



# PULSE

## Trusting the Process and Celebrating Triumphs

Steven M. Horwitz, MD,  
medical oncologist at Memorial  
Sloan Kettering Cancer Center,  
member of LRF's Scientific Advisory  
Board, and co-chair of LRF's  
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## 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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#### 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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## LYMPHOMA RESEARCH FOUNDATION'S YOUTUBE CHANNEL

The Lymphoma Research Foundation's (LRF) 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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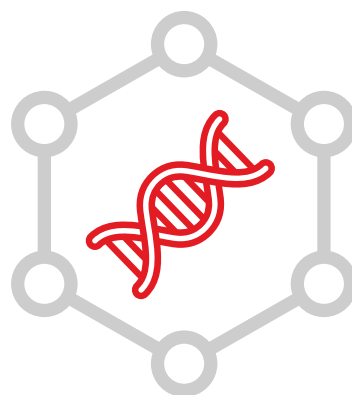
Steven M. Horwitz, MD, a Medical Oncologist at Memorial Sloan Kettering Cancer Center, member of LRF's Scientific Advisory Board, and co-chair of LRF's Lymphoma Scientific Research Mentoring Program (LSRMP), has seen firsthand what perseverance and tenacity can do in his work studying complex T-cell lymphomas, making strides and driving innovation in this once-overlooked disease subtype.



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Sometimes, life has a strange way of preparing us for what's ahead, even though we might not realize it at the time. For Tawny Roeder, a 37-year-old part-time nurse, and full-time wife and mother of two, a rotation in the oncology unit during her final year in nursing school ended up having a much bigger impact on her career — and her life — than she could have ever anticipated.



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9.24

Midwest Lymphoma Workshop

10.28-10.30

National North American Educational Forum on Lymphoma

Despite the pandemic, there is no interruption in our commitment to providing up-to-date patient education for people with lymphoma. **The Lymphoma Research Foundation (LRF) is using digital platforms to deliver virtual patient education programs, including the Ask the Doctor About Lymphoma series, Lymphoma Workshops, 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](https://lymphoma.org/programs)** to register and learn more.

# FROM THE CEO

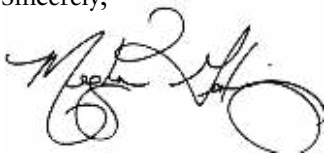
Maintaining momentum in the field of lymphoma/chronic lymphocytic leukemia (CLL) research has always been a priority for the Lymphoma Research Foundation (LRF). Since its inception, the Foundation has awarded more than \$72 million in lymphoma-specific research and supported critical breakthroughs to advance new treatment and cures for this disease. **Our commitment to the lymphoma community remains steadfast as we pursue this lifesaving work.**

You will learn more about our dedication to research in this issue of *Pulse* as we continue to introduce our 2022 grant class. This includes LRF's 12 new Lymphoma Scientific Research Mentoring Program (LSRMP) Scholars, participants in our first-of-its-kind program that provides hematology and oncology fellows and junior faculty a unique training experience and mentorship so they may build successful careers in lymphoma and CLL research. This vital program helps to ensure that the best and brightest scientific minds can commit their careers to the study of lymphomas. It is why LRF Scholars have become regarded as rising stars in the field.

This issue also features a profile of LRF Scientific Advisory Board (SAB) member and LSRMP co-chair, Steven M. Horwitz, MD, from the Memorial Sloan Kettering Cancer Center. Dr. Horwitz describes the challenging work that is required of a clinical oncologist – but how even the smallest victories can make a meaningful difference in the lives of patients. His research in T-cell lymphomas, a rare subtype of the disease, has been instrumental in the development of new therapies and addressing the needs of a historically underserved patient population. We are excited to profile Dr. Horwitz in this issue and to honor him at the upcoming LRF Annual Gala with the Foundation's prestigious Distinguished Leadership Award.

This critical work to invest in research, attract the brightest minds to our field, and support our scientific leadership in the pursuit of cures for every type of lymphoma would not be possible without you, our dedicated supporters who believe in the Foundation and our shared mission to eradicate lymphoma. Thank you for never giving up hope that we will one day see a world without lymphoma.

Sincerely,



Meghan Gutierrez  
*Chief Executive Officer*



# PHILANTHROPY IN ACTION



## **TD FIVE BORO BIKE TOUR LRF TEAM RAISES MORE THAN \$6,000**

During this year's TD Five Boro Bike Tour, held on May 1st, 2022, 32,000 cyclists took to the streets of New York City — including members of Team LRF! This annual event, America's largest bike ride, offers riders the chance to enjoy 40 miles of car-free streets through all five of New York's boroughs. For this year's ride, LRF teammates raised an impressive \$6,420 in support of LRF's mission to fund innovative research and serve as a resource for the patient community. Team LRF rider Matt Silbermann raised the highest individual total, bringing in \$2,950 to help eradicate lymphoma.



## **GOLF INVITATIONAL RAISES MORE THAN \$335,000**

Nearly 100 LRF donors and supporters hit the links at Quaker Ridge Golf Club in Scarsdale, New York, on May 23rd for LRF's 10th Anniversary Golf Invitational. Golfers had the chance to test their skills at this famed course, which has hosted three Met Opens, three Met Amateurs, and three Met PGA Championships, as well as the 2018 Curtis Cup Match, the second USGA championship hosted there. While guests enjoyed the pristine course, they also raised over \$335,000 for LRF's mission. This annual event is chaired by longtime LRF supporters Steve Prince and Jim Stern.



## **NATIONAL CANCER SURVIVORS DAY CAMPAIGN RAISES MORE THAN \$12,000**

On June 5th, we celebrated lymphoma survivors and thrivers as part of National Cancer Survivors Day (NCSD). Our community joined us in celebration by raising over \$12,000 to power cutting-edge research and critical resources for survivors and patients. This year, we also saw LRF donors becoming champions for survivors by starting their own NCSD fundraising campaigns using our peer-to-peer fundraising platform.



### MINNESOTA AND CHICAGO LYMPHOMA WALKS RAISE MORE THAN \$255,000

Over 500 participants and volunteers gathered in Minnesota and Chicago this summer to raise over \$255,000 at the Lymphoma Walks. Many thanks to our speakers, Dr. Kathleen Dixon from the University of Minnesota, Dr. Adam DuVall from the University of Chicago, and Dr. Adam Lin from Northwestern. They highlighted the importance of lymphoma research, being LRF grantees, and the impact fundraising has on the critical research LRF powers.



### SWIRL: CHICAGO RAISES MORE THAN \$90,000

Over 200 guests gathered in Chicago on June 2nd for LRF's Swirl: Chicago Wine Tasting Event where they raised more than \$90,000. Guests tasted a curated selection of Italian wines from Southern Glazer's Wine & Spirits, the Wine Sponsor of the Swirl Series. They also sampled delicious bites as they bid on fabulous prizes offered in the silent auction, all in support of our mission to eradicate lymphoma.



## 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 the Facebook Fundraiser Page and click the "raise money" button.

### STEP 2

When asked "Who are you raising money for?" select LRF by searching "Lymphoma Research Foundation" in the search bar.

### STEP 3

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

### STEP 4

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



A portrait of Paul V. Majkowski, a man with a grey beard and mustache, wearing a dark suit and a red tie. He is standing in front of a backdrop that features the Lymphoma Research Foundation logo and the website lymphoma.org. The text "LYMPHOMA RESEARCH FOUNDATION" and "lymphoma.org" are repeated across the backdrop.

## LRF ANNUAL GALA: RAISING FUNDS, HOPE, AND COMMUNITY TOWARD CURES

Paul V. Majkowski

As LRF's largest fundraising event of the year, the Annual Gala celebrates the advancements made in lymphoma research and patient care — as well as the esteemed researchers, doctors, donors, survivors, and caregivers who have helped make those advancements possible. The event is central to LRF advancing its mission to eradicate lymphoma and serve those touched by the disease.

One regular attendee of past LRF Galas looking forward to resuming the in-person event this year, is longtime lymphoma survivor and LRF Ambassador, Paul V. Majkowski, a Partner at Rivkin Radler LLP and a resident of Long Island. First diagnosed in 1996 with diffuse large B-cell lymphoma (DLBCL), the most common type of non-Hodgkin lymphoma (NHL), Paul has been actively involved with LRF as a volunteer and Ambassador ever since he attended his first LRF Annual Gala in 2004. As a past President of LRF's New York City Chapter, Paul was the 2016 recipient of LRF's Distinguished Service Award for his tireless service to the organization.

"The Annual Gala is the signature event for the Foundation, and as a two-time cancer survivor myself, I recognize just how vital it is to raise the money to further LRF's mission," says Majkowski. "It's gratifying to help enable the investment in promising, life-changing lymphoma research being conducted by the next generation of researchers and to continue to improve patient care through top-notch education programs and patient support services."

Beyond the important fundraising opportunity that the Annual Gala provides, Majkowski looks forward to attending the event in person this year for the sense of camaraderie it provides. He appreciates the opportunity to connect with friends and soon-to-be friends, united by a common cause and a commitment to the greater good of the lymphoma community as a whole.

"LRF has provided me the opportunity to connect with some amazing people in the lymphoma community, to give back, and to serve those touched by the disease, including patients and caregivers, who are so important," Majkowski says. "I feel like I have an obligation to give back, to help others feel like they are not alone, that they can get through this and live full and rich lives."

Majkowski is looking forward to this year's Gala, donning a wardrobe accented in red, and reinvigorating his commitment to a cause that is close to his heart.

"It is supporters like Paul that make the Annual Gala such a special and exciting event," says Rebecca Rausch, Associate Director of Distinguished Events. "We are grateful for his longtime support which helps make the Gala a success and helps ensure that other survivors like him have hope for a brighter future." ○



**RISE TO**  
**THE OCCASION**



**YOU'RE INVITED**  
TO OUR  
**2022 ANNUAL GALA**

**SEPTEMBER 29, 2022 | 6:30 PM ET**  
**ZIEGFELD BALLROOM, NEW YORK CITY**



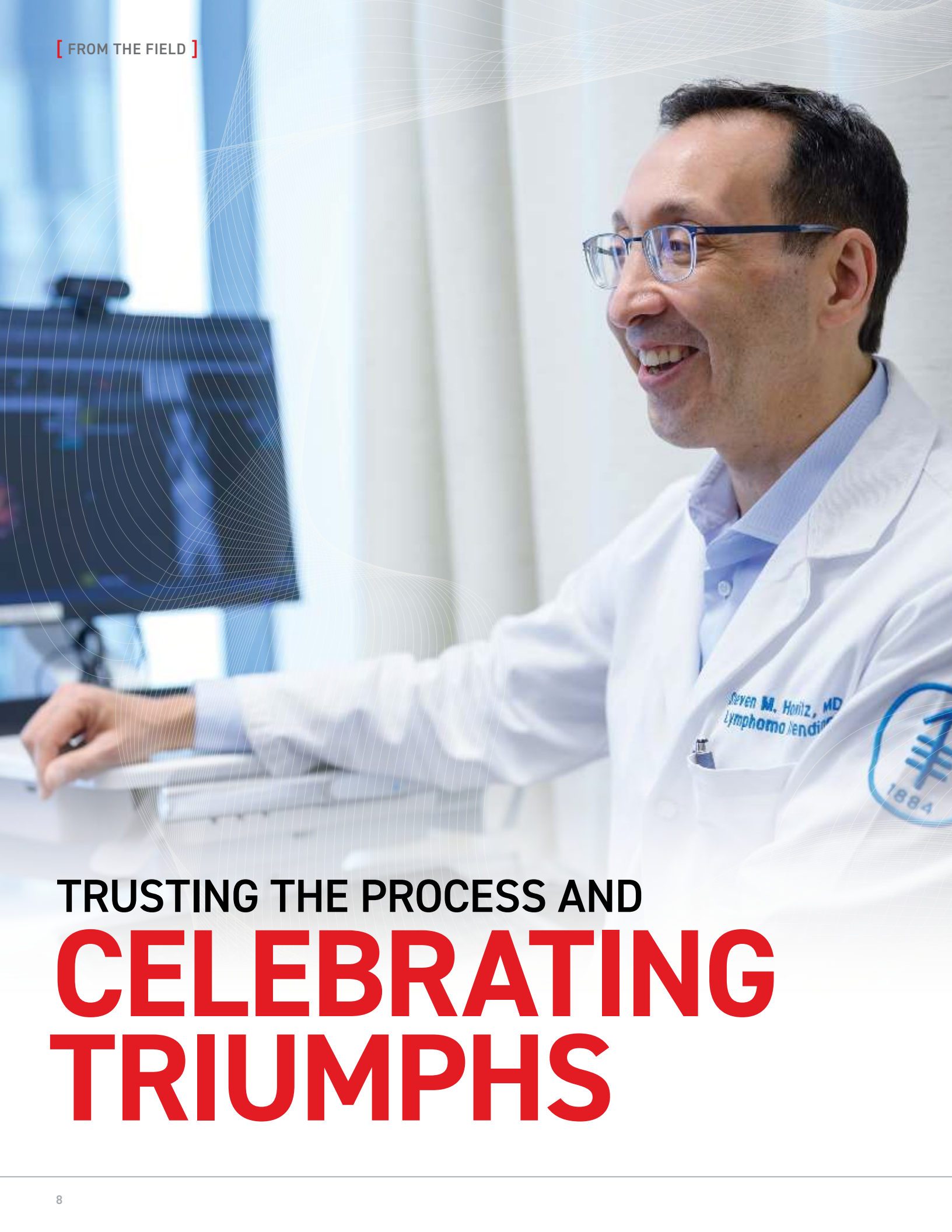
You're invited to a special event celebrating all we've accomplished together to eradicate lymphoma! Join us to raise funds, celebrate our distinguished honorees, and be inspired by the significant achievements and advancements made in lymphoma research over the past year.

**MAKE AN IMPACT. JOIN AS AN EVENT SPONSOR.**

A variety of exciting packages and sponsorship benefits are available for the 2022 LRF Annual Gala. For more information about this year's Gala, contact Rebecca Rausch, Associate Director of Distinguished Events, at 917 882 9036 or [rrausch@lymphoma.org](mailto:rrausch@lymphoma.org).

[lymphoma.org/gala](https://lymphoma.org/gala)

**LYMPHOMA**  
RESEARCH • FOUNDATION



# TRUSTING THE PROCESS AND **CELEBRATING TRIUMPHS**

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**“In oncology, you start too often with not great odds; you have some wins, and too many losses, but you keep coming back to this idea that you’re always working toward something better — there can be satisfaction in the trying.”**

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Growing up in Cleveland, Ohio, Steven M. Horwitz, MD, a Medical Oncologist at Memorial Sloan Kettering Cancer Center, member of LRF’s Scientific Advisory Board, and co-chair of LRF’s Lymphoma Scientific Research Mentoring Program (LSRMP), is familiar with long periods of immense collective effort with occasional triumphs that make it all worth it.

A lifetime Cleveland sports fan, he’s well aware that when the Cleveland Cavaliers won the NBA Championship in 2016, it marked Cleveland’s first national sports title since 1964, when the Cleveland Browns won their last NFL title. The lean years didn’t dim his enthusiasm for Cleveland sports, however. If anything, it strengthened his commitment. For Dr. Horwitz, being a longtime Cleveland sports fan was excellent training for being a successful medical oncologist.

“The first nearly 50 years of my life were spent being a Cleveland sports fan without experiencing the ultimate success of winning a championship, but when you are deeply committed to your teams, you come to understand the beauty of the effort, and the struggle, and the value of the process — even if the result isn’t what you hoped it would be,” says Dr. Horwitz. “In oncology, you too often start with not great odds; you have some wins, and too many losses, but you keep coming back to this idea that you’re always working toward something better — there can be satisfaction in the trying.”

That commitment to the process has been consistent throughout Dr. Horwitz’s career and is reflected in his approach to medicine. His father was a psychoanalyst, and his mother was a teacher who directed an analytic preschool. Both encouraged him to follow his passion, so the choice to pursue medicine was not a particularly difficult one. After graduating from the University of Michigan as an English Literature major, he attended medical school at Case Western Reserve University, where he studied a core medical curriculum combined with a patient-centric, humanistic approach.

“For me, the possibility of going into medicine was always on the table, but my passion and drive for it really took

root as I went through my residency at the University of Rochester, followed by a fellowship at Stanford,” explains Dr. Horwitz. “I witnessed that in oncology, doctor, patient, and the patients’ families were all aligned toward the same goal. I felt that lymphoma was a serious challenge I could work on for a lifetime and hopefully make a meaningful difference, which made it feel worthwhile.”

### **Seeing an Unmet Need**

Coincidentally, Dr. Horwitz began his fellowship at Stanford in 1997, within months of when rituximab was first approved by the FDA for certain relapsed or refractory lymphomas. As a result, researchers were paying a great deal of attention to B-cell lymphoma research at the time, while other rare forms of lymphomas, including T-cell lymphomas which Dr. Horwitz would later go on to specialize in, were overlooked and left behind.

“I saw a group of patients in need that were understudied and poorly understood, and who had no new therapy options being developed,” explains Dr. Horwitz. “I started going to the skin lymphoma clinic at Stanford, and it felt like this was an area where I could add value and develop expertise.”

Upon finishing his fellowship, Dr. Horwitz moved to New York, where he now lives with his wife and two children, to focus on the study and treatment of T-cell lymphomas at Memorial Sloan Kettering Cancer Center (MSK). There, he has developed a large clinical practice and clinical trial program dedicated to people with T-cell lymphomas. Through this program he has led or been instrumental in the development of the current FDA-approved therapies and many advances that have greatly expanded the treatment options for patients.

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**“I felt that lymphoma was a serious challenge I could work on for a lifetime and hopefully make a meaningful difference, which made it feel worthwhile.”**

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### Tackling Complex T-cell Lymphomas

In general, T-cell lymphomas are known for their heterogeneity, clinical complexity, and comparative rarity. Tending to show up disproportionately outside of lymph nodes, many appear in the skin, gastrointestinal tract, and other parts of the body. Skin or cutaneous lymphomas can add an additional component of anxiety and distress as patients see their lymphoma every day when getting dressed or looking in the mirror.

When Dr. Horwitz first came to Memorial Sloan Kettering in 2001, there were no dedicated studies underway for patients with T-cell lymphomas, and they were often excluded from trials for other non-Hodgkin lymphomas. He saw a clear opportunity to move the study and treatment of T-cell lymphomas forward by changing this.

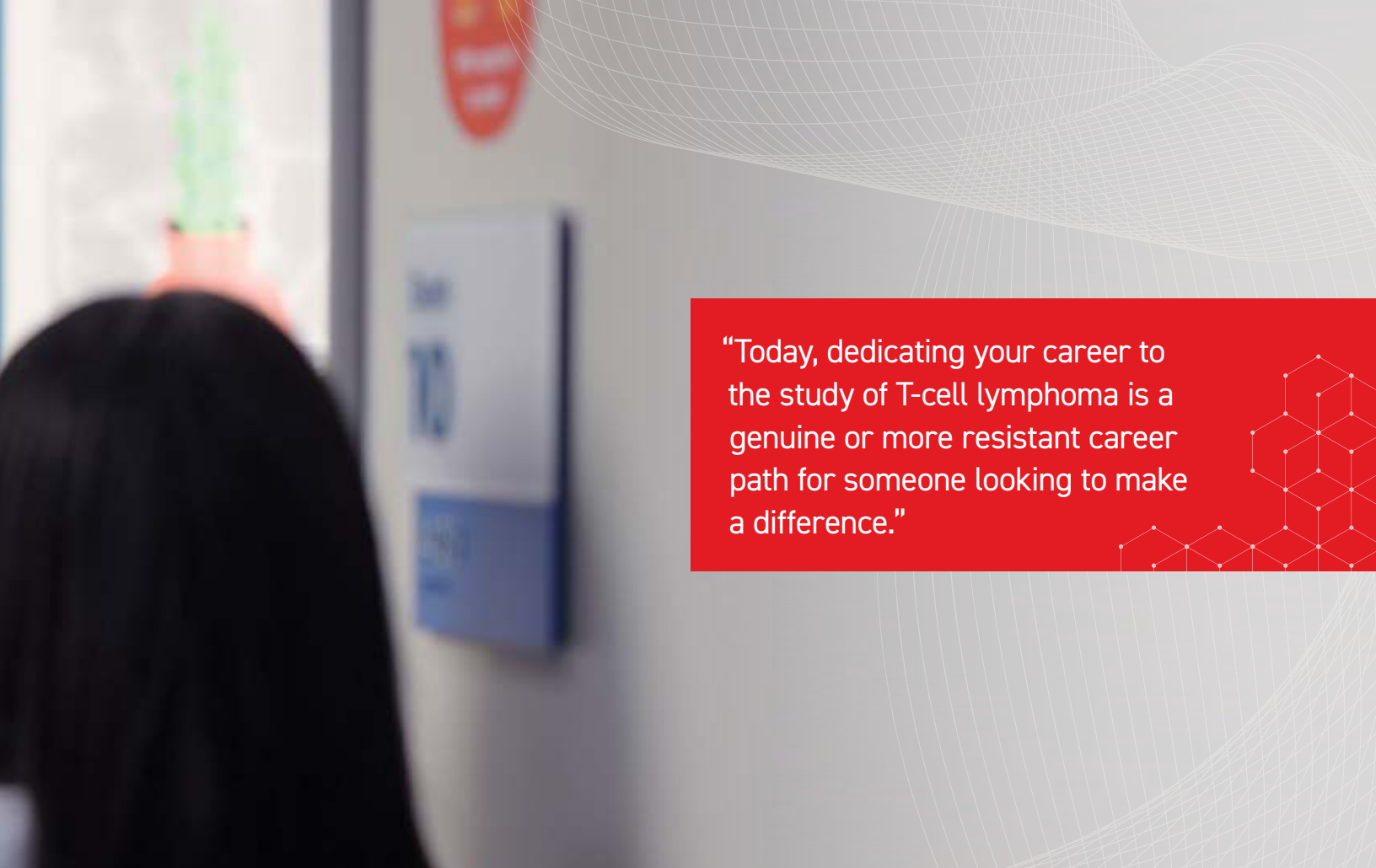
“There’s a big unmet need when it comes to T-cell lymphomas, which represent approximately 7-10 percent of lymphomas but remain understudied,” says Dr. Horwitz. “While the goals, treatment strategies, and dynamics of various T-cell lymphomas may differ, our clinical and research teams believe that optimal care has to include the ready availability of new therapies — of which there are not enough — because the current standard therapies are inadequate for too many people.”

While many T-cell lymphomas had a worse prognosis than most other types of non-Hodgkin and Hodgkin lymphomas, when Dr. Horwitz was first starting out in the field, it was unclear if that was because they were truly worse or more resistant diseases, or because doctors were not using the optimal therapies to treat them. He quickly realized that it was a bit of both.

“They weren’t being specifically studied, but there are also some higher rates of chemoresistance and relapse with T-cell lymphomas,” says Dr. Horwitz. “Over time, we’ve expanded the breadth of therapies to include new classes of drugs, and a big part of our program today is focused on the development of novel therapies, gaining a greater biologic understanding of T-cell lymphoma, and the development of safer, less-toxic treatment options.”

Dr. Horwitz notes that he’s seen a significant increase in interest in T-cell lymphoma across the board, compared to when he first entered the field.

“I’m a clinical investigator, but we now have more laboratory partners, more models and novel therapies in development, and more smart, dedicated people working on T-cell lymphoma than ever before, which is gratifying to see,” Dr. Horwitz says. “Today, dedicating your career to the study of T-cell lymphoma is a genuine or more resistant career path for someone looking to make a difference.”



“Today, dedicating your career to the study of T-cell lymphoma is a genuine or more resistant career path for someone looking to make a difference.”

### Supporting the Future of Lymphoma Research

Dr. Horwitz is encouraged by the increased interest in T-cell lymphomas and the study of lymphoma as a whole. To encourage a continued focus and enthusiasm for this field, he serves as a member of LRF’s Scientific Advisory Board (SAB), which he’s been a member of since 2017. On the SAB, he joins 44 other world-renowned lymphoma experts, who collectively identify the most innovative and promising lymphoma research projects for support.


“I have long believed that we can make a difference with T-cell lymphoma by being focused and persistent, and I think that’s where organizations like LRF are so important because they incentivize the research community to focus on lymphoma, including what are considered to be ‘rare’ subtypes,” says Dr. Horwitz. “Science and medicine can be very competitive, but beyond the generous grants, which support potentially life-changing research efforts, the LRF SAB has created a supportive community where people genuinely like each other, share insights, and identify ways to collaborate.”

In addition to the SAB, Dr. Horwitz currently serves as co-chair of LRF’s Lymphoma Scientific Research Mentoring Program (LSRMP), a first-of-its-kind education and mentoring program for junior scientists who wish to focus on lymphoma clinical and laboratory/translational


research. A program that Dr. Horwitz believes is truly the future of lymphoma research.

“We find talented people just getting started in their medical or research careers with an interest in lymphoma, and we bring them into the lymphoma research community, helping them feel supported,” Dr. Horwitz says. “That dedicated focus on bringing new people into the field is central to our future success and discovering the next big lymphoma breakthroughs.”

In recognition of Dr. Horwitz’s outstanding contributions to help advance the understanding of lymphoma and his commitment to the lymphoma community, the LRF is awarding him the 2022 Distinguished Leadership Award at this year’s Annual Gala on September 29th. An award he is honored and humbled to receive.

“We have to stay focused on what matters because our research changes lives,” says Dr. Horwitz. “During the COVID pandemic, many labs closed their doors and some clinical research programs were forced to slow down, but LRF continued hosting programs via Zoom, issuing grants, and bringing people together to collaborate on science and lymphoma. That’s essential and just one of many reasons why I’m honored to work so closely with the organization.” 

*Photos in cover image, masthead, and this article compliments of Memorial Sloan Kettering Cancer Center. All rights reserved.*



Dr. Gita Thanarajasingam  
is a Medical Oncologist at  
Mayo Clinic, Rochester.

## WHERE ARE THEY NOW?

# GITA THANARAJASINGAM, MD

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

As a result of my father's job as a diplomat, I lived in Brazil during high school and had the opportunity to volunteer in a clinic in the Amazon region. I functioned in community outreach and worked with local, national, and international nurses and physicians working to serve the population in this region. It was then that I knew I wanted to be in medicine, and it was six years later, in my medical school hematology class, when I first met a patient who spoke on his experience as a survivor of aggressive lymphoma, that I knew I wanted to channel my interest into caring for patients and advancing the field in this disease.

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

After having completed my fellowship in hematology and oncology, and while engaged in a lymphoma-specific advanced fellowship, I was honored to be granted funding from the LRF as a Lymphoma Clinical Research Mentoring Program scholar (now known as the Lymphoma Scientific Research Mentoring Program, LSRMP). This is a unique, competitive grant meant to furnish research skills as well as an array of mentors for a small group of developing investigators in lymphoma.

### **What scientific project did you pursue as part of your LRF research grant?**

Many LSRMP Scholars evaluate cutting-edge therapies and design therapeutic/interventional trials. I was fortunate that the LRF could also see the value in the type of work I do, which is translational health outcomes research. I work with biostatisticians, psychometricians, and other methodologists to develop better methods by which to evaluate adverse events in lymphoma clinical trials. The overarching goal of my research is to understand the tolerability of our treatments and improve the patient experience of lymphoma therapy.

### **How has your participation in the Lymphoma Scientific Research Mentoring Program (LSRMP) impacted the work that you are doing today?**

My participation in the LSRMP was an undeniable bedrock to my career as a clinical investigator focused on patient-centered research to better understand lymphoma treatment tolerability. I have expanded on what was initially a project focused on better ways to analyze data on adverse events of lymphoma treatment, into a career niche focused on understanding the patient perspective and trying to better reflect the patient's experience of cancer treatment.

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

The LSRMP program was vital to advancing my research career in lymphoma. The workshop itself provided foundational research skills. However, even more substantially than that, it connected me to an array of renowned mentors in lymphoma nationally and internationally, and it provided the time to harness feedback from this expert group to refine the project at hand and my research career in this field in general.

### **You are an expert in studying the outcomes associated with different lymphoma treatments and their impact on patients and survivors. How has the treatment landscape for lymphoma/CLL changed since you first started conducting your research?**

There has been a dramatic, unprecedented expansion of therapies available to treat lymphoma and CLL which have improved outcomes and demonstrate the hope and promise in the fight against these cancers. Many of these new therapies have novel mechanisms of action, different routes of delivery (oral versus intravenous), chronic administration, and different toxicities (or side effects). In this lens, it is important to make sure that treatments are not only safe for patients but that they are tolerable for our patients to take over time when that is what is needed.

**Why is it important to better evaluate and record patient-related outcomes during treatment and clinical trials? How can this help improve lymphoma treatment in the future?**

To understand tolerability, we need to understand how patients feel and function while on treatment. Historically, the only way we have done that is through clinicians' reporting on a patient's experience with the side effects of treatment. This information, which is vital to evaluating the safety of treatment, is not adequate for understanding tolerability, which required the patient perspective. Evaluating, recording, and analyzing patient-reported outcomes in clinical trials and in real-world patients is necessary to understand treatment tolerability.

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

As an early career LRF grantee, I have now evolved into an established lymphoma translational health outcomes researcher and have had the opportunity to become increasingly involved with the LRF. I have been part of the steering committee for the LRF's recent AYA Symposium and its Virtual Grand Rounds educational program and have been an "LRF All-Star," leading efforts to fundraise for neighborhood walks during the pandemic. I have also had the privilege of participating in several fundraisers, including one spearheaded by the wife of one of my dear patients. This year I was honored with an invitation to be faculty of the LSRMP, which was a full circle moment for me. I was privileged to be involved and meet budding lymphoma clinical researchers in this role, including two outstanding lymphoma health outcomes researchers in my small group.

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

The LRF is a vital support for the lymphoma patients of today and of tomorrow. Today, as a clinician, educational materials, programs, websites, and other high-quality resources made by the LRF form a backbone of support for our patients and their caregivers facing a variety of epochs in lymphoma – from diagnosis to treatment and beyond. For the patients of tomorrow, LRF's focus on lymphoma-specific research bolsters investigation into the newest and best treatments and projects that understand the biology of the disease and how it affects lymphoma patients as people.

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

One of the most exciting projects I am currently leading is a study by which we are measuring physical function in lymphoma patients receiving chemotherapy, the In4M study (Integrating 4 Measures to Assess Physical Function

in Cancer). We are hoping to optimize the assessment of how patients feel and function during treatment in different ways, including using patient-reported outcomes (surveys that ask patients questions), clinician reports on how a patient is functioning, a performance test (6-minute walk test), and, excitingly, wearable device data. We are trying to understand how we can harness these different sources of data to best understand how treatment can affect physical function. When we can capture this better in clinical trials and in practice, we can harness it to improve the treatment experience of our patients.

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

I am very excited about our growing understanding of the biology of different lymphomas and the increasing number of treatments available to our patients. I am most excited to see that in tandem with this progress in biology and treatment, we are also doing a better job of measuring how patients feel and function during treatment and beyond to provide truly patient-centered lymphoma care. ○



## 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.

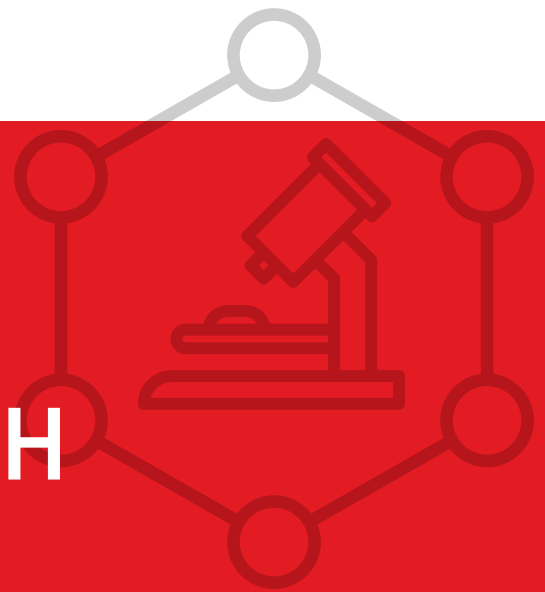
### **TISAGENLEUCEL (KYMRIA®)**

**June 27, 2022** — a chimeric antigen receptor (CAR) T cell therapy, for adult patients with relapsed or refractory follicular lymphoma (FL) after two or more lines of systemic therapy.

### **LISOCABTAGENE MARALEUCEL (BREYANZI®)**

**June 24, 2022** — a chimeric antigen receptor (CAR) T-cell therapy, for adult patients with large B-cell lymphoma who have refractory disease to first-line chemoimmunotherapy or relapse within 12 months of first-line chemoimmunotherapy; or refractory disease to first-line chemoimmunotherapy or relapse after first-line chemoimmunotherapy and are not eligible for hematopoietic stem cell transplantation (HSCT) due to other health conditions or age.

# MEET THE 2022 LYMPHOMA SCIENTIFIC RESEARCH MENTORING PROGRAM SCHOLARS



The Lymphoma Research Foundation's (LRF) Lymphoma Scientific Research Mentoring Program (LSRMP) is a first-of-its-kind education and mentoring program for junior scientists who wish to focus on lymphoma and CLL research, whether in the lab or in the clinic.

The primary goal of the LSRMP is to retain its talented participants — called LRF Scholars — in the field of lymphoma by providing mentoring and education programming and fostering research collaboration among expert faculty and grantees.

Led by the 2022 LSRMP Clinical Research co-chairs, Steven Horwitz, MD (Memorial Sloan Kettering Cancer Center) and Kami Maddocks, MD (The Ohio State University Comprehensive Cancer Center), and Laboratory/Translational Research co-chairs, Ari Melnick, MD (Weill Cornell Medicine) Christian Steidl, MD (BC Cancer, Vancouver), and Laura Pasqualucci, MD (Columbia University), the new class is boasting translational and clinical researchers pursuing a diverse range of research projects with a goal to improve patient outcomes.

## Clinical Research LRF Scholars



**DAI CHIHARA, MD**

THE UNIVERSITY OF TEXAS MD  
ANDERSON CANCER CENTER

Phase I trials are the first step in transitioning new drugs from the bench to the clinic. These trials are intended to evaluate the safety and tolerability of new investigational agents, and many potential therapies do not make it past this stage of development. By studying how the toxicity of these agents compares across subtypes of lymphoma, Dr. Chihara hopes to improve trial designs in the future and allow researchers to better predict how drugs will perform in these early stages of development. “Unveiling key drivers that impact the probability of toxicity and success of drug development can potentially lead to fewer trial failures, faster approval times, and bring therapies to patients sooner,” he explains.

Dr. Chihara earned his medical degree from the Kobe University School of Medicine in Japan. After earning his PhD in epidemiology from the Nagoya University School of Medicine, he completed a lymphoma and myeloma fellowship at The University of Texas MD Anderson Cancer Center. After completing a medical oncology fellowship at the National Cancer Institute, Dr. Chihara returned to MD Anderson Cancer Center, where he now serves as an assistant professor in the Department of Lymphoma

and Myeloma. During his time there, he has used clinical data and population-based cancer registry data to describe the incidence of and survival in lymphoma, as well as the identification of high-risk populations.

“There is a term in Japanese, ‘ikigai’, which describes the concept that your passion, mission, and profession overlap and will lead to a fulfilling life,” Dr. Chihara says. “My ikigai is to provide outstanding care and improve patient outcomes through patient-centered research, and I would like to make a major contribution in clinical science by leading this cutting-edge clinical research to facilitate early phase clinical trials in lymphoma.”



**PAOLA GHIONE, MD**

MEMORIAL SLOAN KETTERING  
CANCER CENTER

Lymphomas are a highly heterogeneous set of diseases, and while many people will do well with treatment, there are subsets of patients whose cancer does not respond or relapses quickly despite treatment. In these cases, therapeutic options are limited, and better treatment options are needed. Dr. Ghione’s LRF research project is aimed at determining the efficacy of two novel drugs that inhibit the disease-causing pathways that lead to T-cell lymphoma. Using tissue biopsy samples, Dr. Ghione is studying these drugs both as single agents and, perhaps with more promising results, as combined therapy.

Dr. Ghione earned her medical degree from the University of Turin in Italy, where she went on to complete a fellowship in lymphoma and molecular biology. Her current research in the Lymphoma Service at Roswell Park Comprehensive Cancer Center is focused on understanding T-cell lymphoma epidemiology, biology, and treatment. “Our treatment options are not satisfactory, and better treatments are urgently needed,” she says. “Challenges have always inspired me to do my best, and the challenge of finding better treatments for lymphoma is truly one of my favorites to pursue.”

Through the connections she has built in the Lymphoma Scientific Research Mentoring Program, Dr. Ghione has already received invaluable feedback on trial design and how to get help moving her studies forward. She hopes to build upon these experiences to help establish herself as a research leader in the field of lymphoma, with the goal of improving treatment options and quality of life for people living with lymphoma.



**DAVID QUALLS, MD**

MEMORIAL SLOAN KETTERING  
CANCER CENTER

Immunotherapies in lymphoma aim to activate the patient’s own immune system to help target and destroy lymphoma cells. While effective, the impact of these types of therapies is often hampered by changes to the immune system caused by the lymphoma itself. Dr. Qualls’ LRF research therefore aims to improve the efficiency of immunotherapy in lymphoma by using a combination treatment approach, combining the use of a T-cell-activating drug with a bispecific antibody that helps facilitate interactions between T-cells, cancer cells, and other immune cells. “We believe that this combination will increase the ability of patients’ immune systems to kill lymphoma cells by several mechanisms,” he explains, “by increasing T-cell activation and simultaneously broadening the immune response to include other types of cells in the immune system, which may prevent some of the mechanisms of resistance to immunotherapy seen in lymphoma.”

Dr. Qualls is currently serving as a clinical fellow in hematology and oncology at Memorial Sloan Kettering Cancer Center. His interest in lymphoma began early in his medical career while he was a medical student at Washington University in St. Louis. One of the first patients he worked with there was an individual with immune thrombocytopenia (ITP), a condition in which his immune system destroyed his platelets and caused bleeding complications. His ITP was ultimately found to be caused by undiagnosed Hodgkin lymphoma, and by treating his cancer, they could improve his platelet counts as well. “Since then, I have been fascinated by the interactions between our immune system and lymphoma and have been driven to understand these interactions more thoroughly, and how we can leverage this understanding to improve patient outcomes,” Dr. Qualls explains.

In the future, Dr. Qualls hopes to establish himself as an independent clinical researcher focused on improving lymphoma treatment options. He is especially interested in how current lymphoma therapies affect the immune system in both the short and long term and what that means for future cancer treatment. Dr. Qualls is also very interested in engaging with patients to learn what matters most to them. “The patients I care for provide the fuel for my research,” he says. “Getting their perspective on the disease on a regular basis provides the fuel to ask why certain processes are happening and explore how we can develop more effective and less toxic therapies.”

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**HELEN MA, MD**

THE REGENTS OF THE UNIVERSITY OF CALIFORNIA

*Stephanie A. Gregory  
Distinguished Scholar*

Veterans who have been involved in combat over the last several decades have been potentially exposed to a variety of carcinogenic elements, such as Agent Orange and chemical smoke from burn pits. Lymphoid malignancies are normally rare but represent one of the most common types of cancer seen in these populations. Through her LRF research, Dr. Ma hopes to better understand the relationship between carcinogen exposure in combat settings and the development of lymphoid malignancies, such as lymphoma. “The results of this research may lead to understanding how exposures may impact outcomes as well as potential novel treatment strategies,” she explains.

Dr. Ma completed her medical degree at the Geisel School of Medicine at Dartmouth. During this time, she became interested in performing outcomes research using national databases as well as clinical trial results. However, at the end of her medical school training, her mother was diagnosed with an aggressive peripheral T-cell lymphoma. “Since then, I have been committed to lymphoma research in all forms,” she says. She is currently an assistant professor in the Division of Hematology and Oncology in the Department of Medicine at the University of California, Irvine, where she continues her outcomes research and involvement in clinical trials. She also serves as an attending physician in hematology and oncology in the VA Long Beach Healthcare System in Long Beach, California. “Treating patients inspires me to continue working toward improving their care with research,” she says.

Through her work with the LRF, Dr. Ma hopes to better characterize the natural history of lymphoma and how treatment responses vary in different populations, including veterans. She notes that the connections she has built through the Lymphoma Scientific Research Mentoring Program are helping to make this dream a reality. “Participation in the LSRMP Workshop has really brought my project to life,” she says. “It has been great working with epidemiologists, biostatisticians, and informaticists to ensure the methods are sound and the research is performed with rigor.”



**HARSH SHAH, DO**

THE UNIVERSITY OF UTAH

*Stedman Family Scholar*

The future of lymphoma treatment is rapidly evolving, and investigator-initiated clinical trials are helping to pave the way toward improved treatment approaches. Dr. Shah’s LRF research is focused on the development of a clinical trial investigating the effects of adding a novel agent, axatilimab, to current immunotherapies in patients with relapsed classical Hodgkin lymphoma who initially have a poor response to treatment. “When I worked with one of my mentors, Dr. Ramchandren, in clinic during fellowship, I saw many young patients with relapsed classical Hodgkin who were refractory to traditional treatments, including immunotherapy, without any FDA-approved treatment options left,” he explains. “This motivated me to think about potential novel agents that could circumvent immunotherapy resistance and help patients.”

**“This motivated me to think about potential novel agents that could circumvent immunotherapy resistance and help patients.”**

Dr. Shah earned his DO from the Kirksville College of Osteopathic Medicine at the A.T. Still University in Missouri. He completed a fellowship in hematology and oncology at Wayne State University and is now an assistant professor in the Department of Hematology at The University of Utah. Dr. Shah is particularly motivated by the lack of treatment options available for patients with relapsed/refractory lymphomas and hopes that his LRF research will help uncover new therapies for these patients. He plans to build on the foundations he gains through the Lymphoma Scientific Research Mentoring Program to continue this work throughout his career and hopes to one day be a research leader in the field of lymphoma, with a focus on running investigator-initiated clinical trials. “Leading a multidisciplinary clinical research team can be a challenge,” he says. “The LSRMP will help me in understanding the concept of forming and sustaining such teams.”



**SAMUEL YAMSHON, MD**

JOAN & SANFORD I. WEILL MEDICAL  
COLLEGE OF CORNELL UNIVERSITY

In recent years, there has been substantial research interest in harnessing the power of the body's own immune system to help fight lymphoma. This type of therapy, known as immunotherapy, has already revolutionized the treatment landscape for lymphoma, and many new investigational agents are still on the horizon. Dr. Yamshon's LRF project goal is to understand if and how follicular lymphoma immunotherapy with the bispecific antibody mosunetuzumab can be improved using combination drug therapy. Specifically, he is studying how the EZH2 inhibitor tazemetostat can be used to help prime the immune system and modify the tumor microenvironment to improve the effectiveness of immunotherapy.

"Our hope is that by using this combination in patients who have never been treated for follicular lymphoma, we can provide them with very prolonged remissions," he says. "We hope that we may even be able to cure a percentage of them, an elusive goal in follicular lymphoma."

Dr. Yamshon is a clinical hematology and oncology fellow at NewYork-Presbyterian and Weill Cornell Medical Center in New York. He has been involved in lymphoma research since medical school, but his interest in lymphoma began long before that. "My grandfather passed away from an aggressive B-cell lymphoma in the late 1980s, when there were very few treatments available," he explains. "When his son, my uncle, got the same diagnosis 15 years later, treatments had improved to the point that, despite multiple relapses, he survived and is cancer-free today. Those therapies improved due to the hard work and dedication of researchers, and my hope is that our work today will allow more families like mine to have time with their loved ones."

### Laboratory/Translational Research LRF Scholars



**OWHOFASA AGBEDIA,  
MBBS, MPH**

UNIVERSITY OF TEXAS M.D.  
ANDERSON CANCER CENTER

Chimeric antigen receptor (CAR) T-cell therapies involve the re-engineering of a patient's own immune cells to help them find and fight cancer cells within

the body. This treatment approach has been very effective for several types of lymphoma. However, in some cancers, such as NK/T-cell lymphoproliferative disorders, the development of CAR T cell therapy has been challenging, as a unique, tumor-specific target has not yet been identified. The goal of Dr. Agbedia's research is to find an appropriate target that can be used to develop CAR T cell therapy for the treatment of these fast-growing lymphomas. "This is an exciting potential therapy that can offer a new healing option and improve patient outcomes," he explains. "Our hope is that with the development of these CAR-T cells, patients will be afforded more time, a better quality of life, and greater hope of beating cancer altogether."

Dr. Agbedia earned his medical degree from the University of Ibadan College of Medicine in Nigeria. He is currently a hematology and oncology fellow at The University of Texas MD Anderson Cancer Center and is also studying for a Master of Science in cancer biology, immunology, and immunotherapy. Building on the work from his LRF research, Dr. Agbedia hopes to one day become an independent translational researcher leading a program focused on the development of immunotherapies for aggressive lymphoid cancers. "The research mentorship and experience I will gain during this project will provide me with the scientific skills and knowledge that can be integrated into the frontlines of patient care and cancer research during the next steps in my career as a translational researcher," he says.



**ROBERT ALBERO GALLEGO, PHD**

COLUMBIA UNIVERSITY

Angioimmunoblastic T-cell lymphomas (AITLs) are aggressive forms of blood cancer and are often resistant to conventional chemotherapy. Certain mutations are very common in AITLs, including mutations in the TET2 and RHOA genes. Through his LRF research, Dr. Alberro Gallego hopes to uncover the role of these genes in the development of AITLs, with the goal of illuminating new vulnerabilities in cancer cells that can potentially be targeted with treatment. "Understanding how both mutations cooperate in lymphoma progression will allow us to design rational therapies and improve overall survival," he explains.

Dr. Alberro Gallego has been interested in cancer research since childhood but was drawn toward lymphoma research in particular during his time in graduate school. He earned his PhD at the University of Barcelona in Spain, where

*Continued on the next page*

he studied epigenetic regulators in lymphoma. He is now serving as a postdoctoral research scientist in the Institute for Cancer Genetics at Columbia University in New York, where he is studying drivers of cancer cell transformation.

Building on his experiences in the Lymphoma Scientific Research Mentoring Program, Dr. Albero Gallego hopes to one day establish himself as an independent principal investigator focused on lymphoma research. Through collaborations with other researchers, as well as industry and clinical research programs, he hopes to use multidisciplinary approaches to better understand what drives cancer formation and how it can be interrupted.



**TAYLA FORAL, PHD**

DANA-FARBER CANCER INSTITUTE

Mature T-cell lymphomas (TCL) are a highly heterogeneous group of diseases with poor treatment options. Currently, many patients with TCL experience relapsed or refractory disease, and outcomes are generally poor. Dr. Foral's LRF research aims to identify crucial elements that drive the development and persistence of TCL, with the goal of illuminating new potential targets for therapeutic intervention. She also hopes that uncovering the mechanisms of disease will help to better understand how resistance to current therapies occurs, potentially revealing opportunities for new treatment approaches to improve outcomes.

Dr. Foral earned her PhD at the University of Nebraska Medical Center, where she used a variety of genomics-based techniques to study drivers of TCL formation. "I was continuously reminded through those years of the progress that still needed to be made to improve therapies and ultimately overall survival for patients with T-cell lymphoma," she notes. Her desire to participate in translational research led her to pursue a postdoctoral research fellowship at the Dana-Farber Cancer Institute, where she is using cutting-edge genomic technology to identify novel therapeutic targets in TCL.

In the future, Dr. Foral hopes to establish herself as an independent translational lymphoma researcher leading the next generation of scientists. "I truly believe that mentorship is an essential component of a successful career," she says. "I would not be where I am today without the guidance from superb mentors at every stage of my training who are passionate about mentoring." Many unknowns remain in the field of lymphoma research, and Dr. Foral is confident that her hunger for discovery will motivate her to continue pursuing the answers that can help improve patient outcomes.



**MATTHEW KLAIRMONT, MD**

NEW YORK UNIVERSITY SCHOOL OF MEDICINE

In many cases, follicular lymphoma (FL) is an indolent and treatable B-cell lymphoma, and most patients live a normal lifespan. However, in a subset of patients, the disease can progress very quickly, and transformation to an aggressive lymphoma can occur early in the disease. High-intensity treatment can help improve responses in these patients, but there currently aren't any markers available to predict which patients will experience aggressive disease. Through his LRF research, Dr. Klairmont hopes to identify features in FL that are predictive of early disease progression that can be used to individualize frontline treatment approaches.

Dr. Klairmont earned his medical degree from Rush Medical College in Chicago and completed a clinical fellowship in hematopathology in the Department of Pathology at the New York School of Medicine. He is now working as a research scientist and early career investigator, working toward a career as an independent translational lymphoma researcher. "Helping patients beat cancer is what drove me to become a physician," he explains. "Unfortunately, despite advances in chemoimmunotherapy, outcomes for many lymphoma subtypes are still very poor, which I think indicates that there is much that needs to be learned about lymphoma biology in order to accelerate the development of more curative therapies."

Although there is much left to understand about FL and other lymphomas, Dr. Klairmont is optimistic that rapidly evolving genomic technologies will help advance research that can be used to help patients. "Recent innovations in genomic technology have the power to unveil answers to many longstanding questions about the mechanisms that drive aggressive lymphomas, and it is the opportunity to leverage these scientific advances to ultimately help patients beat a catastrophic disease like lymphoma that inspires my commitment to research," he says.



**PATRICK REVILLE, MD**

THE UNIVERSITY OF TEXAS MD ANDERSON CANCER CENTER

Chimeric antigen receptor (CAR) T cell therapies are a rapidly emerging form of treatment in many types of cancers, including lymphomas. This type of therapy

involves engineering a patient's own T cells to target and attack cancer cells within the body. In patients with relapsed or refractory large B-cell lymphoma (LBCL), CAR-T cell therapy has shown early promise, but many patients exhibit diminishing responses due to reduced expression of CD19, the antigen typically targeted by these therapies. Dr. Reville's LRF research aims to develop a novel CAR-T cell therapy that targets a different receptor on the surface of lymphoma cells (CD38), to prevent relapse after loss of CD19 expression.

Dr. Reville is currently a hematology and oncology fellow at The University of Texas MD Anderson Cancer Center. He earned his MPH from The Ohio State University before completing his medical degree at Baylor College of Medicine in Texas. Dr. Reville was inspired to pursue a career in lymphoma research during graduate school, where his mentor showed him the importance of building connections with his patients. "Seeing the relationships that he built with his patients and the lasting impact he was making on their lives was the calling I needed to hone my career path," he says.

Dr. Reville values the continued influence all of his mentors have had on his academic and research careers and is excited to continue that mentorship through the Lymphoma Scientific Research Mentoring Program. He notes that his experiences so far have been invaluable, helping to improve his research questions and clinical design. "Based on the suggestions from the LSRMP faculty, we have already begun to implement some of these changes in our experimental design in the lab," he says. Building on these relationships that he has fostered, Dr. Reville hopes to one day become an independent physician scientist in charge of his own research group dedicated to tackling the difficult questions in lymphoma and other hematologic malignancies.

*Dr. Reville is also a 2022 LRF Postdoctoral Fellowship Grant awardee for this research project.*



**LAURIANNE SCOURZIC, PHD**

JOAN & SANFORD I. WEILL MEDICAL  
COLLEGE OF CORNELL UNIVERSITY


*Dr. Joseph R. Bertino  
Memorial Scholar*

Cancer stem cells have been identified in a variety of tumor types, which contribute to the continuous repopulation of cancer cells. Many patients with B-cell lymphomas are resistant to or relapse after treatment, but the existence of a stem-cell-like B-cell population has yet to be identified. Through her LRF research, Dr. Scourzic aims to identify and characterize lymphoma stem-like populations in lymphoma can be used as a predictive

marker for disease progression and potentially be targeted with new or existing therapeutic strategies.

Dr. Scourzic earned her PhD in hematology and oncology from the Gustave Roussy Institute at Paris-Sud University. During that time, she used mouse models to study drivers of cancer formation in T-cell lymphomas and solidified her interest in a career as a lymphoma researcher. She is now working as a postdoctoral associate at the Weill Medical College of Cornell University, where she hopes to gain the skills and experience necessary to transition to a career as an independent investigator. She values the mentorship she has received thus far and looks forward to training the next generation of lymphoma researchers. "Finding the people that guide and support you, in the long run, is not only giving you the confidence to pursue what you are doing but also the grounds for you to evolve along your project and ideas," she explains. "This is something that I try to provide to my mentees as well and that I will always be grateful for."

Dr. Scourzic also notes that the Lymphoma Scientific Research Mentoring Program has been instrumental in her career development and the organizing of the key details of her research project. Through the LSRMP, she was able to network with established investigators and potential collaborators in her field, which she notes was a particular challenge during the COVID-19 pandemic. "I strongly encourage young researchers and fellows to apply for this LSRMP," she says.

*Dr. Scourzic also received the 2020 Lymphoma Research Foundation 2-year Postdoctoral Fellowship Award and was an Oliver W. Press Memorial Postdoctoral Fellowship Grantee. *

**"Finding the people that guide and support you, in the long run, is not only giving you the confidence to pursue what you are doing but also the grounds for you to evolve along your project and ideas."**





# PATIENT PERSPECTIVES

## ADVOCATING FOR ADOLESCENTS AND YOUNG ADULTS

On June 23rd and 24th, 2022, physicians and scientists from more than 40 academic and medical institutions, federal agencies, and pharmaceutical companies were brought together in Jersey City, New Jersey for the second Lymphoma Research Foundation's (LRF) Adolescent and Young Adult (AYA) Lymphoma Consortium Scientific Workshop.

LRF initially launched a multifaceted AYA initiative in 2014 with its founding partner, The Paul Foundation, to assist young lymphoma patients in addressing the medical challenges, psychosocial needs, and access issues they may encounter. The overwhelmingly positive response to this initiative led LRF to found a first-of-its-kind AYA Lymphoma Consortium. The chief objective of the AYA Lymphoma Consortium is to advance the study of AYA lymphomas and improve treatments and care for this patient population, from the point of diagnosis through long-term survivorship.

Both LRF and the physicians who treat adult and pediatric lymphoma believe lymphoma in AYAs warrants special attention, as research suggests that lymphoma-related death occurs more often in the AYA group than in younger children and older adults. The underlying reasons are complex as they are numerous, driven by biology, etiology, treatment patterns as well as social factors. Additionally, factors like the transition from pediatric to adult care and changes in access that come with changing jobs are unique challenges facing young adults transitioning to adulthood.

While the topics covered during the meeting touched on disease biology, epidemiology, molecular biology, clinical trials, and social factors, together, attendees are working to answer the overarching question of “why are these cancers different” and “what can we do to make outcomes better for patients?” One important feature of this meeting that makes it unique is inclusion of a large range of professionals who touch the lives of AYA patients: physicians, clinical and scientific researchers, and regulatory agency, pharmaceutical, and patient advocacy representatives are able to share their unique perspectives and learn from each other within a collaborative forum. This degree of “cross-pollination” between these specialties is rare. Even for pediatric and adult oncologists, a largely siloed model of clinical care creates a landscape where collaboration is uncommon.

### **What Can We Do to Make Outcomes Better for Patients?**

This year’s workshop focused on research developments in the areas highlighted by the Consortium AYA blueprints, focusing on the needs of AYA patients, new clinical trial efforts, and cutting-edge research in support of better understanding and serving these patients. Each session of the meeting included both lectures by selected expert faculty and a panel discussion where audience members could ask questions, learn from colleagues in different disciplines, and work to develop additional strategies to improve AYA care.

To start the meeting, researchers presented on the current understanding of AYA lymphoma biology and detailed the behavior of early, relapsed, and refractory disease. These presentations were followed by a discussion of how newly available drugs have been incorporated into clinical care for both adult and pediatric patients and how they may be best used in the treatment of AYAs. Importantly, attendees discussed the newest research tools available for studying tumor biology, microenvironment, and treatment response in lymphomas. For AYA lymphoma in particular, which is often underrepresented in clinical trials, these new tools are of particular importance because they allow for as much information to be collected as possible and for better definition of AYA disease biology and response to treatment.

One element of AYA research that continued to surface throughout the meeting was the need to engage all stakeholders to improve representation of these patients in clinical trials so that a specialized analysis of AYA patients is not only possible, but can support understanding of disease biology and treatment response. During the scientific workshop, special attention was also paid to long-term monitoring and assessment of barriers to survivorship care.

Following the meeting, researchers will publish the scientific workshop findings and will continue their work to identify avenues that LRF can use to pursue its mission: to eradicate lymphoma and serve those touched by this disease.

### **The Role of Patient Advocates**

Lymphoma patients, survivors, and caregivers have valuable perspectives and experiences which can improve the quality of cancer research, inform education programs, and raise awareness of the disease. That is why the Lymphoma Research Foundation (LRF) offers numerous opportunities for members of the lymphoma community to share their experiences and support the LRF mission. Programs like the Lymphoma Support Network allow volunteers to provide one-to-one peer support programs for people with lymphoma and their caregivers, while the LRF Advocacy Program encourages people to make their voices heard by policymakers through special training and advocacy alerts. The LRF Ambassador Program is instrumental in raising awareness for lymphoma and providing hope to others affected by the disease. Ambassadors share their individual stories and experiences navigating the disease during in-person events, media interviews, and scientific meetings.



*Katie Palay, Lymphoma Survivor  
LRF Ambassador*

Recently, LRF Ambassador Katie Palay attended the LRF Adolescent and Young Adult (AYA) Lymphoma Scientific Workshop to serve as a patient advocate and represent patients who receive a diagnosis between the ages of 15 and 39. In this edition of Patient Perspectives, Katie shares more about her journey and recent experience representing AYAs with lymphoma.

### How did you become involved with the Foundation?

I was introduced to LRF through my oncologist, and LRF Distinguished Leadership Award recipient, Dr. Anas Younes.

### Do you feel comfortable sharing your lymphoma journey?

It's a journey I wouldn't wish on anybody, yet is one I credit with shaping who I am today. If I could share one part of that journey it would be: Never give up the hope that comes from within, and never stop looking for the hope that comes from a science lab.

In under 18 months, I went from a diagnosis of stage 2A Hodgkin lymphoma to refractory disease, followed by autologous stem cell transplant and then relapse. At the time, I was in "under 5% of cases" territory. There was no standard treatment protocol for what came next. I enrolled in a phase 2 clinical trial. Out of dozens of participants, only a few people were put into complete remission. I followed up with 35 rounds of proton therapy — also at the time a novel approach to lymphomas. I am elated to say that was over 10 years ago.

### What resources did you find most helpful after you received a Hodgkin lymphoma diagnosis?

I signed up for numerous peer-to-peer networks in search of hope — both the hope that there were others out there, just like me, and the hope that the scientific discoveries that had saved them could do the same for me. It was important for my mental well-being to surround myself with hope and positivity, not just "good thoughts" but the hope that each day would bring me one step closer to an answer and better yet, a cure. As for the physical tolls extracted by cancer, all I can say is how lucky I was to have an incredible support team, ranging from my mom, siblings, and extended family to doctors, friends, and nurses; all of whom took wonderful care of me.

### Why did you decide to become an LRF Ambassador?

There are so many reasons I wanted to become an LRF Ambassador. I wanted to share my story to provide hope to other patients. I wanted to give my opinions on how to better support the lymphoma community. I wanted to help fundraise to support life-saving science. Being part of LRF allows me to be on the frontline in the fight against lymphoma. There is nowhere else I'd want to be right now.

### What is your impression of the recent AYA Lymphoma Scientific Workshop? What did you learn? Were you nervous?

I left the meeting feeling inspired and hopeful. There are so many incredible minds dedicating their lives not just to fighting lymphoma but to fighting for lymphoma patients during and after cancer.

I wasn't nervous to attend the meeting, but admittedly I was a little nervous to speak up. After all, my only medical training is through osmosis, and I don't have multiple strings of letters attached after my name. But then I realized my perspective is just different, not wrong or less meaningful. It was a privilege to lend my voice on behalf of lymphoma patients, and I hope I served the community well.

### Why do you feel it is important to have patients represented during scientific meetings and discussions?

There were times during the meeting that I felt genuinely ill; that what was being discussed hit too close to home. That's exactly what these meetings need: the human side of cancer. Only the patient perspective can reinforce the importance of defining survival as "living" rather than merely "not dying." The healing isn't done once remission is achieved.

### After attending this meeting, why should other AYA's with lymphoma have hope for the future?

There are so many exciting new drug therapies and treatments in the works. And this groundbreaking science isn't just saving lives, but it's also improving patients' quality of life, not just today but far into the future, too. With consortiums like this, we can save lives faster and better! 🍀

## BECOME AN LRF VOLUNTEER

Whether you are a current volunteer looking for new opportunities, a former volunteer wanting to return to lend your time and efforts, or brand new to LRF volunteering, we can help you find the most meaningful opportunity for you.

Learn more about LRF's volunteer opportunities by visiting one of the following pages on our website:

#### Ways to Help

[lymphoma.org/waystohelp](https://lymphoma.org/waystohelp)

#### Join the Lymphoma Support Network

[lymphoma.org/lsn](https://lymphoma.org/lsn)

#### Become an LRF Advocate

[lymphoma.org/advocacy](https://lymphoma.org/advocacy)





## SAVE THE DATE: Upcoming Lymphoma Walks



### Dallas Lymphoma Walk

October 29, 2022  
Trinity Groves



### Arizona Lymphoma Walk

November 6, 2022  
Phoenix Zoo



### New York Lymphoma Walk

Coming Soon  
Spring 2023

The Lymphoma Walk is a Team LRF-hosted community fundraising event where survivors, caregivers, family, friends, and supporters join together to walk in honor and in memory of those whose lives have been touched by lymphoma.

The walk is an event where we raise awareness and funds to find cures for lymphoma!

#### Have Questions?

Interested in learning more about sponsorships or have questions? Contact us at [walks@lymphoma.org](mailto:walks@lymphoma.org) or 347-920-8535

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# RIGHT PLACE AT THE RIGHT TIME

Sometimes, life has a strange way of preparing us for what's ahead, even though we might not realize it at the time. For Tawny Roeder, a 37-year-old part-time nurse, and full-time wife and mother of two, a rotation in the oncology unit during her final year in nursing school ended up having a much bigger impact on her career — and her life — than she could have ever anticipated.

Originally from Storm Lake, Iowa, and currently living in Papillion, Nebraska, Roeder was in the final semester of her senior year in nursing school in 2008. As she was beginning her nursing preceptorship, she was assigned to the oncology unit where she began taking care of patients facing a lymphoma diagnosis and other health issues. During her first shift, the first room she entered was with a 19-year-old girl with non-Hodgkin lymphoma (NHL) receiving her first treatment.

“As I walked in, I remember seeing her hair all over the pillow, and I didn’t know what to say,” she says. “My heart went out to this girl, and I just could not believe what she was going through. At the time, I didn’t have anyone in my life with cancer, and all I could do was think about how I could best relate to her and help make her comfortable.”

As fate would have it, just two to three weeks after beginning that rotation, Roeder was diagnosed with lymphoma herself and admitted to the same oncology unit where she had been taking care of others just weeks before.

“I was experiencing intense pain that would radiate through the back of my shoulders,” Roeder explains. “It was growing worse, waking me up at night and making it difficult for me to breathe. I was captain of the dance team in college and found myself completely out of breath after just one or two run-throughs of our routine, which wasn’t like me at all.”

Roeder’s mom was the first to notice her shortness of breath during a visit and encouraged her to get it checked out. They went to the doctor together to see if they could get to the bottom of it.

“Honestly at that point in my life, I thought I was invincible, so cancer was the last thing on my mind,” says Roeder. “When my doctor told me that I had a mass on my lung that was causing my back pain and shortness of breath, I was dumbfounded.”

Soon after, Tawny went to have a biopsy in neighboring South Sioux City, Nebraska and they informed her over the phone that she had diffuse large B-cell lymphoma (DLBCL), the most common type of NHL in the United States and worldwide. Later, she would learn that she had gray zone lymphoma, a rare type of lymphoma that has features somewhere between classical Hodgkin lymphoma (HL) and DLBCL.

“I remember hanging up the phone and immediately calling my boyfriend (now husband), Cory, and he came right over, as did family and friends,” says Roeder. “By the end of the day, I was still in shock, but grateful to be surrounded by the people closest to me for support.”

## From Lymphoma Nurse to Lymphoma Patient

For Roeder, the biggest adjustment was going from being a nursing student helping others, to having to come to terms with the fact that she had a potentially life-threatening disease.

“I’m still not sure if I fully processed everything the doctors were telling me,” Roeder says.

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## “My first thought was, ‘Will I ever be able to be a mom?’”

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“I remember feeling very afraid and alone at the time.”

The mass by her lungs was growing quickly and her doctors recommended that she begin a standard R-CHOP regimen immediately (rituximab [Rituxan], cyclophosphamide [Cytosan], doxorubicin [Adriamycin], vincristine [Oncovin], and prednisone [Deltasone]).

“I was only two months away from graduating college, and I didn’t want to jeopardize that, so I decided to get my treatment in my college town,” says Roeder. “I started treatment in April 2008, and I was focused on getting through treatment as quickly as possible so that I could graduate with my friends, get my nursing degree, and take my boards.”

To accomplish her goal, Roeder studied for her boards while getting chemo treatments — and while she didn’t feel great on her graduation day, she was able to attend her graduation as planned and take her boards in mid-July. She received her last round of treatment at the end of July, but much to her dismay, her journey with lymphoma was not yet over.



### A New Challenge

Following her last round of treatment, Tawny's doctors declared her in remission but were still concerned about high-risk factors related to diagnosis and referred her to Nebraska Medical Center in Omaha for an autologous stem cell transplant.

"The transplant seemed so much scarier than the chemotherapy, and I didn't feel prepared for it," Roeder explains. "Still, I understood that I needed the transplant to increase my odds for long-term survival, and so I pushed on."

She received her transplant on September 11, 2008, and it thankfully went smoothly. However, spending a month isolated in the hospital following her transplant took an emotional toll on her that she wasn't expecting. While she watched her friends begin their nursing careers and move on with their lives, she couldn't help but feel lonely, sad, and stuck as she waited to be done with treatment.

"I'll never forget the feeling I had the day I was finally released from the hospital," says Roeder. "It was a beautiful day and I remember rolling down the car window and letting my head hang out of the car, feeling the fresh breeze wash over me and finally feeling free."

Chomping at the bit to start her nursing career, Roeder started her first job in November 2008 — just two months after receiving her stem cell transplant. While she began her nursing career in pediatrics, she felt called to return to the oncology department, becoming a lymphoma transplant case manager, where she guides patients through the treatment process that saved her life. She's been in that role at the University of Nebraska Medical Center for about ten years and uses her own journey with lymphoma to help provide comfort to her patients going through a similar experience.

"When I share with my patients that I was in their shoes about 14 years ago, they are absolutely shocked," Roeder says. "The biggest thing I tell my patients — and it's something that I wish someone would have told me — is that this, too, shall pass. You will not feel like this forever, the side effects are temporary, your treatment will end, and you will feel better."

### Giving Back

Roeder is passionate about giving back and does so not only through her work as a nurse, but also through organizations such as the Lymphoma Research Foundation (LRF). She first got involved with LRF following her treatment, after learning about the organization from one of her doctors. She started by walking in the Nebraska Walk in 2010 and forming "Team Tawny," consisting of her family and friends who helped her raise funds for LRF's mission. In 2018, she was named the honorary chair of the walk, in recognition of her dedication the

Foundation, and continued to participate in the event up until the onset of the pandemic.

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**"The walks create a strong sense of community and the opportunity to meet other survivors who understand what I've gone through," says Roeder.**

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"More than anything, LRF has helped me feel less alone in my diagnosis and has given me the opportunity to give back to a community that means the world to me."

Having begun her lymphoma journey at the age of 23, Roeder is proud of how far she has come since being diagnosed and hopes that her story can inspire other young patients to never give up hope or on their dreams.

"Young people need extra hope that they can have a career, build a family, and just live their lives beyond cancer," says Roeder. "In my case, I went from taking care of people with lymphoma to facing my own lymphoma diagnosis in a matter of weeks. I would encourage any young person dealing with a lymphoma diagnosis to not give up on their dreams. At first, I didn't think I'd be able to be a mom, but we've been able to adopt both of our wonderful kids at birth, and honestly, I can't see it any other way. I'm living proof that life goes on after lymphoma." ○

**"YOUNG PEOPLE NEED  
EXTRA HOPE THAT THEY  
CAN HAVE A CAREER,  
BUILD A FAMILY, AND JUST  
LIVE THEIR LIVES BEYOND  
CANCER"**



# HELP LIGHT THE PATH TO CURES.

September is Blood Cancer Awareness Month — a time to join us in shining a light on lymphoma, to fundraise for innovative research, and to brighten the future of all those touched by this disease.

[lymphoma.org/LightItRed](http://lymphoma.org/LightItRed)

LIGHT IT  
**RED** for  
Lymphoma®



# 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

Blood Cancer Awareness Month .....	<b>9.1-9.30</b>
Virtual Pregunte al Doctor Sobre el Linfoma .....	<b>9.12</b>
National Lymphoma Rounds .....	<b>9.13</b>
Ask the Doctor: Clinical Trials & Treatment Options .....	<b>9.14</b>
Update on CAR T-Cell Therapy Webinar .....	<b>9.21</b>
Philadelphia Lymphoma Rounds .....	<b>9.22</b>
Midwest Lymphoma Workshop .....	<b>9.24</b>
LRF Annual Gala .....	<b>9.29</b>
Lymphoma Research Ride .....	<b>10.2</b>
Medtronic Twin Cities Marathon Weekend .....	<b>10.2</b>
Chicago Lymphoma Rounds .....	<b>10.6</b>
Swirl: New Jersey .....	<b>10.9</b>
New York Lymphoma Rounds .....	<b>10.18</b>
Los Angeles Lymphoma Rounds .....	<b>10.27</b>
North American Educational Forum on Lymphoma .....	<b>10.28-10.30</b>
Dallas Lymphoma Walk .....	<b>10.29</b>
Seattle Lymphoma Rounds .....	<b>11.3</b>
TCS New York City Marathon .....	<b>11.6</b>
Arizona Lymphoma Walk .....	<b>11.6</b>

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



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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)**.

