Increasing numbers of researchers competing for limited resources has led to many pivotal projects going unfunded. However, the information uncovered during basic research provides the foundation for the translational and clinical research that follows.

LRF Solution: LRF is proud to fund the nation's only postdoctoral fellowship program. These grants typically focus on basic science, which paves the way for scientific advancements and discoveries across a wide range of cancers and diseases.

4 Clinical Research



Innovation Gap: Clinical research mentoring programs help solidify the direction of a scientist's research for the rest of their career, and disease-specific grants are often the only way to attract talented researchers to study a particular disease. Only through collaboration can the world's experts design new clinical trials and discuss the use of new therapies.

LRF Solution: The LRF Clinical Investigator Career Development Award (CDA) Program provides grants to advanced fellows or junior faculty members to facilitate their transition to independent clinical researchers. These recipients have the greatest potential to contribute to the development of new lymphoma therapies and diagnostic tools.

5 Patient Access & Education



Innovation Gap: Providing information to patients as soon as new treatments are approved and research findings are published is critical to empowering patients to become their own health advocates. However, finding unbiased information about specific subtypes of lymphoma is an incredible challenge for patients.

LRF Solution: With tremendous support from LRF's 40-member Scientific Advisory Board, the Foundation provides access to the most up-to-date information about lymphoma through subtype-specific patient education programs and its vast library of accessible materials.

TRANSFORMING THE FIELD OF SURVIVORSHIP RESEARCH



Recently, Lymphoma Research Foundation (LRF) CEO Meghan Gutierrez sat down with Congresswoman Debbie Wasserman Schultz, the author of groundbreaking legislation that would transform the field of survivorship research and increase access to survivorship-related healthcare and services. They discussed the bipartisan Comprehensive Cancer Survivorship Act, her motivation to author the legislation, and the needs of cancer survivors.

You shared with me that drafting this legislation was a personal, as well as a professional, journey for you. Can you share your personal story and motivation for drafting the Comprehensive Cancer Survivorship Act?

My story began 15 years ago with the harrowing words, “you have cancer.” I was only 41 when I was diagnosed with breast cancer, and like so many who have heard those dreaded words, I wasn’t sure what was next or what I was about to go through. Fighting through this experience helped me translate my diagnosis and my story into something greater.

Throughout my personal battle against cancer, I came to realize that there are hundreds of considerations aside from appointments, tests, and treatment. My world was turned upside down, and I had to think about what this would

mean for my general health, my well-being, my family, my job, my daily routines, and so much more. These questions and deliberations turned my attention toward survivorship, thinking about how to best help cancer patients navigate through their life experiences and challenges as a result of this diagnosis.

I set out to create legislation that addressed survivorship – the entirety of a person’s journey navigating their cancer diagnosis through the end of life and every aspect along that continuum. I poured my own experiences into the legislation, remembering the challenges and shortcomings I faced going from diagnosis to treatment and surgeries to primary care. I also learned and integrated the same from patients, their families, doctors, and advocates like you what survivors

faced daily – identifying what was missing or incomplete and what we can do better, together.

The underlying motivation behind the Comprehensive Cancer Survivorship Act is to acknowledge and channel these difficult realities and existing gaps into meaningful solutions. This legislation will set standards and create new programs to ensure the best and most seamless experience for survivors, their families, and caregivers, throughout their survivorship journey, from diagnosis to end of life. The goal of this bill is to ensure survivors have the ability to choose their own path, providing them agency and autonomy over their personal health experiences and decisions, all through their difficult journey. For every survivor, the journey will have different needs and challenges, and anyone who begins this life-and-death struggle and eventually comes out the other side cannot be left alone in a wilderness to fend for themselves.

One of the reasons the Lymphoma Research Foundation has been very engaged in the development of this legislation is the fact that it addresses the entire continuum of survivorship – from the point of diagnosis through post-treatment survivorship. Each phase is unique to someone facing a lymphoma/chronic lymphocytic leukemia (CLL) diagnosis, and it impacts every facet of your life, long after the diagnosis is made. Why do you think such a comprehensive policy effort like this one has not been introduced before now?

Every year, cancer diagnoses increase, but death rates have been decreasing. Survivors are living longer because of the many vital tools we have to beat this disease, from early detection to research to clinical trials to treatments and so much more innovation on the horizon, like mRNA vaccines and CAR T-cell therapy. As the number of survivors increases, and as they live longer lives in their fight against cancer, more attention must be paid to the gaps they face along their survivorship continuum. We need to be mindful of survivors' general well-being, their social determinants of health, their financial health, and their particular needs, such as food insecurity, housing, transportation, labor, access to broadband and telehealth, childcare, and more.

Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH), like so many great organizations and cancer centers across the U.S., do engage heavily in survivorship research, care, and resources, but with such a deadly, impactful disease, more work and dedication will always be needed. We need to develop desperately needed standards to improve the overall patient-centered quality of care and address the non-medical needs of cancer survivors and their families.

I wish I had a clear answer to why it has not been undertaken through federal policy, but make no mistake, this is a daunting task. I can also tell you this. It will be a central focus of my legislative agenda moving forward.

The new payment models proposed in this bill and the way in which it attempts to expand patient access to care is a critical piece; we, unfortunately, know that in today's healthcare system, too few patients have access to long-term care and support services that they need. Can you describe the type of care that you wish to make available to survivors?

The goal of this bill is to make the care and support survivors need available throughout their entire survivorship continuum, from the point of diagnosis, through active treatment, to the transition to primary care and the possibility of recurrence, through end-of-life, setting the standards of care all survivors need and deserve. This is an all-of-the-above effort.

Survivorship begins at diagnosis, and the first consideration thereafter is care planning. The bill specifically provides coverage and payment of cancer care planning and coordination services, standardizes these processes, and consolidates treatments to guide survivorship monitoring and follow-up care through transition to primary care.

In addition, throughout this journey, with so many unanswered questions, survivors need proper and comprehensive navigation and the resources necessary to carry out their lives. To that end, this bill also develops effective and comprehensive navigation services that emphasize the survivorship continuum, such as follow-up care, health disparities, and social determinants like food insecurity, housing, transportation, labor, broadband and telehealth access, and childcare. It also pursues improved quality standards and considers situations related to leaving or returning to the workforce, infertility, or resources in the community for general well-being. Cancer doesn't stop for real-life realities like securing daycare and time off, inability to get to appointments, or no money for food or utilities. We need to face that reality. This legislation does that.

Finally, concerning payment, the bill will develop an alternative payment model to ensure a coordinated approach to survivorship care across an episode of care. To institute a workable payment structure, we need to better understand everything from triggering events, length of participation; shared decision-making; necessary services coordination of care; and social determinants of care. This bill does that too.

So many survivors have family and friends by their side, but the emotional toll it takes on their loved ones muddies the waters for the cancer patient and everyone around them. It creates so many new, unexpected challenges.

Fertility preservation is a significant issue for adolescent and young adult lymphoma patients and survivors. Does this bill address this specific aspect of cancer survivorship?

My husband and I faced infertility issues when I was 29, about a decade before I learned of my breast cancer diagnosis. Thanks to in-vitro fertilization, I gave birth to twins and subsequently a third child without assistance. Today, we have three healthy young adults.

Not everyone has the same good fortune to access or ability to afford fertility preservation, but even more devastating is that we do not always catch cancer early enough to preserve fertility in time to reconcile this potential loss. (This leads me to a quick segue to emphasize the importance of staying on top of your preventive care. Please get screened when eligible!) Scientific advancements in fertility preservation continue exponentially, and this bill couples that reality with this ultra-real difficulty that survivors face.

In the bill, we included a section that amends the Social Security Act to ensure Medicaid coverage of fertility preservation services under Medicaid for individuals diagnosed with cancer when it may lead to iatrogenic infertility.

When people call the LRF Helpline, most often they are seeking guidance regarding financial toxicity, healthcare coverage, employment challenges, and even disruption to their education. Can you describe the ways in which this legislation could impact this aspect of a survivor's experience?

Once a survivor learns they have cancer, the work begins. The information is foreign, nerve-wracking, and complex – absorbing everything while fighting for your life is an impossible task. So many survivors have family and friends by their side, but the emotional toll it takes on their loved ones muddies the waters for the cancer patient and everyone around them. It creates so many new, unexpected challenges.

As I mentioned previously, learning from my own experiences and hearing countless stories from survivors, cancer centers, researchers, and providers – those facing this disease from every angle – I made it my priority to ensure no stones were left unturned. A big part of that is proper navigation – a robust guidance platform that can

hold someone's hand through this journey as survivors face the real world with such a heavy weight on their shoulders.

Survivors need to think about follow-ups, tests, nutrition, work, childcare, financials, and the list goes on and on. The bill will review existing navigation programs to determine effectiveness, types of services needed, training needs, federal financing, patient involvement, alternative payment, and existing community resources. And then create a demonstration program through grants to offer navigation services that emphasize these elements. In addition, it directly tackles workforce complications by establishing workforce assistance grants to help survivors, their families, and caregivers when faced with a range of workforce challenges. These grants will prioritize assistance and education pertaining to transportation, childcare, nutrition, and finances, such as accessing existing programs and financial benefits and engaging in training assistance.

What can cancer survivors do to learn more about the Comprehensive Cancer Survivorship Act?

I will continue to do everything I can to amplify the bill, which we plan to reintroduce early this year. In addition, you can visit my website, wassermanschultz.house.gov, to learn more – there is a tab specifically for this bill at the top of my homepage. You also can read about it at lymphoma.org. Several of the supporting organizations have written about the bill and posted about it. I implore everyone reading this to speak to survivors closest to them and be a resource for them, research survivorship to familiarize yourself with the very unique challenges people face, and use your voices to uplift survivors throughout their difficult journeys.

Is there anything else you would like to share with the lymphoma community?

In the 118th Congress, as I mentioned previously, I will make passage of this bill a top priority. I am eternally grateful to my colleagues, Sen. Klobuchar, Sen. Cardin, Rep. Fitzpatrick, and Rep. DeSaulnier, for sponsoring and helping drive this bill – I am so proud to have them by my side. And I am very thankful to all the many, many groups that played a role in bringing this historic legislation to life. This legislation would not be possible without the endless expertise that went into it from so many of the supporting organizations. ○

LYMPHOMA ROUNDS 2024 SERIES

Free CME Program for Professionals

The Lymphoma Research Foundation's (LRF) *Lymphoma Rounds* program provides a series of accredited CME activities that provide a forum for local healthcare professionals to meet on a regular basis and address issues specific to the diagnosis and treatment of their lymphoma patients.

Participants 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.



2024 LYMPHOMA ROUNDS SCHEDULE

1/25 – Virtual National Lymphoma Rounds

2/15 – New York Lymphoma Rounds

2/22 – Washington DC Lymphoma Rounds

3/7 – San Francisco Lymphoma Rounds

3/21 – Philadelphia Lymphoma Rounds

3/28 – Chicago Lymphoma Rounds

4/11 – New England Lymphoma Rounds

5/8 – Seattle Lymphoma Rounds

5/16 – Los Angeles Lymphoma Rounds

5/23 – Virtual National Lymphoma Rounds

Register for an upcoming Lymphoma Rounds program at lymphoma.org/hcpeducation.

Lymphoma Rounds programming is supported by educational grants from:

AbbVie, Inc., Acrotech, Adaptive Biotechnologies, ADC Therapeutics, AstraZeneca, BeiGene, Bristol Myers Squibb, BTG International Inc., Genmab, Kite Pharma Inc., Kyowa Kirin, Lilly, MorphoSys, Pharmacyclics LLC, an AbbVie Company and Janssen Biotech, Inc., administered by Janssen Scientific Affairs, LLC, Seagen

[FROM THE FIELD]

A man with short brown hair and a light beard, wearing a dark blue and red plaid blazer over a light blue and white checkered shirt, stands with his arms crossed. He is positioned in front of a glass wall that has several white plus signs on it. The background is a bright, modern interior with large windows.

BREAKTHROUGHS START WITH **STRONG PATIENT RELATIONSHIPS**

“The intensity of the relationship between doctor and patient is unique to oncology,” said Dr. Epstein-Peterson. “While in residency at different oncology clinics at Memorial Sloan Kettering, I saw almost every patient bring a gift to the clinical director of Lymphoma Outpatient Services during the holidays. That was a bit of an early window, both into the patient population and the clinical issues that arise, and that planted a seed for what the future could hold.”

Many healthcare professionals get into medicine out of a desire to help people, and Zachary Epstein-Peterson, MD, of Memorial Sloan Kettering Cancer Center, is no exception. In fact, one of the primary factors that led him to focus his career on lymphoma was witnessing the close relationships between doctor and patient during his early rotations, and it's those deep connections with patients that continue to inform his lymphoma research today.

Dr. Epstein-Peterson began considering a career in oncology during his first experiences working with cancer patients at Harvard Medical School. After observing both exceptional patient care and opportunities for research advancements, he continued to seek out opportunities in oncology during his residency at the University of Washington, New York-Presbyterian Weill Cornell Medical Center, and finally Memorial Sloan Kettering, where he was propelled forward by several mentors.

“The intensity of the relationship between doctor and patient is unique to oncology,” said Dr. Epstein-Peterson. “While in residency at different oncology clinics at Memorial Sloan Kettering, I saw almost every patient bring a gift to the clinical director of Lymphoma Outpatient Services during the holidays. That was a bit of an early window, both into the patient population and the clinical issues that arise, and that planted a seed for what the future could hold.”

With lymphoma, in particular, Dr. Epstein-Peterson saw an even greater opportunity to foster those deep patient relationships due to the often chronic nature of the disease and the intense treatments with which it is associated. He was fortunate to continue his training in his home state of New York at Memorial Sloan Kettering with a fellowship in hematology and medical oncology before being hired as an attending physician in January 2022. “Even since I started, I've already seen some patients 10 to 15 times,” he said. “The critical diagnosis and the sheer volume of visits means that I'm going to get to know my patients and their families and caretakers really well.”

In his practice, Dr. Epstein-Peterson sees and treats every type of lymphoma, but he has a particular interest in T-cell lymphomas and mantle cell lymphoma (MCL). He recognized during his training that these subtypes face “a major unmet need” because of their rarity and complexity. “I routinely see patients who need better therapies, more effective therapies, and better tolerated therapies, so clearly there's more work we need to do,” said Dr. Epstein-Peterson. One of his mentors, Steven M. Horwitz, MD – an LRF Scientific Advisory Board (SAB) member and lymphoma oncologist at Memorial Sloan Kettering – also contributed to Dr. Epstein-Peterson's decision to specialize. “To be able to work with him, an international expert in this area, and to have his mentorship and guidance along the way was a slam dunk,” Dr. Epstein-Peterson added.

Improving Patient Care through Research

At Memorial Sloan Kettering, Dr. Epstein-Peterson sees patients two days per week in the clinic and spends the other three days handling administrative work, research, and other follow-up clinical issues. In his limited spare time, Dr. Epstein-Peterson enjoys being with family, exploring the outdoors to the extent possible in Manhattan, and listening to classical music and jazz. He also likes to travel and follows the commercial aviation industry “a little bit nerdily,” by his own admission.

Dr. Epstein-Peterson applies this same enthusiasm to his work. One of his current research projects is investigating if isocitrate dehydrogenase 2 (IDH2) enzyme inhibitors can treat angioimmunoblastic T-cell lymphoma (AITL). IDH2 mutations have been identified in a subgroup of patients with this rare form of non-Hodgkin lymphoma (NHL), and there are drugs successfully targeting that mutation in other cancers. “But there aren't really any targeted therapies that are specific to mutations for patients with T-cell lymphomas yet, so if we're able to show that this treatment is safe and effective, it would hopefully be a major advance forward for molecularly targeted therapies,” said Dr. Epstein-Peterson.

In the laboratory, Dr. Epstein-Peterson is trying to understand even more about how and why this form of AITL develops, specifically the different cells that occur in the cancer and how they interact with each other. “The

Continued on the next page



hope would be that somehow we uncover new avenues for treatments by understanding the tumor better,” he said. He is also doing research on another innovative treatment avenue, a form of therapy called EZH2. As an epigenetic enzyme, EZH2 controls which genes are expressed or not expressed in the cell, and he says there’s recently been promising data for a medication that inhibits that enzyme. He’s starting to look now to understand how that medication actually works and why some patients don’t respond to it.

Dr. Epstein-Peterson’s research ideas already stand out in the field. He received the Lymphoma Research Foundation’s (LRF) Clinical Investigator Career Development Award in 2022 for the clinical trial he’s getting off the ground at Memorial Sloan Kettering to test the IDH2 inhibitor for AITL patients. Receiving this award was “a tremendous honor” for Dr. Epstein-Peterson. “I was really humbled and really thankful for

the recognition,” he says. “It was a validation of some of the work that I’ve done with my mentors. They put a lot of wind in the sails to keep pressing forward, because grant success is few and far between in academic medicine.”

Dr. Epstein-Peterson’s completed research is already garnering industry recognition, too. A major journal recently accepted his publication of the high-level results of a clinical trial for a new mantle cell lymphoma treatment approach that was designed and implemented at Memorial Sloan Kettering, mentored by Dr. Anita Kumar, herself a prior LRF Career Development Award recipient.

Dr. Epstein-Peterson is also involved in several other clinical trials still taking place. Building upon earlier work done at Memorial Sloan Kettering that found that one way of targeting a signal transducer and activator of transcription (STAT) pathway showed benefits for T-cell lymphoma patients, he became the Memorial Sloan

“More and more, I see institutions partnering together and working together to try to design trials,” he said. “In the past, things were a little bit more siloed. But even in the past couple of years, I’ve seen even more collaboration occurring over time. That can only benefit researchers and patients because some of these are rare conditions, and you really need a lot of people together to try to study them.”

Kettering head of the multicenter clinical trial that is looking at a different way to target that pathway. He’s also involved in another multicenter study on the use of chimeric antigen receptor (CAR) T-cell therapy in mantle cell lymphoma and is helping to lead a similar effort that will look at the benefits of this therapy. The goal, he says, is to first “understand the patients who clearly seem to really benefit the most from CAR T-cell therapy and then those who unfortunately didn’t benefit as much.” That insight may optimize their patient selection for this treatment moving forward. “If there’s a certain feature or something that shows patients aren’t going to respond as well, then we should understand why that is, and that may inform future efforts there,” he added.

When Dr. Epstein-Peterson looks at a research problem, he first thinks of his patients. “Whatever problem we’re working on, I wish that whatever advances come of this were available for a certain patient in the past who maybe we weren’t able to save. I think about the patient I’m treating right now – maybe somehow this can help them in the future,” he said. On the flip side, the clinical issues he sees arise in his patients’ care directly feed into the research problems he wants to address. For instance, he’s noticed that patients with AITL can sometimes have Epstein Barr Virus (EBV) at the same time – raising questions about that virus’ relationship to the cancer and possible therapy options. “Seeing that in patients that you’re taking care of and looking at that in the biopsy specimen, it then directly feeds into more basic science or translational questions to try to understand it. I think there’s a lot of synergy for seeing patients and being a researcher,” Dr. Epstein-Peterson said.

The Road to a Cure

Looking at the future of lymphoma research, Dr. Epstein-Peterson sees a lot to be excited about. For one, the field is becoming even more collaborative. “More and more, I see institutions partnering together and working together to try to design trials,” he said. “In the past, things were a little bit more siloed. But even in the past couple of years, I’ve seen even more collaboration occurring over time. That can only benefit researchers and patients because some of these are rare conditions, and you really need a lot of people together to try to study them.”

Dr. Epstein-Peterson is also optimistic about the “explosion” of immunotherapy as another research frontier. “Having new approaches that are completely different, that work in a different way and have different mechanisms, is really important and exciting,” he explained. “I think it opens up new avenues for treatment that may benefit people in the future where chemotherapy either doesn’t work or has side effects.”

Always thinking about what will benefit patients most, Dr. Epstein-Peterson believes efforts to deescalate therapy and incorporate patient-reported outcomes (PROs) into clinical trials – two things that have been done in other cancer types – could show a lot of promise for lymphoma treatments in the future. He also highlights the growing recognition that healthcare disparities across underrepresented patient populations need to be addressed, stemming from lymphoma research that shows certain racial and ethnic groups may have inferior treatment outcomes. “We want to be equitable, and we want every patient to have the best chance. So, trying to understand those patterns, I think there’s a growing interest within the field,” he said. “Then the next step after that will be interventions to level the playing field and try to address some of those disparities within the field as much as possible.”

To reiterate why greater investment in lymphoma research is needed, Dr. Epstein-Peterson points to the importance of finding safer therapies without toxicities as well as more palliative therapies that better mitigate side effects and symptoms of the disease itself, like the itching that can be common in cutaneous (skin) lymphoma. He also emphasizes how the chronic nature of some lymphomas presents another challenge. “If we have ‘X’ number of tools in the tool belt, eventually, we’re going to really need to build on that, especially for younger patients who have a whole lifespan ahead of them to deal with this chronic illness,” Dr. Epstein-Peterson said. “We know that over time, as patients go through therapy after therapy, eventually the cancer just starts outsmarting things. For that reason, we need more tools in the tool belt.”

Despite these needs, funding isn't as robust for lymphoma compared to other cancer types. Dr. Epstein-Peterson explains this is because lymphoma patients tend to do better than other types of cancers that are even harder to treat, and that epidemiologically, other cancers are a bit more common as well. It can also be harder to do research for the much rarer lymphoma subtypes since it costs more to conduct clinical trials at multiple centers. "But we're still seeing patients every day who need our help, and we're trying to advance the field forward. LRF and other organizations like it have a unique and needed role to fill that gap and to provide funding where it may not otherwise be present," he said.

Funding to Support the Lymphoma Community

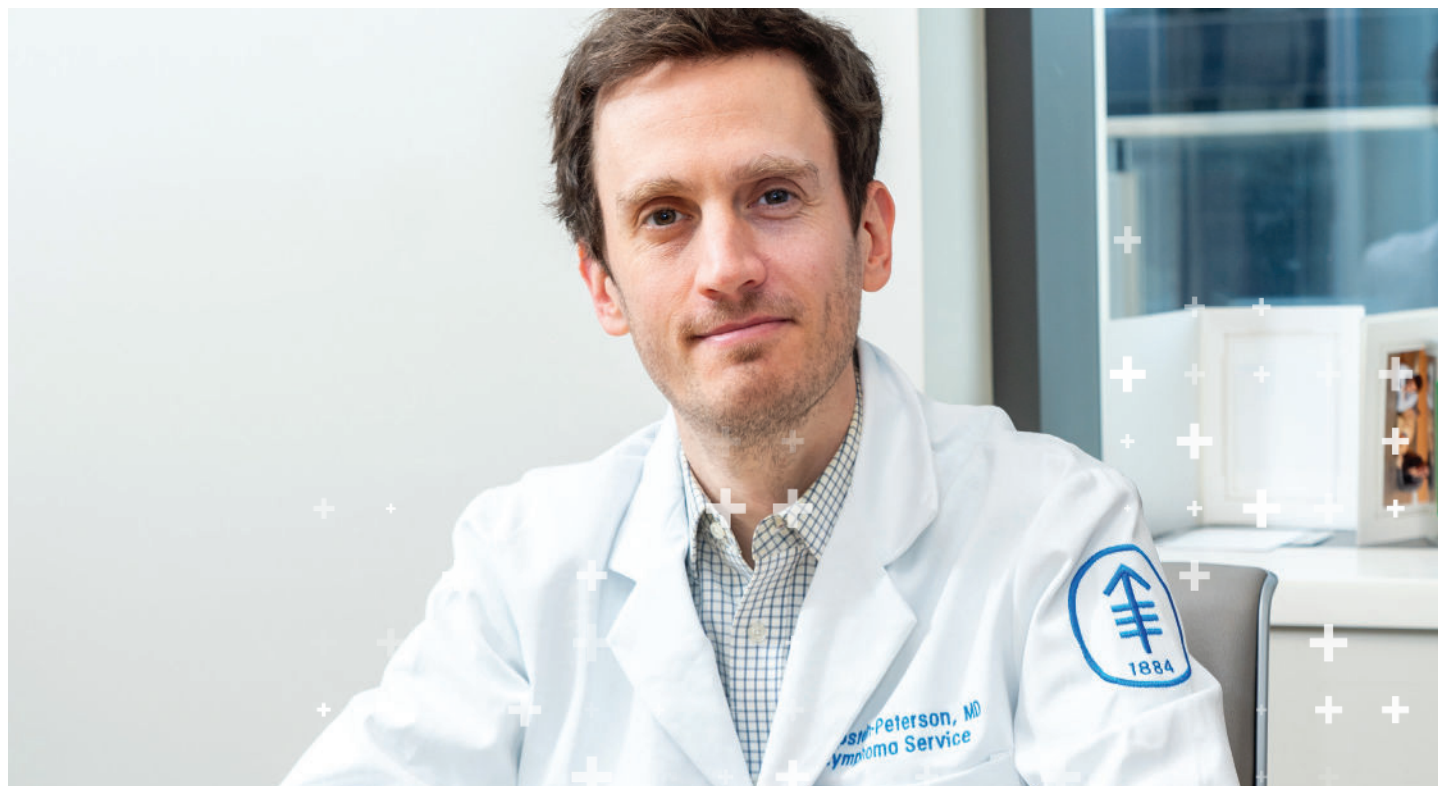
When Dr. Epstein-Peterson was a fellow at Memorial Sloan Kettering, another one of his mentors, David J. Straus, MD, invited him to give a presentation about marginal zone lymphoma at one of the LRF's scientific meetings. "I was immediately impressed," Dr. Epstein-Peterson said about this first encounter with LRF. He believes LRF's sole focus on lymphoma provides a unique opportunity to drive its mission.

Ever since, Dr. Epstein-Peterson has continued to stay close to the organization. In addition to receiving one of LRF's Career Development Awards in 2022, he was named an LRF Scholar in 2021 as part of the Lymphoma Scientific Research Mentoring Program (LSRMP). The funding he's garnered through that program has been

helpful for conferences, training, and hardware purchases to jump-start his career, he says. "The fact that they really promote early career investigators, networking, and career development, I think is extremely important because that's not always possible through traditional funding mechanisms or through other opportunities."

Dr. Epstein-Peterson also emphasizes how LRF's initiatives benefit not only researchers but also patients directly. "Having patients participate in clinical trials is a very tangible way to move the field forward. I know that LRF has a lot of efforts in that regard to help patients find trials," he said. He adds that patient advocacy also goes a long way. "Anything that patients or caregivers or families can do to advocate for more funding for lymphoma research and more awareness of lymphoma as an issue, can only benefit them and benefit us as researchers to get more attention and, ultimately, more funding for what we want to accomplish."

"I think it's fundamental for ultimately achieving more cures and developing better therapies that we have organizations like LRF to get us there," said Dr. Epstein-Peterson. "The efforts that they support, I have every expectation, will majorly benefit patients in the future from many perspectives: new therapies, better therapies, better side effects, better ways to understand the patient experience. All of that will help patients in the future for sure." 🍷



LYMPHOMA RESEARCH
FOUNDATION NAMES

500TH

RESEARCH GRANTEE



ELISE CHONG, MD

*Clinical Career Development Award,
Health Equity Initiative*
University of Pennsylvania,
Perelman School of Medicine

"I'm so honored to be the Lymphoma Research Foundation's (LRF) 500th grantee — the support and funding from LRF has played an invaluable part in ensuring researchers like myself are able to devote their careers to finding new cures for this disease. I am optimistic for the future of lymphoma, thanks to the rapid pace at which research is advancing and the role that organizations like LRF play in driving the field forward. These improvements in our understanding of lymphoma and chronic lymphocytic leukemia have been the catalysts that get us closer to improving outcomes for patients and, one day, eradicating lymphoma altogether.

LRF's focus on supporting early-career scientists ensures the best and brightest remain in the field of lymphoma research so that innovation and progress continue."

WHERE ARE THEY NOW? **ALLISON ROSENTHAL, DO**



Dr. Allison Rosenthal, DO, is a lymphoma specialist at the Mayo Clinic in Phoenix, Arizona.

When did you become interested in the study of medicine? In lymphoma specifically?

My childhood ambition was to be a doctor, which I can only explain by my innate desire “to help.” Despite aiming for a career in orthopedic surgery when I entered medical school, a diagnosis of acute promyelocytic leukemia during my second year reshaped my path. Though it took some time for me to recognize the opportunity I had been given to serve others diagnosed with cancer, I now know a career as an oncologist allows me to live my purpose. Navigating cancer as a young adult patient and then trying to figure out what it means to be a survivor is something I am passionate about helping my patients with. While in hematology oncology fellowship, lymphoma captured my attention. I found lymphoma as a specialty combined all the things I was looking for: diverse patients and presentations, enough acuity that allowed both an inpatient and outpatient practice, varied outcomes, lasting patient bonds, rapidly evolving science, and a focus on survivorship.

At what point in your career did you receive funding from the Lymphoma Research Foundation (LRF)? What kind of grant(s) did you receive?

I was junior faculty at Mayo Clinic, Arizona, when I was accepted into LRF’s Lymphoma Scientific Research Mentoring Program (LSRMP) in 2018.

What scientific project did you pursue as part of your LRF research grant(s)?

My project focused on clinical validation of an assay called “MCL35” in mantle cell lymphoma (MCL). This assay had been shown to risk stratify younger MCL patients who were receiving RCHOP based therapy into high standard and low risk groups with varying outcomes. Through this study we assessed whether the MCL35 assay predicted outcomes in untreated mantle cell lymphoma patients who were over the age of 60 and receiving bendamustine and rituximab. This project required both analytical and clinical validation of this assay. The summary of this work has been submitted for publication, and we continue to try to identify biomarkers that could help us choose optimal therapies for MCL patients.

How has the treatment landscape for lymphoma/chronic lymphocytic leukemia (CLL) changed since you first started conducting your research?

In the past five years, the treatment landscape for lymphoma and CLL has changed dramatically. Immunotherapies have become an integral set of treatment options for patients with lymphoma. We have seen approval of CAR T-cell products for relapsed or refractory aggressive lymphomas, mantle cell lymphoma, and follicular lymphoma. We also now have several new targeted therapies for B-cell malignancies, including bispecific antibodies and antibody drug conjugates. Despite this rapid progress, sequencing these therapies and understanding long-term toxicities are ongoing challenges. With a better understanding of resistance mechanisms, a new generation of BTK inhibitors has emerged. Novel combinations like checkpoint inhibitors and antibody drug conjugates paired with chemotherapy appear to improve outcomes. As treatments become more targeted and personalized, there is a growing emphasis on patients’ quality of life during and after treatment, minimizing side effects and long-term complications.

Was the support and grant funding you received from LRF vital to advancing and dedicating your career to studying lymphoma?

I would not be where I am today without LRF’s support and the mentorship I received during the LSRMP. This program helped me understand the difference between predictive and prognostic biomarkers and how translational studies can be designed to answer vital research questions. The network of mentors, colleagues, and peers I have within the lymphoma community has been vital to many of my accomplishments so far. I have been fortunate to be part of subsequent LRF initiatives – most recently those centered on improving collaboration and outcomes for adolescent and young adult (AYA) patients with lymphoma.

There has been much progress made in the development of targeted therapies for lymphoma/CLL. Can you describe your work in this area? Do these advancements represent a new frontier in the treatment of lymphoma/CLL?

I have been indirectly involved in the development of targeted therapies for lymphoma/CLL as a clinical investigator, participating in several studies in this space. I do think targeted therapies such as bispecific antibodies, antibody drug conjugates, or small molecule inhibitors are representative of a new frontier in the treatment of lymphoma and CLL. Unlike chemotherapy, which often affects both healthy and lymphoma cells, targeted therapies are designed to pinpoint specific markers, molecules, or pathways that are crucial for cancer cell growth and survival. We must recognize that while targeted therapies offer significant promise, we still face challenges, including the potential for resistance and the need for continued research to optimize treatment combinations and sequencing. As the landscape of targeted therapies continues to evolve, I hope we will see more effective and less toxic personalized treatment options for our patients with lymphoma.

How has your involvement with LRF evolved since being an LRF Scholar?

I have participated in two workshops focused on issues related to lymphoma in AYA lymphoma patients. Working with the AYA population and being invested in the development of trials and outcomes research for them is really where my passion lies. I am extremely excited about continuing to contribute to those efforts. I also really enjoy opportunities to educate patients, their caregivers, and colleagues. I have had numerous opportunities through LRF to give presentations at regional and national patient educational meetings and on webinars. Additionally, I am grateful to have been invited to be a member of the steering committee for National Lymphoma Rounds. I have had the pleasure of being a grand marshal for the local LRF walk to raise funds for LRF programs and have continued to engage in efforts to raise awareness about the incredible things LRF does.

Why is LRF’s mission and focus on lymphoma-specific research and programming important? Put another way: How would the lymphoma community be impacted if there was no LRF?

The work the Lymphoma Research Foundation does is INTEGRAL to funding lymphoma research, providing patient education and support, and for raising awareness about lymphoma. LRF provides grants and funding to early career scientists, junior investigators, and established lymphoma researchers that furthers our ability to understand the disease, develop new treatments, and improve patient outcomes. Equally impactful is all

[FROM THE FIELD]

the online resources, webinars, support groups, and educational materials LRF maintains to help patients and their loved ones navigate a lymphoma diagnosis. When talking about raising awareness about lymphoma, LRF does this not just within the healthcare community but also with policymakers, where they advocate for research funding and improved patient care. Finally, LRF builds a sense of community and fosters collaboration amongst physicians, scientists, patients, survivors, and caregivers.

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

I am most excited about being given the chance to develop and implement an Adolescent and Young Adult Cancer program at Mayo Clinic. AYA cancer programs are vitally important to address the distinct needs of adolescents and young adults with cancer. Within such programs we can better ensure this unique patient group gets optimal care, support, and age-appropriate resources from diagnosis through survivorship. With an organized program, we can contribute to better outcomes, improved quality of life, and increased awareness about the issues AYA cancer patients face. One AYA-specific intervention we are exploring is the development and implementation of a survivorship skills course. The transition from being in

treatment into early survivorship is one that many of our patients struggle with, and we hope to equip them with the tools they need to move successfully and confidently into the next stage of their life. I am also currently involved in a number of trials involving targeted therapies, including novel CAR T-cell approaches, immunotherapy combinations, and early-phase therapeutics.

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

I am particularly excited about the rapid evolution in treatment choices for patients with relapsed or refractory aggressive lymphomas. The prospect of reducing or even eventually eliminating the reliance on chemotherapy excites me as I look forward within my career in lymphoma. This shift seems feasible thanks to quick strides in comprehending the biology of some lymphomas and the concurrent development of targeted therapies. With my focus on the AYA lymphoma population, I am equally thrilled about the recent inclusive approach taken in designing trials that span the entire age spectrum. This intentional effort holds the promise of answering critical questions about optimal treatments for young patients with lymphoma. As a result, disparate approaches for adolescent and younger adult patients in pediatric vs. adult clinics may become a thing of the past. ○



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The Lymphoma Research Foundation (LRF) offers a wide range of free disease- and topic-specific guides and fact sheets, in English and Spanish, for people with lymphoma, their loved ones, and healthcare professionals.

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SAVE THE DATE: Upcoming Lymphoma Walks



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MEET THE NEWLY ELECTED LRF SCIENTIFIC ADVISORY BOARD MEMBER

The Lymphoma Research Foundation (LRF) welcomed a new member, Markus Müschen, MD, PhD, to its elite Scientific Advisory Board (SAB) on July 1. The new member will contribute to the global impact of the Foundation.

The volunteer SAB is comprised of experts who guide LRF's research portfolio, seeking out the most innovative and promising lymphoma research projects for support. In addition to their charter of reviewing grant proposals and making recommendations regarding research priorities and funding, the SAB evaluates the progress of ongoing research projects and guides the strategic direction of LRF's research programs and scientific consortia.





MARKUS MÜSCHEN, MD, PHD

YALE SCHOOL OF MEDICINE

Markus Müschen, MD, PhD, is a professor of Hematology and Immunology and director of the Center of Molecular and Cellular Oncology at Yale University in New Haven, CT. He is also the chief of the Division of Basic Science at Yale Cancer Center. He completed his medical training in Germany and France before moving to the University of Chicago for his postdoctoral fellowship in immunology.

Dr. Müschen's research focuses on establishing and describing frameworks that underly B-cell signaling mechanisms and how these processes lead to the development of B-cell malignancies such as lymphoma. By understanding these mechanisms, his research aims to identify new potential targets for therapeutic intervention. As part of these goals, Dr. Müschen's research group has developed an online platform that allows other lymphoma researchers to easily interact with these networks to help identify novel vulnerabilities in B-cell cancers.

As a member of the LRF Scientific Advisory Board, Dr. Müschen is eager to join a group of experts at the forefront of cancer research. "Important concepts that impacted cancer research and treatment as a whole were often first pioneered in the lymphoma field," he explains. "I am excited to be a part of this and look forward to seeing discoveries in the lymphoma field impacting patients with cancer more broadly in the future." Dr. Müschen is also excited about the potential role of the LRF Scientific Advisory Board to impact the future of lymphoma research moving forward. "In identifying the brightest minds among the early career researchers in our field and by providing critical support when it is needed the most, the LRF has always had a key role in shaping our current science and the science of the future," he adds. ○

CONGRATULATIONS TO OUR NEWLY APPOINTED **SCIENTIFIC ADVISORY BOARD LEADERSHIP**



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PATIENT PERSPECTIVES:

WHEN SHOULD A PATIENT SEEK A SECOND OPINION?

When you receive a diagnosis of a complex disease like lymphoma or chronic lymphocytic leukemia (CLL), making treatment decisions can be overwhelming. Due to the heterogeneity of lymphoma and CLL and the variety of treatment options available, finding a doctor who is an expert in lymphoma/CLL and, most importantly, who you trust, is a critical part of your care.

After receiving an initial consultation, you might be interested in finding an additional doctor who can review your test results, provide their take on your diagnosis, and make suggestions for a treatment plan — known as a second opinion. Second opinions can help a patient better understand their options and ultimately make the best decisions for their care.

Lymphoma Research Foundation (LRF) Scientific Advisory Board (SAB) member and lymphoma specialist Loretta Nastoupil, MD, of The University of Texas MD Anderson Cancer Center, discusses why seeking a second opinion can be a helpful tool for patients when making decisions about their care, while lymphoma survivor Larry Simon discusses why he ultimately chose to obtain a second opinion and how that impacted the decisions he made.



Dr. Nastoupil:

When should a lymphoma or CLL patient think about seeking a second opinion?

It is always a good idea to seek out a second opinion, given these are rare tumors, and having more than one assessment is likely to provide a balanced overview of the disease process, treatment options, and clinical trial opportunities. The other reason to consider a second opinion is that it will also result in a pathology review to confirm the diagnosis.

Will seeking a second opinion offend the patient's initial doctor?

It should not, though it is best to keep the line of communication open so that the initial doctor may be part of the conversation and can exchange ideas or thoughts about the disease and treatment approaches. Often patients will receive a second opinion that reinforces the original discussion. This generally enhances the confidence of the initial doctor. The challenge is when the opinions are vastly different, being able to have an open discussion on why and how to reconcile the difference is critical, particularly if the patient prefers to have local therapy but with the treatment recommendation offered by the second opinion. This can be challenging to navigate.

When a patient gets a second opinion, will they need to redo their testing?

Occasionally, there may be indications for repeat testing, particularly as it pertains to lab tests. It is uncommon to repeat a biopsy or imaging study if done recently.

What are the potential benefits of seeking a second opinion?

Gaining knowledge will help patients navigate the various treatment approaches. Having a second opinion that

reinforces the local opinion or initial opinion is helpful and builds trust. Sometimes having the same message delivered in a different style can be helpful. Receiving information on clinical trial options or future developments can be another advantage of seeking a second opinion.

What should they do if the suggestions differ? How should they decide which doctor to choose?

This is challenging. Sometimes patients will seek a third opinion to reconcile the difference. Having an open discussion with the two opposing doctors to reconcile the difference is important to navigate this successfully. There are opportunities to cross-reference a recommendation either through societies such as LRF or via the National Comprehensive Cancer Network (NCCN) guidelines that have patient-directed information. Gut instinct can also be helpful.



Larry Simon:

Why did you decide to seek a second opinion?

At my annual physical exam, I received routine bloodwork in August 2017, and my white blood cell count was at 44,000 after having been in the normal range one year earlier. My primary care physician concluded that I likely had a form of leukemia or lymphoma. Additional testing clearly confirmed a diagnosis of mantle cell lymphoma (MCL). While I was told by my oncologist that my leukemic non-nodal subtype is usually clinically indolent (slow-growing), my test results also confirmed that my form held the potential to be a very aggressive disease. Given these test results, my oncologist was leaning toward starting standard chemotherapy treatment. However, she first decided to reach out to MCL specialists to obtain second (and third) opinions on the best therapy for my

Continued on the next page

rare situation in which she had no direct experience. At the same time, I took it upon myself to research potential treatment options. I wanted to be as sure as possible that we were making the correct treatment decision and obtaining a wide range of opinions, given that the particulars of my type of lymphoma were rare and distressing.

What was the process like? Did you find it to be easy?

The process turned out to be easier than I dared imagine. My oncologist received different opinions, and at the same time, I discovered the LRF's website, including information on current MCL treatment options. Then, my wife and I attended LRF's North American Educational Forum on Lymphoma in 2017, and at the Forum, we were able to attend MCL-specific sessions and speak with several MCL specialists, including LRF SAB members Andrew D. Zelenetz, MD, PhD, and Brad S. Kahl, MD. It became clear in these discussions that in my case, adopting the "watch and wait" option was the most logical and reasonable path forward. We were told that as long as I remained "healthy" with no symptoms and had monthly or quarterly blood work to monitor disease progression, it was better to preserve treatment options for when they were needed and could be most effective. In addition, we were reminded that new and possibly more effective treatment options were being developed.

One year later, we attended another Educational Forum, and it was there that we met with a new group of MCL specialists who, after listening to the description of my type of MCL and my one year of blood test results, reaffirmed my decision to follow the "watch and wait" option.

How did the second opinion impact the decisions you made about your treatment plan?

Getting a second opinion and opting for "watch and wait" preserved my options for future treatment regimens and, more importantly, allowed me to avoid being subjected to unnecessary therapy and associated side effects. As it turned out, while I remained symptom free through the end of 2020, my white blood cell count had steadily increased since initial diagnosis. However, due to my decision to remain on "watch and wait," I was able to participate in a clinical trial in 2021 that led to a complete remission that September. While the remission only held until December 2022, I was then able to start on a BTK inhibitor in February 2023 that continues to reduce my white blood cell counts with no adverse side effects.

What should other patients know about seeking a second opinion?

I believe it's critically important that patients understand and differentiate between the two types of second opinions: one focused on confirming beyond any doubt the accuracy of their diagnosis and one focused on treatment options. I believe obtaining second (and even third) opinions is necessary, both in terms of confirming a diagnosis and for a patient's peace of mind that the treatment decisions being made are the correct ones. In my case, immediately after my diagnosis, my oncologist ordered a series of sophisticated blood analyses to further characterize my lymphoma cancer cells. The results greatly helped in making the decision to delay my treatment until needed. In addition, patients should do their very best soon after diagnosis to understand their disease – from learning the vocabulary to at least the basic science of their disease. This can help you know what types of questions to ask your physician and enable you to understand treatment options, efficacy, and side effects. Lastly, I believe it is critical to have a caregiver to assist you during the second opinion process. Receiving a cancer diagnosis is overwhelming – two heads are better than one in asking questions, processing information, dealing with frustrations, taking notes, and finally making decisions that can have life-altering ramifications. ○



If you have questions about seeking a second opinion, please contact the LRF Helpline at 800-500-9976 or email helpline@lymphoma.org.



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USING SOCIAL MEDIA AS A FORCE FOR GOOD



Social media influencer Anthony Corrado was clearly destined for a life in the entertainment business. Getting his start making YouTube videos for fun as a kid, the 27-year-old now TikTok and Instagram star uses his platform to do what he loves most – make people laugh. In 2023, life threw Corrado a curveball when he was diagnosed with lymphoma. Instead of navigating his diagnosis in private, he decided to stay positive while documenting his lymphoma journey and creating a remarkable community of support among his over 490,000 followers.

Growing up in Detroit and the suburbs of Chicago, Corrado enjoyed acting and theater in high school and went on to take improv classes at The Second City. After repeatedly getting turned down at auditions, Corrado became determined to find a way to build his own audience. For several months in 2022, he curated two TikTok videos every night after working 12 hours as a lighting studio technician for local Chicago tv shows.

Corrado finally got his big break in June 2022, when a TikTok video of him dancing in a parking garage to

“Down” by Jay Sean featuring Lil Wayne went viral. “It was one of the first videos where I decided to put some dancing into the comedy, and it just took off. That video led to a lot of the success that I had later that year and helped me build the audience that I have now,” he says. Corrado soon began pursuing his career as a TikTok creator full time, collaborating with the likes of Joe Jonas and the Detroit Lions, his favorite football team. “I was just living my dream, waking up every day and trying to think of new ways that we could make someone laugh.”

One year into doing something he loved, Corrado’s world was turned upside down. In May 2023, he had surgery to remove a lump in his groin that he thought was a hernia. Corrado had been dealing with pain on and off for two years since badly pulling his groin muscle at work, so he assumed this was related. However, Corrado learned after surgery that the lump was a cyst in his lymph node. He didn’t think more of it while waiting for the results from pathology, which made getting diagnosed with diffuse large B-cell lymphoma (DLBCL) a few days later all the more shocking.

“The first time I heard it, I was scared and shocked. By the second day, that had morphed into anger and bitterness. The third day, though, I was ready to take this thing on because unfortunately, I’m no stranger to cancer,” said Corrado.



DLBCL is the most common form of non-Hodgkin lymphoma in the United States and worldwide. While members of Corrado's extended family have faced many types of cancer, lymphoma in particular hits close to home. One of Corrado's grandmothers is a lymphoma survivor, and his late grandmother passed away from lymphoma. His father was diagnosed with a different form of lymphoma in his early 20s, though he's fortunately "happy and healthy" now over 30 years later. "Seeing that my dad could get through it gave me more confidence and kept me grounded to take it one day at a time," says Corrado.

Starting a New Journey

Corrado's treatment regimen called for six rounds of chemotherapy. After his diagnosis, Corrado resolved to take working out and being healthy more seriously. He cut out processed foods from his diet, stopped eating late at night, and started doing more cardio and weightlifting at the gym. "I made a decision that if I'm going to be going through this and putting my body through chemo, then I'm going to be the healthiest version of me that I can be," he said.

Corrado is grateful to have such a big support system to help him through the challenges of treatment. His girlfriend, Ashley, is his primary caregiver, and his parents and younger brother and sister have all been there for

him, too. He also has a group of eight best friends he's known since the sixth grade who still text and see each other frequently. "I am so lucky. People go through these situations alone, and I haven't had to be alone for one second through any of this," he says.

From the beginning, Corrado knew he wanted to tell his social media followers what was going on. "I didn't want any secrets. I didn't want to not show up for them, and I didn't want to not show up for myself," he explains. However, he had some initial concerns about how his audience would respond to such heavy news coming from someone who usually brightens their day. "I didn't want anyone to be feeling bad. I didn't want people to forget about the funny videos that I have and remember me as the kid with cancer. But the more I thought about it, that was ridiculous," Corrado said. "I'm me. I'm always going to be funny. I'm always going to have my sense of humor, and no one's taking that away from me," he realized. Corrado decided he was up for the challenge of morphing the cancer into something that reflects who he is – something funny. "I was going to find a way to take a serious situation and show people that no matter what it is, you can always laugh at it," he said.

Corrado didn't know at first how he would get started. It was when he was alone at the driving range, one of his favorite places to go to clear his head, that he



spontaneously decided to record a TikTok video about his diagnosis as he whacked golf balls. “I said everything that I wanted to say, and I didn’t have to plan a lick of it. It just goes to show how important it is to be able to find those places where you can sort of meditate in a way.”

Corrado was blown away by the outpouring of support he received from his followers. “I knew that people liked my videos, but I didn’t know that their support of me was this deep,” he says. “There were dozens and dozens of people who were already following me, talking about how they’re going through something similar, or they know somebody going through something similar. I think it made my community closer,” he adds.

Spreading Both Laughter and Awareness

Ever since that first video, Corrado has been forming meaningful connections with his audience. He has continued to document his chemo journey to inspire other cancer survivors through his channel.

Corrado has found it very rewarding to blend together two different worlds into a “beautiful little melting pot of people who are going through something.” There are healthy followers getting to learn more about cancer alongside cancer survivors who are enjoying the funny content too. Corrado gets messages from followers having a hard time at school or work who are grateful for his videos that put a smile on their face and from followers

going through chemo who are grateful to see someone also going through treatment. “I didn’t realize that was an itch that needed to be scratched for people. Turning nothing into something in the way that we did, there are no words for that,” he says.

His biggest advice for others with lymphoma is to try to make light of a bad situation. “Learn to laugh at it,” he says. “I believe part of the reason I’ve been able to feel pretty decent throughout my treatment, not to say that I haven’t had my bad days, is due to my attitude.” Corrado also urges his community to take it one day at a time and tap into their passions. “Make the most of it, and find something that you can do, just because you love it, and try to do as much as you can.”

It’s no surprise Corrado has noticed more engagement with his content since he started telling his lymphoma story. The awareness he’s spreading has had a ripple effect among followers who are not only supporting him but are also supporting each other. “You’ll see people who will comment something like, ‘I’m going through this’ or ‘I’m on my eighth round of chemo,’ and then there’s three or four more follow-up comments attached to that one. That’s what I mean when I say this community is so strong,” says Corrado.



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Supporting Research to Bring Community Together

Corrado has built this interconnected community among his followers because he knows how important it is for anyone going through cancer to have a support system. “What I think is so cool about this community is that if you don’t know someone who’s got your back, there’s someone out there who will. The internet brings us all together, and that’s what makes it possible,” he says. He knew getting involved with a charitable organization could spread that support even further.

The more Corrado started to understand the role research plays in discovering new and more effective treatments, the more the Lymphoma Research Foundation (LRF) stood out to him. He could see the impact when looking at his own family history with lymphoma. Corrado’s father had to go through 12 different surgeries in addition to chemotherapy and radiation when he was diagnosed over 30 years ago, while Corrado was told he might only have six rounds of chemotherapy. “To me, that sounds like progress,” says Corrado. “Hopefully one day, we completely eliminate lymphoma, or the treatment will be so much easier than it is today. It felt like this is an organization that’s going to help lead the way to finding a cure.”

In July 2023, Corrado joined the Lymphoma Research Foundation at its Chicago Lymphoma Walk and raised more than \$25,000 within just a few weeks. Over 100 people came to the event as part of Corrado’s team,

traveling from as far as Indiana, Wisconsin, and New York. One family who had never been to Chicago before even made a weekend trip out of attending in support of their mother back home with cancer. “I was shocked that someone I don’t know from a whole other part of the country has seen what I’m doing, and it had such an impact on them that they hopped on a plane and came to a place they’ve never been before. That still blows my mind,” says Corrado.

Corrado continues to support LRF and even attended the Foundation’s Annual Gala in September as a special guest. He looks forward to getting more involved with the organization in the future. “I want to continue to shine a light on this community and other communities like it. I’m excited to get my health back so that I can do that to the fullest potential,” he says.

“Once I beat this, all that means to me is that I’m going to have more time on my hands to take on bigger challenges, help more people, and hopefully continue to grow. I want to keep building this community because I truly feel like I’m just at the beginning of what this could really be.”

Corrado is determined to emerge from his lymphoma journey stronger than ever. “This has absolutely given me the confidence that I can truly take on anything. I feel like I’m ready for whatever life may throw at me, and I’m going to handle it with a smile on my face.”🙏

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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

Pregunte al Doctor Sobre el Linfoma	12.21
2024 Disneyland Half Marathon Weekend	1.11-14
National Virtual Lymphoma Rounds	1.25
Update on Lymphoma from the 2023 American Society of Hematology (ASH) Annual Meeting	1.29

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