



PULSE

A Dedication to Caring for Others

Dr. LaCasce, respected researcher and clinician, advocates for the advancements that give the lymphoma community new treatments and hope.
page 8

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.

FOUNDATION LEADERSHIP

Steven Eichberg
Chair, Board of Directors

Ann S. LaCasce, MD, MMSc
Chair, Scientific Advisory Board

Meghan E. Gutierrez
Chief Executive Officer

Nichole Musumeci
Editor

Paige Butler
Associate Editor

Editorial Board
Micah Banner
Jesse Brown
Victor Gonzalez
Nick Guercio
Kyle Haines
Eva Migliore
Sarah Quinlan
Rebecca Rausch
Whitney Steen
Laura Wallenstein

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.

Pulse ©2023 Lymphoma Research Foundation



FREE PUBLICATION DOWNLOAD

The Lymphoma Research Foundation 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.

Visit lymphoma.org/publications to download one today.

TABLE OF CONTENTS

[FEATURES]

A Dedication to Caring for Others

Ann S. LaCasce, MD, MMSc, an Associate Professor of Medicine at the Dana-Farber Cancer Institute, grew up in a health care centered family. With a front-row seat to her parents' passion for science and caring for others, it's not surprising Dr. LaCasce is where she is today: a respected researcher and clinician, advocating for the advancements that give the lymphoma community new treatments and hope.

8



Meet the 2023 Lymphoma Scientific Research Mentoring Program Scholars

The new class of LRF Scholars is pursuing research projects covering a diverse range of lymphoma subtypes, with a goal to improve patient outcomes.

16



Finding Light in the Middle of the Woods

While being a lymphoma survivor was never part of her original life plan, Ilyse Leibowitz and her family see her experience with cancer as one of life's most unexpected blessings.

24



[DEPARTMENTS]

Community Impact

Philanthropy in Action
Donor Spotlight

4

From the Field

Where Are They Now?
U.S. Food and Drug Administration Updates

8

Patient Perspectives

Understanding Your Lymphoma Subtype

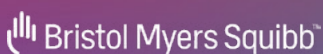
22

HELP US BRING HOPE TO OUR COMMUNITY

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

lymphoma.org/lightitred

Thank you to our supporters for making the
future brighter for all those touched by lymphoma!



LIGHT IT
RED for
Lymphoma®

FROM THE CEO

It is a privilege to introduce you to the next generation of lymphoma researchers in this issue of *Pulse*, as we announce the 2023 class of the Lymphoma Research Foundation's (LRF's) Lymphoma Scientific Research Mentoring Program (LSRMP). The program participants, known as LRF Scholars, are provided with expert and dedicated training, mentorship, and funding so that they may build successful careers in lymphoma and chronic lymphocytic leukemia (CLL) research. **This crucial program helps to ensure that the best and brightest scientific minds can fully commit themselves and their careers to blood cancer research.**

LRF's world-renowned Scientific Advisory Board (SAB) charts the course for the LSRMP and all the Foundation's research programming, identifying the most promising grantees and research projects for support, always with the objective of making meaningful advances in the field.

We also introduce LRF's new SAB Chair, Ann LaCasce, MMSc of the Dana-Farber Cancer Institute, in this issue's *Researcher Spotlight*. Dr. LaCasce shares how mentoring empowers future generations of lymphoma researchers and the impact of the scientific research that she has witnessed firsthand during her career. Finally, this issue also features a profile of LRF SAB member and Adolescent and Young Adult (AYA) Lymphoma Consortium co-chair Kara Kelly, MD from Roswell Park Comprehensive Cancer Center. Dr. Kelly has been instrumental in improving outcomes and ensuring healthy futures for young lymphoma patients with her pioneering work in the field of Hodgkin lymphoma and the development of novel therapies. We are excited to profile Dr. Kelly in this issue and to honor her at the upcoming LRF Annual Gala in New York City on September 28, with the Foundation's prestigious Distinguished Leadership Award.

The efforts to invest in life-saving research, empower the brightest minds in our field, and support our patient community are critical to achieving the future we envision and hope for: one free of this disease. None of this work would be possible without you, our dedicated supporters, who believe in the Foundation and our shared mission to eradicate lymphoma. Thank you for your steadfast commitment to helping us create a world without this disease.

Sincerely yours,



Meghan E. Gutierrez
Chief Executive Officer



PHILANTHROPY IN ACTION



PARTNERS IN HOPE CHICAGO RAISES MORE THAN \$110,000

On June 1, over 200 attendees gathered in Chicago for the inaugural Partners in Hope: A Scientific Social event, chaired by Kristi Hendriks, wife of lymphoma survivor and Chicago White Sox player Liam Hendriks. This evening honored longtime Lymphoma Research Foundation (LRF) Scientific Advisory Board member Dr. Leo I. Gordon, MD, of the Robert H. Lurie Comprehensive Cancer Center of Northwestern University for his decades of commitment and care to his patients and his pioneering work that has changed the landscape of lymphoma research. Guests enjoyed a world-class wine tasting and raised more than \$110,000 in support of critical lymphoma research on this special night.



HARMONY 4 HOPE RAISES MORE THAN \$108,000

Team LRF members are always coming up with creative new ways to support LRF's mission through Fundraise Your Way! This year, Bob McAuley found a musical way to make a difference with the inaugural Harmony 4 Hope event, held on June 11 in McAuley's hometown of Smith Mountain Lake, Virginia. This all-day concert featured six bands, with many of the performers directly impacted by lymphoma, including Kimberley Dahme, bassist for the classic rock band Boston and lymphoma survivor. The concert was held in honor of McAuley's neighbor John Chellberg, a lymphoma survivor, and raised over \$108,000 in support of LRF.



MINNESOTA LYMPHOMA WALK RAISES MORE THAN \$75,000

Over 200 members of Team LRF took a step toward a world free of lymphoma at this year's Minnesota Lymphoma Walk, held on June 3 at Lake Nokomis in Minneapolis. This year's walk raised more than \$75,000 to power vital research and patient support programs, with top fundraising teams like the Mayo Clinic Team, The Knockouts, and the Pirates of the Cure-ibbean leading the charge. This event was made possible with the support of sponsors like Canal 22, BeiGene, Bristol Myers Squibb, Merck, AstraZeneca, SPIRE and Minnesota Oncology.



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

Login to Facebook

STEP 2

On the left, click the tab labeled "Fundraisers"

STEP 3

On the left, click Raise money

- A. Scroll to find the nonprofit you want to raise money for
- B. Type into the search bar to find the nonprofit you want to raise money for

STEP 4

Select the nonprofit

STEP 5

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

STEP 6

Click Create.



Join Team LRF Today

Raise awareness and funds to support LRF's mission of eradicating lymphoma serving those touched by this disease.

A portrait of Kara Kelly, MD, a woman with long brown hair, smiling. She is wearing a dark blue sweater. The background is a red gradient with white speckles.

GALA SPOTLIGHT: KARA KELLY, MD

Kara Kelly, MD is Waldemar J. Kaminski Endowed Chair of Pediatrics and Professor of Oncology at Roswell Park Comprehensive Cancer Center, and Division Chief of Pediatric Hematology/Oncology at Oishei Children's Hospital and professor at the Jacobs School of Medicine and Biomedical Sciences at the University at Buffalo. She also serves as a member of the LRF Scientific Advisory Board and Co-Chair of the LRF Adolescent and Young Adult (AYA) Lymphoma Consortium. Dr. Kelly specializes in hematologic malignancies with a unique focus on adolescents and young adults AYA.

Recognized as a leader in the field, Dr. Kelly has chaired the Hodgkin lymphoma (HL) committee for the Children's Oncology Group (COG) for more than a decade and has overseen the development of a large portfolio of clinical trials and correlative studies that have improved the care of children and adolescents with HL. She currently co-chairs a large phase 3 clinical trial comparing standard chemotherapy with a novel immunotherapy approach for children and adults with early-stage HL.

Dr. Kelly is also a tenured member of the Dana-Farber Cancer Institute's Acute Lymphoblastic Leukemia (ALL) Consortium and leads studies investigating nutrition-related factors contributing to treatment toxicity as well as the development of interventions to improve adherence to oral chemotherapy.

In recognition of Dr. Kelly's many contributions to the field of lymphoma and her dedication to advancing cures for lymphoma, LRF is awarding her the 2023 Distinguished Leadership Award at this year's Annual Gala on September 28 at the Ziegfield Ballroom in New York City.

You helped to found LRF's AYA Lymphoma Consortium and were elected its inaugural Co-Chair. Can you explain why founding this unique consortium was important, and what you hope to accomplish through LRF's investment in the consortium?

Several of the more common lymphomas cross the interface between pediatric and medical oncology. Often patients in the AYA age group get caught in the middle, and there really hasn't been a good mechanism to bring

together pediatric and medical oncology providers to make sure that the needs of this AYA population are being addressed. LRF serves a unique role as a convener in being able to bring us together, where we can share best practices, collaborate on research, and work to address the myriad of issues that AYA patients face.

Having LRF bring us together has already, in a short time, led to some significant advances directly benefiting patients with lymphoma in this age group.

Why is there such a great need in AYA research? Why is greater investment in AYA research needed?

AYA patients face a myriad of unique issues, including toxicity concerns, survivorship issues, and the need for psychosocial support. Studies in the past have shown that AYAs with cancer don't have as favorable outcomes as pediatric and older adult patients. We haven't until recently had a great understanding of what the factors contributing to these outcomes are, due to several challenges, including low rates of entry into clinical trials from this age group. For me as a pediatric oncologist, one of the challenges I've faced is that patients have not had access to clinical trials that typically start at age 18, which creates an artificial barrier for my patients.

One of the things we have been working on is lowering the age of entry for clinical trials and, through this consortium, we are already making changes there – and that is a huge win, especially for these AYA patients.

What impact has the Foundation made in the field of AYA lymphoma research?

LRF has been incredibly helpful in bringing together all the stakeholders in this field, and this has already resulted in demonstrable results. I anticipate many initiatives to come out of LRF's work and can't wait to see the impact we can make together on these patients.

You are receiving LRF's Distinguished Leadership Award at the 2023 Annual Gala—what does that mean to you?

I am incredibly humbled to receive this award. For me, it has always been about the patients, advancing research in the field, and working collaboratively with my colleagues. A special thank you to my colleagues and the broader lymphoma community who have worked with me and given up their time to help me support this patient population.

For me to be recognized in this way, especially among my incredible colleagues who have received this award in the past few years, is quite an overwhelming honor. To be the first pediatric oncology recipient of this award also demonstrates LRF's commitment to the AYA field, and I am excited to have my receiving the award highlight the needs of this population. 🌟



CAN'T ATTEND THE GALA IN PERSON?

You can still participate by browsing and bidding in our silent auction or making a gift in support of the event. Visit lymphoma.org/gala to view our auction items and make a gift today.



A DEDICATION TO **CARING FOR OTHERS**

Ann S. LaCasce, MD, MMSc, an Associate Professor of Medicine at the Dana-Farber Cancer Institute, grew up in a healthcare-centered family. Her father was an internist in a small community in Maine, and as a teenager, Dr. LaCasce would work in his office when not in school. Her mother worked as a nurse and later became a high school science teacher. With a front-row seat to her parents' passion for science and caring for others, it's not surprising Dr. LaCasce is where she is today: a respected researcher and clinician advocating for the advancements that give the lymphoma community new treatments and hope.

“Lymphoma is so varied and there’s so much to do to move research forward. Seeing patients over time is like seeing old friends. My job is a privilege – I just can’t describe it any other way.”

Dr. LaCasce majored in biochemistry at Bowdoin College but didn’t immediately gravitate toward healthcare. With an underlying affection for art history, she moved to New York City after graduation to manage a contemporary art gallery. She enjoyed the experience but quickly realized that she wanted to do something where she could care for others – as she’d seen her parents do her whole life. After setting off for medical school at Tufts University, she took a first-year hematology course directed by Dr. Jane Desforges, a world-leading hematologist who was recognized with Tufts University School of Medicine’s Outstanding Teacher Award for 13 consecutive years. Dr. LaCasce was enthralled by Dr. Desforges and had instantaneous respect for her as a female trailblazer in medicine.

“Dr. Desforges was an early female member in the American Society of Hematology (ASH) and a former president. I wanted to be just like her. I just knew this is what I wanted to do,” says Dr. LaCasce.

Dr. LaCasce soon found herself drawn to lymphoma and recalls being particularly interested in the pathology of lymphoma early on in her medical school studies. She thoroughly enjoyed her hematopathology (the study of diseases of the cells that make up our blood) rotation, but still found herself yearning for the opportunity to care for others firsthand.

She completed her training in internal medicine at Brigham and Women’s Hospital in Boston, where she later served as a Chief Medical Resident. She completed her fellowship in hematology at Dana-Farber/Mass General Brigham, where she homed in on lymphoma and ultimately landed her “dream job” as a lymphoma physician, clinical researcher, and later as the Director of the Dana-Farber/Mass General Brigham Fellowship in Hematology/Oncology.

“Lymphoma is so varied and there’s so much to do to move research forward. Seeing patients over time is like seeing old friends,” says Dr. LaCasce. “My job is a privilege – I just can’t describe it any other way.”



Meaningfully Mentoring the Next Generation of Scientists

Dr. LaCasce’s multifaceted role also includes supporting and ushering in the next generation of hematologists and oncologists at Dana-Farber. As a chief resident, she thoroughly enjoyed working with trainees, and now she gets to work with fellows every day.

“As you progress in your career, you recognize it’s not about what you accomplished in terms of publications and talks,” says Dr. LaCasce. “It’s about promoting the next generation and making sure they have opportunities, making sure they feel they have something to contribute, and making sure they’re recognized – because they’re our future.”

Dr. LaCasce recalls not fully grasping the importance of mentorship when she was in training, and along with LRF’s engagement in mentorship, she feels her appreciation of it has evolved dramatically. She wants trainees to engage in mentorship deliberately and to find mentors who are as excited to work with them as they are for the opportunity to work with their mentor.

“There’s nothing like it, watching these pairings and watching people’s careers take off. It’s really fun,” says Dr. LaCasce. “Lymphoma investigators are an incredibly tight-knit community of amazing people. You can be part of this community that works together and collaborates. And you can have the opportunity to structure a fulfilling career in so many different ways.”

As a female leader in her field, Dr. LaCasce feels fortunate to have worked alongside other remarkable women and wants even more women to join her in the field. Whether through mentoring or representation in leadership roles, women are a huge part of the workforce, with endless talent and potential.

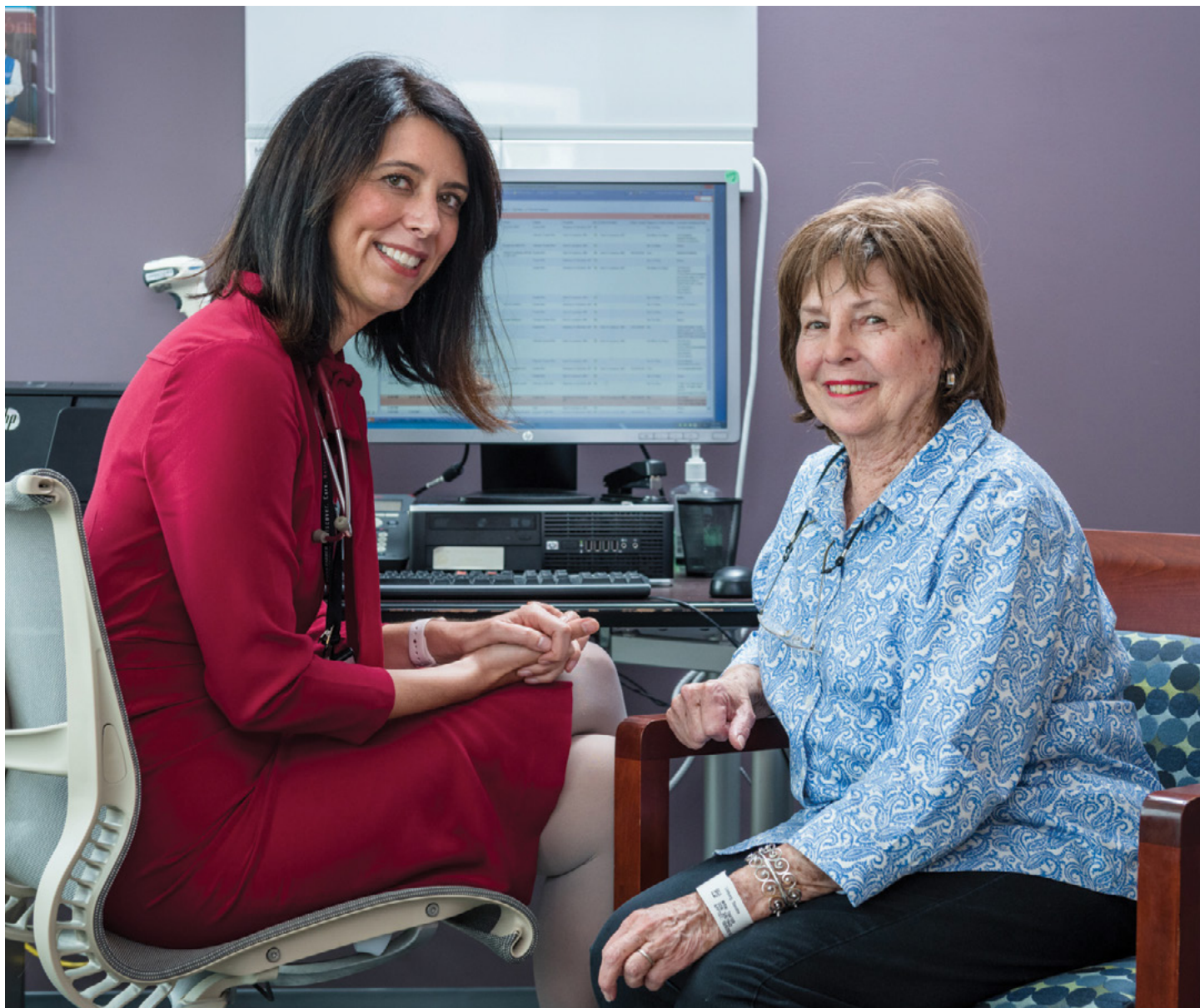
“I’ve met the most incredible women around the world who are doing remarkably inspiring work. There are a

lot of ways to have a career in medicine, so we need to support and guide these women to stay in academics and in the lymphoma field specifically,” Dr. LaCasce says.

A Commitment to Research Is a Commitment to a Cure

Dr. LaCasce’s day-to-day is varied, from treating patients to performing clinical research and running the fellowship program. When she’s not at the clinic, she’s catching up on research projects, writing, and editing. Seeing all facets in the continuum of care, she feels each element makes the other stronger.

“I think it makes you a better clinician to be involved in research studies. When you’re treating a patient on a clinical trial, you work with a team and you’re following the patient very closely – you’re always thinking about the patient sitting in front of you, trying to come up with



a plan. And when you're a clinical researcher, you really think about what's best for the patient. Both will hopefully improve outcomes for patients," says Dr. LaCasce.

In the past 20 years that Dr. LaCasce has been a clinician, she's seen firsthand how research has led to improved outcomes. Going from using standard chemotherapy in every situation to having multiple different treatment options today, she says it's "unbelievable" to watch the improvement in treatments for chronic lymphocytic leukemia (CLL) in particular.

"Looking at cellular therapies, our scientists helped drive the new therapies and give them to patients. Previously, patients who had aggressive lymphomas, who recurred quickly after chemotherapy, had very limited options. And now that's completely changed."

"Looking at cellular therapies, our scientists helped drive the new therapies and give them to patients. Previously, patients who had aggressive lymphomas that recurred quickly after chemotherapy, had very limited options. And now that's completely changed," says Dr. LaCasce. "We have bispecific antibodies that are going to be applicable across multiple different lymphomas. It's mind boggling how much the field has changed, particularly within the past 10 years."

When asked about what new treatments she's most excited about, Dr. LaCasce is excited about them all – immunotherapy, targeted agents, new treatment combinations, chimeric antigen receptor (CAR) T-cell therapy, etc. She has never experienced anything quite like the huge difference being made in people's lives because of the research and clinical trials being conducted. She's seen patients' white blood cell counts go from 300,000 to a normal count of less than 10,000 in a day. Other patients are now able to take oral drugs instead of undergoing standard chemotherapy.

"We've watched people's CLL melt in front of our eyes. They're living their lives, and it's really had such an enormous impact on patients. It's just incredible," says Dr. LaCasce.

Dr. LaCasce is dedicated to finding a cure for lymphoma and is quick to point out that LRF is a big part of that commitment.

"I think it's our responsibility as hematologists and oncologists to present clinical trials to patients and to discuss these options, but some of our patients may not live in areas with easy access to care. LRF has such great resources for patients to learn about their diseases, by phone or through online materials. Patients and their families can attend patient symposiums, they can ask about clinical trials, they can contribute their information or patient samples to a database trial – all because of LRF," Dr. LaCasce says.

Dr. LaCasce points out that many CLL patients gave their blood to research projects that allow scientists to have access to tumor cells, which are in the blood. Patients who contributed their blood and materials have helped move the field forward, directly leading to the development of new therapies.

"Clinical trials aren't right for everybody," Dr. LaCasce is quick to point out. "Sometimes the burden is too much, or the commute is too far, or you may not be able to tolerate the trial. It's a matter of asking, getting the information, and working together with your provider to understand what the options are and if it works for you. But it's always worth asking because we're now starting clinical trials that are specifically geared toward elderly patients, for example, who may not tolerate full-dose therapy, and these are very, very important trials for us to better understand how to treat this growing population of vulnerable patients."

With a promising pipeline of researchers and clinicians and groundbreaking research and trials, the field of lymphoma has had a lot of positive outcomes that other cancers haven't yet experienced, but there's still a lot of work to do. Lymphoma diseases affect people at every stage of life, and while many patients live for many years with lymphoma as lymphoma survivors, there is a lifelong commitment to ensuring patients can continue to have productive, healthy lives.

"LRF impacts the future of clinical, basic, and translational lymphoma research in so many different ways, from the scientific mentoring program to supporting lab scientists and clinical researchers through regular grants," she says. "All of the things that LRF does to support lymphoma will lead to more breakthroughs and cures." ○

"We've watched people's CLL melt in front of our eyes. They're living their lives, and it's really had such an enormous impact on patients. It's just incredible."

WHERE ARE THEY NOW?

MANTLE CELL LYMPHOMA CONSORTIUM AND INITIATIVE

20 YEARS IN REVIEW



Mantle cell lymphoma (MCL) is a rare, typically aggressive form of non-Hodgkin lymphoma (NHL) that accounts for roughly six percent of all NHL cases in the United States. Recognizing that a targeted research focus on MCL would benefit this underserved and understudied patient population, the Lymphoma Research Foundation (LRF) began awarding MCL-specific research grants and gathering its MCL grantees for a regular scientific meeting to report on their findings and form collaborations.

As the LRF MCL research program grew, so did the meeting and requests from scientists who wished to attend. Recognizing the importance of this meeting and LRF's role as the world's largest private funder of MCL research, the LRF Mantle Cell Lymphoma Consortium (MCLC) was formed and the annual meeting – now a global scientific workshop – and the research infrastructure created by LRF was opened to MCL researchers from around the world.

LRF has convened its Mantle Cell Lymphoma Scientific Workshop since 2003. The goal of the biennial Workshop is to bring together the world's leading experts in MCL to discuss the latest research findings, receive updates on the progress of LRF grantees, foster collaboration within the MCL research community, create a direction for MCL research, and ultimately improve MCL diagnosis and treatment for patients.

In addition, a keynote address is offered by a global thought leader in the field of MCL research, and expert debates are staged to discuss pivotal topics in the treatment and care of people with MCL. After the conclusion of the Workshop, LRF and its scientific advisors publish a proceedings paper that is considered a blueprint for future MCL research and is sought out by researchers and clinicians worldwide.



The goal of the biennial Workshop is to bring together the world's leading experts in MCL to discuss the latest research findings, receive updates on the progress of LRF grantees, foster collaboration within the MCL research community, create a direction for MCL research, and ultimately improve MCL diagnosis and treatment for patients.

MANTLE CELL LYMPHOMA CONSORTIUM HIGHLIGHTS



LRF has awarded over 50 MCL-specific research grants



\$25M in MCL-specific funding



LRF MCL Consortium has more than 130 members



231 MCL Initiative publications

Twenty years since the Workshop's initial establishment, LRF hosted an MCL Scientific Workshop in May 2023 chaired by LRF Scientific Advisory Board Member Dr. Eduardo Sotomayor, MD (Tampa General Hospital Cancer Institute). The program also included a keynote speech from world-leading MCL expert Elias Campo, MD, PhD (Institut d'Investigacions Biomèdiques August Pi i Sunyer), who was honored with LRF's Leadership Award for his contributions to the field of MCL research. Dr. Campo and Dr. Sotomayor shared more about this year's meeting and what the future of MCL research holds.



ELIAS CAMPO, MD, PHD

.....

What did receiving the Leadership Award mean to you?

I was particularly honored by the award because I have been researching MCL from the beginning of my research career. I started when I returned to Barcelona 30 years ago after spending two years at the National Institute of Health (NIH), where I became interested in MCL thanks to Drs. Elaine Jaffe and Mark Raffeld. Since then, MCL has been the main research focus of our group involving different students, post-docs, and colleagues from our institution and other great consortiums such as the LLMPP (Leukemia/Lymphoma Molecular Profiling Project), the European Mantle Cell Lymphoma Network, and LRF's Mantle Cell Lymphoma Consortium and initiative. LRF has also been instrumental in our career because they funded three projects for MCL over the years that were instrumental to some of our major contributions. The Leadership Award is a recognition of this long-shared journey confronting the challenges of this intriguing lymphoma.

What do you think is the most exciting thing happening in MCL research right now?

The most rewarding aspect of MCL research is seeing how far we have come since I started. Patient outcomes have improved drastically since the tumor was more clearly recognized over 30 years ago. It is amazing how the precision in the diagnosis of this lymphoma and its variants, the better understanding of the heterogeneous evolution, and the improvement in management strategies have changed the outcome of patients. We have come so far that in this year's LRF Mantle Cell Lymphoma Workshop, we started to discuss the possibility of a "functional cure" for MCL. This is clear evidence of how creative thinking, hard work, and collegial collaboration can transform our view of these diseases and improve the lives of our patients.

Why is MCL research vital to helping us understand the more than 100 other subtypes of lymphoma?

The discoveries in MCL over the years have been a paradigm of how the iterative dialogue between clinical practice and research has been a driving force that has transformed the understanding of this lymphoma and, as I said before, changed the diagnostic and clinical practice resulting in a significant improvement in the quality of life and outcome of patients. This approach is now common ground in all types of lymphomas. I am sure we will continue seeing tremendous improvements in most of these diseases in the next years.



EDUARDO SOTOMAYOR, MD

.....

Why is there such a great need for MCL research? Why is greater investment in MCL research needed?

MCL is a historically underserved and understudied patient population. Without funding and greater investment in the research of this subtype, we will not be able to continue to advance treatments for these patients.

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

It has been 20 years since the first-ever MCLC meeting. What do you think the next 20 years of MCL research holds?

There have been many significant advances over the past 20 years in the study of MCL. We now have novel targeted therapies developed that have changed the way we treat patients, and I can only hope that in next 20 years we can say that we have found a cure for this disease. ☺

"I think it is fair to say they have changed the history of new formulation and treatment, and I would say a significant portion of the advances in lymphoma are because of LRF, period."

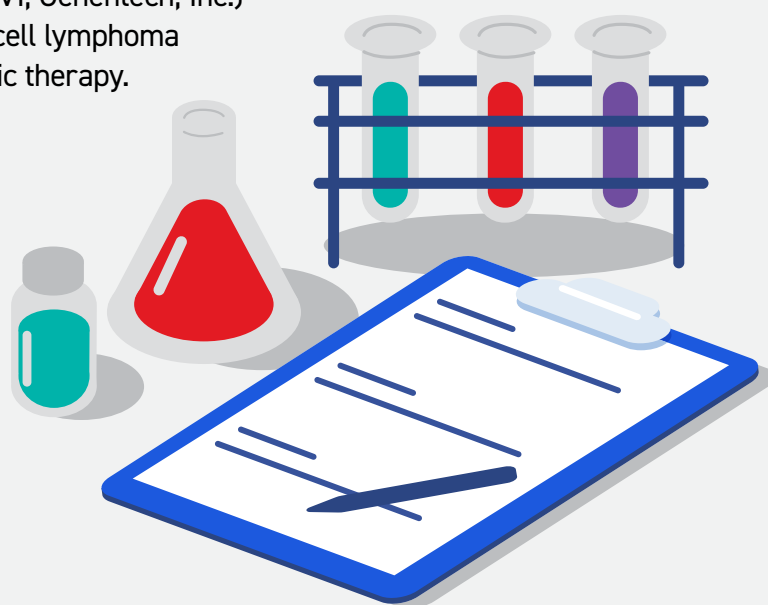
LATEST U.S. FOOD AND DRUG ADMINISTRATION (FDA) APPROVALS

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.

April 19, 2023 - polatuzumab vedotin-piiq (POLIVY, Genentech, Inc.) with a rituximab product, cyclophosphamide, doxorubicin, and prednisone (R-CHP) for adult patients who have previously untreated diffuse large B-cell lymphoma (DLBCL).

May 19, 2023 - epcoritamab-bysp (EPKINLY, Genmab US, Inc.) for relapsed or refractory diffuse large B-cell lymphoma (DLBCL) after two or more lines of systemic therapy.

June 15, 2023 - glofitamab-gxbm (COLUMVI, Genentech, Inc.) for relapsed or refractory diffuse large B-cell lymphoma (DLBCL) after two or more lines of systemic therapy.



MEET THE 2023 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 chronic lymphocytic leukemia (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 2023 LSRMP clinical research co-chairs Steven Horwitz, MD (Memorial Sloan Kettering Cancer Center) and Nancy Bartlett, MD (Washington University in St. Louis, Missouri, and Laboratory/Translational Research co-chairs Laura Pasqualucci, MD (Columbia University) and Michael Green, PhD, MD (University of Texas MD Anderson Cancer Center), 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



AYUSHI CHAUHAN, MD

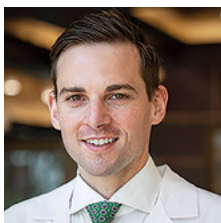
AUGUSTA UNIVERSITY
RESEARCH INSTITUTE, INC.

*Stephanie A. Gregory
Distinguished Scholar*

Primary central nervous system lymphoma (PCNSL) is a rare and aggressive form of non-Hodgkin lymphoma that predominantly affects older adults over the age of 60. Standard frontline treatment for PCNSL consists of high-dose methotrexate-based chemotherapy followed by a second course of intensified chemotherapy and bone marrow transplant. Relapse after this course of treatment is common though, and treatment options for patients with relapsed or refractory disease are limited. Dr. Chauhan's LRF research project aims to determine whether the oral medication zanubrutinib can be used to effectively treat this patient population. "This is a drug that inhibits a protein called Bruton's tyrosine kinase and blocks a signaling pathway that is important for lymphoma cell survival," explains Dr. Chauhan. She hopes that her research will help achieve better response rates for patients with PCNSL in the relapsed/refractory setting.

Dr. Chauhan aspired to a career in medicine from an early age. “My parents are both physicians serving tribal and rural populations in India,” she says. “Since my siblings and I were young, my parents have been engaged in donating their time, effort, and finances to help the underprivileged, and they have encouraged us to do the same.” As she looks ahead to the future, she is similarly inspired by work that serves patients who have historically been excluded from lymphoma research. “I think the recent pushes toward expanding clinical trial eligibility for elderly and underserved patients, as well as the move to make trials more diverse and inclusive, is what gives me the most hope for the future,” she says. “Novel therapies, whether targeted or cellular, have changed the landscape of indolent and aggressive lymphomas. However, unless we make trials generalizable and widely accessible, these gains remain out of reach for the patients who need it the most.”

Dr. Chauhan earned her medical degree from Maulana Azad Medical College in New Delhi, India. She completed her fellowship in Hematology and Oncology at MedStar Georgetown University Hospital in Washington, D.C., and was part of a lymphoma rotation at the National Cancer Institute in Bethesda, Maryland. She now serves as an Assistant Professor in the Division of Hematology-Oncology at Georgia Cancer Center in Augusta, Georgia. She hopes to leverage her experiences as a Clinical Research LRF Scholar to establish herself as an independent clinical lymphoma researcher, with the hope of catering her research to the underserved populations of Georgia.



DANIEL ERMANN, MD

THE UNIVERSITY OF UTAH

Patients with chronic lymphocytic leukemia (CLL) are at increased risk for infections due to the immune dysfunction associated with the disease. Bacterial pneumonia is a particular concern, and while vaccination with a broad spectrum 20-valent pneumococcal conjugate vaccine (PCV20) is recommended to prevent illness, this vaccine hasn't been specifically studied in people with CLL. Through his LRF research project, Dr. Ermann aims to determine whether a 2-dose series of the PCV20 vaccine used in conjunction with another pneumonia vaccine can help reduce the burden of infectious pneumonia in these high-risk patients. “Our research hopes to provide the best guidance for patients about how to prevent pneumonia and to provide optimal guidance for physicians on how to prevent pneumonia and its complications,” he explains.

Dr. Ermann was inspired to pursue a career in lymphoma research from an early age, when his father was diagnosed with lymphoma. “It was his illness, and my early experience of it, that catalyzed my inspiration and passion to become a lymphoma physician with the goal of improving outcomes of future lymphoma patients for generations to come,” he says. To this end, he earned his medical degree from St. George's University in Grenada, and is currently a Hematology and Oncology Fellow at the University of Utah Huntsman Cancer Institute in Salt Lake City, Utah.

Leveraging his experience from the Lymphoma Scientific Research Mentoring Program, Dr. Ermann hopes to establish himself as a dedicated academic lymphoma researcher, with the goal of investigating novel combinations of treatments to help improve outcomes for CLL patients in need. “Quality of life and length of life are so important in patients with cancer,” he says. “That's why we pursue our CLL-related research to reduce infections, which are the leading cause of morbidity and death for patients with CLL.” Dr. Ermann hopes that his work on this study, as well as his future research, will help to prolong life and reduce complications for people living with CLL and lymphoma.



JULIE ERIKA HAYDU, MD, PhD

MASSACHUSETTS
GENERAL HOSPITAL

Runge Lymphoma Project Scholar

Follicular lymphoma (FL) remains an incurable disease with current treatment options. Initial treatment of FL often involves the use of chemotherapy, and there are no approved chemotherapy-sparing regimens available for frontline treatment of FL patients with high tumor burden. Given the potential side effects associated with chemotherapy, Dr. Haydu's LRF research aims to investigate a novel non-chemotherapy-based approach for patients with previously untreated FL. “I hope my study will ultimately yield a new up-front treatment for FL patients that has minimal side effects and results in long remissions,” she says.

Dr. Haydu is a physician scientist pursuing a career as an academic lymphoma researcher. She earned her PhD in Cancer Genetics alongside her medical degree at Columbia University in New York. She completed her fellowship in Hematology and Oncology at the Dana-Farber Cancer Institute/Massachusetts General Hospital in Boston and is currently an Assistant Professor of Medicine at Massachusetts General Hospital. In addition to her participation in the Lymphoma Scientific Research Mentoring Program, Dr. Haydu has also been recognized as a Runge Lymphoma Project Scholar.

Dr. Haydu's commitment to lymphoma research is driven by her patients, who inspire her to be at the forefront of developing new treatment options that address all of their needs. "Follicular lymphoma provides unique challenges in that it often needs to be treated multiple times over a person's life, and thus avoiding toxicity and maximizing remissions is critically important," she says. "My patients with FL inspire me to come up with new non-chemotherapy approaches that result in durable remissions and preserve quality of life so my patients can keep doing the things they love."



SWETHA KAMBHAMPATI, MD

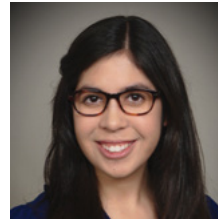
CITY OF HOPE COMPREHENSIVE
CANCER CENTER

Eric Cohen Distinguished Scholar

Patients with diffuse large B-cell lymphoma (DLBCL) who experience relapse after chimeric antigen receptor (CAR) T-cell therapy have limited treatment options, and there is a need for new therapies in this setting. The goal of Dr. Kambhampati's LRF research is to study the effects of combination therapy with the antibody-drug conjugate loncastuximab tesirine and the bispecific antibody mosunetuzumab in patients with relapsed/refractory DLBCL, with the aim of improving treatment options for patients with advanced disease.

Dr. Kambhampati earned her medical degree from Stanford University School of Medicine. She is now an Assistant Professor in the Division of Hematology and Hematopoietic Cell Transplantation at City of Hope in Duarte, California. "I was drawn to lymphoma research given the exciting bridge between immunotherapies, cellular therapies, and targeted therapies and the ability to cure patients with aggressive disease, even at an advanced stage," she says.

Dr. Kambhampati hopes that her LRF research project and the support of the Lymphoma Scientific Research Mentoring Program will serve as a launchpad for her career as an academic clinical investigator, through which she hopes to develop and lead studies into novel therapies to help lymphoma patients. "I would like to be a clinical investigator focused on developing novel therapeutic combinations to improve outcomes of lymphoma patients, particularly those with DLBCL, follicular lymphoma, and Hodgkin lymphoma," she says. "The advancements we have made in immunotherapies such as cellular therapies and bispecific antibodies give me a lot of hope for the future."



CHRISTINE RYAN, MD

DANA-FARBER CANCER INSTITUTE

Kanti R. Rai, MD Clinical Scholar

Richter's transformation (RT) represents a devastating progression of chronic lymphocytic leukemia (CLL) or small lymphocytic leukemia (SLL) into an aggressive B-cell lymphoma. Prognosis with RT is poor, with many patients surviving just 6 to 12 months after diagnosis. Dr. Ryan's research aims to identify novel therapies to help improve outcomes for patients with RT. To this end, her LRF project aims to study the effects of a bispecific antibody, glofitamab, in patients with RT, alone or in combination with other anti-lymphoma therapies. "Promising results have been shown with bispecific antibodies in several other types of lymphoma, but there has not yet been a dedicated study of glofitamab in RT," she explains. "Completion of this project will lay the foundation for future clinical research studies of glofitamab and other novel immunotherapies in RT."

Dr. Ryan is a Clinical Fellow in Hematology and Oncology at the Dana-Farber Cancer Institute in Boston. She is also a Kanti R. Rai, MD Clinical Scholar. Dr. Ryan's interest in lymphoma research began during her time as a medical student at the Stanford University School of Medicine, where she had the opportunity to work alongside researchers studying the use of ibrutinib in patients with CLL who had relapsed after transplant. "Seeing how a novel targeted therapy transformed outcomes for patients who otherwise had very limited treatment options was incredibly inspiring," she says. As she transitions to a faculty position at Dana-Farber this year, Dr. Ryan is excited to leverage her experiences studying CLL and RT to help patients with other forms of lymphoma, including mantle cell lymphoma.

Building on her experiences as an LRF Clinical Research Scholar, Dr. Ryan hopes to continue leading clinical trials and research that directly benefit patients. "My goal is for patients' lives to not necessarily be defined by their cancer or the challenges of treatment," she says. She is inspired not only by her experiences in the clinic but also her own personal connection with lymphoma through her grandmother's diagnosis. "Having experienced firsthand the emotional rollercoaster of the cancer journey, I am motivated to be an oncologist who helps my patients through both their day-to-day struggles and the long-term journey of fighting lymphoma," she says.



TIMOTHY VOORHEES, MD

THE OHIO STATE UNIVERSITY
COLLEGE OF MEDICINE

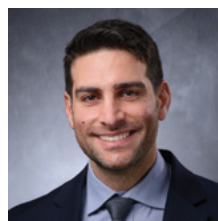
Schroder Family Scholar

Post-transplant lymphoproliferative disorders (PTLD) are an aggressive group of lymphomas that occur in the setting of immunosuppression after solid organ transplant. There are very few treatment options available to patients who do not respond to or relapse after initial treatment for PTLD. “I am developing a trial to evaluate the safety and efficacy of treating patients with relapsed or refractory PTLD with a novel bispecific antibody, epcoritamab,” explains Dr. Voorhees. “This drug targets the lymphoma and the patient’s immune system to create an immune response at the location of the disease.” Through this research, Dr. Voorhees hopes to improve outcomes for people with relapsed/refractory PTLD.

Dr. Voorhees’ interest in lymphoma began early in his academic career, when he had the opportunity to work in an immunology lab studying immune cell function. “I found this fascinating, and as I approached medical school, I knew that I wanted to find a place in medicine to utilize these skills,” he says. He earned his medical degree from the Ohio State University College of Medicine. After completing a fellowship in Hematology and Oncology at the University of North Carolina, he returned to the Ohio State University, where he now serves as an Assistant Professor of Clinical Internal Medicine. He also holds a Master of Science in Clinical Research from the University of North Carolina.

Dr. Voorhees’ passion for lymphoma research is driven by his interactions with his patients and their families. “I absolutely love taking care of my patients, and there is nothing better than designing a trial to provide new treatments for patients with the possibility of better outcomes and a better-tolerated treatment,” he says. He is excited by the advances that have been made in cellular and bispecific antibody therapies and looks forward to a career leveraging these therapies to help his patients. “I think we have only scratched the surface of our understanding of how to best manipulate the immune system to treat lymphoma,” he says. “There will be many exciting trials to come as these advancements are evaluated in the future.”

Laboratory/Translational Research LRF Scholars



AJLAN AL ZAKI, MD, PHD

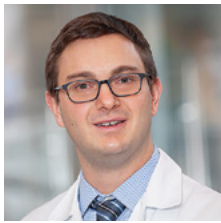
MD ANDERSON CANCER CENTER

Chimeric antigen receptor (CAR) T-cell therapies represent a meaningful treatment option for lymphoma, but many patients who receive these therapies will experience side effects caused by inflammation. In some cases, macrophage immune cells activated by CAR T cells in the blood can migrate into the brain and cause neuroinflammation. Using novel imaging approaches, Dr. Al Zaki’s research aims to understand CAR T-cell-induced inflammation in the brain and how these effects can be inhibited in a mouse model. “Our hope is that this might help provide a deeper understanding of the mechanisms of toxicity and help identify new strategies for prevention or treatment, enabling more widespread adoption of current and emerging cellular-based therapies,” he says.

Dr. Al Zaki earned his PhD from the University of Pennsylvania and his medical degree from George Washington School of Medicine and Health Sciences in Washington, D.C. He is currently a Hematology and Oncology Fellow at the University of Texas MD Anderson Cancer Center in Houston, Texas. Dr. Al Zaki’s passion for understanding the neurotoxic effects of CAR T-cell therapies stems from personal experience, having had a close friend who was hospitalized with side effects from CAR T-cell therapy. “She shared with me how painful and frightening this experience was to her and her family,” he says. Dr. Al Zaki hopes to leverage his background in molecular imaging to help physicians and patients better understand these effects, in turn enabling more safe and effective use of these agents.

Looking ahead to the future, Dr. Al Zaki hopes to one day manage his own laboratory as an independent physician scientist, caring for patients with lymphoma and training future oncology researchers. He is excited about the future of immunotherapies such as CAR T cells and antibody-based therapies and expects them to continue changing the landscape of lymphoma treatment. While he acknowledges that there is more work to do in the relapsed and refractory setting, Dr. Al Zaki sees this as an opportunity. “The silver lining is that we can continue to learn from this and build upon our knowledge to develop therapies that are more efficacious and less toxic, bringing us one step closer to finding cures,” he says.

Dr. Al Zaki is also a 2023 LRF Postdoctoral Fellowship Grant recipient for this research project.



ALEXANDER BOARDMAN, MD

MEMORIAL SLOAN KETTERING
CANCER CENTER

Dobosh Family Scholar

Treatment of lymphoma has been revolutionized by the emergence of CD19-directed chimeric antigen receptor (CAR) T-cell therapies, but many patients still relapse after treatment. Dr. Boardman's LRF research seeks to validate a new target on the surface of lymphoma cells – CD24 – in the hope of developing novel treatment strategies for these patients. Evidence suggests that, unlike CD19, CD24 may be necessary for tumor growth, making it less likely lymphoma cells will adapt to evade treatment. "Successful CD24-[directed] CAR T-cell designs may improve response rates and prevent relapses in lymphoma patients," Dr. Boardman explains.

Dr. Boardman's interest in oncology began early in life when his grandmother was diagnosed with metastatic breast cancer. "My desire to push oncology research forward is partially fueled by these memories," he says. Dr. Boardman began his medical training at the University of Massachusetts Chan Medical School in Worcester, Massachusetts, where he earned his medical degree. His passion for lymphoma was ignited during his internal medicine residency at Brigham and Women's Hospital in Boston, where he was intrigued by the complexities of managing patients who relapsed after treatment. "At the time, CAR T-cell therapy was mainly investigational (not yet standard of care), and I had the great fortune of caring for patients after infusion," he says. "These experiences drew me to the field and have fueled my passion for improving CAR T-cell therapy in the lab."

Over the next 10 years, Dr. Boardman hopes to leverage his experiences engineering novel CAR T-cell therapies – and the mentorship he gains through the Lymphoma Scientific Research Mentoring Program – to develop a career as a translational medical oncologist leading early-phase clinical trials of CAR T-cell therapies. "I believe we are well positioned as a field to greatly improve outcomes in lymphoma patients, but there is still plenty of work to be done," he says.



ANDREW JALLOUK, MD, PHD

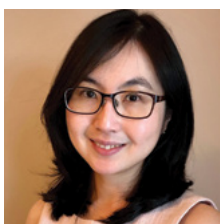
VANDERBILT UNIVERSITY
MEDICAL CENTER

Errol M. Cook Memorial Scholar

Chimeric antigen receptor (CAR) T-cell therapy represents a highly effective treatment option for many types of lymphoma. Currently available CAR T-cell therapies are engineered on a patient-by-patient basis from an individual's own blood cells, which represents a costly and time-consuming process. One way to overcome these barriers is through the use of allogeneic CAR T cells engineered from the T cells of a healthy donor. However, this approach is currently hindered by the potential for the host immune system to recognize these allogeneic CAR T cells as foreign, leading to immune-mediated destruction and limiting their efficacy and durability. "My project will study the mechanisms by which this immune rejection occurs and develop strategies to prevent it from happening," Dr. Jallouk explains. "In so doing, my project will help to reduce cost and improve accessibility to life-saving CAR T-cell treatments for patients with lymphoma."

Dr. Jallouk is currently an Assistant Professor of Medicine at Vanderbilt University Medical Center. "Throughout my training, I have been fascinated by the development and application of new technologies for the treatment of cancer," says Dr. Jallouk. "As an engineer by training, I have been particularly interested in CAR T-cell therapies and the use of engineering principles to design and optimize these treatments." After completing his undergraduate training in biomedical engineering and chemistry, he earned a dual MD-PhD from Washington University in St. Louis, Missouri. "As I gained more experience with lymphoma through my clinical rotations, I realized I was drawn not only to the cell therapy aspects of lymphoma management but to the disease process in general," he says.

Building on his experiences in the Lymphoma Scientific Research Mentoring Program, Dr. Jallouk hopes to establish himself as an independent translational lymphoma researcher. In this role, he hopes to design and lead clinical trials on novel agents for the treatment of lymphoma as well as conduct laboratory research to better understand the biology of these therapies. "With the recent development of so many new agents for treating lymphoma, there are more opportunities than ever before to ask interesting questions and conduct research that will improve the lives of patients with this disease," he says.



**WEN-HSUAN WENDY LIN,
MD, PHD**

COLUMBIA UNIVERSITY

Peripheral T-cell lymphomas (PTCL) represent a group of aggressive blood cancers with poor outcomes. A common phenomenon in PTCL is the development of a pro-inflammatory microenvironment in which lymphoma cells recruit healthy cells that support tumor cell growth and lead to inflammation and possible autoimmunity. Dr. Lin's LRF research is aimed at characterizing the inflammatory signals in PTCL to better understand this phenomenon. Using mouse models of PTCL, she then seeks to determine how interrupting these signals affects tumor growth. "If the strategies I proposed show a promising anti-lymphoma effect in pre-clinical mouse models," she says, "it will bring us closer to developing these drugs into new targeted treatments for PTCL patients, which hopefully will prolong their lives and minimize their discomfort from getting the conventional chemotherapy."

Dr. Lin is an instructor and attending hematopathologist at Columbia University Irving Medical Center in New York. She earned her medical degree from National Cheng Kung University in Tainan, Taiwan, and her PhD from Johns Hopkins University in Baltimore, Maryland. "Before I became a hematopathologist, I spent several years studying how normal T-cells protect our body from pathogens," she explains. "During my clinical training, I was struck by how devastating T-cell lymphomas are in terms of outcome and our limited treatment options." Through her LRF research project, Dr. Lin hopes to better understand the mechanisms that drive the transformation of T-cells in lymphoma as well as design new therapies to target these aberrant cells.

Leveraging her background in immunology, pathology, and cancer biology, Dr. Lin hopes to one day become an independent physician scientist working in a multidisciplinary research program aimed at understanding T-cell lymphomas. "I want to translate findings from my lab to aid precision lymphoma diagnosis and treatment with the goal of treating everyone's lymphoma individually and most optimally based on the tumor's unique genetics and phenotypic features," she says.



ERIN PARRY MD, PHD

DANA-FARBER CANCER INSTITUTE

Dr. Parry's research is centered at the intersection of genomics and cancer immunotherapy, with a focus on B-cell lymphomas. Her LRF research project is aimed at understanding the processes that underlie the transformation of chronic lymphocytic leukemia (CLL) into an aggressive state known as Richter's syndrome (also known as Richter's transformation). Using single-cell techniques, she hopes to characterize the mechanisms that drive this process. "Through studying the biology and genetics of transformation, I hope to advance knowledge and learn new approaches to target lymphoma cells so that we can improve our lymphoma therapies," she says. She also aims to determine whether cell-free DNA obtained from blood samples can be used to quickly and easily detect evidence of transformation in patients with CLL.

Dr. Parry is a physician at the Dana-Farber Cancer Institute and an instructor at Harvard Medical School in Boston. She earned her medical degree and PhD from Johns Hopkins University School of Medicine in Baltimore, Maryland. "As a physician-scientist, I spend time caring for lymphoma patients and conducting laboratory-based research," she explains. "In the lab, I am dedicated to studying transformation and improving outcomes for patients with transformed lymphoma."

With the support of the Lymphoma Scientific Research Mentoring Program, Dr. Parry hopes to establish herself as an independent researcher in the field of lymphoma biology. "This is an exciting time for research in lymphoma, and there's a lot of hope for the future," she says. "I think there's a real opportunity to better understand lymphoma in the lab and translate these findings back to the clinic."

"This is an exciting time for research in lymphoma and there's a lot of hope for the future. I think there's a real opportunity to better understand lymphoma in the lab and translate these findings back to the clinic."

– Erin Parry MD, PhD



PATIENT PERSPECTIVES

UNDERSTANDING DIAGNOSTIC TESTING



Doctors need the results of different diagnostic tests to accurately determine whether or not a patient has lymphoma. These tests can also determine a patient's specific lymphoma subtype. After the initial diagnosis of lymphoma, a doctor may order other tests, such as blood, molecular genetics, or biomarker tests, to gain a more accurate diagnosis and develop the most appropriate treatment plan based on the results.

Lymphoma specialist Lisa Rimsza, MD (Mayo Clinic, Arizona) provides an in-depth description of these tests how they can help patients understand their lymphoma subtype and become their own best health advocate.

How are lymphomas and chronic lymphocytic leukemia (CLL) generally diagnosed?

The diagnosis comes through a biopsy of tissue, bone marrow, or sometimes blood, which undergoes microscopy and some combination of immunophenotyping (looking at the proteins on the abnormal cells), cytogenetics (looking at the chromosomes), Fluorescence in situ hybridization (FISH) (looking at specific parts of chromosomes or genes), and molecular studies (looking at particular gene sequences and other features). The pathologist correlates this information with the patient's clinical history, blood findings (counts, protein electrophoresis or immunofixation, and others), and radiological findings.

What types of biopsies are acceptable for an accurate diagnosis?

For a new diagnosis, the more tissue, the better the chance to identify all of the needed diagnostic features. With advanced techniques and a specific type of lymphoma, a small biopsy, such as a needle core biopsy, might be conclusive. However, usually there is a better chance of getting a specific diagnosis from an initial procedure if a larger excisional biopsy is obtained. Think of it as trying to figure out what type of car you have from just a photo of a tire and a seat (pieces of tissues from aspirates and needle cores) or having a photo of the entire car (excisional biopsy).

“For a new diagnosis, the more tissue, the better the chance to identify all of the needed diagnostic features.”

We hear the term “next-generation sequencing” quite a bit nowadays. Can you please explain what this refers to and how it might be useful for blood cancers?

First-generation sequencing refers to Sanger sequencing (developed by Dr. Frederick Sanger in the 1970s). It used electrophoresis and was laborious (although technology improved over the years); however, Sanger is extremely accurate and still used in certain situations. Since the mid-2000s, multiple other methods have been developed, all of which are considered “next generation”; these are quick, generate a lot of data, and are automated.

What are biomarkers? What are some common biomarkers that exist on either B-cell or T-cell lymphomas?

Biomarkers are any type of test that helps to classify disease, estimate a patient’s prognosis, or provide information on potential effective treatments. For B-cell lymphomas, common biomarkers are related to lymphoma classification and prognosis, such as the presence of chromosomal rearrangements involving the MYC, BCL2, BCL6, or CCND1 genes; while some gene mutations may suggest therapeutic approaches such as MYD88 or EZH2. Serum markers such as “M-protein” or LDH enzyme are also biomarkers. In T-cell lymphoma, classification and prognosis might be related to ALK or DUSP22 gene rearrangements.

If patients experience a relapse, are diagnostic tests necessary at this point as well?

Yes, it is important to determine if the lymphoma is showing similar features to the original. Particularly if the first tumor was considered “low-grade,” then progression to a “high-grade” tumor would be very important to know. This is also a time point at which additional testing might be performed to evaluate the tumor for alternative therapies. It is also always possible that it is an entirely different tumor or process.

Are there any diagnostic tests that patients should request?

Testing algorithms are established by the pathologists and laboratory based on medical practice and the context provided by the patient’s treating hematologist. The panel of tests that the tissue will undergo is part of the triage process that happens when the material is received in the laboratory so that certain protocols are followed. The guidelines are highly complex and evolving. The specific features of the patient’s tumor, such as size, presence of dead tissue, dilution with blood, or other factors, will also be considered. Often, the hematologist will ask for a very specific test based on their knowledge of the situation. After the testing is complete and the diagnosis is established, the patient may wish to discuss with their doctor the testing rationale and if there is anything else that needs to be done.

“Each lymphoma has a different biology and clinical course and therefore different treatment and monitoring strategies.”

In your opinion, why is it important for patients to know their specific type of lymphoma?

There are now more than 100 different types of lymphomas. Each lymphoma has a different biology and clinical course and therefore different treatment and monitoring strategies. What is true for one type of lymphoma may be completely incorrect with regard to another type. The basis of a patient understanding their disease is knowing their specific lymphoma diagnosis.

If a patient doesn't know their specific subtype, what should they do to seek/understand that information?

If a patient doesn’t know what type of lymphoma they have, they should first start with their hematologist or other treating physician to clarify the working diagnosis. The patient can also request to see the pathologist’s report on their tissue describing the testing that was done and the conclusions. In an emerging trend, some patients have requested to directly meet with the pathologist who made the diagnosis. Armed with the information about a specific subtype, the patient can then approach groups such as the Lymphoma Research Foundation or the American Society of Clinical Oncology, which have great patient resources.

FINDING LIGHT IN THE MIDDLE OF THE WOODS

Ilyse Leibowitz always dreamed of having a second home in the Berkshires. A former elementary school teacher and certified yoga instructor with a deep connection to nature and spirituality, she calls the middle of the woods her “happy place.” It wasn’t until she found herself facing a lymphoma diagnosis that her dream of owning a house in the middle of the woods finally came true. While being a lymphoma survivor was never part of her original life plan, for Leibowitz and her husband of 30 years, Barry, and their daughters Lauren, 25, and Hannah, 23, their family’s lymphoma experience has been one of life’s unexpected blessings.



Leibowitz's love of the outdoors and discipline as a high school and college track athlete kept her in excellent shape throughout her adult life. She saw her primary care doctor annually and was always "healthy as an ox." Then things took a turn in 2017. Despite normal bloodwork, she knew something wasn't right when a few itchy skin patches weren't going away. For a year, she tried several natural remedies, including acupuncture, essential oils, cupping, and bleeding her ears, but her symptoms only got worse – as the cause continued to go undetected.

Leibowitz started experiencing night sweats but attributed them to being perimenopausal like many of her friends also in their late 40s. She also developed a bulge in her groin that she first thought was a hernia, though it wasn't hurting like the three others she'd had before. It wasn't until a surgeon biopsied the "hernia" in April 2018 that she was diagnosed with stage 4 non-Hodgkin T-cell lymphoma. Leibowitz passed out upon receiving the news.

"That was the only time in this whole process where I just let go. I couldn't believe it," she recalls. "It was like out of a movie. You don't think it's ever going to happen to you, especially when you take such good care of yourself."

T-cell lymphomas are known for their heterogeneity, clinical complexity, and comparative rarity. It took a long time for Leibowitz to get an accurate diagnosis of Sézary syndrome, a subtype of cutaneous T-cell lymphoma (CTCL) characterized by the presence of lymphoma cells in the blood. Tests initially showed she had peripheral T-cell lymphoma (PTCL) because sometimes there can be a crossover between both types.

"I think that's why it took so long for me to get the right kind of treatment, because the pathology showed peripheral T-cell and that is much more aggressive than cutaneous T-cell. So, they needed to go after that," she says.

"That was the only time in this whole process where I just let go. I couldn't believe it. It was like out of a movie. you don't think it's ever going to happen to you, especially when you take such good care of yourself."

A Long Journey

Since beginning treatment two weeks after diagnosis, Leibowitz has followed seven different protocols in the last five years. She tried six different therapies that didn't work, starting with five months of Romidepsin infusions once a week for six hours; four months of twice-daily photopheresis blood filtering two days in a row every other week; six rounds of chemotherapy once every three weeks; and three daily treatments of a different drug every three weeks. She also participated in a clinical trial for an oral drug being tested in T-cell lymphoma.

These treatments brought many challenges far beyond some of the uncomfortable side effects. There was enormous amounts of paperwork, exhausting travel back and forth from Long Island to Connecticut for her treatment at Yale, and the overall emotional toll of facing a diagnosis of cancer. Leibowitz kept herself in shape as best she could and leaned on the support of family and friends.

"I did a lot of sleeping, a lot of crying, a lot of praying, and had a lot of belief in myself," she says. "I just never felt that my body was failing me, ever."

She changed her eating habits, added supplements, and relied on acupuncture, massage, and physical therapy. Most importantly, she realized she couldn't do it alone. "I had a lot of people helping me. It's a multidimensional experience, and you need a multidisciplinary team to do it," she says, adding, "I've learned I don't have to be so tough. I don't have to be in charge all the time. I can allow other people do some stuff for me. And it feels really good to receive."

Leibowitz's husband was her "rock" throughout this experience, staying by her side at nearly every doctor's appointment. He was the one who pushed her into buying their summer home in the Berkshires in June 2020 while she was still in treatment. She recalls, "he said this is exactly the time that we're going to do this, because we need something creative to focus our energy on. We need something happy that we're going to look forward to and build together."

Above all, Leibowitz found solace in her yoga practice. "Honestly, it saved me," she confesses. Her yoga mentor and spiritual adviser helped her modify her practice to keep her moving at a gentler pace. The Leibowitzes even redid part of the basement in their new Berkshires house to be a "beautiful spiritual yoga space" where she could meditate and center herself throughout treatment.

"I've learned I don't have to be so tough. I don't have to be in charge all the time. I can allow other people to do some stuff for me. And it feels really good to receive."



Turning a Corner

In October 2020, Leibowitz started her seventh treatment protocol – a monoclonal antibody that was not yet available when she was first diagnosed. Monoclonal antibodies are proteins made in a laboratory meant to stimulate your immune system. When taking this immunotherapy drug for the first time, she had a near-death experience from a rare infusion reaction called tumor lysis syndrome, caused when cancer cells break apart in the blood and the debris toxifies your system.

Leaving the infusion center that day, Leibowitz was in so much pain that her husband had to reroute them to the nearest hospital as she screamed in agony. Within two hours of being hydrated by IVs, she was thankfully fine. Leibowitz thinks back on the experience as "horrifying but liberating." "It changed my whole life for the better," she muses. "I am so grateful that I had it and that it's behind me, because it opened up my world in a way that I had been preparing for all these years."

Despite a rocky start, this latest treatment has been "unbelievably effective" for Leibowitz. She started to turn a corner in January 2021 and has been in remission for two years, but since it's such a new drug, her oncology team doesn't yet know what maintenance or possible long-term effects look like.

For the first time in five years, Leibowitz is pausing treatment to prioritize healing from inflammation due to her treatment. Until now, she had been afraid to discontinue treatment, but she's calmly taking this bump in the road as an opportunity to see what happens. "I'm optimistic," she says. "I have an appointment coming up and I'm just meditating to the universe and calling it all in that I am good."

"I am so grateful that I had it and that it's behind me because it opened up my world in a way that I had been preparing for all these years."

Strength Through Hardship

As a survivor of chronic lymphoma, Leibowitz has accepted that her current treatment regimen will not work for her forever. But as she observes, "It's never all in the past, even for the people that have a 'cure.'"

Despite the hardship, lymphoma has taught both Leibowitz and her family a lot. As a Type A personality, she reflects on how she was "missing so much in the busyness of life" before her diagnosis. "I could cry from how great we are from all this," she says when thinking about her experience now. "It's like peeling the onion. It has just revealed the sweetness of all of us and what we can handle in life." She adds, "I'd rather have a shorter life living so awake and aware and alive. This was the vehicle for the unfolding, the dusting away."

One "game changer" in Leibowitz's journey has been a new addition to the family: a sheepadoodle puppy named Red. After their poodle passed away in January 2019, her husband promised they could get a puppy when the time was right. Opportunity struck about three years later when Leibowitz's best friend asked if she would consider adopting sheepadoodle puppies together. Now, Leibowitz lights up when talking about snuggling and taking selfies with Red. "We call her the joy machine because everybody wants a piece of her because she's so funny." Red is currently in training for the Memorial Sloan Kettering Cancer Center Canine Cares program as part of Leibowitz's eagerness to help others going through hospital care.

Finding and Spreading Hope

It was Leibowitz's passion for yoga, teaching, and seeing the light in everything that first helped her to inspire other patients. Looking back on treatment, she says, "I was determined every single time I went in that I was going to find something that was magical about the day that I was connecting to because I wasn't going to waste my experience. This is my *life*." Doing yoga while hooked up to her IV and listening to music would often turn into Leibowitz leading the whole room in deep breathing exercises or dancing for fun. She once had the entire infusion center singing along to the Bee Gees' "Stayin' Alive." "I make the best of things wherever I go," she says.

Among the many resources she's turned to for support, LRF stands out to Leibowitz for its "intimacy." "The way that they share the information really shows you exactly what they're working on. When you scroll through their website and see your subtype on the page, see the person who's researching it – that makes me feel so, so hopeful."

When Leibowitz's current oncologist and LRF Scientific Advisory Board (SAB) member, Dr. Steven M. Horowitz, MD, of Memorial Sloan Kettering Cancer Center,

approached her about serving on the benefit committee for last year's Annual Gala, she jumped at the chance to get more involved. In addition to supporting and attending the Annual Gala, Leibowitz offered to give a spontaneous speech during the night's event to help raise even more money toward the Foundation's mission.

Leibowitz recalls how one of the most impactful videos she watched after being diagnosed was from LRF. From these videos to email updates on new drugs in the works, she is grateful for the support. "I'm learning so much about what's ahead," she says.

For Leibowitz, the years ahead are about "marinating in the delight of life." In a message of hope to the lymphoma community, Leibowitz reiterates that "it's so important that when you receive a diagnosis, you don't let it define you." She reflects on how the journey has helped her expand into her true self: "I'm having a cancer experience, but that's not who I am. I've found myself. I am here, having a human experience to live out my purpose and my life and to enjoy and teach and learn and evolve." 🍷



SCIENTIFIC ADVISORY BOARD

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

2023-2024 MEMBERSHIP

ANN S. LACASCE, MD, MMSc
Chair

Harvard Medical School
Dana-Farber Cancer Institute

ANDREW M. EVENS, DO, MSc, FACP
Chair-Elect
Rutgers Cancer Institute of New Jersey

RANJANA ADVANI, MD
Stanford University School of Medicine

ASH A. ALIZADEH, MD, PhD
Stanford University School of Medicine

STEPHEN ANSELL, MD, PhD
Mayo Clinic, Rochester

KRISTIE A. BLUM, MD
Winship Cancer Institute of Emory University

JENNIFER BROWN, MD
Dana-Farber Cancer Institute

JAMES CERHAN, MD, PhD
Mayo Clinic, Rochester

ETHEL CESARMAN, MD, PhD
NewYork-Presbyterian Hospital
Weill Cornell Medicine

BRUCE D. CHESON, MD, FACP, FAAAS, FASCO
Past Chair, 2010-2012
The Center for Cancer and Blood Disorders

SANDEEP DAVE, MD, MS
Duke University

KIERON M. DUNLEAVY, MD
Lombardi Cancer Center of Georgetown University

KOJO S.J. ELENITOBA-JOHNSON, MD
Memorial Sloan Kettering Cancer Center

CHRISTOPHER R. FLOWERS, MD, MS
The University of Texas MD Anderson Cancer Center

JONATHAN W. FRIEDBERG, MD, MMSc
University of Rochester
James P. Wilmot Cancer Institute

LEO I. GORDON, MD, FACP
Past Chair, 2015-2017
Robert H. Lurie Comprehensive Cancer Center
of Northwestern University

MICHAEL GREEN, PhD
The University of Texas MD Anderson
Cancer Center

THOMAS M. HABERMANN, MD
Past Chair, 2017-2019
Mayo Clinic, Rochester

STEVEN M. HORWITZ, MD
Memorial Sloan Kettering Cancer Center

ERIC D. HSI, MD
Wake Forest

BRAD S. KAHL, MD
Washington University School of Medicine

KARA KELLY, MD
Roswell Park Comprehensive Cancer Center
University at Buffalo Jacobs School of Medicine

JOHN P. LEONARD, MD
Past Chair, 2012-2015
NewYork-Presbyterian Hospital
Weill Cornell Medicine

IZIDORE S. LOSSOS, MD
University of Miami Health System
Sylvester Comprehensive Cancer Center

PETER MARTIN, MD
Weill Cornell Medicine

ARI MELNICK, MD
NewYork-Presbyterian Hospital
Weill Cornell Medicine

LINDSAY MORTON, PhD
National Cancer Institute

MARKUS MÜSCHEN, MD, PhD
Yale School of Medicine

LORETTA NASTOUPIL, MD
The University of Texas MD Anderson
Cancer Center

TERESA PALOMERO, PhD
Institute for Cancer Genetics,
Columbia University

LAURA PASQUALUCCI, MD
Institute for Cancer Genetics,
Columbia University

BARBARA PRO, MD
Columbia University

LISA RIMSZA, MD
Mayo Clinic, Arizona

LISA ROTH, MD
Weill Cornell Medicine

KERRY J. SAVAGE, MD
British Columbia Cancer

DAVID SCOTT, MBChB, MD
BC Cancer, Vancouver

LAURIE SEHN, MD, MPH
BC Cancer, Vancouver

MARGARET SHIPP, MD
Harvard Medical School
Dana-Farber Cancer Institute

SONALI M. SMITH, MD
Immediate Past Chair, 2021-2023
The University of Chicago

EDUARDO M. SOTOMAYOR, MD
Tampa General Hospital

CHRISTIAN STEIDL, MD
BC Cancer, Vancouver

JOHN M. TIMMERMAN, MD
UCLA Jonsson Comprehensive Cancer Center

SVEN de VOS, MD, PhD
UCLA Jonsson Comprehensive Cancer Center

HANS-GUIDO WENDEL, MD
Memorial Sloan Kettering Cancer Center

ANDREW D. ZELENETZ, MD, PhD
Past Chair, 2019-2021
Memorial Sloan Kettering Cancer Center

SAB EMERITUS

MORTON COLEMAN, MD
NewYork-Presbyterian Hospital
Weill Cornell Medicine

BRIAN LINK, MD
University of Iowa

KANTI R. RAI, MD
Donald and Barbara Zucker School
of Medicine at Hofstra/Northwell

MICHAEL E. WILLIAMS, MD, ScM
University of Virginia Cancer Center



UPCOMING EVENTS

| | |
|--|-------|
| New York Lymphoma Rounds | 9.14 |
| Update on Relapsed/Refractory Diffuse Large B-Cell Lymphoma Webinar | 9.19 |
| Para el sobreviviente: Como orientarse a la vida después del tratamiento | 9.20 |
| Philadelphia Lymphoma Rounds | 9.27 |
| LRF Annual Gala | 9.28 |
| Understanding Diagnostic and Biomarker Testing Webinar | 9.28 |
| 2023 Lymphoma Research Ride | 10.1 |
| San Francisco Lymphoma Rounds | 10.5 |
| North American Educational Forum | 10.6 |
| Seattle Lymphoma Rounds | 10.11 |
| Los Angeles Lymphoma Rounds | 10.26 |
| Phoenix Lymphoma Walk | 11.4 |
| TCS New York City Marathon | 11.5 |
| New England Lymphoma Rounds | 11.9 |
| Chicago Lymphoma Rounds | 11.16 |
| Washington D.C. Lymphoma Rounds | 11.30 |

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



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

NONPROFIT
ORGANIZATION
U.S. POSTAGE
PAID
NEW YORK, NY
PERMIT NO. XXX

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 Laura Wallenstein at lwallenstein@lymphoma.org, or visit lymphoma.org/legacy.

