

PULSE

INSTILLING HOPE FOR LIFE AFTER LYMPHOMA

Dr. Manali Kamdar's unique and empathetic approach to patient care and lymphoma research leaves a lasting impact on the lymphoma community.
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**\$10 MILLION COMMITMENT TO FOLLICULAR
LYMPHOMA INITIATIVE ACCELERATES RESEARCH
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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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The Lymphoma Research Foundation (LRF) understands that a diagnosis of lymphoma may bring about many different emotions and that everyone's journey is personal.

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

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

Visit lymphoma.org/podcast to listen and subscribe to upcoming episodes.

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Instilling Hope for Life After Lymphoma

People often say that eyes are the window to the soul — the concept that you can understand a person's emotions, and perhaps even their thoughts, by looking at life through their lens. Manali Kamdar, MD, an oncologist and researcher at the University of Colorado, approaches patient care and lymphoma research in a similar and unique empathetic manner.

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Meet the Newly Elected LRF Scientific Advisory Board Members

LRF welcomed three new members to its elite Scientific Advisory Board (SAB). The new members represent distinct specialties that will contribute to the global impact of the Foundation.

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LRF COVID-19 IMPACT IN NUMBERS

As we continue to learn and live through the current pandemic, we want you to know that the Lymphoma Research Foundation (LRF) is here for you. LRF remains committed to being a resource for lymphoma patients, survivors and their loved ones, providing the most up-to-date and evidence-based information about lymphoma and connecting them to the support and resources they need.

LRF has been hard at work developing COVID-19 — specific educational programming and resources for the lymphoma community, including webinars, fact sheets and social media live streams with experts. Below is a snapshot of LRF's response and impact amid COVID-19*.



6,355
downloads of
the LRF COVID-19
fact sheets



2,698
attendees of the
LRF COVID-19
webinar series



2,926
people assisted through
the LRF Helpline.
That's a 21% increase
from the same time
last year.



948
views of the LRF COVID-19
Facebook Live: *Careers,
Health Insurance and
Employee Rights*



PEOPLE IN ALL
50 STATES
(including the District of Columbia)
and more than 50 countries
accessed LRF digital
resources



11,035
visits to the
LRF COVID-19
Learning Center
and Resources



27
virtual educational
programs hosted



279
Patient Aid Grants
awarded

*Stats from March 2020 – September 2020

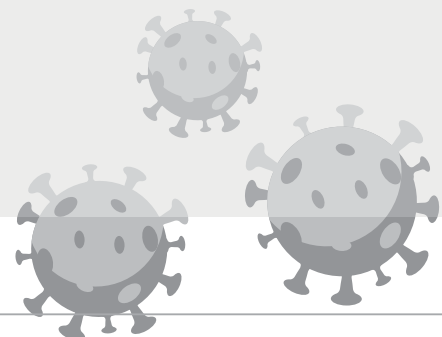
REGULAR UPDATES ON COVID-19

The health and safety of the lymphoma community is our top priority. We are taking proactive measures to help patients, survivors and their loved ones during the novel coronavirus/COVID-19 pandemic. Visit the COVID-19 Learning Center at lymphoma.org/covid19 for ongoing updates on the virus and LRF events and educational programs.

Need to know how COVID-19 is impacting the lymphoma community? Download our fact sheet, call LRF's Helpline (800 500 9976), watch COVID-19 — specific webinars and attend the virtual Ed Forum to stay informed.

The most important thing you can do to prevent contracting and spreading COVID-19 is **practice good hygiene and social distancing**. Visit the Centers for Disease Control and Prevention at cdc.gov/coronavirus/2019-ncov on steps you can take to prevent the virus.

Feeling anxious? It's normal. The LRF Helpline remains a resource for support and to answer questions you may have. Contact the LRF Helpline at 800 500 9976 or helpline@lymphoma.org.



FROM THE CEO

What we hear time and time again from members of the lymphoma community — and what we truly take pride in — is our disease-specificity and hyper-focus on finding cures for every type of lymphoma. Lymphoma patients, survivors and their loved ones look to the Lymphoma Research Foundation (LRF) for the latest evidenced-based information regarding their disease to assist them through their journey and empower them to be their own health advocate. They also see the impact and value of our research programs and scientific consortia, which advance our understanding of the more than 100 different subtypes of lymphoma and convene the world's leading lymphoma experts to collaborate and accelerate the pace of scientific discovery.



In this issue of *Pulse*, we are excited to share examples of how we fund disease-specific research with a goal of advancing cures. We profile one of the Foundation's most promising early-career scientists, LRF Scholar Manali Kamdar, MD, from the University of Colorado Anschutz Medical Campus. Dr. Kamdar describes her work as the University of Colorado's very first Clinical Director of Lymphoma Services and her LRF-funded clinical trial on the implementation of novel therapies for relapsed or refractory indolent non-Hodgkin lymphomas (NHL), like follicular lymphoma (FL) and marginal zone lymphoma (MZL), with the goal of improving patient outcomes. We are also pleased to introduce you to three new members of the Foundation's elite Scientific Advisory Board, who remain on the cutting edge of lymphoma research.

In the face of the COVID-19 pandemic, it is critical for patients to receive up-to-date information on their disease and receive timely and effective care. This issue of *Pulse* features stories on emerging issues in healthcare, including telemedicine and access to reliable information to inform patients' and caregivers' treatment decision-making.

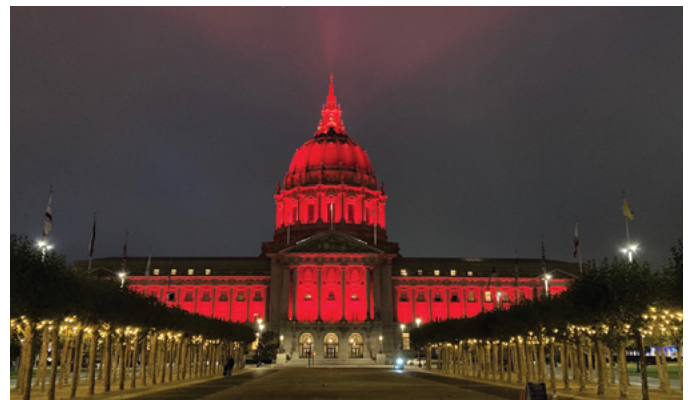
Lastly, we are excited to share more on the Foundation's newest global disease-specific initiative in follicular lymphoma. Building upon the success of other Foundation scientific initiatives and more than two decades' experience convening world-leading experts for scientific workshops and consortia, the Jaime Peykoff Follicular Lymphoma Initiative is poised to change the research and treatment landscape for this disease. Initiatives such as these and major breakthroughs achieved by our researchers are all made possible by your continued support. Thank you for all you do to aid the Foundation and the broader lymphoma research community in seeking to eradicate lymphoma and serve those touched by this disease.

Sincerely,

A handwritten signature in black ink, appearing to read "Meghan Gutierrez". The signature is fluid and cursive, with a large loop at the end.

Meghan Gutierrez
Chief Executive Officer

PHILANTHROPY IN ACTION



San Francisco City Hall

RALLY ON! CHICAGO

On August 2, 2020, hundreds joined the Lymphoma Research Foundation (LRF) for the live YouTube event *Team LRF Rally On! Chicago*.

As a way to safely come together amid the pandemic, hundreds of Chicago supporters gathered around their computers, televisions, phones and tablets to rally for a cure. *Rally On! Chicago* featured stories from lymphoma survivors, spotlights on Chicago fundraising teams and a meet-and-greet with the 2020 Lymphoma Clinical Research Mentoring Program (LCRMP) Scholars. Together, the Chicago community raised more than \$160,000 to support the LRF mission. To view the archived program, visit LRF's YouTube channel at youtube.com/lymphomaresearch.

LIGHT IT RED FOR LYMPHOMA: A BLOOD CANCER AWARENESS MONTH INITIATIVE

Buildings and landmarks around the world shined a light on lymphoma during Blood Cancer Awareness Month (BCAM) in September.

Culminating on World Lymphoma Awareness Day (WLAD) on September 15, national and international buildings and landmarks joined LRF's BCAM initiative *Light it Red for Lymphoma* to help raise awareness for this disease. Lighting partners included: the CN Tower in Ontario, Canada; Bell Tower in Perth, Australia; Pier 17 in New York, NY; Wrigley Building in Chicago, IL; and the Los Angeles International Airport (LAX) in California. "The first step in eradicating a rare disease like lymphoma is raising awareness on behalf of all those affected by this type of blood cancer," said Meghan Gutierrez, LRF Chief Executive Officer. "Each year, we at the Lymphoma Research Foundation are honored to convene so many wonderful and committed lighting partners from around the world in this truly global show of support for the lymphoma community, with the hope of raising awareness for all those touched by this disease." To learn more about *Light it Red for Lymphoma*, visit lymphoma.org/lightitred.




**FINDING CURES STARTS WITH YOU:
LRF 25TH ANNIVERSARY GALA**

Supporters from around the world came together to raise more than \$760,000 to advance research and patient support services and celebrate the LRF 25th Anniversary Gala on September 30.

This special online event honored AstraZeneca with the Corporate Leadership Award and past Scientific Advisory Board Chair and current member Thomas M. Habermann, MD, (Mayo Clinic, Rochester) with the Distinguished Leadership Award. The evening program featured an exclusive segment called *Heroes Among Us*, which honored impactful individuals in lymphoma research and patient care. To view the archived program, visit LRF’s YouTube Channel at youtube.com/lymphomaresearch.

14TH ANNUAL LYMPHOMA RESEARCH RIDE

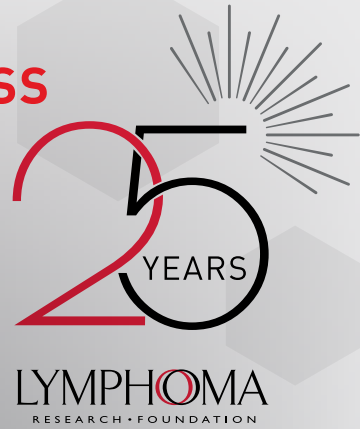
On October 4, 2020, hundreds of cyclists around the country pedaled for a cure at the *Ride On! America* Lymphoma Research Ride.

COVID-19 didn’t stop supporters from hopping on their bikes and cycling around their cities, towns and neighborhoods to raise more than \$290,000 to support the LRF mission. This year’s Research Ride featured a bring-your-own carbo-loaded pasta kickoff rally where Riders joined virtually from the comfort of their homes. The kickoff also featured a Champion Council discussion with lymphoma experts and prominent healthcare professionals from healthcare institutions including Georgetown University, George Washington Cancer Center and Johns Hopkins. To watch the kickoff rally and remarks, visit LRF’s YouTube Channel at youtube.com/lymphomaresearch. 

**FINDING CURES STARTS HERE:
25 YEARS OF INNOVATION AND PROGRESS**

This year marks 25 years of LRF’s commitment to eradicate lymphoma — 25 years of innovation and progress that have changed the way we advance lymphoma research and 25 years of impacting the lives of all those touched by this disease.

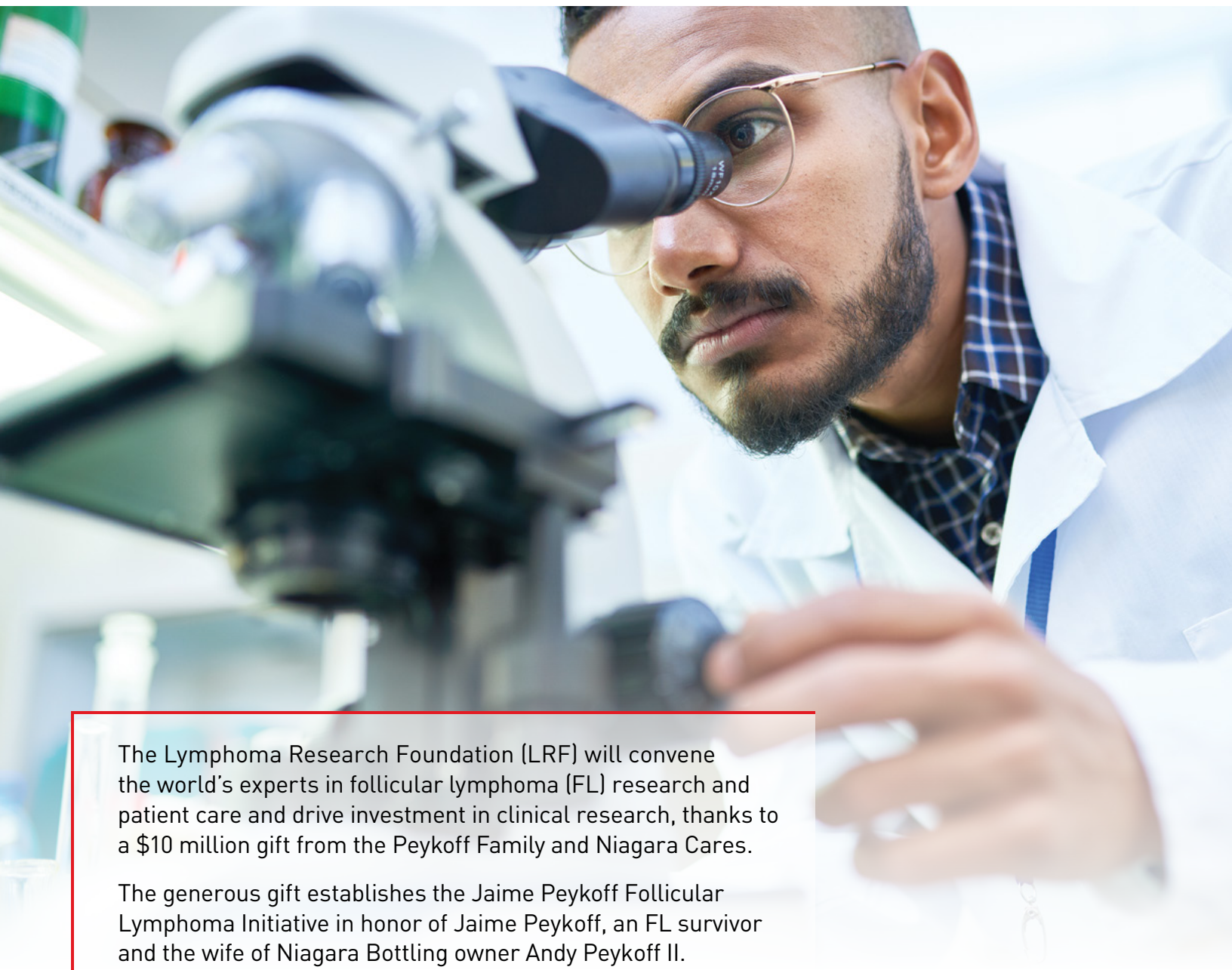
Learn more about LRF’s history and how you can support 25 additional years of innovation and progress at lymphoma.org/25.



\$10 MILLION COMMITMENT TO

FOLLICULAR LYMPHOMA INITIATIVE

ACCELERATES RESEARCH AND PATIENT CARE



The Lymphoma Research Foundation (LRF) will convene the world's experts in follicular lymphoma (FL) research and patient care and drive investment in clinical research, thanks to a \$10 million gift from the Peykoff Family and Niagara Cares.

The generous gift establishes the Jaime Peykoff Follicular Lymphoma Initiative in honor of Jaime Peykoff, an FL survivor and the wife of Niagara Bottling owner Andy Peykoff II.

“We were so very impressed by the Lymphoma Research Foundation’s extensive background in partnering with world-leading experts to advance the field of lymphoma research as well as the caliber of its Scientific Advisory Board,” says Jaime Peykoff. “We also loved their commitment to investing in early-career scientists to help push forward the pace and openness of lymphoma research. We are very excited to see what will be uncovered and accomplished with this new disease-focused initiative. It’s going to be a great journey!”

Follicular lymphoma is an indolent (slow-growing) form of non-Hodgkin lymphoma (NHL). Although an indolent form of lymphoma, FL remains incurable and a continuing challenge for researchers and clinicians. While most patients respond to the current standard of care, many will require treatment throughout their lifetime; the inability for some patients to achieve a complete remission and the early progression of disease in others can both result in poorer long-term outcomes.

Through the Jaime Peykoff Follicular Lymphoma Initiative, LRF will mobilize the research community to better understand FL, accelerate therapeutic development and bring innovations and advances to patients who require them faster and more efficiently.

“The Lymphoma Research Foundation seeks to eradicate this disease by supporting innovative research and the development of new and improved treatments for lymphoma. Direct investment in cutting-edge science is the primary way we advance our mission,” says Meghan Gutierrez, Chief Executive Officer for the Lymphoma Research Foundation. “This generous gift will allow us to develop and provide the critical tools and resources necessary to meaningfully advance the study of follicular lymphoma and impact patient care.”

LEADERSHIP

LRF assembled a Steering Committee of FL experts to provide thought leadership for the Initiative. This multidisciplinary, multi-institutional panel will ensure all key

stakeholders are informed of the Initiative’s goals and identify the most significant unmet needs in clinical FL research. The Steering Committee will also work with LRF to develop collaborative partnerships with other research institutions and organizations to maximize the Initiative’s investment.

The Initiative’s Steering Committee includes the following distinguished experts:

ANDREW D. ZELENETZ, MD, PHD
Memorial Sloan Kettering Cancer Center, *Chair*

SONALI M. SMITH, MD
The University of Chicago Medical Center,
Vice Chair

STEPHEN ANSELL, MD, PHD
Mayo Clinic, Rochester

JOHN P. LEONARD, MD
Weill Cornell Medicine

BRIAN K. LINK, MD
University of Iowa,
Holden Comprehensive Cancer Center

LAURA PASQUALUCCI, MD
Columbia University Medical Center

JOHN M. TIMMERMAN, MD
UCLA Jonsson Comprehensive Cancer Center

“We are honored to have assembled such an elite group of experts as part of the Initiative’s leadership,” says Andrew D. Zelenetz, MD, PhD, who also serves as Chair of the LRF Scientific Advisory Board (SAB). “Their extensive background in researching and treating follicular lymphoma and overall dedication to advancing the field of lymphoma research and clinical care makes me confident in and excited for future breakthroughs in this disease.”

Continued on the next page



INTERNATIONAL FOLLICULAR LYMPHOMA SCIENTIFIC WORKSHOP


Building upon more than two decades' experience as a convener of international scientific consortia and disease-specific research workshops, LRF will develop and convene an international Scientific Workshop intended to drive collaboration, which can often lead to scientific breakthroughs and prevent duplicative use of resources. Follicular lymphoma thought leaders will share early research findings, discuss the results of pivotal clinical trials and engage in planning exercises designed to advance FL research.

CLINICAL RESEARCH GRANTS

LRF is committed to funding the most promising lymphoma researchers who have the greatest potential to improve patient care and ultimately, to improve patient outcomes. Under the expert leadership of the Jaime Peykoff Follicular Lymphoma Initiative Steering Committee and the LRF SAB, LRF will fund FL research through two programs: the LRF Clinical Investigator Career Development Award for early-career researchers and a Disease Focus Area award focused on FL for senior faculty researchers.

“Amidst the continuing COVID-19 pandemic, many scientific research labs across the country were forced to

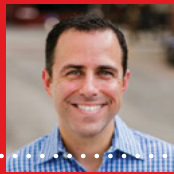
shut down, and funds for senior and early-career scientists continue to decrease,” says Gutierrez. “We are proud to continue our commitment to the lymphoma community by offering these additional grants within our research portfolio. We thank our supporters, like the Peykoff family, for making this important work possible.”

For more information about the Jaime Peykoff Follicular Lymphoma Initiative or additional LRF research programs, visit www.lymphoma.org/research. 

HELP ACCELERATE THE PACE OF RESEARCH

With your support of LRF, you ensure that the next generation of cancer researchers dedicate their careers to studying lymphoma. To learn how you can accelerate the pace of research like the Jaime Peykoff Follicular Lymphoma Initiative, contact Kate LeBoeuf at kleboeuf@lymphoma.org.

INVESTING IN RESEARCHERS TODAY BRINGS HOPE FOR TOMORROW



Matt Runge

In 2010, Matt Runge was diagnosed with follicular lymphoma (FL), an incurable and indolent (slow-growing) type of non-Hodgkin lymphoma (NHL). “I remember before receiving the results from

my needle-point biopsy, my ear, nose and throat physician told me, ‘It’s either going to be mononucleosis or lymphoma,’” recalls Runge. “I had never heard of lymphoma before and never knew that someone like me — 36 years old and in good health — could receive that kind of diagnosis.”

After receiving the confirmation of follicular lymphoma and discussing treatment options with an oncologist, he decided to seek out a second opinion. That’s when he found out about an upcoming Lymphoma Research Foundation (LRF) *Ask the Doctor About Lymphoma* program in his area. “I ended up seeing a total of four oncologists. I attended one of LRF’s *Ask the Doctor* programs and really liked the speaker,” he says. “I made an appointment with him and ended up choosing him as my oncologist.”

Throughout his treatment and subsequent remission in 2011, Runge stayed connected with LRF by attending patient education programs, becoming an Ambassador and participating in the annual *Team LRF Dallas Lymphoma Walk*. To date, Runge and his *Dallas Lymphoma Walk* Team Runge have raised more than \$80,000 to support LRF research programs, patient education and support services.

After a recurrence of follicular lymphoma in 2019, Runge wanted to take his support further. He started his family foundation, the Runge

Lymphoma Project, which will raise funds to benefit LRF research programs. His foundation’s first endeavor is to help to fund the new class of Scholars of the LRF Lymphoma Scientific Research Mentoring Program (LSRMP) with a specific investment in an FL researcher. Since launching in 2014, the LSRMP, formerly known as the Lymphoma Clinical Research Mentoring Program (LCRMP), has become a critical education and mentoring program for junior scientists. Many Scholars have gone on to make breakthroughs and develop new approaches to the diagnosis and treatment of lymphoma. “LRF has been a part of my lymphoma journey since day one, and I look forward to helping the Foundation make an impact on the lymphoma community” Runge says. “I hope our investment in LRF’s LSRMP and connecting young scholars with mentors early on in their career will prove dividends in follicular lymphoma.”

Continued investment in innovative research is a top priority for LRF, as is keeping the best and brightest scientists in the field of lymphoma research. For Runge and his family foundation, investing in a program like the LSRMP brings him hope for a future where a cure for follicular lymphoma can be achieved.

“The more brilliant minds we have behind this effort, the better chance we have of advancing treatments and finding cures.”

[FROM THE FIELD]

INSTILLING HOPE FOR LIFE

AFTER LYMPHOMA

“My goal is to have my patients’ lymphoma journey be a part of them, but never the whole part.”



Manali Kamdar, MD, is an oncologist and researcher at the University of Colorado who approaches patient care and lymphoma research in a unique and empathetic manner.

SCIENCE BY SERENDIPITY

Born and raised in Mumbai, India, Dr. Kamdar had dreams of becoming a professional dancer. She danced from the ages of 2 to 18, until an unfortunate fall on stage left her with an injured back and neck and a large decision to make about her future. While healing from her injury, Dr. Kamdar was inspired by her physician's dedication to helping her get back on the dance floor. "I have always been surrounded by medicine in one way or another," says Dr. Kamdar. "My mom and grandma have always been interested in integrative medicine. I was an asthmatic child, and I have always felt very well taken care of." It was then that she decided it was time to reconsider her future and pursue a career in medicine.

"It was my parents who first said to me, 'You have consistently excelled in the sciences, why don't you look into that?' and so I decided to take my medical exams," says Dr. Kamdar. "Like the saying goes, life is what happens when you're busy making other plans. I never intended on choosing medicine, it chose me, and I became very passionate about it." She completed medical school in India and later moved to the United States to complete her residency at East Carolina University. During her training in internal medicine she took an interest in hematology/oncology and then applied for a fellowship to delve deeper into the field of clinical cancer care.

"I never intended on choosing medicine, it chose me, and I became very passionate about it."

As she began her fellowship, she initially split her training between malignant hematology and lung cancer, but it was one of her mentors who nudged her to pursue a career in hematological malignancies. "My mentor suggested I do a rotation at Weill Cornell Medicine with John P. Leonard, MD, and it was during that time I received my first real exposure to the intricacies of lymphomas," says Dr. Kamdar. With her focus set on a career in lymphoma, she applied for fellowships across the country in the hopes of learning more about lymphomas and transplantation and was accepted into the program at Stanford.

Following her fellowship, she wanted to return to India to begin a lymphoma practice in Mumbai, but again her plans changed when she was offered a position as the director of the lymphoma program at the University of

Colorado. "I was very nervous to take on such a huge responsibility as a freshly graduated fellow. However, the idea of building something from scratch in a region devoid of lymphoma expertise was extremely exciting. My dad jokingly said, 'Look at it as a start-up opportunity; it will either work well or you will fall flat on your face and return home — either way it would be a win-win for us!,'" says Dr. Kamdar. "I took on the challenge, excited to be able to create the lymphoma program of my dreams — and I started my clinics in January of 2015 and have never looked back." She credits the leadership at the University of Colorado and several advisors along the way who encouraged and supported her vision. "I have been blessed to have met fantastic senior clinical researchers like Ginna Laport, MD, and Sonali Smith, MD, who stood by me through my professional journey. I hope to do the same for future lymphoma investigators."

"I took on the challenge, excited to be able to create the lymphoma program of my dreams — and I started my clinics in January of 2015 and have never looked back."

PRIORITIZING PATIENTS

Dr. Kamdar strives for her lymphoma program to deliver the most comprehensive and advanced care to patients. Her goal is to be able to provide them with the care they need so they may live happy lives beyond lymphoma. To help ensure a brighter future for her patients, Dr. Kamdar has put an emphasis on the psychosocial effect that a diagnosis of lymphoma can have on a patient's life post-treatment. "I want my patients to see that there can be so much more to life than just being a 'cancer survivor,'" says Dr. Kamdar. "I never want my patients waking up every morning worried that their disease will relapse — the goal is to have their lymphoma journey be a part of them, but never the whole part." By collaborating with a team of psychologists at her institution, she has ensured that her patients have access to a robust support system to help them transition to life after lymphoma. "Being able to be a part of patients' journeys and make an impact on their lives has undoubtedly been the highlight of my career."

As an oncologist and a clinical researcher, Dr. Kamdar sees every interaction with patients as an opportunity to learn more about lymphoma and the best ways to treat it. "My clinic days are critical to being able to see my research being put into practice." While Dr. Kamdar has witnessed many advancements in the field over the past five years,

Continued on the next page

she still thinks that we have only begun to scratch the surface. “Treating lymphoma can be a tricky because of its heterogeneous nature, and while it’s extremely gratifying to be able to cure several patients, there are still so many who are unable to be cured,” says Dr. Kamdar. “The outcomes of my patients across the board are very disparate, and so the opportunity to develop new treatments for my patients is something I knew I had to be a part of.”

“Being able to be a part of patients’ journeys and make an impact on their lives has undoubtedly been the highlight of my career.”

The major focus of Dr. Kamdar’s research is assessing the efficacy of the newest available agents and determining whether they would be a viable option for her patients. She accomplishes this by developing clinical trials that can compare the use of current treatment regimens with ones that have not yet become a standard of care to treat patients. “As a clinical researcher I am most interested in outcomes and how these new regimens may improve my patients’ overall quality of life long-term,” says Dr. Kamdar.

RECENT RESEARCH

Currently, Dr. Kamdar is researching new treatment approaches for patients with indolent (slow-growing) lymphomas such as follicular lymphoma (FL) or marginal zone lymphoma (MZL) — a project that is being funded in part by the Lymphoma Research Foundation (LRF). Dr. Kamdar is an LRF Scholar on the clinical track of the Lymphoma Scientific Research Mentoring Program (LSRMP), the first and only early-career mentoring program focused exclusively on clinical researchers in lymphoma. Her LRF research project was inspired by her indolent lymphoma patients who found “watch and wait” more akin to “watch and worry.”

“My hope is that offering these patients a viable option outside of ‘watch and wait’ will improve their quality of life by mitigating the potential psychological impact that this diagnosis can cause.”

Subtypes such as FL and MZL are chronic, frequently relapsing diseases that can vary widely in clinical

presentation. Therapies can vary from a “watch and wait” plan (where the patient receives regular monitoring and only receives treatment if their disease begins to spread) to antibody and/or chemotherapy treatments. However, Dr. Kamdar states that clinical trials have shown no difference between patients who go on “watch and wait” and those who receive early treatment. “There is data coming out that shows that earlier treatment might actually put these patients in remission faster and prevent them from needing therapy in the future,” says Dr. Kamdar. “My hope is that offering these patients a viable option outside of ‘watch and wait’ will improve their quality of life by mitigating the potential psychological impact that this diagnosis can cause.”

Her clinical trial proposes testing a new monoclonal antibody, ublituximab, in advanced-stage indolent lymphoma patients. If patients have a complete response (no detectable disease) following ublituximab therapy, they will end treatment; patients without a complete response will receive a combination of ublituximab and a new non-chemotherapy pill called umbralisib. “If this novel treatment strategy shows excellent durable responses, I believe it will allow patients to have longer remissions, thus translating into fewer relapses and decreased need for future treatments,” says Dr. Kamdar.

Dr. Kamdar notes that the support and mentorship that she received through the LSRMP helped to push her concept forward and turn it into something tangible. “The investigators that I was able to collaborate with through the LSRMP offered fantastic insight and helped solidify that my idea was worthy of executing,” says Dr. Kamdar.

“As researchers, we have so many new tools and ways to collaborate than ever before, and I see this as just the beginning of something even greater for lymphoma patients.”

Dr. Kamdar is committed to developing targeted drugs that are less toxic and more efficacious and affordable. Due to the rapid advancement and tremendous progress made in the study of lymphoma in the past decade, she feels that there is more hope than ever for the future of lymphoma patients. “Each one of us [researchers] eventually wants to say that we have made a meaningful difference in a patient’s life,” says Dr. Kamdar. “As researchers, we have so many new tools and ways to collaborate than ever before, and I see this as just the beginning of something even greater for lymphoma patients.” ○



No matter what else happens in our world, **three things remain constant:**

LRF, your support and our collective commitment to continue the research to **find a cure.**

Become a *Circle of Hope* Partner: Make a Difference in Our Community

As a *Circle of Hope* partner, you will join a group of committed donors who support the Lymphoma Research Foundation (LRF) on a monthly basis. This will ensure LRF can respond to the needs of our community and further groundbreaking research year-round.

To join the *Circle of Hope*, go to lymphoma.org/circleofhope to make your monthly commitment. For more information about this monthly giving program, please contact the development team at development@lymphoma.org.

Circle
of HOPE
MONTHLY GIVING PARTNERSHIP
LYMPHOMA
RESEARCH • FOUNDATION

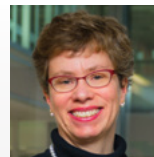
MEET THE NEWLY ELECTED LRF SCIENTIFIC ADVISORY BOARD MEMBERS

The Lymphoma Research Foundation (LRF) welcomed three new members to its elite Scientific Advisory Board (SAB) on July 1. The new members represent distinct specialties that will contribute to the global impact of the Foundation.

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

The new members of the SAB include Jennifer Brown, MD, of Dana-Farber Cancer Institute; Lisa Rimsza, MD, of Mayo Clinic, Arizona; and David Scott, MBChB, PhD, of BC Cancer. The new members will serve as volunteer advisors under the leadership of SAB Chair Andrew D. Zelenetz, MD, PhD, of Memorial Sloan Kettering Cancer Center.

"This year's addition of members continues to add to the prominence of our Scientific Advisory Board," said Dr. Zelenetz. "Our new members reinforce the unique nature of the Lymphoma Research Foundation's Scientific Advisory Board as the leading advisory body in lymphoma research and education in the United States and around the world."



JENNIFER BROWN, MD

DANA-FARBER CANCER
INSTITUTE

Dr. Brown is a Professor of Medicine at Harvard Medical School and Director of the CLL Center at Dana-Farber Cancer Institute. She received her MD from Harvard Medical School and completed her residency at Massachusetts General Hospital before a fellowship at Dana-Farber; she received a Career Development Award from LRF in 2005. She has been speaking faculty for LRF patient education teleconferences and helped develop patient education publications.

Dr. Brown's research interests focus on clinical trials for chronic lymphocytic leukemia (CLL), with interest in developing novel therapies targeting recurrent somatic (acquired) mutations. She was fundamental in the clinical development of idelalisib (Zydelig) and ibrutinib (Imbruvica), which expanded her interest in characterizing the genomics of specific subgroups of CLL and identifying resistance mechanisms, and the genetics and heritability of familial CLL. Dr. Brown has long-standing research on CLL, with over 150 papers in scientific literature predominantly on the disease subtype. She is an active member of the CLL Research Consortium and serves on the Alliance Leukemia and Leukemia Correlative Science Committees and the National Institutes of Health (NIH) Cancer Biomarkers Study Section.

45

world-leading
lymphoma experts
comprise the SAB

10

SAB members are LRF
Grantees; 13 Grantees
overall served on the SAB



LISA M. RIMSZA, MD

MAYO CLINIC, ARIZONA

Dr. Rimsza is the Getz Family Research Professor, a Consultant in the Division of Hematopathology and a Professor of Laboratory Medicine and Pathology at Mayo Clinic, Arizona; Chair of the Southwest Oncology Lymphoma Translational Medicine Subcommittee; and current principal investigator of the Leukemia and Lymphoma Molecular Profiling Project. She was inspired by her mentors Dr. Tom Grogan and Dr. Tom Miller to pursue a career in lymphoma research.

Dr. Rimsza’s research focuses on clinical assay development in B-cell NHL, HIV-related lymphomas, immune evasion and oncogene dysregulation in lymphomas. Diffuse large B-cell lymphoma (DLBCL) encompasses two molecular subgroups; this classification determines a patient’s response to specific therapies in the early stages. Dr. Rimsza and her colleagues developed a cell-of-origin called Lymph2Cx assay, which is used to subtype DLBCL molecularly. Lymph2Cx is currently undergoing commercialization. “The biology behind this discovery completely changed the understanding of diffuse large B-cell lymphoma,” Dr. Rimsza shares. Her lab also focuses on examining the differences between lymphoma arising in individuals with HIV versus individuals without HIV. Her lab is predominantly interested in altered cancer signaling in lymphoma development, specifically DLBCL, in individuals with HIV.

Dr. Rimsza received her MD from the University of Arizona College of Medicine before completing her residency at the University of Arizona and fellowship at the University of New Mexico. She is a past member of the LRF Scientific Advisory Board (2008-2013) and current member of the MCL Consortium and has also been a faculty member for the 2014 and 2020 Mentoring Program Workshops.



DAVID SCOTT, MBChB, PHD

BC CANCER

Dr. Scott is an Associate Professor at the University of British Columbia, Deputy Head of the Department of BC Cancer Lymphoid Cancer Research, and Clinical Director of the BC Cancer Centre for Lymphoid Cancer. His interest in hematology began while he was completing his residency. “[My residency] allowed me to combine my passion for patient care with bench research — going from diagnosing the patient in the pathology laboratory through to treatment and survivorship,” he shares.

Dr. Scott’s lab focuses on discovering and developing clinically relevant biomarkers to improve disease classification and patient care, including genomic mechanisms underlying treatment failure in aggressive lymphoma and the genome biology of relapsed lymphoid cancers. “My primary research focus is developing better ways to put lymphoid cancers into categories based on their biology,” Dr. Scott says. “This will allow us to better tailor treatment to patients, reduce unnecessary side effects and maximize the best outcomes.” Dr. Scott’s passion is projects that improve patient incomes. His past projects include translating the cell-of-origin subtypes of diffuse large B-cell lymphoma (DLBCL) into a test used in routine patient care. “It is an extension of that assay to identify patients whose tumors have the biology of so-called ‘double hit’ lymphoma, which is associated with poor outcomes when standard treatment is used,” he explains.

Dr. Scott received his MBChB and Ph.D. in Medicine from the University of Auckland in New Zealand and completed training for an FRCPA in Pathology/Hematology from the Royal College of Pathologists of Australasia as well as an FRACP in Internal Medicine/Hematology from the Royal Australasian College of Physicians before a clinical and research fellowship at BC Cancer. He is a member of the Lymphoma/Leukemia Molecular Profile Project (LLMPP) Consortium and Lunenberg Biomarker Consortium. He is a past LRF grantee, having received an Adolescent/Young Adult Lymphoma Correlative Studies Award in 2015 and a Mantle Cell Lymphoma Correlative Studies Grant in 2016. He was also a visiting faculty member for the 2019 Mentoring Program Workshop. “It is a privilege to be part of an organization that has an enduring impact on lymphoma research and care,” Dr. Scott shares. “I am looking forward to working with a fantastic group of lymphoma researchers and physicians, supported by the LRF organization and donors/supporters, to nurture early-career investigators and drive forward excellent and clinically impactful research.”

.....**2,900+**

total volunteer hours dedicated by SAB members to LRF research programs and patient and professional education programs in 2019

WHERE ARE THEY NOW?

HANS-GUIDO WENDEL, MD

Hans-Guido Wendel, MD, is a Cancer Biologist in the Hans-Guido Wendel Lab at the Memorial Sloan Kettering Cancer Center.

WHEN DID YOU BECOME INTERESTED IN LYMPHOMA?

During my residency in Germany, I had the opportunity to work with and treat many lymphoma patients. At the time, I was struck by the limited treatment options that patients had and the complexity of the disease's biology. This made me think that there had to be more to discover.

WHEN DID YOU RECEIVE FUNDING FROM LRF? WHAT KIND OF GRANT DID YOU RECEIVE?

I received a generous grant from Lymphoma Research Foundation (LRF) in 2010 to continue my research in follicular lymphoma (FL).

WHAT RESEARCH PROJECT WERE YOU WORKING ON?

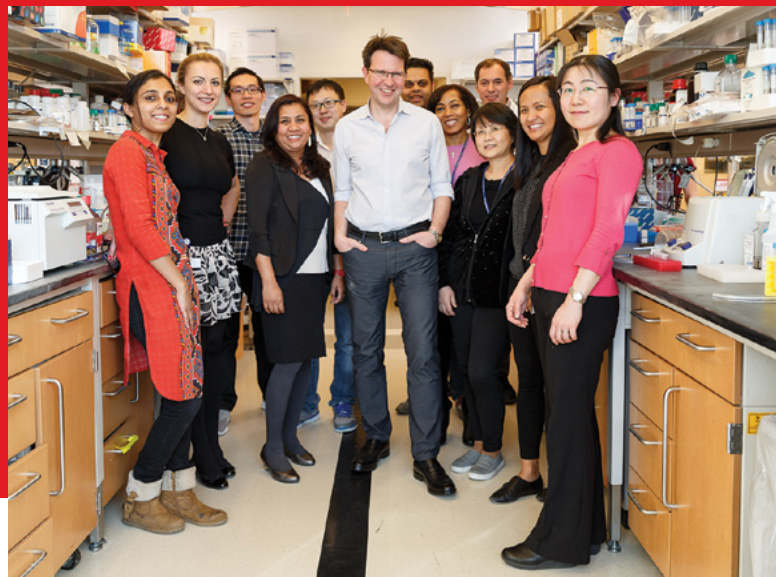
My project was investigating a class of immune receptors called ephrin receptors, which had not been previously implicated in lymphomas. They were thought to have a role mainly/only in neurons and in guiding where their axons would go. We established that the same receptors play a role in lymphoma and that it is possible to target these receptors because they are on the cell surface. We then developed a new antibody-peptide conjugate that would target ephrin receptors on the surface of lymphoma cells. In later work, we identified other immune receptors and engineered patient-specific CAR T cells that locally and continuously produce and secrete proteins that specifically kill lymphoma cells, called 'micro-pharmacies.'

WHY DID YOU CHOOSE TO FOCUS ON FOLLICULAR LYMPHOMA IN YOUR INITIAL RESEARCH?

Follicular lymphoma had not been studied in much detail — particularly not from a biology/mechanistic perspective. We had begun developing models of the disease and understanding how genetic lesions in patient tumors led to the disease. I saw all of this as a great opportunity for progress and way to advance cures. I also treated many FL patients and felt a connection to providing care and treatments for them.



“Follicular lymphoma (FL) had not been studied in much detail — particularly not from a biology/mechanistic perspective ... I saw this as a great opportunity for progress and a way to advance cures.”



HOW HAS THE TREATMENT LANDSCAPE FOR FOLLICULAR LYMPHOMA EVOLVED SINCE YOU FIRST STARTED CONDUCTING YOUR RESEARCH?

When I started my research, the only treatment option available was poly-chemo (CHOP), and then rituximab (Rituxan, an anti-CD20) was developed, which helped make a real difference. Since then, we have seen a plethora of targeted inhibitors developed (e.g., BTK, PI3K, EZH2, BCL2 inhibitors), some of which show promise. I think we still have to explore combinations of these non-chemo drugs and also investigate further into immune therapies, both antibodies that stimulate the body’s immune response and CAR T cells.

WHY WAS THE FUNDING YOU RECEIVED FROM LRF VITAL TO ADVANCING YOUR CAREER IN STUDYING AND TREATING LYMPHOMA?

I received an LRF grant early on in my career, when my lab was just getting off the ground. It made a big difference, provided support for my work and allowed me to work with scientists who could help me achieve my goals.

HOW HAS YOUR RELATIONSHIP/INVOLVEMENT WITH LRF EVOLVED SINCE RECEIVING THIS GRANT?

I am now on LRF’s Scientific Advisory Board and help the Foundation to develop research priorities for grants.

WHY IS LRF’S FOCUS ON RESEARCH/RESEARCH PROGRAMS SO IMPORTANT?

New therapies for lymphoma will only come from an investment and focus on research. To effect change, we must focus on the basic science and the broad advancements emerging from there.

WHAT RESEARCH ARE YOU CURRENTLY WORKING ON THAT YOU’D LIKE TO SHARE?

CRISPR/Cas9 has massively enhanced our ability to

do genetic research. This was originally a bacterial mechanism, but we can now use it to engineer in cells any genetic change that is interesting to us. This allows us to do precise mechanistic studies. Most importantly, we can use ‘libraries’ of CRISPR/cas9 mutations to cover the entire genome in lymphoma cells and search for those genetic lesions that lymphoma cells cannot tolerate. This is an exciting step in identifying new drug targets to either develop ourselves or collaborate with industry partners on developing.

“New therapies for lymphoma will only come from an investment and focus on research. To effect change, we must focus on the basic science and the broad advancements emerging from there.”

WHAT ARE YOU MOST EXCITED ABOUT IN THE FIELD OF LYMPHOMA RESEARCH? WHY?

New immunotherapies offer a completely different approach, and they will be tremendously important in patients who have relapsed from more conventional therapies. Previously, we did not have much to offer these patients, but now there is a whole new class of therapies, and we are no longer ‘empty-handed’ in these difficult situations. ○



PATIENT PERSPECTIVES

Understanding Telemedicine

Since the COVID-19 pandemic, many healthcare practitioners have started to increase their virtual conference offerings — like video conferences — to continue to care for patients while following guidelines set by the Centers for Disease Control and Prevention (CDC) to mitigate the spread of the virus. This is just one example of telemedicine (also known as telehealth), which is distributing health-related services and information via electronic information and telecommunications, and the need is on the rise. In fact, according to McKinsey & Co., the use of telemedicine has increased by 11 percent since last year.



**AMEET DOSHI,
MD, MBA**
.....
HEALTHPARTNERS

With telemedicine trending to be a mainstay in how healthcare professionals treat patients, Ameet Doshi, MD, MBA, Lead Hospitalist for Telemedicine at HealthPartners, shares what is contributing to the surge and how it affects lymphoma patients and survivors:

WHAT FACTORS ARE CONTRIBUTING TO TELEMEDICINE'S SURGE?

The COVID-19 pandemic has accelerated many of the existing trends towards using telemedicine. Some of the benefits of telemedicine that have become apparent in the last few months include the convenience and safety factors for patients and expanding care (especially specialty care) to patients who otherwise do not have access. Also, the Centers for Medicare and Medicaid Services (CMS) and private insurers have broadened covered telemedicine services, which has helped with ensuring that health care organizations can create sustainable telemedicine programs.

WHAT ARE THE BENEFITS OF TELEMEDICINE?

As mentioned above, telemedicine visits allow patients the convenience of staying at home, not having to arrange transportation and often providing more flexible scheduling. Telemedicine can often be a more affordable service for patients without limiting the quality of care being received. Last, one overlooked aspect of telemedicine visits is the potential for the inclusion of the patient's family members or other loved ones. Many of the most commonly used telemedicine applications allow for video-conferencing, meaning family can be involved in the patient's care even from thousands of miles away.

WHAT KINDS OF TELEMEDICINE VISITS ARE AVAILABLE TO LYMPHOMA PATIENTS AND SURVIVORS?

Telemedicine visits can be done from a variety of locations. Patients can be at home and have phone or video visits with their healthcare provider, whether the provider is in the clinic, hospital or at home. Other options include going to a healthcare center and having a virtual visit with a healthcare provider in another healthcare center; this can help in situations where patients do not have internet access at home.

Want to learn more about Telemedicine?



Watch the LRF webinar *Addressing Telemedicine Now and in the Future* at lymphoma.org/webinars.

WHAT SHOULD LYMPHOMA PATIENTS AND SURVIVORS PREPARE BEFORE THEIR TELEMEDICINE VISIT? (INTERNET, PEN/PAPER, QUESTIONS FOR THE DOCTOR, ETC.?)

Having a list of questions prepared is always helpful — it's hard to remember everything you wanted to ask on the spot! I would also make sure you check your internet connection, headphones, speakers or any other device you're using; you don't want to spend any of your valuable visit time troubleshooting technical problems. If you don't feel comfortable with technology, ask your doctor's office for assistance or even to try making a test call.

DOES INSURANCE COVER TELEMEDICINE VISITS?

In March of this year, CMS issued temporary policy changes that broadened coverage of telemedicine and waived many of the previous restrictions; this allowed home visits, audio-only visits and other services to be reimbursed. Our hope is that many of these changes will become permanent, as it will help patients continue to benefit from telemedicine care. Most private insurers also expanded coverage in line with CMS recommendations; however, it is important to check with your insurer about which specific telemedicine services are covered. Some insurers even partner with certain telemedicine providers to allow affordable care options.

HOW WILL TELEMEDICINE CHANGE HEALTHCARE IN THE FUTURE?

Telemedicine has a revolutionary potential for bringing patient care into the 21st century. It allows patients to get the services they need regardless of their geographical location and without sacrificing quality of care. In the future, I hope to see advances such as patients being able to conference with multiple specialists at once, just as if they were in an advanced care hospital. I also hope it will continue to make healthcare more affordable for patients, so that no one has to limit their care because of cost. As technology continues to improve and we learn how to create better virtual visits, I am excited about what progress lies ahead.

ANYTHING ELSE TO ADD?

Telemedicine is a rapidly changing field, and there is always much to learn, and to ask, for both myself and my patients — I always appreciate any questions, concerns, comments or thoughts that you want to share with me! 🗨️



TRADING PLACES

A father and daughter's story as both lymphoma survivors and each other's caregivers, and their mission to empower themselves through education and connect with others at Lymphoma Research Foundation (LRF)'s North American Educational Forum on Lymphoma.



“Here we are in a room with 600 or so people — lymphoma patients, survivors and their caregivers — taking charge of their disease. It was a truly remarkable experience.”

Bob Meyers and his daughter Leslie Watson have always been close. In fact, they live right down the street from one another in their Georgia neighborhood. So, when Watson received the diagnosis of clear cell carcinoma in the summer of 1996, and then follicular lymphoma (FL) later that fall, Meyers was there by her side as her devoted caregiver. “We were totally swept up with emotion. At the time, the prognosis for follicular lymphoma was not like it is today,” says Meyers. “I was determined to learn as much as I could about the disease and be her advocate.”

Follicular lymphoma is an indolent (slow-growing) form of B-cell non-Hodgkin lymphoma (NHL) and accounts for 20 to 30 percent of all NHL cases. Common symptoms of FL include enlargement of the lymph nodes in the neck, underarms, abdomen or groin, fatigue, shortness of breath, night sweats and weight loss. Sometimes, patients with FL have no apparent symptoms of the disease at diagnosis. Follicular lymphoma is usually not considered curable, but more of a chronic disease, and patients can live for many years with this form of lymphoma.

“We were totally swept up with emotion. At the time, the prognosis for follicular lymphoma was not like it is today. I was determined to learn as much as I could about the disease and be her [Leslie’s] advocate.”

Watson was only 30 years old and ready to start her life as a new bride before her first diagnosis. A diagnosis of two cancers was unexpected — especially follicular lymphoma — a cancer she never heard of before. She and Meyers immediately went to work looking for oncologists to discuss treatment options. “The first oncologist we spoke with wanted to treat it very aggressively with FND

(fludarabine, mitoxantrone, dexamethasone). This was before rituximab (Rituxan) was widely prescribed,” says Watson. “After just receiving a hysterectomy to treat my clear cell carcinoma, we wanted to speak with other oncologists to get an idea of other options. That’s when we learned of watch and wait.”

Watch and wait (also known as active surveillance, or watchful waiting) is often recommended for selected patients with indolent lymphomas. This approach may be started after the initial diagnosis or following relapse, depending on individual circumstances. Active treatment is started if the patient begins to develop lymphoma-related symptoms or there are signs that the disease is progressing based on testing during follow-up visits.

After much research provided by her father and two second opinions, Watson decided the best option was watch and wait, where she received CT and PET scans every 6 months. “We wanted to learn as much as we could about the disease to make the best-informed decision for Leslie,” says Meyers. “I started to look up doctors and researchers on the internet and just started cold-calling them. Many of them were happy to speak to me. In particular, researchers were rather flattered that I wanted to talk with them about their research!”

During his research, Meyers found out about the Lymphoma Research Foundation’s inaugural North American Educational Forum on Lymphoma and recommended that he and Watson attend. “When we attended the Ed Forum, we were just blown away,” recalls Watson. “Here we are in a room with 600 or so people — lymphoma patients, survivors and their caregivers — full of hope, intellectual curiosity, and taking charge of their disease. It was a truly remarkable experience.”

For Watson, attending the Ed Forum was her first time connecting with other lymphoma patients and survivors, and sharing her lymphoma journey with others outside her family. “I was a fiercely private person at the time. But here I am among survivors, attending amazing lectures, speaking informally with leading doctors and feeling so supported. Knowledge replaced fear of the unknown.”



“We started from ground zero, like many of the lymphoma patients we have met year after year.”

After Watson’s initial diagnosis in 1996 and the decision to watch and wait, she has undergone three treatments for her FL. Her first and second treatments were with rituximab in 2002 and 2008, and then five weeks of pencil beam proton radiation in 2015, which was only approved for pediatric brain tumors and testicular and prostate cancer. “Although pencil beam radiation was not approved for lymphoma at the time, we learned that it was a highly accurate form of radiation therapy with less radiation scatter,” says Watson. “Because only one of my lymph nodes was affected, and we learned that rituximab loses its efficacy the more one uses it. We felt that pencil beam would be the best option for me, and we’re glad we did it.”

For several years, Watson’s lymph nodes continued to shrink until 2019, when she received the news that there was no measurable evidence of disease. This was the first time she heard that in her 22 years with FL.

Throughout this time, Meyers and Watson continued to attend the LRF Ed Forum to stay up-to-date on the latest treatments for follicular lymphoma and to network with others in the community — having attended more than a dozen since the inaugural Forum in 1996. “Every year, we learn something new, and we continue to meet people who are surviving and thriving for years with this disease. It’s been amazing, and it’s thanks to my dad and his research for finding LRF and their amazing resources.”

AN UNEXPECTED TURN OF EVENTS

After a routine annual physical in October 2019, Meyers received a call from his physician’s office that his blood work showed something was amiss and recommended he visit an oncologist. After additional tests, he received the diagnosis of chronic lymphocytic leukemia (CLL). “My experience with Leslie over the years prepared me not to be shocked when bad news comes,” says Meyers. “I just knew this is a new disease we had to learn. The LRF Ed Forum was two weeks after my diagnosis of CLL. Leslie and I went to the Forum for me this time.”

Chronic lymphocytic leukemia and small lymphocytic lymphoma (SLL) are forms of NHL that arise from

B lymphocytes. CLL and SLL are essentially the same diseases, with the only difference being the location where the cancer primarily occurs. When most of the cancer cells are located in the bloodstream and the bone marrow, the disease is referred to as CLL, although lymph nodes and the spleen are often involved.

The outlook for patients with CLL/SLL has improved in recent years, but the disease course still varies widely. Many patients with CLL do not require treatment at diagnosis and perhaps for months to years after that.

Meyers’s and Watson’s roles were now reversed, with Watson being the caregiver and Meyers, the patient. Although they’d attended many Ed Forums by the time of Meyers’s diagnosis, they didn’t know much about CLL. “We went to learn about a new disease. We started from ground zero, like many of the lymphoma patients we have met year after year,” says Meyers.

After attending the Ed Forum in 2019, speaking with other CLL survivors and doctors, and conversations with Meyers’s oncologist, they have decided on watch and wait. “We came home full of knowledge, ideas and hope,” says Meyers. “The LRF staff is competent, caring and totally committed. The give and take among patients and close interactions with outstanding doctors are so important. To add the fact that the Forums are held in genuinely nice locations with top-notch accommodations and service helps make each conference a special, uplifting and memorable experience.”

Although the 25th Annual Ed Forum will be held virtually this year due to precautions amid COVID-19, Meyers and Watson are still looking forward to attending and learning what is new in treatment and research for FL and CLL.

“There is always something new to learn. There is always a story you can connect with. There is always a new doctor you get a chance to speak with,” says Meyers. “LRF is truly a unique organization that has helped thousands of people through education, human interaction and understanding. They have given hope and solace to so many in times of great need, including Leslie and me.”



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*This program will be archived following live event.

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UPCOMING EVENTS



A TASTY NEW WAY TO FIGHT CANCER!

North American Educational Forum on Lymphoma — <i>Virtual</i>	10.23–10.25
The Great Bake	through 2020
The Nightmare Before Christmas Broadway Concert — <i>Virtual</i>	10.31
Updates on Oral Therapies in Lymphoma and Chronic Lymphocytic Leukemia (CLL) — <i>Webinar</i>	11.5
Rally On! Arizona — <i>Virtual</i>	11.8
Understanding Stem Cell Transplantation and Graft Versus Host Disease — <i>Webinar</i>	11.10
Lymphoma Workshop — <i>Virtual</i>	11.14
Swirl: America — <i>Virtual</i>	11.14
Updates on Chronic Lymphocytic Leukemia/ Small Lymphocytic Lymphoma (CLL/SLL) — <i>Webinar</i>	11.18

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



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