



# PULSE

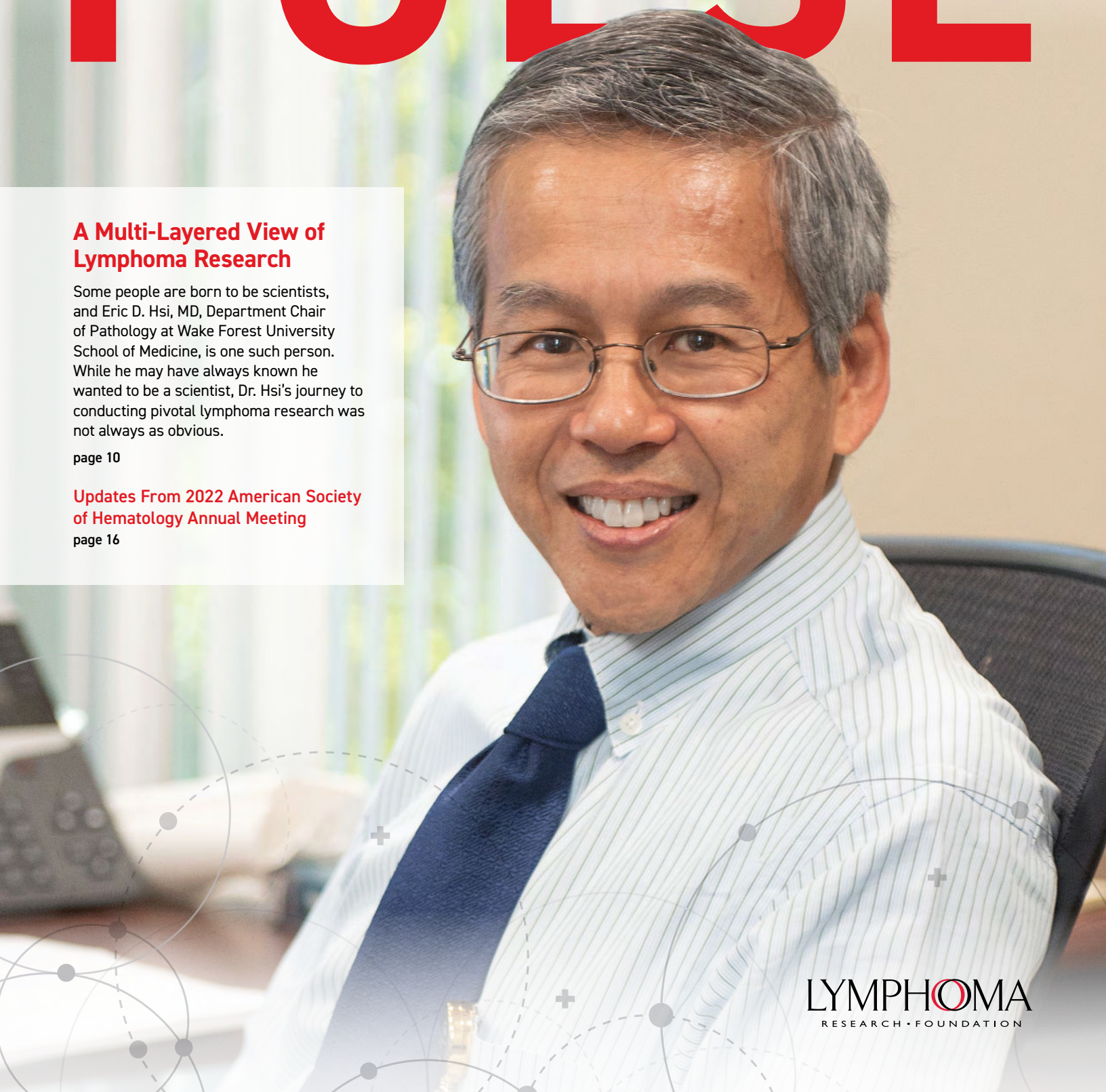
## **A Multi-Layered View of Lymphoma Research**

Some people are born to be scientists, and Eric D. Hsi, MD, Department Chair of Pathology at Wake Forest University School of Medicine, is one such person. While he may have always known he wanted to be a scientist, Dr. Hsi's journey to conducting pivotal lymphoma research was not always as obvious.

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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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## 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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### Updates From 2022 American Society of Hematology Annual Meeting

LRF returned to the American Society of Hematology (ASH) Annual Meeting and Exposition, with more than 300 LRF-affiliated scientists contributing to an abstract presented at the conference.

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### The Importance of Being Seen and Heard

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# RISE TO THE OCCASION



## LRF ANNUAL GALA

Thank you to the generous sponsors and supporters listed below and to our many other donors who helped to contribute to the success of the 2022 Annual Gala, which helped to raise almost **\$1.1 million** to support the Lymphoma Research Foundation's (LRF) mission of eradicating lymphoma and serving those touched by the disease.

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LRF is delighted to announce the 2023 Annual Gala taking place **Thursday, September 28, 2023**, at the Ziegfeld Ballroom in New York City. If you are interested in pledging your 2023 support early or would like to be added to our list to be the first to hear about our event details, please reach out to **Rebecca Rausch**, Associate Director of Distinguished Events, at [r-rausch@lymphoma.org](mailto:r-rausch@lymphoma.org)

# FROM THE CEO

What sets the Lymphoma Research Foundation (LRF) apart is our commitment and dedication to advancing the study and understanding of lymphoma. **Our focus on supporting experts in the field today and powering the next generation of lymphoma researchers brings us closer to our mission of eradicating this disease.**

In this issue of *Pulse*, we profile one of these groundbreaking researchers, Eric D. Hsi, MD, Department Chair of Pathology at Wake Forest University School of Medicine in Winston-Salem, North Carolina, and a member of the Foundation's prestigious Scientific Advisory Board (SAB). Dr. Hsi has seen firsthand the role that research has played in expanding our understanding of lymphoma over the course of his career and credits LRF's strong focus on research in advancing new cures and treatments for this disease.

You will also read an inspiring story about Paula, a young Hodgkin lymphoma survivor who cares deeply about advocating for those who may not have the resources to advocate for themselves. Through her own self-advocacy and the resources and care provided by her oncologist, Paula turned her despair into optimism and is now using her platform to empower others.

Lastly, you will read about the Foundation's impact at the 2022 American Society of Hematology Annual Meeting & Exposition, the world's premier event in malignant hematology. With over 90 LRF-affiliated scientists in attendance, our grantees and SAB members presented pivotal data that will inform the development and adoption of new therapies across the spectrum of lymphoma subtypes. Many of these studies will be highlighted during LRF patient education programs throughout 2023.

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

Sincerely yours,



Meghan Gutierrez  
Chief Executive Officer



# PHILANTHROPY IN ACTION



## DALLAS LYMPHOMA WALK RAISES OVER \$80,000

On October 29, 2022, LRF friends and supporters gathered in Dallas, Texas, to raise critical funds for LRF's mission with every step. The 2022 Dallas Lymphoma Walk raised over \$80,000 and honored Dr. Robert Collins from the University of Texas Southwestern Medical Center with the Lee Grubman Hero of the Year Award. LRF was joined by a number of teams and longtime supporters, including Wendy's Eagles, Jon Ross, Team Riordan, Team Sandra, Team Tommy, and M/I Homes – DFW.



## ARIZONA LYMPHOMA WALK RAISES OVER \$45,000

Over 300 members of the LRF community walked to raise awareness and funds for lymphoma patients, survivors, caregivers, and researchers as part of the 2022 Arizona Lymphoma Walk, held on November 6, 2022 at the Phoenix Zoo in Phoenix, Arizona. LRF supporters raised over \$45,000 to power lifesaving lymphoma research and vital patient resources and honored the Mayo Clinic team with the Lee Grubman Caregiver of the Year Award. Keynote speaker Michael Yudell shared his inspiring story of his experience as a mantle cell lymphoma survivor.



## MEMBERS OF TEAM LRF RAISE OVER \$31,000 AT THE NYC MARATHON

On November 6, 2022, 10 runners representing Team LRF joined nearly 48,000 other participants as they took to the streets of New York City in the 2022 TCS New York City Marathon. The group of first-time racers, experienced marathoners, lymphoma survivors, and those running in honor of a loved one raised over \$31,000 and counting as they ran 26.2 miles through NYC's five boroughs all in support of LRF's mission. "It was truly the race of a lifetime for me. Running with a purpose deepened the entire experience in a way I couldn't have imagined. I am forever grateful I had the opportunity to run for LRF," said Meredith, a three-time marathoner who ran in honor of her mother, a lymphoma patient.

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**Event Benefiting the Lymphoma Research Foundation**

# SUPPORTING LRF TOWARD AN END TO LYMPHOMA

Luke Griffin has been an avid sports fan for as long as he can remember. In fact, his love of sports contributed to him meeting his wife, Barbara, and his storied career in sports broadcasting that has spanned more than 40 years. It also gave him a creative means to support the Lymphoma Research Foundation (LRF), an organization that took on significant importance to the Griffin family after Barbara was diagnosed with mantle cell lymphoma (MCL) in 2004.



Luke and Barbara met in college during a summer broadcasting job near Boston. They married in 1972, and as was common at the time, Luke was soon drafted in support of the nation's Vietnam war efforts. He enlisted in the Navy, and he and Barbara soon found themselves stationed in Iceland for two years. There, Luke put his sports broadcasting experience to use and did sports commentary on Armed Forces Radio Service. Barbara, as a civilian, lent a hand and did the weather.

When Luke's service was complete, he and Barbara eventually settled in Boston. Luke's sports broadcasting career spanned covering Notre Dame football, his alma mater, and working at the famed WFAN in New York and the Red Sox Network in Boston. With five children, Luke and Barbara looked forward to numerous high school and college graduations as they entered their 40s.

## A DIAGNOSIS WHEN IT WAS LEAST EXPECTED

In 2004, Barbara was on a vacation with her two daughters in San Francisco and noticed a lump on her

neck. She went to the doctor when she got home and soon was diagnosed with lymphoma.

"It was out of the blue. If there was anybody who took good care of herself, it was her," recalls Luke. "She didn't drink, smoke, or overeat. We were both floored."

Upon receiving Barbara's diagnosis, they went to Dana-Farber Cancer Institute for additional testing, and there they learned that Barbara had MCL. She was just 52 years old at the time and was told she only had about three years to live. At that time, MCL wasn't widely diagnosed, and there weren't many resources to learn about the disease and understand what it's like to live with a diagnosis. Barbara met her diagnosis head-on, but despite two stem cell transplants and excellent care and treatment, she passed away in September 2007, leaving behind her grieving husband and family.

"I can't say enough about the care she got. The care she received was fabulous," recalls Luke. "She was strong and determined to go out guns blazing."

## TOKENS OF LOVE

Before Barbara passed away, she and Luke visited their son, Stephen, and his wife, Julie, in Scottsdale, Arizona. With a new house to settle into, one of the first things Stephen and Julie did was adopt a dog – a pug named Deuce that everyone immediately fell in love with, especially Barbara. Undergoing treatment at the time, Barbara couldn't have a pug or any pets of her own, but that didn't stop her from surrounding herself with adorable dogs. "She just loved pugs from afar," says Luke. "She decorated the house with pug pillows and pug pictures. That's what started it – our pug movement. Our kids are fascinated by pugs, too."



After Barbara's passing, Julie got Luke a pug to keep him company. Ernie the pug was his constant companion and,

in the following years, one of several pugs in the extended family.

“It’s wall-to-wall pugs at our house. It’s always very interesting at Christmas time when we all get together,” Luke notes.

Back in Scottsdale, Stephen and Julie came in contact with the Lymphoma Research Foundation (LRF) through the annual LRF Lymphoma Walk in Phoenix, sharing with Luke how impressed they were by the organization. In 2008, Luke and Ernie the pug participated in their first LRF walk. Struck by the work LRF was doing, Luke was inspired to begin to donate to LRF on an ongoing basis.



After a long and rewarding career in sports broadcasting, Luke had amassed an impressive collection of sports memorabilia, which he realized he could use to do some good in Barbara’s memory. In the early days of eBay, Barbara opened an account, and wanting to find a memorable name for their eBay store, she landed on Luv Token. Now, Luke sells highly sought-after sports-related items on Luv Token, donating 10% of the store’s sales to LRF and Save the Children, one of Barbara’s favorite charities. Luke’s ongoing contributions specifically support LRF’s Patient Aid Grant.

“When Barbara got diagnosed, we were just speechless and didn’t know where to go or what to do,” says Luke. “I think that having that support network through LRF is very important to people because it’s not something you discuss in everyday conversation. I think it helps the process – the learning curve is very high, and you learn more about lymphoma than you ever wanted to learn in a short space of time.”

### WORKING TO END LYMPHOMA

Barbara was a loving mother and wife, a talented seamstress, and an aspiring college professor with a master’s degree in English. With five children, Luke describes Barbara as the glue that held the Griffin household together.

“She had the spirit, the gumption, the will to survive,” says Luke. “After her diagnosis, we went to Ireland, and Italy, and visited the kids. Stephen and Julie got married the September after Barbara was diagnosed, and Barbara told her doctor that she was going to dance at their wedding. He told her she was crazy, but sure enough, she was the belle of the ball.”

In Barbara’s memory, Luke and his children have participated in numerous LRF Boston and Phoenix Lymphoma Walks and remain active LRF donors. Their walkathon team name, “Barbara’s Buckaroos,” has seen a variety of team members of both the two-legged and four-legged varieties. Luke’s eBay sales and resulting LRF donations support the Foundation year-round. And he has made additional contributions to fund MCL research and provide matching grants for LRF’s Show Your Love Campaign as well.

“It is not an easy undertaking to try and beat lymphoma. The more support you can give, the better,” said Luke. “Thank God we had plenty of support; the support was priceless for us.”

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**“I think that having that support network is very important to people because it’s not something you discuss in everyday conversation. I think it helps the process – the learning curve is very high, and you learn more about lymphoma than you ever wanted to learn in a short space of time.”**

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Although Luke has moved to more cheering than walking in recent years, he continues to actively advocate for the important work LRF is doing. He, like so many others, is hoping for an end to lymphoma altogether.

“I don’t mean to be cruel, but it would be a dream to see LRF out of business in five more years,” says Luke. “Barbara loved to laugh; she had a lot of talent in many different areas. She had hope. And I can assure people that if they’re faced with that diagnosis, there’s no reason to give up hope. There’s always hope.” 🍷



If you would like to support LRF's Patient Aid Grant program, please visit [lymphoma.org/supportpatients](https://lymphoma.org/supportpatients).



# 2023 PUBLIC POLICY AGENDA

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

The 2023 Public Policy Agenda outlines LRF's policy priorities for the year ahead and will direct the efforts of thousands of patient and caregiver advocates across the United States. This year, LRF will continue to prioritize federal funding for lymphoma research and education, ensure patient access to high-quality cancer care, and place a unique focus on the needs of survivors.

## Supporting Lymphoma Research

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

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

## Supporting Access to Quality Cancer Care

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

- Legislation and regulations that ensure access to adequate and affordable health insurance coverage for people with lymphoma and protect access to quality cancer care, as well as maintaining coverage for pre-existing conditions.
- Payment and delivery reform efforts that assist health care providers in improving the quality of cancer care in all communities in the United States.

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

## Supporting Lymphoma Survivors

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

- Legislation which prioritizes the study of cancer survivorship and the needs of cancer survivors.
- Legislation which protects access to quality health insurance for anyone with a preexisting condition.
- Health care payment and delivery reforms that will incentivize delivery of quality survivorship care for patients across the cancer care continuum. Among these reforms are education and provider reimbursement for cancer care planning to improve planning services for all people with lymphoma. ○



## BECOME AN LRF ADVOCATE

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



[ FROM THE FIELD ]

# A MULTI-LAYERED VIEW OF **LYMPHOMA RESEARCH**

Some people are born to be scientists, and Eric D. Hsi, MD, Department Chair of Pathology at Wake Forest University School of Medicine, is one such person. While he may have always known he wanted to be a scientist, Dr. Hsi's journey to conducting pivotal lymphoma research was not always as obvious.

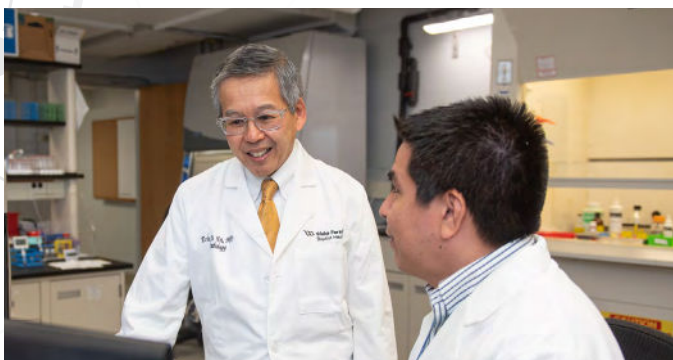
Growing up in Michigan, Dr. Hsi was always interested in science. Having a father who was an organic chemist at a pharmaceutical company in Kalamazoo was definitely a contributing factor, Dr. Hsi concedes. After receiving his bachelor's degree in chemistry from Kalamazoo College, he continued on to the University of Michigan for medical school, residency, and fellowship. Work opportunities brought him to Chicago for a short period, and then he moved to the Cleveland Clinic, where he spent much of his career before making the move to Wake Forest.

The leap from chemistry to pathology doesn't happen overnight, and for Dr. Hsi, the process was one of self-discovery.

"I was always interested in the science of medicine, so I knew that I'd be a chemistry major, and I always liked working in or around laboratories," says Dr. Hsi. "I think I sort of backed into a career in pathology as I figured out what I really liked to do."

After being named a Howard Hughes scholar in medical school, Dr. Hsi took a year off to conduct research at the National Institute of Health (NIH), where, while studying lymphocyte biology cell signaling, he grew interested in the immune system and lymphocyte biology. This experience at the NIH coupled with guidance from mentors during his residency flipped the switch for Dr. Hsi.

"I really enjoyed my hematopathology rotation, and it just clicked that I could be involved in laboratory medicine, clinical work, and academic work in hematopathology. It suddenly became obvious what my career choice should be."



**"One thing about the lymphoma research community is they're very open and looking for new investigators to bring in and mentor."**

## Prognostic Progress

Dr. Hsi's interest in lymphoma came at a time when lymphoma classifications were in the process of changing. He soon realized that much of what he was doing in the research lab could be applied to diagnosis and classification.

In his current role as the Department Chair of Pathology at Wake Forest University School of Medicine, Dr. Hsi has a front-row view of the research and the latest technology available to better understand the biology of lymphoma and how that informs diagnosis and disease classifications. In addition to the research he conducts, he works with residents and fellows, conducts laboratory hematology and diagnostic work, and consults with clinicians.

"Conducting biomarker research is both clinical and translational work, all aimed at identifying ways to better diagnose the malignancies, to better classify them, and to better prognosticate or even predict response to therapies in hematologic malignancies," explains Dr. Hsi.

A biomarker is a biological molecule that is a sign of a normal or abnormal process or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition. The work that Dr. Hsi is doing is an exciting frontier for the entire lymphoma community. The development of multi-omics, which combines discovery across multiple levels of biology, provides Dr. Hsi and his fellow researchers with a much deeper and unbiased understanding of hematologic malignancies. Previously, a small set of biomarkers that piqued interest would typically lead to questions and further investigation. Now, new technologies allow scientists to broadly survey the landscape and analyze tissues or single cells at the genomic, transcriptomic, epigenetic, and even proteomic levels to look at those features in the malignancies in tissues – and obtain an unbiased look at markers.

"These markers can really help inform treatment decisions by better-risk-stratifying patients," says Dr. Hsi. "Some predictive biomarkers can help predict how well a patient will respond to different types of treatments, and these biomarkers also play a role in the development of new drugs."

## On the Brink of Breakthroughs

Researchers often share that day-to-day progress can feel slow at times, but reflecting on all that has been accomplished to date, it's possible to have a greater appreciation for how far we've come. That's particularly true with lymphoma research, according to Dr. Hsi.



**“It’s an exciting time in science, in general, and for lymphoma, in particular. We’re learning new things about lymphoma at a faster rate, building upon the research of those who have come before us.”**

“Lymphoma is many diseases, not just one, and each deserves further investigation,” says Dr. Hsi. “We’ve made great progress over the last 10-20 years. When you look back at when I started training to where we are today, it’s night and day. One thing about the lymphoma research community is they’re very open and looking for new investigators to bring in and mentor.”

As a member of LRF’s Scientific Advisory Board (SAB), Dr. Hsi works alongside 44 other lymphoma experts to seek out the most innovative and promising lymphoma research projects for the Foundation to support. He has also been actively involved in LRF’s professional education series, Lymphoma Rounds, and has served as a research mentor through LRF’s Lymphoma Scientific Research Mentoring Program (LSRMP).

As a researcher, Dr. Hsi understands and appreciates the widespread impact LRF is making on the field, from shepherding the next generation of clinicians

and scholars through mentoring programs to funding research, supporting lymphoma patients, and bringing people together to focus on finding a cure for lymphoma. According to Dr. Hsi, we are currently on the brink of a wealth of knowledge, insights, and advancements as a result of LRF’s continued focus on lymphoma research.

“It’s an exciting time in science, in general, and for lymphoma, in particular. We’re learning new things about lymphoma at a faster rate, building upon the research of those who have come before us,” says Dr. Hsi. “The pace of discovery is much faster, along with our general understanding of the biology of these diseases, and in turn, we must continue to train the next generation of clinicians and scholars. Today, some types of lymphoma are now quite curable and many of them quite treatable. One of the most important things patients can do is to arm themselves with the information, resources, and support that LRF provides.” ○



## LYMPHOMA ROUNDS 2023 SERIES

### Free CME Program for Professionals

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

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



## 2023 LYMPHOMA ROUNDS SCHEDULE

**3/2 San Francisco Lymphoma Rounds**  
(Hyatt Regency San Francisco)

**3/21 Philadelphia Lymphoma Rounds**  
(The Westin Philadelphia)

**3/30 Chicago Lymphoma Rounds**  
(Crowne Plaza Chicago West Loop)

**4/13 Los Angeles Lymphoma Rounds**  
(Sheraton Grand Los Angeles)

**4/26 New England Lymphoma Rounds**  
(The Westin Copley Place)

**5/10 Seattle Lymphoma Rounds**  
(Crowne Plaza Seattle)

**5/18 Virtual National Lymphoma Rounds**

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

Lymphoma Rounds programming is supported by educational grants from:

AbbVie, Inc., Acrotech, ADC Therapeutics, AstraZeneca, BeiGene, Bristol Myers Squibb, BTG International Inc., Genmab, Kite Pharma Inc., Kyowa Kirin, Lilly Oncology, Pharmacyclics LLC, an Abbvie Company and Janssen Biotech, Inc., and Seagen

## WHERE ARE THEY NOW?

# DEBORAH STEPHENS, DO



Dr. Deborah Stephens is a medical oncologist at the University of Utah Health.

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

I grew up on a farm, and my mom told me she knew that I would go into medicine because I loved to watch my grandpa and dad deliver calves and give cows their vaccinations. In high school, I hurt my back playing basketball and was treated by a chiropractor. I thought I wanted to be a chiropractor and started shadowing him. Based on the questions that I asked, he asked me if I had ever thought about going into osteopathic medicine. I had actually never heard of osteopathic medicine before. However, I started shadowing our local family doctor and I really liked the integration of holistic medicine and the long-term connection that physicians have with their patients.

On hematology consults as a resident at Cleveland Clinic, I remember seeing a very sick patient with HLH that was related to an underlying T-cell lymphoma. This experience piqued my interest in lymphoma.

Then, as a fellow at The Ohio State University, I met with former Scientific Advisory Board (SAB) member Dr. John Byrd and started working on a research project with him. After about a week of working in his clinic, I knew I wanted to see patients with CLL and lymphoma and focus on clinical research. Looping back to my original experience, I liked the long-term connection with the patients.

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

During my last year of fellowship, I received the Lymphoma Research Foundation Scientific Research Mentoring Program grant (LSRMP).

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

My project was a phase 1 clinical trial of ibrutinib and selinexor for patients with CLL and lymphoma. We determined the maximum tolerated doses of the combination. This trial is now completed and published in *Clinical Cancer Research*.

### How has the treatment landscape for lymphoma/CLL changed since you first started conducting your research?

When I was a fellow at The Ohio State University, I had the opportunity to see patients treated in the first clinical trials with ibrutinib. These patients would come to the clinic saying that their doctor had told them that there were no more options for treatment of their cancer. Then, they would go on a trial with ibrutinib and it would change their lives. Patients who were previously

in hospice were feeling well and back to living their lives. After ibrutinib, many other highly efficacious targeted therapies have been developed, changing the treatment landscape, especially for patients with CLL. I have been honored to be a part of the development of acalabrutinib and nemtabrutinib, second- and third-generation BTK inhibitors improving upon ibrutinib's success.

Another breakthrough since I started conducting my research was chimeric antigen receptor T-cell therapy (CAR T). I wanted to open a clinical trial using CAR T therapy in patients with CLL at Huntsman Cancer Institute. Minor problem was that we didn't have a CAR T program and had never done this treatment at HCI. So with the help of a fantastic team, I helped establish the CAR T program at HCI. Subsequently, we opened the phase 1 study with liso-cel for patients with CLL, and I hope these data will support FDA approval for patients with CLL at some point in the future.

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

The LRF grant that I received was vital to advancing my career. I cannot say enough good things about this program. It helped me to understand the design and management of clinical trials. It also helped me to form a mentoring network of experts across the country. My co-awardees and friends still meet up at ASH every year to catch up. Shout out to the LRF Class of 2014!

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**"The LRF grant that I received was vital to advancing my career. I cannot say enough good things about this program. It helped me to understand the design and management of clinical trials."**

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

I have evolved from a mentee to a mentor. Since I feel that the LSRMP is so crucial to career development, I have encouraged junior faculty working with me to apply. Two junior faculty have successfully earned the award and one of the fellows I'm working with is applying this year. I have enjoyed serving as a mentor for this program.

Additionally, I enjoy educating patients and have given many educational talks for patients with lymphoma and CLL through LRF's outreach programs.

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

LRF is critical for so many reasons:

- The patient education and assistance provided to patients is invaluable to help them understand their diseases.
- The career development grant programs help fellows and junior faculty form a network of mentors and colleagues across the country to collaborate on nationwide research that changes the standard of care for these patients. The career development grants also help to protect time for junior faculty to complete these important research projects.

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

I now serve as the CLL Lead for the SWOG Leukemia Group. As a part of this group, I developed, planned, and now lead an international clinical trial investigating early intervention for patients with CLL, the S1925 EVOLVE CLL study. We are actively enrolling over 200 patients in an attempt to determine whether early intervention can prolong the lives of these patients.

As CLL causes immunosuppression leading to advanced second cancers and severe infection, I'm invested in finding ways to prevent the complications of CLL. I currently have a trial with the goal of preventing skin cancer and pinpointing the origin of skin cancer in patients with CLL. I received an NCCN grant to complete this project. Additionally, I have a clinical trial looking at vaccine strategies for patients with CLL with the goal of preventing pneumonia.

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

Everything is exciting in the field of lymphoma research today! The field is advancing so quickly that treatments I talk to my patients about today may be replaced by something even better in just a few short years. I'm specifically interested in next-generation B-cell receptor signaling inhibitors, immunotherapy with CAR T and bispecific antibodies, and novel treatments for Richter's transformation. ○

# UPDATES FROM 2022 AMERICAN SOCIETY OF HEMATOLOGY ANNUAL MEETING

The Lymphoma Research Foundation (LRF) returned to the American Society of Hematology (ASH) Annual Meeting and Exposition, with 300 LRF-affiliated scientists, including past and present members of LRF's world-leading Scientific Advisory Board (SAB) and grantees, contributing to an abstract presented at the conference.

## 300

LRF-affiliated  
scientists contributed  
to an abstract  
presented at ASH

## 183

LRF grantees  
were authors on  
ASH abstracts



Widely regarded as the premier event in malignant and non-malignant hematology, the ASH Meeting provides a critical forum for leading hematologists/oncologists to present their findings to over 20,000 of their peers. Among the distinguished scientists attending, more than 90 LRF-affiliated scientists presented at the 2022 ASH Annual Meeting.

In addition to LRF's representation through presentations, LRF researchers contributed to 705 abstracts across all hematology and 522 lymphoma-related abstracts. Eighty percent of LRF scholars – participants in LRF's Lymphoma Scientific Research Mentoring Program (LSRMP) – authored at least one abstract at ASH.

### UPDATES FROM THE 2022 AMERICAN SOCIETY OF HEMATOLOGY ANNUAL MEETING WEBINAR

Learn more about pivotal lymphoma research presented at the 2022 American Society of Hematology (ASH) Annual Meeting from Laurie Sehn, MD, MPH and Pierluigi Porcu, MD. View the 2022 ASH webinar on demand at [lymphoma.org/webinars](https://lymphoma.org/webinars).

LRF researchers  
contributed to:

**705** & **522**  
abstracts across  
all hematology lymphoma-related  
abstracts



### Short-course Brentuximab Vedotin with Chemotherapy is Highly Active in Early-Stage Bulky Hodgkin Lymphoma

Treatment with short-course brentuximab vedotin (Adcetris; BV), an antibody-drug conjugate, combined with chemotherapy in early-stage, bulky Hodgkin lymphoma (HL) was associated with four-year overall and progression-free survival (PFS) rates over 90%, according to extended follow-up results.

The research team, which included LRF Scientific Advisory Board member and Immediate Past Chair Andrew D. Zelenetz, MD, PhD of Memorial Sloan Kettering Cancer Center, presented updated results from a study that was initially published in 2021. Alison Moskowitz, MD of Memorial Sloan Kettering Cancer Center, another contributing author, serves as a faculty member for LRF's Lymphoma Scientific Research Mentoring Program (LSRMP). The study included 116 patients with untreated, bulky HL who were given four courses of BV plus chemotherapy (doxorubicin, vinblastine, and dacarbazine; AVD). Patients were divided into four groups, and after initial BV+AVD treatment, they received various levels of consolidative radiation therapy, including none.

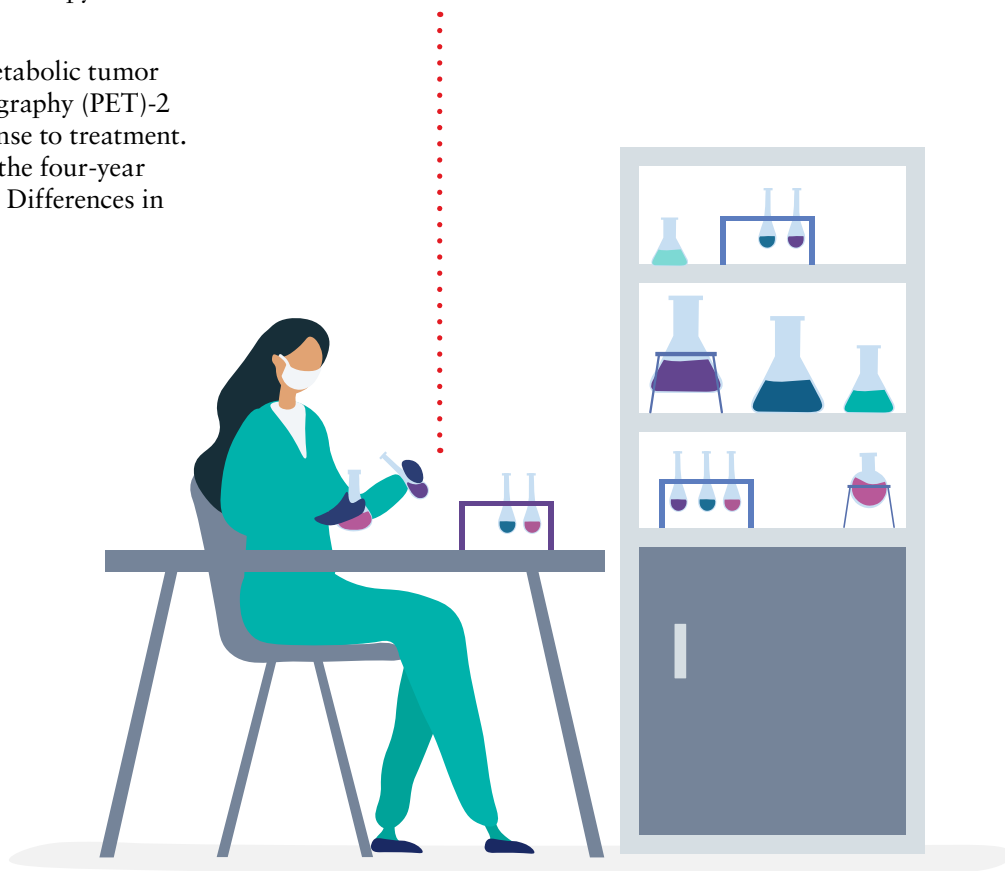
Across all groups, the four-year overall survival rate was 93%, and the PFS rate was 98%. The PFS rate did not vary significantly based on how much radiation therapy was received (90 to 96% for all groups).

The researchers also evaluated whether metabolic tumor volume (MTV) or positron emission tomography (PET)-2 results at baseline were predictive of response to treatment. Among patients with high and low MTV, the four-year PFS rate was 91% and 100%, respectively. Differences in PFS were greater in patients stratified by PET2 (79% in the PET2-positive and 95% in the PET2-negative groups). When both measures were combined, the strongest predictor of poor response to therapy was high MTV/PET2-positive disease, with a four-year PFS rate of 60%; PFS was 95% in the MTV-low/PET2-positive group, and 100% in both PET2-negative groups, regardless of MTV status.

The researchers concluded that short-course BV-AVD in early-stage bulky HL, with or without consolidative radiation therapy, remains highly active and well tolerated at four years, though people with high baseline MTV and PET2 positivity may be at greater risk for treatment failure.

*This study also included contributions from LRF grantees Connie Lee Batlevi, MD, PhD of Memorial Sloan Kettering Cancer Center; Carla Casulo, MD of University of Rochester Medical Center; Niloufer Khan, MD of Memorial Sloan Kettering Cancer Center; Anita Kumar, MD of Memorial Sloan Kettering Cancer Center; and M. Lia Palomba, MD of Memorial Sloan Kettering Cancer Center; LRF SAB members Ranjana Advani, MD of Stanford University School of Medicine; Jonathan Friedberg, MD, MMSc of the University of Rochester Medical Center; and Steven Horwitz, MD of Memorial Sloan Kettering Cancer Center; LRF SAB member and Past-Chair, Andrew D. Zelenetz, MD, PhD of Memorial Sloan Kettering Cancer Center; LRF Mantle Cell Lymphoma Consortium (MCLC) member Elizabeth Budde, MD of City of Hope; New York Lymphoma Rounds Steering Committee member David Straus, MD of Memorial Sloan Kettering Cancer Center; and past Scientific Advisory Board (SAB) member Craig Moskowitz, MD University of Miami Health System.*

More than  
**90** LRF-affiliated scientists  
presented an abstract  
during ASH



## Quality of Life Improves Quickly in Survivors of Aggressive Lymphomas

Lymphomas are a potentially curable subset of cancers, but long-term treatment or disease effects may impact quality of life. Researchers, therefore, sought to determine how quality of life changed from diagnosis over up to nine years of follow-up in patients with aggressive forms of lymphoma.

The study, which included Carrie Thompson, MD, an LRF advisor faculty speaker for LRF Patient Education Programs as an author, studied more than 2,000 patients with diffuse large B-cell lymphoma (DLBCL), grade 3 follicular lymphoma, Hodgkin lymphoma, T-cell lymphoma, non-Hodgkin lymphoma not otherwise specified (NOS), B-cell lymphoma NOS, or composite lymphomas. Within nine months of diagnosis, patients completed a quality-of-life assessment of their physical, social/family, emotional, and functional well-being. Survivors, defined as those who were still alive with no active disease or treatment within six years of assessment, were invited to complete the assessment again at one, two, three, six, and nine years after diagnosis.

At diagnosis (baseline), physical, emotional, and functional well-being were lower in people with aggressive lymphomas compared with historical estimates for the general United States (US) population; social/family well-being were higher. However, quality of life with regard to all four measures of well-being increased over the entire follow-up period, with the greatest improvements seen in the first year after diagnosis. At all follow-up points after diagnosis, quality-of-life measures were higher in survivors of aggressive lymphomas than in the general US population.

Results were similar across all subtypes explored and in those who had not yet started treatment at baseline.

*This study also included contributions from LRF SAB member and Past-Chair, Thomas M. Habermann, MD of Mayo Clinic Rochester; LRF grantee Gita Thanarajasingam, MD of Mayo Clinic Rochester; LRF SAB member Brian Link, MD of the University of Iowa; and LRF SAB member James Cerhan, MD, PhD of Mayo Clinic Rochester.*

## Durable Responses Observed with Mosunetuzumab Monotherapy in Relapsed/Refractory Follicular Lymphoma

In research presented by Nancy Bartlett, MD, a past Scientific Advisory Board (SAB) member and LRF grantee, durable clinical responses were observed in patients with relapsed/refractory follicular lymphoma (FL) who received mosunetuzumab monotherapy, according to updated results from a phase II study.

Mosunetuzumab (Lunsumio) is a T-cell-engaging bispecific monoclonal antibody that works by directing anti-cancer T cells to malignant B cells. Results from a phase II study involving the use of mosunetuzumab monotherapy in 90 patients with relapsed/refractory FL who had received at least two prior treatments were previously published in August of 2022. Here, the researchers presented updated results.

After a median 27 months of follow-up, approximately 78% of patients in the study achieved an objective response, and 60% achieved a complete response. Among complete responders, 79.5% remained in remission for at least 24 months. The 24-month progression-free survival rate among all patients was 51.4%. The researchers also reported that more patients responded to mosunetuzumab than their last prior therapy, and that the duration of responses was also higher, though retrospective comparisons are difficult to interpret without standardization of assessments.

Cytokine release syndrome (CRS) events occurred in 44.4% of patients, most of which occurred during the first cycle of therapy and were mild in nature. All CRS events resolved. The investigators reported that no new CRS events, or other serious or severe/fatal adverse events, had occurred since results were originally published and concluded that there was no evidence of chronic toxicity observed with mosunetuzumab therapy.

*This study also included contributions from LRF SAB members Laurie H. Sehn, MD, MPH of BC Cancer, Vancouver; and Loretta Nostoupi, MD of The University of Texas MD Anderson Cancer Center; Philadelphia Lymphoma Rounds Steering Committee Chair Stephen J. Schuster, MD of Abramson Cancer Center/the University of Pennsylvania; and LRF Mantle Cell Lymphoma Consortium (MCLC) member Elizabeth Budde, MD of City of Hope.*

# 13

abstracts related to recent LRF-funded research were presented, including 6 oral presentations

## Next-Generation BTKi Zanubrutinib Demonstrates Improved Efficacy and Tolerability Compared with Ibrutinib

The Bruton tyrosine kinase inhibitor (BTKi) ibrutinib (Imbruvica) has become the standard treatment for relapsed/refractory chronic lymphocytic leukemia (CLL) and small lymphocytic leukemia (SLL) but can cause unwanted off-target effects. Investigators therefore sought to compare the efficacy and safety of ibrutinib with the next-generation BTKi zanubrutinib (Brukinsa), which has greater specificity for cancer cell types.

Final results from the phase III ALPINE study, presented by Jennifer Brown, MD, PhD, an LRF Scientific Advisory Board (SAB) member, included 652 patients with relapsed or refractory CLL or SLL. Patients received either zanubrutinib or ibrutinib until disease progression or unacceptable toxicity. Approximately 23% of patients who received ibrutinib discontinued treatment due to adverse events compared with 16% in the zanubrutinib group.

Over 29.6 months of follow-up, zanubrutinib use lowered the likelihood of disease progression by 35% compared with ibrutinib. Progression events occurred in 26.9% of zanubrutinib-treated patients compared with 36.9% in the ibrutinib group. Overall response rates in the zanubrutinib group were also higher – 86.2% vs 75.5% in the ibrutinib group. Results were similar in patients with high-risk disease features.

Severe or serious adverse events were more frequent among ibrutinib-treated patients than those who received zanubrutinib, leading to fewer dose interruptions and reductions. Discontinuation due to cardiac toxicity was lower in the zanubrutinib group (0.3%) than the ibrutinib group (4.3%), and no fatal cardiac events were observed among zanubrutinib-treated patients (six occurred in the ibrutinib group).

The investigators concluded that these results suggest zanubrutinib is both more effective and better tolerated than ibrutinib in patients with relapsed/refractory CLL or SLL, leading to lower rates of discontinuation and fewer cardiac complications.

*This study also included contributions from past SAB member Susan O'Brien, MD of the University of California, Irvine.*

## Updated Index Improves Prognostication for Survival in Advanced-Stage Hodgkin Lymphoma

Models that have historically been used to predict survival outcomes in advanced-stage classical Hodgkin lymphoma (A-HL) are outdated and less useful in the modern treatment era. Members of the Hodgkin Lymphoma International Study for Individual Care (HoLISTIC) Consortium, therefore, sought to develop a new model for prognostication of outcomes in A-HL using modern data. Andrew Evens, DO, MBA, MMSc, one of the contributing authors for the publication detailing these results is an LRF Scientific Advisory Board member.

The prognostic model, known as the Advanced-Stage Hodgkin Lymphoma International Prognostication Index (A-HIPI), was developed using data from more than 4,000 patients treated in eight international clinical trials from 1996 to 2012. The primary outcomes for prognostication were five-year overall and progression-free survival. Variables found to be predictive of these outcomes included age, sex, disease stage, presence of bulk disease, lymphocyte count, and hemoglobin and albumin concentrations.

The A-HIPI model was externally validated using a sample of more than 1,500 patients included in HL registries from Canada, the United States, and Australia. Compared with historical models, the researchers reported that the A-HIPI model showed modest improvement in prediction of five-year progression-free survival and meaningful enhancement in the predictive capacity for overall survival. The investigators noted that there is additional room for improvement in future models, which could also include treatment regimen, imaging results, and treatment-related late effects.

An online calculator will be made available to physicians to simplify the application of the A-HIPI model in the clinic.

*This study also included contributions from LRF SAB members Jonathan Friedberg, MD, MMSc of the University of Rochester Medical Center; Brian K. Link, MD of the University of Iowa; and Kerry J. Savage, MD, MSc, FRCPC of BC Cancer, Vancouver.*

# 80%

of scholars authored at least one abstract at ASH .....

### **Addition of Lenalidomide to Rituximab Therapy is Associated with Improved Survival in Relapsed/Refractory Indolent Non-Hodgkin Lymphoma**

Combination therapy with rituximab (Rituxan) and lenalidomide (Revlimid) was approved for use in relapsed/refractory indolent non-Hodgkin lymphoma (iNHL) based on the results of the phase III AUGMENT study, which were published in 2019. At ASH, John Leonard, MD, an LRF SAB member and Past-Chair, presented five-year results from AUGMENT, including survival and safety updates.

The AUGMENT study included 358 patients with R/R follicular lymphoma grade 1-3a or marginal zone lymphoma who were not refractory to rituximab. Participants received weekly rituximab with either lenalidomide or placebo for up to one year. Survival and safety outcomes were assessed every six months during follow-up. The five-year overall survival rate was 83.2% in the rituximab-lenalidomide group and 77.3% in the rituximab-placebo group.

After a median 66 months of follow-up, the median duration of progression-free survival was 27.6 months in the lenalidomide group compared with 14.3 months in the control group. Time to next anti-lymphoma therapy was approximately 73.1 months vs 31.8 months in the lenalidomide and placebo groups, respectively.

Investigators noted that the updated safety profile was similar to what was previously reported, though additional second primary malignancies (SPMs) had occurred; a total of 13 (7%) and 21 (12%) SPMs were reported in the lenalidomide and placebo groups, respectively. The overall incidence of SPMs was lower in patients who received rituximab-lenalidomide compared with those who received rituximab-placebo.

The investigators concluded that the superior efficacy and more favorable safety profile compared with rituximab monotherapy support the use of rituximab-lenalidomide therapy as a standard of care for patients with relapsed/refractory iNHL.

Durable responses achieved with glofitamab therapy in relapsed/refractory large B-cell lymphoma glofitamab is an investigational T-cell-engaging bispecific monoclonal antibody that directs T cells to eliminate cancerous B cells. Investigators reported results from a pivotal phase I/II study involving the use of glofitamab in patients with relapsed/refractory large B-cell lymphoma (LBCL). The study included 214 participants with diffuse LBCL not

otherwise specified, high-grade B-cell lymphoma, primary mediastinal LBCL, or transformed follicular lymphoma who had received at least one prior therapy. Patients received one week of obinutuzumab (Gazyva) pre-treatment followed by 12 cycles of glofitamab.

At the end of treatment, 29% of patients had achieved a complete response (CR). At six months following the end of treatment, CR was maintained in 74% of these patients. At 12 months, 56% remained in complete response. Disease progression was observed in 2% of patients during this time. The median duration of CR was not reached by the time of analysis, approximately 18 months post-treatment.

The investigators concluded that relapse rates are low among patients with relapsed/refractory LBCL who achieve a complete response to glofitamab, though longer follow-up is needed to confirm the off-treatment durability of responses beyond 12 months.

*This study also included contributions from Seattle Lymphoma Rounds Steering Committee member Krish Patel, MD of the Swedish Cancer Institute; LRF grantee Lorenzo Falchi, MD of Memorial Sloan Kettering Cancer Center; and past Scientific Advisory Board (SAB) member and LRF grantee Nancy Bartlett, MD of the Washington University School of Medicine.*



## Primary Central Nervous System Lymphoma Survival Improved with Consolidation Therapy

Consolidation with either whole-brain radiation therapy (WBRT) or autologous stem cell transplant (autoSCT) improves overall survival in patients with primary central nervous system lymphoma (PCNSL), regardless of first-line therapy, according to the results of a multicenter study.

PCNSL is a rare form of non-Hodgkin lymphoma with poor survival outcomes. High-dose methotrexate (HD-MTX)-based chemoimmunotherapy is the current standard for treatment, with or without combination high-dose cytarabine. Subsequent consolidation therapy with WBRT or autoSCT is preferred but is not performed in all cases. In this study, investigators sought to compare response rates and survival outcomes in PCNSL patients who received various HD-MTX-based chemoimmunotherapies with and without consolidation therapy.

Three high-intensity and two moderate-intensity regimens were used. Of the 250 patients included in the study, 45% received high-intensity treatment and 55% received moderate-intensity treatment. No difference in overall survival was seen between patients who received high- vs moderate-intensity treatment or between any of the different HD-MTX-based regimens. Patients who received consolidation therapy, however, had better responses and improved overall survival compared with those who didn't receive consolidation therapy. Approximately one-third of patients received consolidation therapy in the study, of which approximately two-thirds received WBRT and one-third received autoSCT. No survival differences were observed based on consolidation therapy type.

Consolidation therapy was used more often in younger patients than older patients, so investigators sought to identify additional potential factors that may have impacted survival. Older age, worse performance status ( $\geq 2$ ), and elevated lactate dehydrogenase (LDH) were all found to be predictive of greater risk for death. In patients with these risk factors, use of consolidation therapy reduced the risk for death by 56%.

Based on these results, the researchers suggested that PCNSL treatment algorithms should emphasize the use of consolidation therapy with WBRT or autoSCT following initial HD-MTX-based therapy, regardless of regimen.

## High Rates of Progression-Free Survival and MRD Undetectability in Patients with Chronic Lymphocytic Leukemia Receiving Ibrutinib Plus Venetoclax

Investigators reported updated results from a phase II trial exploring the use of ibrutinib-venetoclax combination therapy in patients with high-risk chronic lymphocytic leukemia (CLL). Results of the study involving 80 patients were previously published in 2019 and 2021. Here, investigators provided a four-year update on these patients plus an additional 40 others included as part of a study expansion.

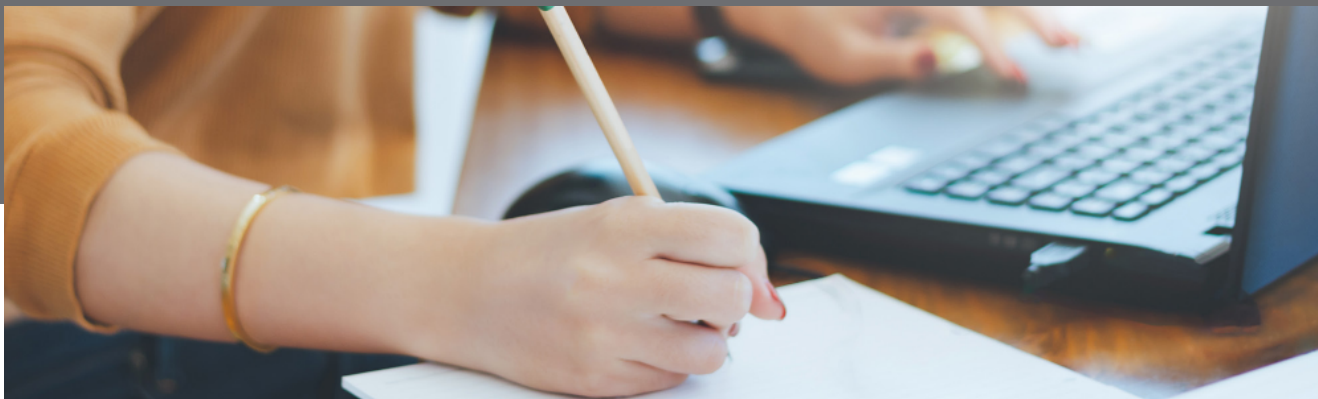
The study included patients with previously untreated CLL with at least one high-risk feature of disease: del(17p), mutated TP53, del(11q), unmutated IGHV, or age 65 years or greater. Combination therapy was given for twenty-four 28-day cycles, with up to 12 additional cycles given for patients who remained bone marrow (BM) minimal residual disease (MRD)-positive at the end of 24 cycles.

Fifty-two percent of patients achieved MRD undetectability by cycle 12; after 24 cycles of combination therapy, 64% achieved BM undetectable-MRD. Of the 24 patients who remained BM MRD-positive after 24 cycles, 18 with low MRD positivity resumed combination therapy. Of these patients, 61% achieved undetectable MRD during a third year of treatment. The four-year rates of progression-free and overall survival were 94.5% and 96.6%, respectively.

The only high-risk disease feature found to be associated with MRD detectability was the presence of a TP53 mutation, which was associated with a lower rate of BM undetectable-MRD at six months. However, this association was lost at 12 months. None of the high-risk features included were associated with progression-free survival. ○



# VIRTUAL EDUCATION PROGRAMS



## Winter Virtual Education Programs:

2.22

Virtual Pregunte al Doctor Sobre  
el Linfoma

4.1

National Virtual Lymphoma  
Workshop

4.6

Ask the Doctor: Information for  
Newly Diagnosed Patients

Despite COVID-19, there is no interruption in our commitment to providing up-to-date patient education for lymphoma. While in-person educational events have been postponed, **the Lymphoma Research Foundation (LRF) is using digital platforms to deliver virtual patient education programs around the country, including Virtual Ask the Doctor About Lymphoma 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.

[ LIVING WITH LYMPHOMA ]

# THE IMPORTANCE OF BEING **SEEN** **AND HEARD**





In April 2021, Paula Ngon was an active, young public relations professional living in New York City, navigating life amid a global pandemic. One day, not feeling well and concerned about swollen lymph nodes, she went to the emergency room but was sent home and told that nothing was wrong with her. With pressure on her neck increasing from her now golf ball-sized nodes, Ngon decided to trust her gut and booked an appointment with a doctor immediately. Thankfully, the physician she found listened to Ngon's concerns and led her to an important diagnosis.

“The doctor instantly validated me, reassuring me that we would get to the bottom of whatever was going on with me,” says Ngon. After an X-ray and ultrasound, the physician shared with Ngon that she saw a shadow in her chest and immediately connected her with another doctor to get a biopsy. By the end of the following week, Ngon was diagnosed with Hodgkin lymphoma (HL).

### **FACING SETBACKS**

After the initial shock waned and the reality of her diagnosis set in, Ngon's lymphoma journey continued to throw challenges her way. As an otherwise healthy 26-year-old, Ngon elected to freeze her eggs before undergoing treatment, in case she wanted to start a family in the future. She experienced complications following the egg retrieval, and again, Ngon knew that something wasn't right. Frustratingly, her concerns fell on deaf ears, and she took matters into her own hands and went to the emergency room. They discovered blood was filling up one of her lung cavities, and they had to perform a procedure to drain the blood so her lungs could expand again.

Chemotherapy brought its own complications. When Ngon's port was put in for chemotherapy, her right arm

felt numb, and when dropped by her side, it began to turn blue. She showed her oncologist and was told the tumor on that side could be causing her pain, and the anesthesia from the port procedure could be affecting the feeling in her arm. When Ngon had her port removed, she was hopeful these issues would subside. When it didn't, she called her oncologist and was told to give it time and not to worry. As the days passed, the numbness and discoloration continued, and Ngon refused to accept that there wasn't something bigger going on.

“I felt in that moment I had to challenge my doctor – challenge his authority and make him understand my issues were urgent,” recalls Ngon.

Ngon's oncologist finally sent her to radiology, who immediately spotted that something was wrong and sent her to the emergency room, where they identified several blood clots up and down her arm. Due to the seriousness of blood clots, she spent over a week in the ICU for treatment. During the next few weeks, Ngon was overwhelmed with decisions she needed to make, and her oncologist was nowhere to be found. She made the important decision to look for a new doctor, someone she felt would listen to her needs and prioritize her health.



**It was her doctor who helped Paula through – providing resources and care that helped her see a path forward.**

“As a Black woman having to go through that experience, I just felt like I wanted someone Black – or at least someone who knows someone – so that there’s accountability,” says Ngon.

Fortunately for Ngon, the president of the company she works for is also her executive sponsor for the Black employee resource group that Ngon leads in her workplace. This close relationship led Ngon to her new doctor, a connection of her company’s president. She had finally found the accountability and trust that she was seeking. Her new physician also happened to be a nationally recognized oncologist and member of the Lymphoma Research Foundation’s (LRF) Scientific Advisory Board.

“My experience with my new doctor was completely different – everyone took such great care of me,” says Ngon. “By the time I switched doctors I had already started chemo and understood my treatment plan, but I just felt like if I needed him, he was there. I felt like the compassion was there.”

### ADVOCATING FOR HEALTH EQUITY

Ngon’s experience made her passionate about advocating for others who may not have the resources to advocate for themselves. She is quick to point out that her education, personal network, and understanding and salaried job all worked in her favor, but not every young Black woman being diagnosed with lymphoma is as fortunate.



“Most people who look like me don’t have those advantages. It’s great that I was able to find a new doctor and everything worked out, but not everyone has that. I think that’s where my voice is most needed in this space.”



“Most people who look like me don’t have those advantages. It’s great that I was able to find a new doctor and everything worked out, but not everyone has that,” says Ngon. “I think that’s where my voice is most needed in this space.”

Throughout Ngon’s treatment, she faced a myriad of challenges, ranging from confusing billing practices to finding an in-network wig shop that understood the unique needs of Black women. Juggling recovery, being her own advocate, and maintaining the will to keep going, Ngon at one point wondered if she would survive. She recalls calling her dad and saying maybe she didn’t want to fight anymore, overwhelmed from fighting insurance companies, the stress, and the mountain of bills.

It was her doctor who helped Paula through – providing resources and care that helped her see a path forward. Doing her own research, Ngon learned that lymphoma is a treatable disease, and survivors were living for 20 years and more. Over time, and as she made steady progress, her despair turned into optimism, and she made a goal to go to Italy when she was done with treatment to celebrate persevering.

On Dec. 1, 2021, Ngon’s doctor informed her she was in remission. Ringing in the new year on Jan. 1, 2022, she finally felt hopeful for the first time in a long while – and eventually took her trip to Italy to mark this momentous occasion. 🍷



# 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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### **HANS-GUIDO WENDEL, MD**

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#### **Immediate Past Chair, 2019-2021**

Memorial Sloan Kettering Cancer Center

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NewYork-Presbyterian Hospital  
Weill Cornell Medicine

### **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

Show Your Love Campaign	2.1-2.28
Virtual Pregunte al Doctor Sobre el Linfoma	2.22
Washington, DC Lymphoma Rounds	2.23
Rare Disease Day	2.28
Irish Whisper Walk	3.1
San Francisco Lymphoma Rounds	3.2
Los Angeles Marathon	3.19
Philadelphia Lymphoma Rounds	3.21
National Doctors' Day	3.30
Chicago Lymphoma Rounds	3.30
National Virtual Lymphoma Workshop	4.1
Swirl Orange County	4.1
Ask the Doctor: Information for Newly Diagnosed Patients	4.6
Los Angeles Lymphoma Rounds	4.13
New England Lymphoma Rounds	4.26
2023 Golf Invitational: Maryland	4.28
Washington, D.C., Lymphoma Workshop	5.6
Seattle Lymphoma Rounds	5.10
National Lymphoma Rounds	5.18
2023 Golf Invitational	5.22
2023 Swirl: Chicago	6.1

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



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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)**.

