

#### **PULSE**

#### A Publication for Friends of the 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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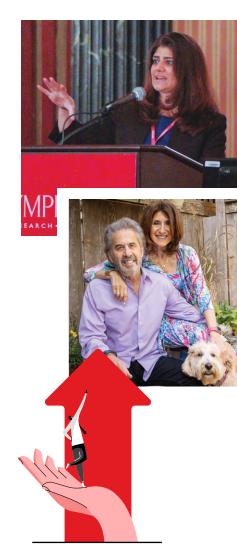
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Join Us for a Virtual

# Lymphoma ROUNDS ROUNDS Program



The Lymphoma Rounds continuing medical education (CME) program provides a virtual forum for practicing physicians from academic and community medical centers to meet on a regular basis and address issues specific to the diagnosis and treatment of their lymphoma patients.

Register for an upcoming Lymphoma Rounds program and learn more about other professional education opportunities at lymphoma.org/hcpeducation.

**SAVE THE DATE** for *Targeted Therapies in CLL/SLL: Treatment Sequencing and Adverse Events Management*, taking place December 10 preceding the 63rd American Society of Hematology Annual Meeting.



## FROM THE CEO

#### Thank you to our caregivers.

Family caregivers are the backbone of the country's healthcare system. The demands placed upon caregivers can be daunting and often bring overwhelming stress and exhaustion. We, at the Lymphoma Research Foundation (LRF), want our caregivers to know that they are appreciated and that we stand ready to support them.

In this issue of *Pulse*, we highlight the responsibilities of caring for a loved one with lymphoma, helpful tools to manage caregiving and the importance of self-care. The issue also features a touching story of a survivor who credits the love and care of her husband for helping her face five relapses and six different treatments during her more than two-decades-long journey with lymphoma. It is truly remarkable what we can achieve together—grounded on a foundation of hope and built from an ongoing and relentless drive for progress. The progress that, more than ever before, is driven by partnerships between scientists.



LRF's elite Scientific Advisory Board (SAB) steers the Foundation's research program in this very way, working together to identify the best research to fund and drive significant advances in the field. These 45 world-leading lymphoma experts devoted more than 2,600 hours to LRF's research portfolio and patient and professional education programs last year alone. At the helm of it all, and profiled in this issue, is newly elected SAB Chair Sonali M. Smith, MD, FASCO, of The University of Chicago Medicine. Dr. Smith describes her focus on ensuring patients of all backgrounds are represented and have access to quality care, and shares her goal to expand the world's vision of a leader.

Survivors, caregivers, scientists, donors and all who are dedicated to finding cures for lymphoma will be inspired by the stories of these remarkable people. Like me, I believe you will draw strength and hope from the transformative power of partnership. Thank you for your ongoing support.

Sincerely,

Meghan Gutierrez Chief Executive Officer

## PHILANTHROPY IN ACTION



#### **LRF 2021 ANNUAL GALA**

On September 30, hundreds from across the country joined virtually to raise nearly \$800,000 at the Lymphoma Research Foundation's (LRF) Annual Gala.

This year's Gala honored Kite, A Gilead Company, with the Corporate Leadership Award and Scientific Advisory Board (SAB) member Christopher R. Flowers, MD, MS (The University of Texas MD Anderson Cancer Center), with the Distinguished Leadership Award. The evening program featured special messages of hope from friends including Ethan Zohn (CBS Survivor: Africa winner, co-founder of Grassroot Soccer); Montel Williams (media personality and healthcare advocate); Juju Chang (anchor, ABC Nightline); Cameron Mathison (actor and TV host, General Hospital, Entertainment Tonight) and others. To view the archived program, visit LRF's YouTube channel at youtube.com/lymphomaresearch.



#### **WALK ON! CHICAGO**

On August 1, supporters from all over Chicagoland came together for the *Walk On!* Chicago Lymphoma Walk—LRF's first in-person outdoor walk event since 2019.

Those who were unable to join in person had the opportunity to create their own neighborhood walk or join the event virtually. Walk On! Chicago featured stories from lymphoma survivors, spotlights on Chicago fundraising teams, and presented the Lee Grubman Caregiver of the Year Award to hematology/oncology nurses Sarah Miyata and Caroline Mangan of Northwestern Medicine, and Denise Hauser and Terri O'Brien of Rush University Medical Center. Together, the Chicago community raised more than \$245,000 through virtual fundraisers and neighborhood walks in support of LRF's mission. To learn more about Team LRF and how you can get involved, visit lymphoma.org/teamlrf.





On October 3, cyclists pedaled in celebration of the 15th Annual Lymphoma Research Ride.

Following COVID-19 safety protocols, supporters hopped on their bikes and cycled around beautiful Montgomery County, MD to raise more than \$250,000 for lymphoma research. This year's Research Ride, coined *Ride On!*, began on September 25 by mobilizing the community for a special online celebration with the esteemed Champion Ride Council. Riders who were unable to attend the in-person cycling event were able to join a Peloton® group or create their own ride in their neighborhood.



#### SUPPORT LRF WHILE YOU SHOP

AmazonSmile is a simple and automatic way to support your favorite charitable organizations every time you shop, at no cost to you. Just visit smile.amazon.com and choose Lymphoma Research Foundation as your charitable organization.

AmazonSmile is a website operated by Amazon with the same products, prices and shopping features as Amazon.com. The difference is that when you shop on AmazonSmile, the AmazonSmile Foundation will donate half of one percent of the purchase price of eligible products to the charitable organization of your choice.

## DON'T MISS YOUR CHANCE TO **DOUBLE YOUR GIFT ON NOVEMBER 30**



The Lymphoma Research Foundation is excited to announce a \$120,000 Matching Gift Challenge.

Starting on **GivingTuesday** (November 30), all first-time donors will have their gifts matched, dollar for dollar. **Donors who increase their annual support will also be eligible for a partial match.** Want to know if your gift will qualify? Contact a member of the development team at development@lymphoma.org or 212 349 2910.

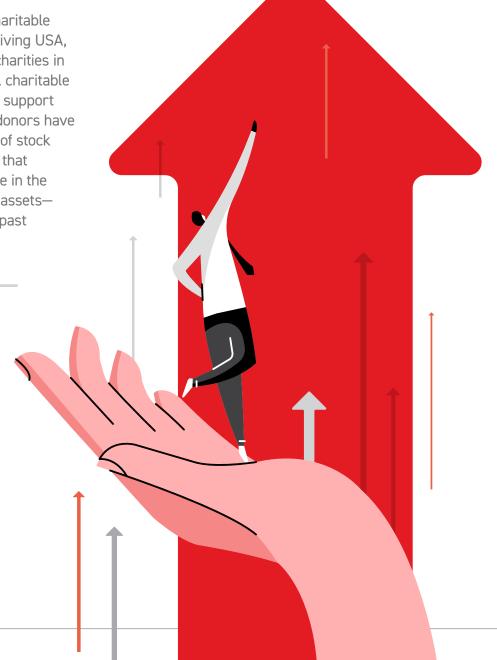
Save the date, and make your gift go twice as far on GivingTuesday!

## GROWING STOCK, GROWING GENEROSITY

HOW A GIFT OF STOCK CAN SUPPORT LRF NOW AND IN THE FUTURE

Individual donors are the backbone of charitable giving. According to a recent report by Giving USA, Americans donated over \$324 billion to charities in 2020 which represented 69 percent of all charitable giving. While many individuals choose to support charities through cash donations, some donors have adopted a new way of giving in the form of stock gifts. In 2020, Fidelity Charitable reports that 68 percent of its contributions were made in the form of non-publicly and publicly-traded assets—a trend that has been on the rise for the past several years.

In 2020, Americans donated over **\$324 billion** to charities which represented 69 percent of all charitable giving.



If an individual has owned stock for at least one year that has increased in value, they have the unique opportunity to make a philanthropic contribution to the cause of their choice. Donating stock offers several benefits to both the designated charities and the donors gifting them. When someone chooses to donate stock, they receive the same income tax savings as they would if they wrote a check, with the added benefit of eliminating capital gains taxes on the transfer, which can be as high as 20 percent.

#### **DIVIDENDS FOR RESEARCH**

Making a gift of securities to support scientific research is not a new practice for Lymphoma Research Foundation (LRF) donors. For longtime supporter Toby Gottesman, donating to LRF through appreciated stocks is a win-win. "I began donating to the Lymphoma Research Foundation 12 years ago and always thought that cash donations were the way to go," says Gottesman. "However, years ago, I realized that I could make stock gifts and found this to be a great method to support the Foundation's mission."

Gottesman says that donating through stock allows him to give a "cheap gift that goes further," due to the tax-saving benefit for both himself and LRF. "If I were to donate cash, I would have to sell the stock first and pay capital gains," says Gottesman. "If I donate stock directly, I can add what I saved in taxes to my gift and therefore end up donating more in the long run."

As a lymphoma survivor, Gottesman is grateful for the opportunity to support the type of research that helped to save his life, hoping that future lymphoma patients benefit from it the same way he did. "I am a survivor because of the medical knowledge and research that existed at the time I needed treatment, and I give so that the person who will be diagnosed in 10 years can survive as well," he says.



Are you interested in making a gift of appreciated securities to the Lymphoma Research Foundation?

Visit lymphoma.org/plannedgiving to learn more and download helpful stock-transfer instructions. Contact Kate LeBoeuf with any questions at kleboeuf@lymphoma.org or call 646 531 5184.

"I am a survivor because of the medical knowledge and research that existed at the time I needed treatment, and I give so that the person who will be diagnosed in 10 years can survive as well."

#### PLANNING YOUR GIFT

Using assets other than cash allows donors more flexibility when planning gifts, and there are even more potential benefits when donors plan their gifts creatively. "LRF strives to make supporting our mission as easy as possible," says Kate LeBoeuf, associate director of major gifts at the LRF. "Many of our donors have thoughtful and specific philanthropic goals. By accepting a variety of assets, we create flexibility for donors to advance cures for lymphoma by leveraging their assets in taxadvantageous ways."

LRF has received nearly \$4 million in support through gifts of securities, and the number of donors giving stocks has more than quadrupled in the last 10 years. "My hope is that more donors learn about how they can support LRF's work in a way that is best for them," says LeBoeuf. "Gifts of appreciated securities, charitable gift annuities, IRA rollover gifts and many other forms of planned giving, are some of the many giving avenues that fosters incredible partnerships between LRF and our donors."

Stock gifts not only yield great benefits, but they are also easy to set up. Donors can instruct their broker to transfer shares or, if they have the physical securities, mail the certificates along with a stock power to LRF. Donors are encouraged to contact LRF of any plans for stock-transfer gifts to ensure that the process is seamless. "Finding a balance between financial and philanthropic goals can sometimes feel complicated," says LeBoeuf. "However, we hope that our donors feel empowered to plan ahead to ensure their support for LRF continues into the future." O

## BEYOND BARRIERS



Lymphoma Research Foundation (LRF) Scientific Advisory Board (SAB) Chair Sonali Smith, MD, FASCO of The University of Chicago Medicine (UChicago Medicine) is a natural-born leader. Over the past 20 years, her contributions to the field of lymphoma have been impactful, making her one of the world's leaders in lymphoma research and patient care. Her work in the clinic and research realms are only surpassed by the humanity and kindness that she shows her patients and peers. Undeterred by barriers and challenges associated with lymphoma and the medical field, Dr. Smith is advancing cures for this disease.

#### **DESTINED TO MAKE A DIFFERENCE**

Growing up in Chicago, Dr. Smith always wanted to be a teacher. As a child, she would pretend to run classrooms with her siblings—even so far as creating tests to give them. However, as she began to learn more about science, it sparked her curiosity about becoming a doctor. "My parents, who emigrated from India, never pressured me to become a doctor," says Dr. Smith. "I truly came to medicine on my own."

Dr. Smith initially was drawn to medicine due to her interest in biology, but she was also enticed by the constant atmosphere of learning that comes with being a doctor. She also found that medicine allowed her to do one of the things she is most passionate about—helping others. "I have always enjoyed helping people and doing what I can to make them feel better," says Dr. Smith.

"I realized being a doctor was a natural marriage of all the things I was interested in and could allow me to make a real difference in people's lives."

Dr. Smith completed her undergraduate studies, medical school and her residency at Northwestern University. It was during this time that she decided she would pursue a career in oncology, and more specifically, hematology. "One of the most impactful rotations I ever did was on the oncology consult service," says. Dr. Smith. "It was really the first time I saw people living with cancer rather than dying from it, and I knew I wanted to play a larger role in caring for these patients."

As a child, she first became fascinated with the immune system from watching her mother, an immunologist—and more so when she studied immunology in college and medical school. "I was amazed that immune cells, the very thing that is supposed to protect us, could turn into something like cancer," says Dr. Smith.

#### **BUILDING A LYMPHOMA PROGRAM**

In 1998, Dr. Smith began her hematology/oncology fellowship at UChicago Medicine and devoted her career to lymphoma research and patient care. Three years later, she was appointed to the faculty at UChicago Medicine and helped to rebuild the institution's lymphoma program which had dissolved in the years prior to her faculty appointment. She was subsequently promoted to Professor, was named the Elwood V. Jensen Chair of Medicine and has led the lymphoma program since 2011. "I think what I love most about working in lymphoma is there are no 'cookie-cutter' patients," says Dr. Smith. "I have the opportunity to treat young and old, male and female, and patients of all races and ethnicities." With the help of her colleagues, Dr. Smith has built an inclusive program focused on clinical investigation for patients with all subtypes of lymphoma.

The diversity of Dr. Smith's patients not only makes her work extremely exciting but also helps her to adapt to their needs in an instant. She feels one of the most important aspects of working in the clinic is providing a variety of emotional responses and support for whomever she sees. "You go in and out of exam rooms, and every room is different," says Dr. Smith. "Sometimes it's someone who is newly diagnosed and you're preparing them for what is ahead. Other times, it's a long-time survivor and it feels like seeing an old friend, but it can also be someone whose lymphoma has relapsed, and you need to deliver difficult news." It is this ability to change from optimism and joy to realism that allows her to provide personalized care in a compassionate manner.

#### **CATALYST FOR CURES**

Dr. Smith's diverse array of patients also has a substantial impact on her research. For her, seeing patients stimulates her research and allows her to detect areas of unmet needs. "All good questions come from patients," says Dr. Smith. "You always want to answer questions that are important and can make a great impact." She loves the ability to offer her patients new and exciting treatments that arise from her research, sharing that it makes for a more optimistic way to practice medicine.

As a clinical researcher, Dr. Smith works on several clinical trials with the goal being to advance new treatment options for lymphoma patients for relapsed/refractory disease. She says that these trials are critical to helping individuals impacted by this disease live better and longer lives. "We cannot be satisfied with the status quo," says Dr. Smith. "We are not curing everybody, nor are we helping everyone to live to their best potential. We need to continue to conduct research until this happens and until we hopefully find cures."

"We cannot be satisfied with the status quo. We are not curing everybody, nor are we helping everyone to live to their best potential. We need to continue to conduct research until this happens, and until we hopefully find cures."

While clinical trials do not often provide instant gratification or results, Dr. Smith says the progress she witnessed over the past 20 years of her career is truly exciting. "Every few years there seems to be a leap forward in this field," says Dr. Smith. "We have more and more walking miracles each and every day." Dr. Smith hopes clinical trials will soon be more inclusive of all types of lymphoma patients to help fine-tune treatments based on everyone's personal case and background.

#### **BREAKING DOWN BARRIERS**

Barriers in care and research are not the only ones Dr. Smith has been instrumental in knocking down. In January 2021, she became the first woman appointed to chief of the section of hematology/oncology for The University of Chicago Medicine and the UChicago Medicine Comprehensive Cancer Center. Dr. Smith was honored to take on the new role and have the opportunity to lead her colleagues in continuing to advance the future of cancer research and care.

Being the first woman to be at the helm is the honor of a lifetime for Dr. Smith and something she hopes will inspire other women in the medical field. "I think that what defines a leader today, fits women quite well," says Dr. Smith. "For 50 years, there's always been a similar phenotype that has led, and to be able to break that is incredibly exciting." Building on this achievement, Dr. Smith became the first woman and person of color elected chair of the LRF SAB in July 2021. "Being elected by my peers on the Scientific Advisory Board was by far one of the greatest highlights of my career," says Dr. Smith. "I am so looking forward to helping to shape the next several years of how LRF grows and mentor and train the next generation of bright scientists."

She strives to empower others like her and bring awareness to disparities that exist in the field. "The vision of what a leader looks like has been in one box for a long time," says Dr. Smith. "There have been many times throughout my career that I have been the only woman in the room, and I think it is because of a historical lack of acknowledgment of what women bring to the table." To help address the underrepresentation of women in medicine, Dr. Smith serves as a steering committee member for a group called Women in Lymphoma. With more than 200 members, the group supports each other as they navigate a historically maledominated field and strives to ensure that women feel empowered to participate in prestigious lymphoma meetings and share their findings. Dr. Smith does what she can to make sure that all of her colleagues feel validated and heard. Dr. Smith also serves as co-chair of the LRF Health Equity Initiative alongside SAB Chair-Elect Dr. Ann LaCasce (Dana-Farber Cancer Institute) to steer LRF's efforts in addressing the challenges and barriers that exist in lymphoma research and access to quality patient care.

#### **TEACHER AND MENTOR TO ALL**

As someone who always wanted to be a teacher, it is no surprise Dr. Smith is touted for her ability to educate her peers. Throughout her career, she has won numerous teaching awards, including the 2021 ASCO Excellence in Teaching Award, and considers mentorship a key aspect of her work. Dr. Smith oversees a staff of over 250 people and helps to foster a community of learning and collaboration. "Creating a collaborative environment allows us all to learn from each other and also helps us to connect the dots in care and research faster."

Dr. Smith also serves as a mentor and teacher through various LRF programs. As an educator, she thinks it is critical to mentor and coach the next generation of lymphoma scientists to make sure their talents are being utilized in the best way possible. "Mentoring allows us to capture the most from what a person has to offer," says Dr. Smith. "We are not only investing in their careers and helping them to succeed, but we are ultimately making strides forward for patients in the future."

For Dr. Smith, the key to improving patient outcomes is through mentorship, support and funding. "Funds for lymphoma research, in general, are quite tight and lymphoma-specific funds are relatively limited," says Dr. Smith. "Fostering the careers of young scientists, clinical investigators and doctors ensures that the brightest minds focus their talents on this field."



"There have been many times throughout my career that I have been the only woman in the room, and I think it is because of a historical lack of acknowledgment of what women bring to the table."

#### **SMARTER SCIENCE**

While she knows that there is still much to be done to find cures for lymphoma, Dr. Smith feels that treatments are becoming smarter, and the research is more exciting than ever. She believes with more targeted agents being the new frontier, individualized medicine is on the horizon. "We are not at a place of using individualized medicine in cancer treatment quite yet," says Dr. Smith. "However, there are enough targeted drugs that we can start to say there is no one-size-fits-all treatment."

She believes that a continued understanding of the biology of these diseases will provide clues as to how to treat different subtypes of lymphoma. Dr. Smith has been at the forefront of advancing new treatments for years, and she looks forward to the continued progress she can help make. "I am looking forward to shepherding lymphoma research for years to come—to make a difference in a way that helps patients most."

#### LRF WELCOMES

## TERESA PALOMERO, PHD, TO THE SCIENTIFIC ADVISORY BOARD

The Lymphoma Research Foundation (LRF) welcomes Dr. Teresa Palomero, associate professor of pathology and cell biology at Columbia University Irving Medical Center, to the Scientific Advisory Board (SAB). Dr. Palomero is poised to offer a wealth of knowledge and expertise in cancer genetics to the elite group of lymphoma experts and to help steer LRF's research programs and its pursuit to advance its understanding of lymphoma.



#### TERESA PALOMERO, PhD

COLUMBIA UNIVERSITY IRVING MEDICAL CENTER

Dr. Palomero received her PhD in biochemistry and molecular biology at the University of Oviedo in Spain, where she focused her research on the characterization of intercellular signaling pathways activated by the thyrotropin-releasing hormone (TRH) receptor, a pituitary receptor that influences thyroid function. Following her PhD studies, she pursued her postdoctoral work at Dana-Farber Cancer Institute under the supervision of Dr. Thomas Look, and participated in pioneer work in developing the ChIP-on-chip technique in collaboration with Dr. Rick Young at the Broad Institute. Her work with Dr. Young allowed her to apply the ChIP-onchip method to better understand the signaling pathways that feed into the TAL1 oncogene, one of the primary sources of the genetic mutations that lead to the development of malignant cells in T-cell acute lymphoblastic leukemia (T-ALL).

Dr. Palomero's research interests focus on understanding the genetic and molecular bases of T-cell leukemia and lymphoma, with a special interest in developing targeted therapies for these aggressive blood cancers. She was instrumental in identifying a mutation in a gene call RHOA found in 70 percent of patients with angioimmunoblastic T-cell lymphoma (AITL).

Dr. Palomero and her team discovered that the role of RHOA G17V mutation is instructing the cells to become the cell of origin of AITL in a multistep process. This discovery can be used to develop and test novel therapies for AITL.

Dr. Palomero has long-standing research on T-cell malignancies, with over 20 years of experience on the disease subtype. "The advances in the field of immunotherapy also represent a tremendous milestone for the treatment of many lymphomas, and it is only getting started," she shares. "I am deeply honored to be a part of the LRF as a member of the SAB, and I am looking forward to working with the foundation and my colleagues at the SAB to advance our understanding of lymphoma biology, improve clinical outcomes and support the patients as they navigate their disease."

World-leading experts comprise the SAB

**2,600** Volunteer hours dedicated to supporting LRF's research programs, patient resources, and patient and professional programs by SAB members in 2020

#### REMEMBERING

Joseph R. Bertino, MD

A Visionary Leader and Pioneer of Cures for Lymphoma

Through his characteristic commitment to excellence, gentle persuasion, and visionary thinking,

Joseph R. Bertino, MD organized and developed the Lymphoma Research Foundation (LRF) Scientific Advisory

Board (SAB) in 1995—now the nation's most prestigious body of lymphoma clinicians and scientists. He is remembered by his LRF family and patients and colleagues across the nation as a world-renowned oncologist and cancer researcher, teacher and mentor, and lifelong advocate for people with lymphoma.

Dr. Bertino was University Professor of Medicine and Pharmacology at Rutgers-Robert Wood Johnson Medical School and Senior Advisor to the Director of the school's Cancer Institute of New Jersey in New Brunswick, after previously serving as Director. He was an American Cancer Society professor since 1976. Before joining The Cancer Institute of New Jersey at Robert Wood Johnson Medical School, Dr. Bertino served as chair of the Molecular Pharmacology and Therapeutics Program, and member and co-head of the Program in Developmental Therapy and Clinical Investigation at Memorial Sloan-Kettering Comprehensive Cancer Center, including director of the center and associate director for clinical research. Dr. Bertino is internationally recognized for his role in finding curative treatments for leukemia and lymphoma.

Dr. Bertino received many honors for his work. He was the past president of the American Association for Cancer Research (AACR) and American Society of Clinical Oncology (ASCO), and the founding editor of the Journal of Clinical Oncology (JCO). He received many awards throughout his career including, but not limited to, the AACR Lifetime Achievement in Cancer Research Award, the University of Texas MD Anderson Cancer Center Jeffrey A. Gottlieb Memorial Award, and the LRF Key to the Cure Award and Freundlich Leadership Award.

Dr. Joseph Bertino (1930-2021), founding chair of the LRF Scientific Advisory Board, and internationally recognized leader in lymphoma research and clinical care



#### WHERE ARE THEY NOW?

## JACOB SOUMERAI, MD



Jacob Soumerai, MD, is a hematologist/oncologist at Massachusetts General Hospital Cancer Center.



#### When did you become interested in lymphoma?

Before attending medical school, I studied Waldenström macroglobulinemia (WM) with Dr. Steven Treon (Dana-Farber Cancer Institute). We made several important contributions to this field, and I personally felt very proud to have played an important role in research that contributed to our understanding of WM and had a positive impact on patient care. From this experience, I developed a passion for clinical research and its potential to advance patient care. I later joined Massachusetts General Hospital Cancer Center as an internal medicine resident, where I was mentored by Dr. Jeremy Abramson (LRF Lymphoma Rounds Steering Committee member). I then joined Memorial Sloan Kettering Cancer Center as a hematology and medical oncology fellow, where I was mentored by Dr. Andrew Zelenetz (current member and immediate past-chair of the LRF Scientific Advisory Board). I was inspired to pursue a career as a clinicianscientist in lymphoma, to rigorously test the next generation of lymphoma therapies and to have a positive impact on our patients.

### When did you receive funding from LRF? What kind of grant did you receive?

I participated in the LRF Lymphoma Scientific Research Mentoring Program (LSRMP) from 2017-2019. My LRF research project in the LSRMP paved the way to receive the LRF Clinical Investigator Career Development Award (CDA) in 2018.

#### What research project were you working on?

My LRF research project in the LSRMP tested zanubrutinib (Brukinsa®) and zandelisib as a combination therapy for patients with B-cell lymphomas and chronic lymphocytic leukemia (CLL). Zanubrutinib inhibits Bruton's tyrosine kinase (BTK), and zandelisib inhibits phosphatidylinositol 3-kinase δ (PI3Kδ), two signaling proteins that are critical to tumor cell growth and survival. We led this research to test whether using these drugs in combination would have a more powerful effect on lymphoma cells and help patients achieve more profound and durable remissions. (EHA 2021). My CDA project tested zanubrutinib, obinutuzumab (Gazyva®) and venetoclax (Venclexta®)—a combination called BOVen —as first-line therapy for patients with CLL. We found that BOVen was well-tolerated and achieved high rates of undetectable minimum residual disease (MRD), allowing for early treatment discontinuation. We also found that early response kinetics predicted treatment outcomes and is a potential biomarker for guiding the duration of therapy. (ASCO 2020, EHA 2020, ASH 2020).

### Why did you choose to focus on targeted therapies, including BTK inhibitors, in your initial research?

Targeted therapies have transformed the care of patients with lymphoma and chronic lymphocytic leukemia. Since I started conducting this research, we have learned that these therapeutic agents can be combined to achieve synergistic therapeutic effects and improve outcomes for patients. My research focuses on studying rational combinations of targeted therapies in CLL and other B-cell lymphomas with the goal of eradicating and ultimately curing the disease.

## Why was the funding you received from LRF vital to advancing your career in studying and treating lymphoma?

The funding I received from LRF has been vital to advancing my career as a clinical investigator in lymphoma. The LRF [CDA] grant allowed me to dedicate 75 percent of my time and effort to developing and leading clinical trials and translational research projects which aim to improve outcomes for patients with lymphoma and CLL. The CDA and LSRMP provided additional funding to support my attendance at academic conferences, which are opportunities to disseminate my research findings, learn, network and build collaborations.

### How has your relationship/involvement with LRF evolved since receiving this grant?

The LSRMP was a unique opportunity to be mentored by and learn from successful leaders in lymphoma research and patient care. I built lasting relationships with my fellow LRF Scholars and mentors. We frequently call on one another to discuss how best to care for our patients. These relationships have also led to research collaborations that have been critical in my career development.

My involvement with LRF evolved from participating in the LSRMP as an LRF Scholar to participating in LRF patient education programs (e.g., North American Educational Forum on Lymphoma and Ask the Doctor About Lymphoma) and professional education programs (e.g., New England Lymphoma Rounds) as speaking faculty. These are unique opportunities to join and interact with our community of clinicians, researchers, patients and caregivers who are all invested in improving the care of people living with lymphoma.

### Why is LRF's focus on research/research programs so important?

The Lymphoma Research Foundation's focus on research is vital to its mission to eradicate lymphoma, and its role in supporting lymphoma research through its grant programs has been a driving force behind significant clinical and translational research advances

in lymphoma. But perhaps most important is LRF's focus on cultivating and training lymphoma researchers through its LSRMP, which provides promising junior physician-scientists with the expertise, skills and networking necessary to achieve their research goals and ultimately become independent lymphoma researchers.

"For many junior investigators, including myself, programs like the LSRMP serve to introduce the lymphoma research community and help launch their lymphoma research careers."

#### What research are you currently working on that you would like to share?

We recently initiated a multicenter phase 2 trial testing the B-cell maturation antigenantibody-drug conjugate belantamab mafodotin as a treatment for patients with relapsed or refractory plasmablastic lymphoma and Anaplastic lymphoma kinase-positive large B-cell lymphoma. These patients need better therapies, and this trial is supported by interesting preclinical data suggesting that BCMA-directed therapies may have a role in treating these lymphomas with plasmablastic features. This trial is available at the Massachusetts General Hospital Cancer Center and will be activated soon at Memorial Sloan Kettering Cancer Center and The University of Texas MD Anderson Cancer Center. If effective, this trial has the potential to change how we treat these rare diseases.

We have also initiated a multicenter phase 2 trial testing venetoclax-obinutuzumab, with the addition of acalabrutinib (Calquence®) based on MRD response, as a treatment for patients with relapsed or refractory CLL who are at high or intermediate risk based on the BALL risk score (Lancet Haematol 2019). This risk assessment tool allows the identification of a group of people with CLL who are at increased risk, and we hope that this MRD-directed treatment will improve how we care for these people. This trial is available at the Massachusetts General Hospital Cancer Center and will be activated soon at Memorial Sloan Kettering Cancer Center.

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

I am most excited by efforts to develop biomarkers to predict which patients will benefit from certain therapies—and who will not—which eventually may be useful to guide therapeutic decisions in the clinic, with a growing list of therapeutic options. 

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## INVESTING IN THE FUTURE, PRESERVING A LOVING MEMORY



Eric Cohen led a vibrant life built on the bedrock of a solid and loving family, including his wife, Stacey, and four children, Cameron, Charlie, Clair and Caitlin. He was in constant motion, determined to take advantage of all the adventure and opportunity offered by the world.

Eric Cohen (in memoriam)

At the time of his lymphoma diagnosis, Eric served as the chief executive officer for Learners Edge, a professional development and continuing education platform for educators, and sat on the Lymphoma Research Foundation (LRF) Board of Directors. Eric served both organizations with steadfast resolve and commitment until his passing in July 2020.

In recognition of Eric's tremendous service and partnership with LRF, the Learners Edge, LRF Directors, and Eric's friends and family joined together to make an investment that will celebrate his life and support the lymphoma community for years to come. The Lymphoma Research Foundation established the Eric Cohen Distinguished Scholar as part of its Lymphoma Scientific Research Mentoring Program (LSRMP) to support the next generation of lymphoma researchers. Participants in the LSRMP—known as LRF Scholars—receive education and mentoring from LRF's elite Scientific Advisory Board (SAB). Scholars identified and supported in this program have made breakthroughs and developed new approaches to diagnosing and treating lymphoma.

"When I first heard that a Scholar was established in Eric's memory, I was so humbled by the outpouring of love and support of our friends, family, community, colleagues and fellow LRF Directors," says Stacey Cohen, wife of Eric Cohen. "It was a testament to Eric and the lives he touched. In looking at the names of the people who donated, they were from all seasons of life. It is bittersweet, but I do feel happy that Eric's legacy will live on."

Through the tremendous generosity of more than 100 donors, nearly \$120,000 has been raised for the Eric A. Cohen Distinguished Scholar and will support a new Scholar every year for the next eight years. The Lymphoma Research Foundation continues to receive gifts in Eric's memory, and the family hopes that over time, a growing number of Scholars will be funded.

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David Bond, MD [The James, The Ohio State University Comprehensive Cancer Center (OSUCCC)], was named the inaugural Eric A. Cohen Distinguished Scholar in March 2021. His LRF research project aims to develop more effective second treatment options for patients with relapsed/refractory diffuse large B-cell lymphoma (DLBCL)—an aggressive (fast-growing) form of non-Hodgkin lymphoma (NHL). For Dr. Bond, his patients are a constant source of inspiration and motivate him to invest long hours in advancing research. Regarding being named the Eric A. Cohen Distinguished Scholar, Dr. Bond shares, "I would like to thank the family of Eric Cohen, including Michael, Patty and Stacey. It was an honor to meet his family over Zoom, and it provided me with another source of inspiration for my work."

As for the future of lymphoma research and treatment, Stacey is hopeful investments in the Eric A. Cohen Distinguished Scholar will accelerate the pace in which treatments are developed and will improve the lives of those impacted by this disease. "I am hopeful that the scientists given this grant will continue to find new treatments to eradicate this disease so that those impacted can witness a cure that so eluded Eric," she shares. "LRF has brought so much exposure to lymphoma, and their focus on research is the reason success rates are positive. More research is always necessary, but LRF continues to encourage, invest and support scientists seeking curative treatments. For that, I am grateful."

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

The U.S. Food and Drug Administration (FDA) is responsible for the approval of drugs, including biological products, for human use in the United States.

#### BELUMOSUDIL (REZUROCK™)

**July 16, 2021** — A kinase inhibitor, for chronic graft-versus-host disease (cGVHD) in adult and pediatric patients 12 years and older after the failure of at least two prior lines of systemic therapy.

#### COMIRNATY (PFIZER-BIONTECH COVID-19 VACCINE)

August 23, 2021 — The first COVID-19 vaccine approved for individuals 16 years of age or older. The vaccine also continues to be available under emergency use authorization (EUA), including for individuals 12 through 15 years of age and for the administration of a third dose in certain immunocompromised individuals.

#### ZANUBRUTINIB (BRUKINSA®)

**August 31, 2021** — A Bruton's tyrosine kinase (BTK) inhibitor approved for adult patients with Waldenström macroglobulinemia (WM).

**September 15, 2021** — Approved for adult patients with relapsed/refractory marginal zone lymphoma (MZL) who have received at least one anti-CD20-based regimen.

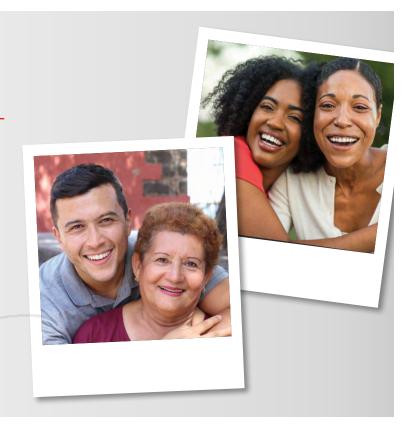
#### **RUXOLITINIB (JAKAFI®)**

**September 22, 2021** — For chronic graft-versus-host disease (cGVHD) in adult and pediatric patients 12 years and older after the failure of at least one prior line of systemic therapy.

## NOVEMBER IS NATIONAL FAMILY CAREGIVERS MONTH

Celebrated every November, National Family Caregivers Month (NFCM) is a time to recognize and honor family caregivers across the country.

This November, raise awareness of caregiving issues and celebrate the contribution of family caregivers on social media. Learn more about National Family Caregivers Month and access caregiver resources at lymphoma.org/nfcaregiversmonth.





## MANAGING THE RESPONSIBILITIES OF CARING FOR A LOVED ONE

A lymphoma diagnosis not only affects the patient; it affects their caregivers too. Caregivers are relatives, friends, partners or anyone who has a significant relationship with the patient and is an essential extension to the patient's healthcare team. While being a caregiver can often be a rewarding experience, it can also be a very challenging one. Responsibilities of caregivers may vary but can range anywhere from attending doctor visits, keeping track of medication, providing transportation to treatments, assisting with childcare responsibilities and providing emotional support. While it seems counterintuitive, often a diagnosis of cancer is harder on the caregiver than it is on the patient itself.

Watch the LRF webinar
Caring for a Loved One
with Lymphoma at
lymphoma.org/
webinars

According to a study published by the National Alliance for Caregiving, cancer caregivers spend an average of 32.9 hours a week providing care to their loved one. As a result, caregivers reported experiencing increased anxiety, depression, fatigue and other emotional stress—with more than 50 percent of caregivers rating their stress level as "highly stressed."



#### THOMAS M. HABERMANN, MD

CONSULTANT, DIVISION OF HEMATOLOGY, DEPARTMENT OF INTERNAL MEDICINE AND PROFESSOR OF MEDICINE, MAYO CLINIC, ROCHESTER; PAST CHAIR AND MEMBER, LRF SCIENTIFIC ADVISORY BOARD

For over 36 years, Lymphoma Research Foundation (LRF) Scientific Advisory Board member, Thomas M. Habermann, MD, of Mayo Clinic, Rochester, has witnessed the impact that caregivers have on lymphoma patients' journeys and the often-overwhelming emotional toll it can have on them. He shares some helpful strategies on how to help cope with some of the pressures of caregiving.

#### **BEING AN EFFECTIVE CAREGIVER**

Caregivers provide support and encouragement for patients and are essential to their journey. The most important thing you can do is show up and be present. By doing this, you will feel more empowered to be an advocate for your loved ones to help them make the best decisions about their care. The more you are ingrained in the process, the more helpful you can be overall.

- Use LRF's free educational resources to get educated about lymphoma.
- Prepare questions to ask the doctor prior to appointments.
- If permissible, attend doctor's appointments.
- Be on time to appointments.
- Take detailed notes during appointments.
- Assist with insurance-related issues.
- Facilitate resilience strategies:
  - Communication
  - Walks
  - Exercising
  - Reading materials
  - Hobbies

#### SEEK SUPPORT AND ACCEPT HELP

Just as much as patients need a support system, so do caregivers. Remain connected with family and friends who can offer support and help you when you are feeling overwhelmed. While it can often feel like the weight of the world is on your shoulders, it is crucial to take breaks and allow others in your community to utilize their skills and assist in the caregiving process. There are also several resources that you can utilize for support.

- Join LRF's Lymphoma Support Network to get matched with a caregiver who can offer support and words of encouragement.
- Ask the patient's healthcare team if their institution offers emotional support groups for caregivers.
- Network with other patients, family and friends.
- Seek professional help if needed.

#### MANAGE STRESS AND PRACTICE SELF-CARE

It is important to remember that to take care of others, you must first take care of yourself. Practice self-care to support both your emotional and physical needs. It may be difficult to take time for yourself, especially if you are someone's sole caregiver, but by setting aside time just for you, you will find that you can avoid caregiver burnout and be more effective in the long run.

- Get enough sleep.
- Practice healthy eating habits.
- Go for a walk to clear your mind.
- Find time to exercise to relieve stress.
- Journal your feelings.
- Maintain hobbies to relax and unwind.
- Communicate with physicians and healthcare team.

#### STAY HOPEFUL

While learning your loved one has cancer is never easy, advances in lymphoma research continue to improve the way people are diagnosed with and treated for lymphoma, and mortality rates have decreased dramatically over the past 25 years, especially within the last decade. With the help of organizations like LRF, we will continue to see improvements in patient care, outcomes and ultimately find cures for this blood cancer.  $\bigcirc$ 



# HE PE FOREVER AND A DAY

For more than 23 years, Marla Briskman faced her lymphoma—enduring five relapses and six different treatments. What gave her hope: Incredible treatment advancements and the support of family, friends, and her husband and caregiver, Rickey.

In 1998, Marla Briskman was getting ready for Rosh Hashanah dinner at her parents' house when she received an unexpected visit from her brother and sister-in-law. Briskman had been waiting for results from a biopsy to come back, and when she heard her brother at her door—a physician at the hospital where she underwent the biopsy—she was terrified. "Sure enough, my brother told me I had a subtype of non-Hodgkin lymphoma called mantle cell lymphoma," says Briskman. "The moments following were devastating, and with the help of my brother, I began to think about how I would prepare for the journey ahead."

Mantle cell lymphoma (MCL) is typically an aggressive, or fast-growing, rare form of non-Hodgkin lymphoma (NHL). Mantle cell lymphoma arises from cells originating in the "mantle zone" and accounts for roughly six percent of all NHL cases in the United States.

The type of treatment selected for a patient with MCL depends on multiple factors, including the stage of disease, the age of the patient and the patient's overall health. Mantle cell lymphoma is usually diagnosed once it has spread throughout the body, and the majority of these patients will require treatment. While MCL is considered a difficult cancer to treat, tremendous progress has been made in discovering new treatments for this disease.

Continued on the next page

#### LIVING WITH LYMPHOMA

Since Briskman was not yet experiencing side effects, her doctor suggested that they hold off on treatment and that they instead put her on "active surveillance," also known as "watch and wait." With this strategy, patients' overall health and disease are monitored through regular checkups and various evaluating procedures, such as laboratory and imaging tests. Active treatment starts if the patient begins to develop lymphoma-related symptoms or shows signs that the disease progressed based on testing during follow-up visits.

Briskman was on "active surveillance" for four years until her doctors deemed it necessary to start treatment due to the enlargement of her lymph nodes. "I was nervous to begin treatment but trusted my doctor, so I was confident that I could face the challenges that this disease threw my way," says Briskman. She immediately began rituximab (Rituxan®) and made it through treatments with the support of her family and friends. "My mother was with me every time, and intermittently I had my sister-in-law, friends and my soon-to-be sisters-in-law joining the visits."

"I was nervous to begin treatment, but trusted my doctor, so I was confident that I could face the challenges that this disease threw my way."

One year after completing her initial treatment, Briskman's lymph nodes enlarged once again. Her healthcare team recommended she now start R-CHOP chemotherapy (rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone). R-CHOP is typically administered in 21-day cycles (once every 21 days) for an average of six cycles. However, the length and number of cycles can vary based on the patient's individual disease and health status.

Before starting treatment, Briskman's sister-in-law convinced her to go on her dream trip to the Galapagos Islands. "She really encouraged me to do something for myself before starting a grueling round of treatments," she explains. When she returned, much to her surprise, she received the news that her lymph nodes had receded and she no longer needed to start treatment.

Unfortunately, in 2004 she felt an enlarged lymph node in her neck again, and her doctor confirmed that her MCL had relapsed and now had blastoid features—a highly aggressive feature that often has a poor outcome. Her doctor suggested that she undergo eight cycles of R-CHOP. "He said that most older patients tolerated this treatment well, so at 53, I wasn't concerned," says Briskman. "Sadly, that was not the case for me." The treatment left Briskman feeling extraordinarily dizzy and eventually caused her to have vertigo. "The doctors put

me in the hospital to give me fluids, but I still suffered," says Briskman. Luckily, the treatment eventually paid off, and her lymph nodes reduced in size.

Then one night in 2005, Briskman realized she was in the throes of yet another setback in her journey. "I rested my chin on my hand and felt a gigantic lump," she says. "I knew this could not be good." Now her third bout with the disease, her doctor suggested radiation would be the next course of action. "They molded a mask with little holes all around it to my head and then strapped my head down to the table. I was terrified," says Briskman. "I was thankful to have Rickey—we were dating at the time—who came running into the room to keep me calm and help me get through."

Briskman enjoyed three years of remission until 2008, when she felt another enlarged lymph node. The doctor confirmed that her lymphoma had reared its head again. She underwent several treatments, including a stem cell transplant. "I was in the hospital for eleven days, weak, with mouth sores that precluded me from even drinking water without being in pain. I found it extremely difficult to regain my strength upon leaving," says Briskman. "It was Rickey's love, strength and serving me chicken noodle soup that helped get me through."

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While in remission, Briskman and Rickey decided to marry and begin their "happily ever after." Five years later, she discovered another lump under her neck and began to take a new oral therapy available called ibrutinib (Imbruvica®). Also, in a turn of events, Rickey was diagnosed with follicular lymphoma (FL) one year after her relapse. "It was now my turn to become a caregiver," says Briskman. "Rickey was quite panicked, but I did the best I could to reassure him, especially given my own journey with lymphoma." Briskman made sure to reinforce and encourage him during his journey, just as he did during her diagnosis and treatment.

Fortunately, after three rounds of bendamustine (Treanda®), Rickey was in remission. He completed the treatment and then was put on a two-year maintenance regimen of rituximab to keep the lymphoma from returning. "To this day, we are so thankful that he is healthy without relapse," says Briskman.

Briskman continued to take ibrutinib, which kept her lymphoma at bay for five years. When her lymphoma returned for the sixth time, a new drug combination of lenalidomide (Revlimid®) and rituximab was available. She was placed on that combination therapy until she found out if she was eligible for a clinical trial testing the use of chimeric antigen receptor (CAR) T-cell therapy.

At the time, the CAR T-cell therapy clinical trial was mainly administered to patients with diffuse large B-cell lymphoma (DLBCL)—an aggressive form of NHL—but Briskman was hopeful it would be a viable option for her.

She had her T-cells removed and then re-infused within one month, while also in and out of the hospital negotiating pretreatment protocols, inconsistent blood pressure, weakness and pain. "It was a terrifying time, and for the first time, I felt I might not make it through," says Briskman. "Without the support of my husband every step of the way helping me walk, shower, and even indulging my craving for cheeseburgers and malteds—I don't know how I would have made it through."

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Now, more than three years after her CAR T-cell therapy treatment, Briskman remains in remission. "My rabbi calls me a 'miracle,' and I would have to agree," says Briskman. "Thanks to my incredible healthcare team and my amazing husband, I went from the darkest moment of my life to the brightest."

Briskman and her husband now do their part to give back to the lymphoma community by supporting LRF and participating in the Team LRF Chicago Lymphoma Walk. She hopes her story and willingness to face these hard challenges can provide hope to other lymphoma patients facing their journeys. "For anyone who feels like there is no light at the end of the tunnel," she says, "remember that I started this journey in 1998, and it is now 2021. Now that's hope!" \(\infty\)



## 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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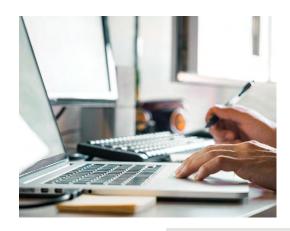
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In Memoriam

Rutgers Robert Wood Johnson Medical School Rutgers Cancer Institute of New Jersey







## UPCOMING EVENTS

San Francisco Lymphoma Rounds, Virtual	10.13
Ask the Doctor About Lymphoma, Virtual	
National Lymphoma Rounds, Virtual	
Los Angeles Lymphoma Rounds, Virtual	
Update on T-Cell Lymphoma Webinar	
National Family Caregivers Month	
Philadelphia Lymphoma Rounds, Virtual	
Midwest Lymphoma Workshop, Virtual	
Ask the Doctor About Lymphoma, Virtual	
GivingTuesday	

Want to receive information about Lymphoma Research Foundation events happening in your area? Visit 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, or visit lymphoma.org/legacy.



