

# PULSE

## THE RIPPLE EFFECT OF LYMPHOMA 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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Victor Gonzalez

Kyle Haines

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Rebecca Rausch

Whitney Steen

Michelle Steiner

William White

#### CONTACT US

**National Headquarters**

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

Tel: 212 349 2910

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

**LRF Helpline**

800 500 9976

[helpline@lymphoma.org](mailto:helpline@lymphoma.org)

**Contact the Editor**

For more information or to share comments, please email [editor@lymphoma.org](mailto:editor@lymphoma.org).

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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](http://lymphoma.org/podcast)**

to listen and subscribe to upcoming episodes.

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# 2020 IMPACT REPORT

We give thanks for our community — donors, volunteers, friends and advocates — who come together to help us achieve a world without lymphoma. **Through the work of the Lymphoma Research Foundation (LRF), you touched the lives of more than 2 million people in 2020.** Together, we will continue to make an impact and support all those touched by this disease. Thank you.

More than  
**2 MILLION PEOPLE**  
served through education  
programs, digital resources  
and support services



Provided more than  
**70 PATIENT AND  
PROFESSIONAL  
PROGRAMS**



More than  
**10,000 PATIENTS,  
SURVIVORS AND  
CAREGIVERS**  
served through the LRF Helpline



**15 NEW GRANTS**  
awarded and more than 40,000  
research hours funded — enabling  
early-career scientists to maintain  
a research focus on lymphoma



People in all  
**50 STATES**  
(including the District of  
Columbia) and more than  
**50 COUNTRIES**  
accessed LRF digital resources



## 25 YEARS OF INNOVATION AND PROGRESS

In 2020 LRF celebrated 25 years of innovation and progress! Through lymphoma-specific research grants and consortia, LRF seeks to understand the nearly 100 subtypes of lymphoma and support the development of new treatments. As a result, LRF-supported researchers have been involved in many of the most significant lymphoma breakthroughs witnessed in the past quarter-century.



### MULTIMILLION DOLLAR RESEARCH INVESTMENT

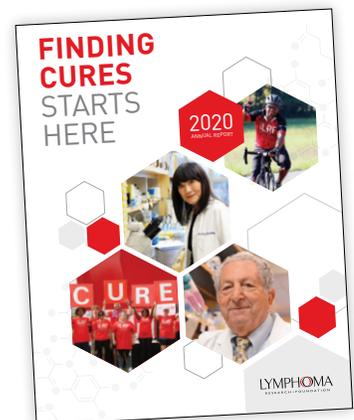
Established in 2020 through the generosity of the Peykoff Family and Niagara Cares, the \$10 million Initiative is poised to transform the follicular lymphoma treatment landscape for tens of thousands of patients by harnessing LRF's unique resources, convening the world's experts in follicular lymphoma research and patient care, and driving direct investment in clinical research.



### LRF COVID-19 CRISIS RESPONSE

In the blink of an eye, COVID-19 swept the world and disrupted the way we interact, communicate, conduct business and live. As the pandemic began to unfold, LRF quickly responded by coming up with new and creative ways to meet the needs of the lymphoma community.

Read more about LRF's impact in the **2020 Annual Report** at [lymphoma.org/financials](https://lymphoma.org/financials).



# COVID-19 UPDATES & RESOURCES

The Lymphoma Research Foundation (LRF) COVID-19 programming and resources provides members of the lymphoma community with the latest information on COVID-19, financial assistance and resources for emotional support.



## COVID-19 WEBINAR SERIES

LRF's free webinars are hour-long interactive programs led by leading lymphoma experts. Watch/listen to the following archive programs:

- COVID-19: What the Lymphoma Community Needs to Know
- COVID-19: Managing Concerns for Lymphoma Patients
- COVID-19: Addressing Telemedicine Now and in the Future
- Updates on COVID-19 from the 2020 American Society of Hematology Meeting

## COVID-19 FACT SHEETS

LRF's free fact sheets covering the topics below are available for download at [lymphoma.org/publications](https://lymphoma.org/publications):

- Understanding COVID-19
- Understanding the Immune System and Lymphoma
- How to Prepare for and Cope with a Pandemic or Crisis Situation
- Resources for COVID-19 Financial Assistance and Emotional Support



## FINANCIAL ASSISTANCE

LRF's Patient Aid Program provides limited financial assistance for people with lymphoma/chronic lymphocytic leukemia (CLL) in active treatment to help with costs including food, transportation, lodging or housing, utilities, child care and/or devices (e.g., canes, wheelchairs, ramps).

Access these resources, articles, FAQs and more in LRF's COVID-19 Learning Center at [lymphoma.org/covid19](https://lymphoma.org/covid19).

**CONTACT THE LRF HELPLINE**

800 500 9976 | [helpline@lymphoma](mailto:helpline@lymphoma)

# FROM THE CEO

This past year was challenging at best, but made one thing very clear: our work together can transform the landscape of lymphoma research and provide critical support to patients and their loved ones when they need it most.

Because of generous supporters like you, we continue to fund the most promising lymphoma researchers and advance our understanding of the more than 100 different lymphoma subtypes.

**Finding cures truly starts here.**



We are excited to start the new year with a new *Pulse* issue that highlights all the incredible strides made in lymphoma research and how supporters like you make them possible. We profile one of the world's leading lymphoma clinical researchers, Michael Williams, MD, ScM, of University of Virginia School of Medicine. Dr. Williams has led the way in furthering our understanding of novel targeted therapies — like oral anti-cancer therapy — and mantle cell lymphoma (MCL), outlining challenges and areas of future study to improve patient outcomes. Dr. Williams's and other leading lymphoma researchers' contributions inform our MCL patient education programming and resources, and have led us to develop the first-ever resources focused on oral therapies in the treatment of lymphoma and chronic lymphocytic leukemia (CLL).

This issue also features two topics impacting our community: cancer survivorship and managing stress during treatment and a pandemic. We offer numerous resources to patients and their caregivers to address these critical topics highlighted in these important pieces.

We also share updates from the most extensive global scientific conference for lymphoma research and clinicians, the American Society of Hematology Annual Meeting & Exposition. Lymphoma Research Foundation (LRF) grantees and scientific advisors, supported by LRF funding, presented pivotal data that will inform the development of new therapies across the spectrum of lymphoma subtypes. Many of these studies will be highlighted during LRF patient education programs throughout 2021.

As we look towards a new year of innovation and progress, we will continue to invest in the best and brightest researchers. We will deepen our understanding of lymphoma. And we will continue to support the thousands of people affected by this blood cancer. Thank you for supporting this vital work.

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



## WALK ON! ARIZONA

On November 8, 2020, hundreds joined the Lymphoma Research Foundation (LRF) for Team LRF *Walk On! Arizona* live on Zoom.

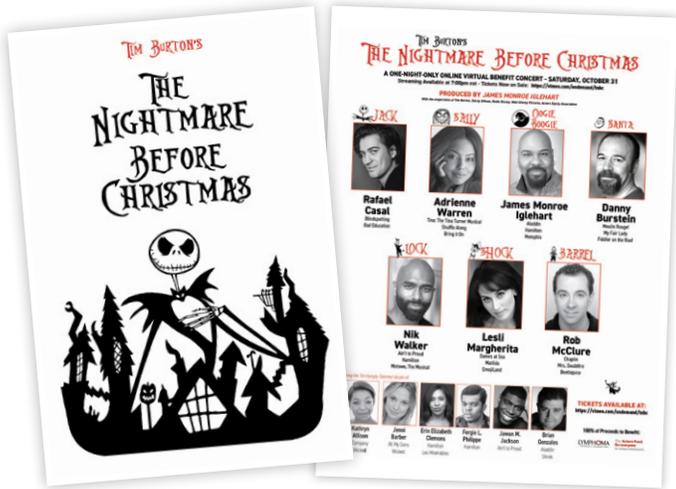
The pandemic did not stop Arizona supporters from gathering around their computers, televisions, phones and tablets to rally for the lymphoma community. *Walk On! Arizona* was hosted by Nick Ciletti, anchor at ABC-15 in Phoenix, and featured stories from lymphoma survivors and spotlights on Arizona fundraising teams. Grand Marshal and LRF Scientific Advisory Board member Lisa Rimsza, MD of Mayo Clinic, Arizona, shared information about the importance of lymphoma awareness, fundraising and research. Together, the Arizona community raised more than \$45,000 to support the LRF mission.



## SWIRL: AMERICA, EPISODE TWO

On November 14, 2020, LRF hosted its second episode of *Swirl: America*, An At-Home Tasting Event.

LRF's new online tasting series brings the most coveted new wine and cocktail trends to the comfort of your home. The program featured an exciting tasting of three wines from Barbieri Wine Company. Barbieri produces world-class wines in Santa Barbara County, California, and is owned by husband-and-wife duo Erin Kempe & Paolo Barbieri. Barbieri, a Master Sommelier, led participants through a personalized wine tasting, while Kempe walked viewers through different food pairings to complement the tasting. The event raised over \$50,000 to support LRF's mission. Thank you to our *Swirl: America* Host Committee and co-chairs AJ and Michelle Manas as well as Series Sponsors AbbVie and Karyopharm Therapeutics for supporting the program. To learn more about LRF's in-person and virtual ticketed fundraising events, visit [www.lymphoma.org/ticketedevents](http://www.lymphoma.org/ticketedevents).



## THE NIGHTMARE BEFORE CHRISTMAS BENEFIT CONCERT

On Halloween night, thousands joined LRF and The Actors Fund to watch Broadway’s most talented artists fill their screens with an evening of music and storytelling.

Tony award-winning actor James Monroe Iglehart and friends performed songs from *Tim Burton’s The Nightmare Before Christmas*. The spook-takular event raised \$36,000 in support of The Actors Fund and vital LRF support services, resources and research programs.



## THE GREAT BAKE

Bakers from across the country are joining LRF’s new fundraising initiative.

The Great Bake is a unique fundraising event that invites bakers to create their own virtual bake sale. Bakers made their most delicious desserts to sell to friends, family and neighbors. Thirty participants from around the country have joined and raised \$10,000 (and counting!). There’s still time to join in on the fun! Visit [lymphoma.org/greatbake](http://lymphoma.org/greatbake) to learn more about the Great Bake and to register. ○

## SHOW YOUR LOVE FOR LYMPHOMA PATIENTS AND CAREGIVERS

**This February, support LRF’s Patient Aid Program.**

Receiving a lymphoma diagnosis can be overwhelming, and the financial burden associated with treatment can be devastating. Many lymphoma patients must, unfortunately, choose between paying for living expenses or potentially life-saving treatment.

LRF’s Patient Aid Program seeks to help patients in need by assisting them in covering out-of-pocket expenses associated with their care.

Show your love for lymphoma patients by donating to LRF’s Patient Aid Program. Visit [lymphoma.org/showlove](http://lymphoma.org/showlove) to learn more.





# ADDRESSING CANCER SURVIVORSHIP

A cancer survivor is defined as anyone living with a history of cancer — from the moment of diagnosis through the remainder of life. Current data shows that 87 percent of people with Hodgkin lymphoma (HL) and over 72 percent of people with non-Hodgkin lymphoma (NHL) are still alive five years after their diagnosis. Better diagnostic tools and more effective treatments play a critical part in improved survival rates; however, the challenge now facing many survivors is how to achieve long-term quality of life after treatment has ended.

**Emily Tonorezos, MD, MPH, Director of the Office of Cancer Survivorship at the National Cancer Institute (NCI), in the Division of Cancer Control & Population Sciences**, shares what she and the agency are doing to raise awareness of and address issues that cancer survivors may face, as well as future directions in cancer survivorship research.



## **EMILY TONOREZOS, MD, MPH**

Director of the Office of Cancer Survivorship,  
National Cancer Institute (NCI)

### **Can you share how the NCI Office of Cancer Survivorship started?**

It is actually the cancer survivorship community that helped launch the Office of Cancer Survivorship and has continued to inspire hundreds of others to work in the field. Twenty-five years ago, Ellen Stovall of the National Coalition for Cancer Survivorship — herself a three-time cancer survivor, including lymphoma — acting on behalf of the broader cancer survivorship advocacy community, presented a report to the NCI director at the time, Dr. Richard Klausner. That report highlighted recommendations by several dozen cancer survivors and their family members, healthcare providers, researchers and advocates to advance the science and care necessary to better understand and meet the needs of the growing number of people living long-term after a cancer diagnosis. It was in response to that report that Dr. Klausner established the Office of Cancer Survivorship (OCS) to support and direct research designed to improve the length and quality of life of individuals diagnosed with cancer.

### **What are your responsibilities as Director of the Office of Cancer Survivorship?**

The Director of the Office of Cancer Survivorship's role has evolved greatly, as cancer treatment and what we know about how cancer affects the body have evolved. As the director, I try to emphasize the definition of a *cancer survivor*, in that it starts at the time of diagnosis and continues through the rest of one's life. This definition lays the foundation of all the work we do. We also recognize the extremely important role that caregivers play in cancer survivorship.

The most recent iteration of the definition was put forward by Deborah K. Mayer, PhD, RN, AOCN, FAAN, who served as interim director before I joined the NCI. She specifically called out this population of people living with cancer to emphasize that "cancer survivor" applies to anyone who has had a cancer diagnosis, whether or not treatment has been completed or is expected to be completed. Underscoring that definition, as director, I lead NCI's efforts to

support research on behalf of cancer survivors and their care, health longevity and wellbeing. My work includes fostering partnerships with other agencies, organizations, the advocacy community and other leaders in the field to identify research gaps as our knowledge of cancer survivorship grows and the needs of the field change.

### **What are some key initiatives or programs you are addressing?**

There is a growing population of people, including people with various types of lymphoma, who may never enter a phase of post-treatment or are expected to live with cancer and be on and off treatment for the balance of their lives. Research is needed to understand the patient experience fully, including the challenges patients face despite therapy and supportive care improvements.

For every advance made in cancer treatment and understanding cancer, the cancer survivor population continues to grow, and we continue to learn. About a year ago, Dr. Mayer brought together investigators and advocates outside the National Institutes of Health to discuss critical gaps in cancer survivorship research and care, including financial hardship, training and education for providers, care coordination and health promotion. A follow-up webinar sought additional input from the wider survivorship community. With these resulting insights in hand, we're now working to systematically address those gaps identified to improve cancer survivors' outcomes and experiences.

### **What do you find most rewarding in your position and your work at the NCI?**

I genuinely love working at the NCI and the Division of Cancer Control and Population Sciences. My colleagues all have a sense of commitment and dedication to promote health and wellbeing through scientific research. Before joining the NCI as the Cancer Survivorship Director, I was a clinical doctor caring for adult survivors of childhood and young adult cancers. Now I can help generate ideas and make an impact on a much larger scale. Having that platform and opportunity to do something meaningful is rewarding for me.

### **What led you to a career in oncology?**

By profession, I am a general internist. I completed my residency at Columbia University Medical Center in New York City. I loved caring for patients with complicated medical histories, comorbidities, financial challenges and language barriers. You really have to think carefully about prioritizing care for patients and understanding the range of factors in your patient care to make sure they will have the best outcome. After completing my general internal medicine fellowship, I joined as a junior faculty

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“Oncology is advancing at a magnitude never experienced before. We are discovering new therapies, new strategies, new methods for diagnosing cancer, and expanding supportive and palliative care.”



member in the survivorship program at Memorial Sloan Kettering Cancer Center, working under Drs. Kevin Oeffinger, Mary McCabe and Charles Sklar. I did not have experience in cancer survivorship, but quickly learned that caring for cancer survivors was like the best of internal medicine: cancer screenings, surveillance for recurrence, care coordination, managing toxicities — all things that intrigued me in treating patients in internal medicine.

**Why is understanding cancer survivorship so essential, and do any specific aspects of cancer survivorship research impact people with lymphoma?**

Cancer survivorship is unique, and cancer diagnosis and treatment are not like any other experience. Yes, there are parallels in other illnesses and parallels in other aspects of health services, but there is nothing like cancer survivorship. At the same time, I feel we as providers in primary care and some subspecialty services can care for cancer survivors. Studies demonstrate that providers share a desire to do a good job in caring for survivors, but often lack knowledge. The ability to connect providers to resources to support the best care for cancer survivors remains a challenge. Improving electronic medical recordkeeping and better care coordination are two significant steps we can take to assist providers in caring for cancer survivors.

Lymphoma holds a special place for cancer survivorship researchers because many early survivorship research stems from Hodgkin lymphoma (HL) and discoveries about mantle radiation and chemotherapy treatments for that disease. Hodgkin lymphoma survivorship research provided the paradigm for the late effects of cancer and

evidenced-based survivorship care. Lymphoma is also leading the way in our understanding of how people can live with cancer. For example, many patients with follicular lymphoma (FL) may go many years with no discernable disease and yet will continually need to be monitored by an oncologist.

Further, their primary care physician continues to care for them for other aspects of their health. So you have a patient who belongs in both the oncology and primary care world. We recognize there are survivors who are in this situation, and we have developed new strategies to care for those types of patients.

**How do you see survivorship evolving in the next 10 years?**

Oncology is advancing at a magnitude never experienced before. We are discovering new therapies, new strategies, new methods for diagnosing cancer, and expanding supportive and palliative care. Oncology is solving problems that we never asked in the past. With that, we benefit in the field of survivorship research because we always have an influx of calls, questions and challenges to address. Cancer survivorship research has the responsibility to understand and address the effects of these new and exciting treatments.

In addition to significant innovation in treatment and supportive care, there are substantial advances in understanding how people make treatment decisions, social sciences, behavioral medicine, healthcare delivery and epidemiology. All of these advances influence one another and cancer survivorship. It is an incredibly exciting time to be in the field. ○



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.**

## **Join the *Circle of Hope*: 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.

*Circle*  
**of HOPE**  
MONTHLY GIVING PARTNERSHIP  
— LYPHOMA —  
RESEARCH • FOUNDATION

To join the *Circle of Hope*, go to [lymphoma.org/circleofhope](https://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](mailto:development@lymphoma.org).

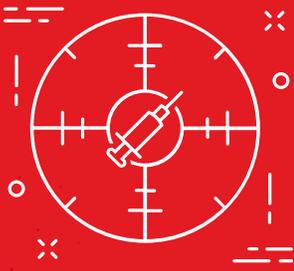


# THE RIPPLE EFFECT OF LYMPHOMA RESEARCH



Lymphoma Research Foundation (LRF) grantee and Scientific Advisory Board (SAB) member **Michael Williams, MD, of University of Virginia School of Medicine**, sees lymphoma research as having a ripple effect. Like ripples expanding across the water when an object is dropped into it, being a lymphoma researcher has a much larger impact on the lives of those touched by this disease than the sum of their individual research and improving patient outcomes.

“Every intention sets energy in motion, whether you are conscious of it or not,” says author Gary Zukav. Dr. Williams feels similarly about his role as a lymphoma clinician and researcher and the effect healthcare professionals have on accelerating cures.



“What has been especially exciting in recent years is that we’ve learned how to extend those responses using several treatment modalities. While MCL is usually difficult to control long-term with traditional chemotherapy, it is very susceptible to several specific targeted agents, which has greatly expanded the treatment landscape.”

### **Fascination with lymphoma**

After completing his undergraduate degree at his home state school of the Ohio State University, Dr. Williams received a Master of Science from the Harvard T.H. Chan School of Public Health. During graduate school, he pursued research in immunology and was surrounded by several physicians as classmates. It was then that he became inspired to obtain a career in the medical field. Dr. Williams attended the University of Cincinnati College of Medicine and completed his residency and fellowship at UVA Health in Charlottesville, Virginia. “During medical school, I planned to become an infectious disease specialist, but once I started my training, I did several rotations on our hematology/oncology services, taking care of acute leukemia and lymphoma patients, and felt drawn towards this field,” says Dr. Williams.

At the onset of Dr. Williams’s career, his lab pursued genetic analyses of clonality and chromosomal translocations in lymphomas. He quickly became fascinated by the clinical links in lymphoma and chronic lymphocytic leukemia (CLL) that he could discover in the lab. Collaborating with hematopathologist Dr. Steven Swerdlow at the University of Pittsburgh, Dr. Williams found a connection between mantle cell lymphoma (MCL) and a molecular translocation between chromosomes 11 and 14. Their further work led to confirmation that the relevant gene, later called cyclin D1 (a regulator of cell cycle progression), was activated in almost all MCL and has become a standard test to diagnose MCL.

### **A Unique Interest in mantle cell lymphoma clinical research and patient care**

While Dr. Williams began his career treating patients with a broad spectrum of hematological malignancies, he has spent the last 20 years focused on B-cell lymphomas and CLL. This unique interest was sparked by his involvement with an early pivotal clinical trial examining the use of rituximab to treat certain types of lymphomas — a drug that has since become a standard in treatment of most B-cell malignancies. “That was around the time I was starting to transition from the lab to clinical and translational research,” recalls Dr. Williams. “Being able to see a drug improve the way we treated patients who previously had a very poor prognosis made me passionate to focus on these subtypes of lymphoma,” he says.

Dr. Williams remains intrigued by the complexity of B-cell lymphomas such as MCL and motivated to improve outcomes for patients diagnosed with this disease. “While many MCL patients achieved a good initial response to traditional treatment regimens, most relapsed within two or three years, after which it became harder and harder to get their disease under control,” says Dr. Williams. “What has been exciting in recent years is that we’ve learned to maintain those responses and induce second and third remissions with specific targeted agents and immunotherapeutics.” “What has been especially exciting in recent years is that we’ve learned how to extend those responses using several treatment modalities. While MCL is usually difficult to control long-term with traditional chemotherapy, it is very susceptible to several specific targeted agents, which has greatly expanded the treatment landscape.”

With an increasing number of novel therapeutics becoming available for lymphoma patients, Dr. Williams is excited by the ability to offer his patients, with particularly complex cases, hope for the future. “We have many treatments now that are FDA approved with many more in the pipeline, that not so long ago would not have been imagined,” he says. “If that doesn’t make you excited about going to work and seeing patients, collaborating with colleagues across many academic centers and the LRF, then you are probably in the wrong field.”

### **Impacting the Lymphoma Research Foundation**

Furthering his impact in MCL research and patient care, Dr. Williams became involved with LRF’s Mantle Cell Lymphoma Initiative. He became a member and founding Chair of the MCL Consortium (MCLC), which was established in 2005 to help accelerate developments in the understanding and treatment of MCL by convening leaders in the field.

“LRF began awarding MCL-specific research grants — I applied for one and received funding to support work that I was doing within the disease,” says Dr. Williams. He was integral in leading the consortium and has since played a pivotal role in the continued development of the initiative. “Many advances in the field of mantle cell lymphoma have arisen from LRF’s presence in this area and their ability to catalyze important work that has the greatest potential to

*Continued on the next page*

## [ FROM THE FIELD ]

create an impact on this disease,” he says. In recognition of Dr. Williams’s outstanding contributions to help advance the understanding of MCL and its treatment, the LRF is awarding him its first-ever Mantle Cell Lymphoma Leadership Award.

**“The ripples that the LRF created in advancing progress in lymphoma and CLL continue to grow via basic and translational research, patient education and by supporting the next generation of lymphoma investigators and clinicians.”**

Dr. Williams also serves as a member of LRF’s Scientific Advisory Board (SAB) and feels privileged to work with colleagues in the field who are helping to advance lymphoma care and understanding of the disease. “The LRF has supported and encouraged many bright young scientists and clinicians to pursue careers in lymphoma who otherwise may not have chosen this field,” says Dr. Williams. “The ripples that the LRF created in advancing progress in lymphoma and CLL continue to grow via basic and translational research, patient education and by supporting the next generation of lymphoma investigators and clinicians.”

### **The research continuum**

With each advance, Dr. Williams is filled with optimism and curiosity — recognizing that new treatment regimens open the door to both opportunity and room for further improvement. “It’s not like, ‘well now we’ve got a new drug, and we’re done,’ because these drugs are still not curative and not everybody responds, so questions

continually arise as to how we can improve these therapies to be more useful for more patients,” says Dr. Williams.

**“We have so many treatments available now that are FDA approved, that at one time could not have even been dreamed of, which just shows how exciting the field can be.”**

He says that answering these questions requires collaboration amongst basic, translational and clinical investigators. Dr. Williams believes progress in cancer, and more specifically lymphoma, derives from a deep understanding of basic science, allowing translational researchers to develop appropriate and targeted drugs. “A simple example is that many B-cell lymphomas are driven by abnormalities in gene expression and function in cell signaling pathways. It’s a bench researcher’s job to say ‘if that pathway is turned on, what happens if you turn it off? Can we identify a molecule to do that, and in turn create a therapeutic?’” says Dr. Williams. “The clinical researchers then take on the design of early-phase clinical trials, by which you can safely test in patients to determine whether it ultimately can become a new treatment option.”

Although Dr. Williams and all lymphoma investigators are continuously thinking of the next questions that need to be answered, he also feels that the progress made over the last 20 years in lymphoma is nothing short of remarkable. “I think that these advances are among the best stories in all of medicine, not just cancer care, but I think across the entire spectrum of medicine,” he says. “There is very little that’s been as dramatic as the progress in lymphoma and CLL.” ○

### **LIVING WITH LYMPHOMA PODCAST: ORAL THERAPY AND ADHERENCE IN LYMPHOMA**

An increasing number of lymphoma and chronic lymphocytic leukemia (CLL) patients receive their chemotherapy not from intravenous (IV) treatments administered in a hospital or clinic, but via a pill taken at home on a regular basis. LRF Scholar Craig Portell, MD (UVA Health) sat down with *Living with Lymphoma* hosts Victor Gonzalez and Izumi Nakano to explain oral therapies and their use for the treatment of certain types of lymphoma. They were joined by CLL survivor Geoff Grubbs, who shared his experience with oral therapies and how this treatment regimen has been beneficial to him throughout his journey.

Visit [lymphoma.org/podcast](https://lymphoma.org/podcast) to listen.





## FINDING CURES STARTS WITH YOU

Thank you to the generous sponsors and supporters listed below and to our many other donors who helped to contribute to the success of the 25th Anniversary Gala, which helped to raise more than \$775,000 to support the Lymphoma Research Foundation's (LRF) mission of eradicating lymphoma and serving those touched by the disease.

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LRF is delighted to announce that our 2021 Annual Gala has been scheduled for

**Thursday, September 30, 2021.**

If you are interested in pledging your 2021 support early or would like to be added to our list to be the first to hear about our event details, please reach out to **Rebecca Rausch, Senior Manager of Distinguished Events**, at [r-rausch@lymphoma.org](mailto:r-rausch@lymphoma.org).

LYMPHOMA  
RESEARCH • FOUNDATION

— 25<sup>TH</sup> ANNIVERSARY GALA —

# 2020 AMERICAN SOCIETY OF HEMATOLOGY MEETING UPDATES

The Lymphoma Research Foundation (LRF) returned to the American Society of Hematology (ASH) Annual Meeting and Exposition with nearly 70 LRF-affiliated scientists, including past and present members of LRF's world-leading Scientific Advisory Board (SAB) and grantees, presenting abstracts at the virtual conference.

Widely regarded as the premier event in malignant and non-malignant hematology, the ASH Meeting, held virtually from December 5-8, 2020, due to the COVID-19 pandemic, provided a critical forum for leading hematologists/ oncologists to present their findings to over 20,000 of their peers. Among the distinguished scientists attending, more than 50 percent of LRF Scholars — participants in LRF's Lymphoma Scientific Mentoring Program — presented abstracts at the 2020 ASH Annual Meeting.

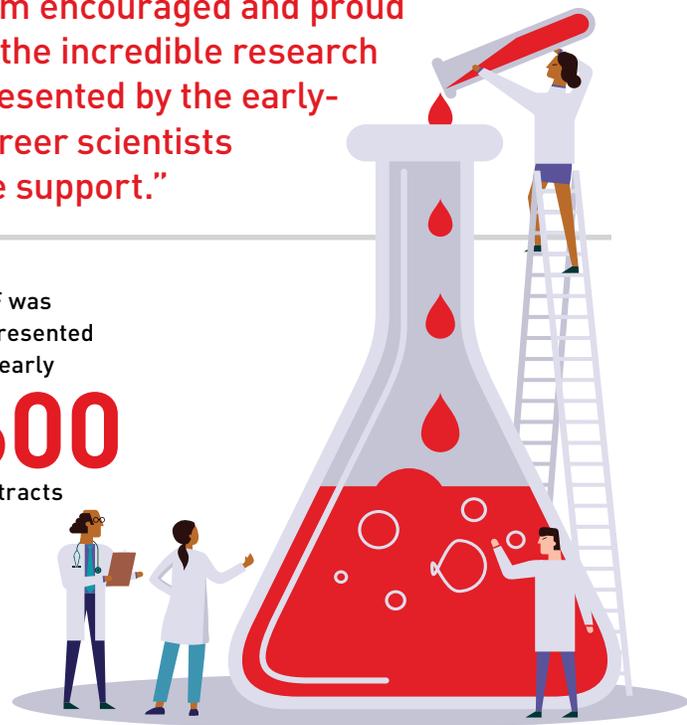
In addition to LRF's representation through presentations, more than 40 percent of LRF grantees (including 90 percent of LRF Scholars) were authors on abstracts selected for the annual meeting. LRF is also represented in nearly 600 abstracts through grantees, Lymphoma Rounds Steering Committee members, Mantle Cell Lymphoma Consortium (MCLC) members, and current and past SAB members.

The 2020 ASH Annual Meeting also featured 10 abstracts and presentations stemming from LRF-funded research and 15 COVID-19-related research authored by LRF-affiliated scientists.

**“The fact that we have nearly 90 percent of LRF's Scientific Advisory Board members and more than 40 percent of LRF grantees involved in abstracts at the 2020 ASH Meeting speaks to the caliber of LRF's world-class scientists and research investment,” says Andrew D. Zelenetz, MD, PhD, Chair of the LRF Scientific Advisory Board. “As Chair of the prestigious SAB, I am encouraged and proud of the incredible research presented by the early-career scientists we support.”**

LRF was represented in nearly

**600**  
abstracts





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**Ranjana Advani, MD**  
 and other SAB members  
 contributed to the  
 odrontextamab study.  
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### Early Trial for Bispecific Antibody in Non-Hodgkin Lymphoma Shows High Response Rate

Odrontextamab, a bispecific antibody targeting CD20 and CD3, led to response rates as high as 90 percent in patients with refractory B-cell non-Hodgkin lymphoma (B-NHL), including patients who underwent chimeric antigen receptor (CAR) T cell therapy, according to early trials results.

The study researchers, including current and past Scientific Advisory Board (SAB) members, reported findings for 136 patients with previously treated NHL — 57.4 percent of patients had relapsed/refractory diffuse large B-cell lymphoma (DLBCL), and 27.3 percent of patients had follicular lymphoma (FL).

Data showed that 27 of 30 patients with FL responded to odrontextamab, including complete responses (CRs) in 21 cases. The median duration of response had yet to be reached, and 22 of 27 responses lasted at least three months, with some lasting as long as 41 months. Six of 11 patients with DLBCL responded to odrontextamab, and so did one-third of post-CAR T cell therapy DLBCL patients.

Researchers have noted that enrollment has begun for a phase II trial of odrontextamab in relapsed/refractory NHL, and studies of chemotherapy-free and chemotherapy-containing combinations are being planned.

*This study included contributions from SAB members Ranjana Advani, MD of Stanford University School of Medicine; Stephen Ansell, MD, PhD of Mayo Clinic, Rochester; Jennifer R. Brown, MD, PhD of Harvard University/Dana-Farber Cancer Institute; Peter Martin, FRCPC, MD, MS of Weill Cornell Medicine; and past SAB member Susan O'Brien, MD of the University of California, Irvine.*



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 SAB member  
**Sven de Vos, MD, PhD**  
 and LRF grantees contributed  
 to the ZUMA-12 trial.  
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### ZUMA-12 Trial Exhibits Promising Results in Frontline CAR T Treatment for Aggressive Lymphoma

Axicabtagene ciloleucel (axi-cel), a chimeric antigen receptor (CAR) T cell therapy, appeared an effective frontline (initial) treatment for high-risk large B-cell lymphomas, according to results of the ZUMA-12 study — the first study to evaluate CAR T cell therapy as frontline therapy for high-risk large B-cell lymphomas. Several CAR T cell therapies are currently approved for the treatment of relapsed/refractory diffuse large B-cell lymphoma (DLBCL) and mantle cell lymphoma (MCL).

The researchers, including various LRF-affiliated scientists, enrolled and leukapheresed (a procedure in which white blood cells are separated from blood) a total of 37 patients. Thirty-two patients were evaluated for safety at a median follow-up of 9.5 months, and 27 patients were evaluated for efficacy at a median follow-up of 9.3 months. The patients' enrolled median age was 61 years, and most had advanced-stage disease (stages III and IV).

The objective response rate was 81 percent, and the complete response rate was 74 percent, with a median time to both response rates within one month. Four patients converted from partial response to complete response, and one patient converted from stable disease to complete response. The researchers note a higher frequency in one specific T-cell, CCR7+CD45RA+, in the pre-infusion product, which suggests improved T-cell fitness in frontline treatment.

*This study included contributions from Scientific Advisory Board (SAB) member Sven de Vos, MD, PhD of David Geffen School of Medicine at UCLA; LRF grantees Alex F. Herrera, MD of City of Hope National Medical Center; Peter Riedell, MD of The University of Chicago Medicine; and LRF Marginal Zone Lymphoma International Scientific Workshop Steering Committee member Catherine Thieblemont, MD, PhD of Hôpital Saint-Louis.*

## Chemotherapy-Free Combination Treatment for Chronic Lymphocytic Leukemia Reveals High One-Year Disease-Free Survival Rate

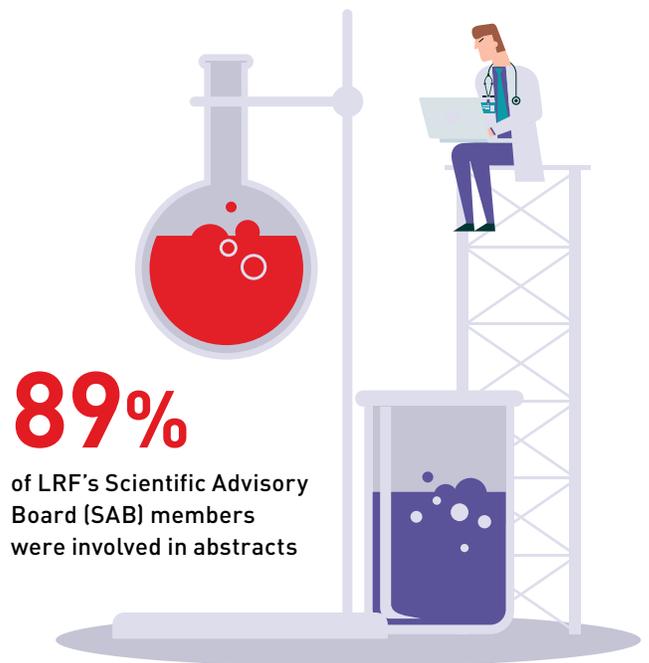
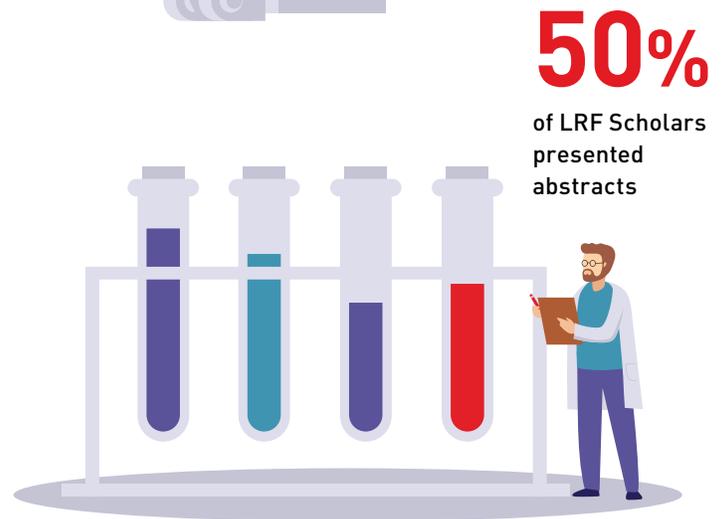
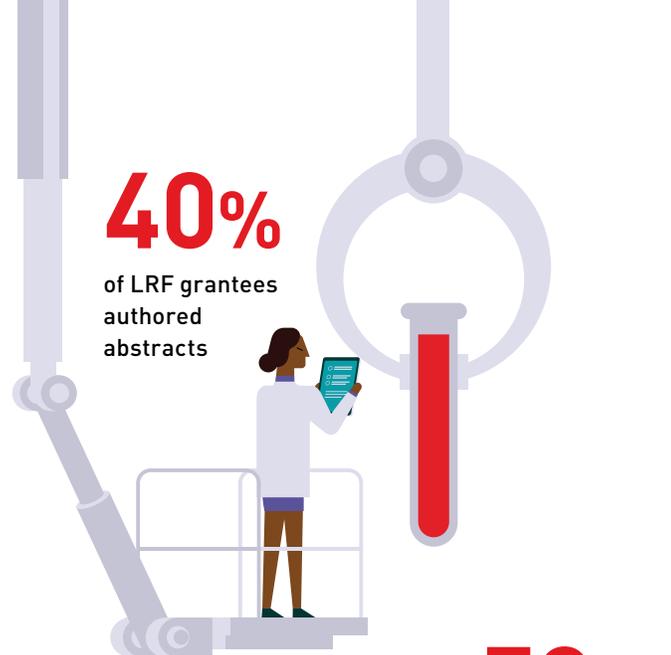
A time-limited, frontline combination of ibrutinib (Imbruvica) and venetoclax (Venclexta) shows to mobilize and clear chronic lymphocytic leukemia (CLL), leading to deep responses for patients who achieved undetectable minimal residual disease (MRD) status, according to results from the CAPTIVATE study. Currently, ibrutinib and venetoclax are approved as frontline single oral agent treatments.

The study, which includes contributions from several LRF grantees, Mantle Cell Lymphoma Consortium (MCLC) and Scientific Advisory Board (SAB) members, evaluated 164 CLL/small lymphocytic lymphoma (SLL) patients who received frontline treatment with ibrutinib plus venetoclax. Initial results showed the combination treatment led to undetectable MRD in 75 percent of patients. Patients with confirmed undetectable MRD at the end of the combination period were randomized to receive either further treatment with ibrutinib alone or a placebo. Patients with unconfirmed undetectable MRD were also randomized to receive ibrutinib alone or continued combination treatment.

Across all patient cohorts, the 30-month progression-free survival (PFS) rate from the time of initial treatment was greater than 95 percent (confirmed undetectable MRD group was 95.3 percent with placebo, 100 percent with ibrutinib; unconfirmed undetectable MRD group was 95.2 percent with ibrutinib, 96.7% with combination treatment). MRD status was improved with continued combined therapy versus an ibrutinib monotherapy for patients who did not achieve confirmed undetectable MRD.

The best overall undetectable MRD rates improved in bone marrow as well, from 32 percent after initial combination treatment to 42 percent with ibrutinib; and from 31 percent to 66 percent in patients who continued combination treatment. In peripheral blood, the undetectable MRD rate remained unchanged with ibrutinib; yet, it improved from 50 percent to 69 percent with combination treatment.

*This study included contributions from LRF grantees Danelle F. James, MD, MAS (now with Pharmacyclics, LLC, an Abbvie Company, and Janssen Biotech, Inc.), and James M. Pagel, MD, PhD of Fred Hutchinson Cancer Research Center; Mantle Cell Lymphoma Consortium member Ian W. Flinn, MD, PhD of Sarah Cannon Research Institute/Tennessee Oncology; and past SAB member Thomas J. Kipps, MD, PhD of the University of California, San Diego/Moores Cancer Center.*





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**Anthony Mato, MD**  
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**Michael Wang, MD**  
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### **BTK Inhibitor Shows Promise in Previously Treated Chronic Lymphocytic Leukemia, Mantle Cell Lymphoma and other Non-Hodgkin Lymphomas**

Over the past decade, covalent bruton tyrosine kinase (BTK) inhibitors have transformed how chronic lymphocytic leukemia (CLL) is treated, leading to more than a handful of chemo-free treatment options for patients. However, according to researchers in the phase I/II BRUIN study, treatment failure can occur by developing resistance and discontinuation for adverse events, leaving many patients with fewer treatment options. Also, covalent BTK inhibitors may pose other issues, including reduced or absent activity in the presence of BTK cysteine binding site (C481) mutations and pharmacologic liabilities that may lead to acquired resistance.

According to study results led by New York Lymphoma Rounds Steering Committee member Anthony Mato, MD of Memorial Sloan Kettering Cancer Center, LOXO-305, a highly selective, non-covalent BTK inhibitor, may be an efficacious option for the treatment of heavily pretreated/poor prognosis relapsed/refractory chronic lymphocytic leukemia.

The study included 186 patients with B-cell non-Hodgkin lymphoma (NHL) — including 94 patients with CLL/small lymphocytic lymphoma (SLL). The patients were previously treated at least once, with 84 percent previously receiving a BTK inhibitor, 69 percent previously receiving an anti-CD20 antibody, chemotherapy, and BTK inhibitor, 21 percent previously receiving a PI3K inhibitor, and 31 percent previously receiving venetoclax (Venclexta). All patients received seven dose levels, with observed responses at the first dose level and a median follow-up of three months for all patients and 6.7 months for responders. The researchers note an overall response rate (ORR) of 57 percent, with some patients receiving deeper responses of 77 percent with at least six months of follow-up.

*This study also included contributions from Scientific Advisory Board member Jennifer R. Brown, MD, PhD of Dana-Farber Cancer Institute; LRF grantee John M. Pagel, MD, PhD of Swedish Cancer Institute; and Philadelphia Lymphoma Rounds Steering Committee Chair Stephen J. Schuster, MD of Abramson Cancer Center/the University of Pennsylvania.*

In another BRUIN trial led by LRF Mantle Cell Lymphoma Consortium (MCLC) member Michael Wang, MD of the University of Texas MD Anderson Cancer Center, patients with previously treated mantle cell lymphoma (MCL) treated with LOXO-305 received high response rates with no dose-limiting toxicities or dose reductions during the study follow-up.

A total of 323 patients with advanced B-cell non-Hodgkin lymphoma, including 61 patients with MCL, were enrolled and analyzed for the trial. As in its sister study, patients in this analysis were heavily pretreated with a median of three prior therapies, including previous BTK inhibitors. Approximately 93 percent of MCL patients received a previous BTK inhibitor.

Researchers observed an overall response rate (ORR) of 52 percent for MCL patients and noted that at a median follow-up of six months, 24 of 29 patients with an initial response to LOXO-305 have an ongoing response. Waldenström macroglobulinemia (WM) patients received a promising ORR as well at 68 percent.

Although these are preliminary results, the researchers note that LOXO-305 could be a potentially effective treatment option for difficult-to-treat MCL, as well as Waldenström macroglobulinemia (WM) and other non-Hodgkin lymphomas (NHLs).

*This study also included contributions from LRF grantees Jonathon B. Cohen, MD, MS of Winship Cancer Institute; M. Lia Palomba, MD of Memorial Sloan Kettering Cancer Center; and John M. Pagel, MD, PhD of Swedish Cancer Institute; as well as LRF Mantle Cell Lymphoma Consortium members Timothy S. Fenske, MD of the Medical College of Wisconsin; Ian W. Flinn, MD, PhD of Sarah Cannon Research Institute/Tennessee Oncology; and New York Lymphoma Rounds Steering Committee member Anthony Mato, MD of Memorial Sloan Kettering Cancer Center.*

## Transplant Increases Overall Survival in Older, High-Risk Patients with Myelodysplastic Syndromes

Myelodysplastic Syndromes (MDS), also known as “bone marrow failure disorder,” are a group of diverse bone marrow disorders in which the bone marrow does not produce enough healthy blood cells. Patients who take chemotherapy drugs or who receive radiation therapy to treat Hodgkin and non-Hodgkin lymphoma are at risk of developing MDS for up to 10 years following treatment. Allogeneic hematopoietic cell transplantation (HCT) remains the only curative therapy for MDS. Although widely used in younger patients, HCT is infrequently offered to older patients because the relative benefits over non-HCT therapy have not been well defined.

In a multicenter, biologic assignment study, a trial compared older (aged 50-75) higher-risk de novo MDS patients (IPSS Intermediate-2 [Int-2] or High) who received reduced-intensity conditioning (RIC) allogeneic HCT with a suitable 8/8 human leukocyte antigen (HLA)-matched donor to those without a donor. Both patient cohorts underwent RIC HCT or non-HCT therapy according to institutional standards.

The adjusted overall survival rate at three years from study enrollment in the Donor cohort was 47.9 percent compared with 26.6 percent in the no-donor cohort. The researchers note a significant overall survival in older patients with high-risk MDS who are RIC HCT candidates and have an HLA-matched donor. The benefit of having a matched donor was seen across subgroups as well, including Medicare age (65+) and younger. It is recommended by the researchers that HCT should be offered to all individuals between the ages of 50 and 75 with Int-2 and High IPSS risk MDS where there is a suitable donor.

*This study included contributions from LRF grantee, Mantle Cell Lymphoma Consortium member and past Scientific Advisory Board (SAB) member Stephen J. Forman, MD of City of Hope; and past SAB member Frederick R. Appelbaum, MD of Fred Hutchinson Cancer Research Center.*



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**Neha Mehta-Shah, MD**  
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## Retrospective Study Reveals Transplant Potentially Curative for Mature T-cell Lymphoma

Allogeneic hematopoietic stem cell transplant (allo-HSCT) may be a successful curative treatment for T-cell patients with poor survival and/or limited treatment options, according to a retrospective study led by LRF grantee Neha Mehta-Shah, MD of the Washington University School of Medicine in St. Louis.

As a follow-up from their 2017 study that showed 31 percent of patients remain disease-free three years after HCT, Shah and a group of researchers expanded their efforts to include more academic centers with longer follow-up.

The follow-up study included 508 patients with a median age of 51 years. More than 86 percent of patients had known remission status at the time of their allo-HSCT, with more than 54 percent obtaining a complete remission, 37 percent a partial remission, 23 percent stable disease and 3 percent progressive disease. Seventy-eight percent of patients received a prior autologous HCT.

After an allo-HSCT, the two- and five-year progression-free survival (PFS) rates were 45.8 percent and 39.4 percent, respectively; and the two- and five-year overall survival (OS) rates were 59.1 percent and 50.8 percent, respectively. The study showed no significant difference in PFS for patients with angioimmunoblastic T-cell lymphoma (AITL), peripheral T-cell lymphoma — not otherwise specified (PTCL-NOS), ALK-positive, or ALK-negative anaplastic large cell lymphoma (ALCL). However, when compared specifically, AITL trends towards improved media PFS and OS. At five years, PFS cutaneous T-cell lymphoma (CTCL) trends lower compared to PTCL subtypes, but overall survival was similar.

*This study included contributions from LRF grantee and Scientific Advisory Board (SAB) member Steven Horwitz, MD of Memorial Sloan Kettering Cancer Center; LRF grantee Pamela Allen, MD, MSc of Winship Cancer Institute, Emory University; LRF grantee and LRF Mantle Cell Lymphoma Consortium (MCLC) member Jia Ruan, MD, PhD of Weill Cornell Medicine; LRF Mantle Cell Lymphoma (MCL) Consortium member and New York Lymphoma Rounds Steering Committee member Koen van Besien, MD, PhD of Weill Cornell Medicine; New England and New York Lymphoma Rounds Steering Committee member Francine Foss, MD of Yale Cancer Center; and Philadelphia Lymphoma Rounds Steering Committee member Stefan Barta, MD, MRCP, MS of Abramson Cancer Center, University of Pennsylvania.*

Join Us for a Virtual



# Lymphoma ROUNDS

Program



The Lymphoma Rounds 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.

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

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

**LYMPHOMA**  
RESEARCH • FOUNDATION

This program is supported by AstraZeneca, Bristol Myers Squibb, BTG International, Inc, Pharmacyclics, LLC, an Abbvie Company, and Janssen Biotech, Inc., administered by Janssen Scientific Affairs, LLC, Kite Pharma, Inc., Karyopharm Therapeutics, Seagen and TG Therapeutics.

WHERE ARE THEY NOW?

# SAMANTHA KENDRICK, MD

Samantha Kendrick, MD, is the Assistant Professor in the Department of Biochemistry and Molecular Biology at the Winthrop P. Rockefeller Cancer Institute at the University of Arkansas for Medical Sciences.

## When did you become interested in lymphoma?

Towards the end of my doctoral studies, around 2009/2010. I was motivated both academically as well as personally to learn more about lymphoma. The oncogene I studied for most of my thesis work started to gain recognition as a poor prognostic factor for patients diagnosed with diffuse large B-cell lymphoma (DLBCL), thus it made sense to apply my research to this disease. At the same time, my husband was diagnosed with non-classical, nodular lymphocyte-predominant Hodgkin lymphoma (HL).

## When did you receive funding from LRF?

### What research project were you working on?

### What kind of grant did you receive?

I received funding from a Postdoctoral Fellowship Grant from LRF in 2013. We were investigating the feasibility of simultaneously targeting gene expression of two key oncogenes in diffuse large B-cell lymphoma pathogenesis, cellular-myelocytomatosis (MYC) and B-cell lymphoma gene-2 (BCL2). We were studying unique structures that can form in the promoter regions of these genes, the areas of the gene that initiates expression, and serve as molecular switches by which we can modulate to turn expression “on” or “off” through small molecules.

**SAMANTHA KENDRICK, PHD**





“LRF’s research programs are instrumental for cultivating and supporting the next generation of scientists and discoveries to impact the treatment of lymphoma.”

### **How has research regarding molecular targets changed the understanding of and treatment landscape for lymphoma/CLL and evolved since you first started conducting your research?**

Over the last 10 years or so, advancements in methods to profile the gene expression patterns of tumors have broadened our understanding of the complex pathways that drive specific lymphoma types. Consequently, this comprehensive snapshot also generated a catalogue of putative molecular targets that provides additional targets for relapsed disease that otherwise would have limited treatment options. In addition, this data allows for the ability to identify particular subsets of patients who can benefit from such targeted therapies. We are excited about the ongoing and future development of personalized medicine for lymphoma and CLL patients.

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

LRF’s funding was critical at the postdoctoral stage of my career, as it not only helped establish a track record in funding specific to the study of lymphoma, but also provided the necessary financial support to conduct the work, which offered insight into how we can target two key oncogenes, BCL2 and MYC, for effective chemosensitization, and led to publications for advancing my career.

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

I continue to follow LRF events and initiatives, looking for opportunities to partner with the LRF. I was recently invited and participated in the LRF Adolescent/Young Adult Lymphoma Scientific Workshop.

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

The LRF’s research programs are instrumental for cultivating and supporting the next generation of scientists and discoveries to impact the treatment of lymphoma. The LRF also is ideally positioned for accomplishing these goals, as the foundation also provides a network of physician and research colleagues and patients that lends well to collaborative efforts to really drive the field forward.

### **What research are you currently working on that you’d like to share?**

We are currently exploring how secondary structures that form within the promoter regions of signaling pathways important for the more aggressive forms of diffuse large B-cell lymphoma, including those associated with the B-cell Receptor, regulate expression of these lymphoma-enabling and chemo-resistant genes and leveraging these mechanisms to develop new, targeted therapies.

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

I am most excited about how the field is delving deeper into the molecular characterization of lymphomas, highlighting the idea that these lymphomas are not single diseases, but consist of multiple subsets that will require personalized medicine to achieve successful long-term disease-free survival for patients. This work is also foundational for understanding how these tumors develop and what pathways play a role in the aggressive phenotype. ○

# VACCINES AND THE LYMPHOMA COMMUNITY

WITH JOHN P. LEONARD, MD

Richard T. Silver Distinguished Professor of Hematology and Medical Oncology, Senior Associate Dean for Innovation and Initiatives, Executive Vice Chair, Joan and Sanford I. Weill Department of Medicine, Weill Cornell Medicine



On December 11 and 18, 2020, the U.S. Food and Drug Administration (FDA) issued two COVID-19 vaccines, Pfizer BioNTech and Moderna, with emergency use authorization (EUA). LRF Scientific Advisory Board member John P. Leonard, MD of NewYork-Presbyterian Hospital, Weill Cornell Medicine answered common questions on how these vaccines work and what lymphoma patients should know before receiving the vaccine.

## **It has been reported that the COVID-19 vaccine will be distributed first to high-risk groups. Do cancer patients and survivors fall into that group?**

The Centers for Disease Control and Prevention (CDC) has an Advisory Committee on Immunization Practices (ACIP) that has made recommendations for a phased rollout of the vaccine. ACIP has prioritized initial supplies of the vaccine to be allocated to healthcare personnel and long-term care facility residents. People with certain underlying medical conditions, such as cancer, are among the groups being prioritized for earlier access to the COVID-19 vaccine. Both before and after you receive the vaccine, it is important to continue to follow public health guidelines such as those relating to social distancing and wearing masks in many public settings.

## **How will COVID-19 vaccines be distributed and where should lymphoma patients go to receive one?**

COVID-19 vaccines are being distributed and allocated based on a tiered system. Details of this process will in part be determined by processes and prioritizations established by individual states. Healthcare professionals will likely be in communication when the vaccine becomes

available to you, and you can expect that there will be local announcements via news and other media. Health experts anticipate that these vaccines will become more widely available to the general public in late spring or early summer 2021. Be sure to speak with your oncologist about whether a COVID-19 vaccine might be appropriate for you and details of availability at your medical center or elsewhere in your community.

## **Should lymphoma patients and survivors receive the COVID-19 vaccine right away or wait?**

Most lymphoma patients should receive the COVID-19 vaccine as soon as it is available. However, given that some lymphoma treatments might affect the efficacy of a vaccine (by impacting the immune system), lymphoma patients and survivors should consult their oncologist or healthcare team prior to receiving the COVID-19 vaccine — particularly if they are in the midst of lymphoma treatment or have had it recently (e.g., within the last 6-12 months). Studies at this point suggest that the COVID-19 vaccines are safe for even those who have underlying health conditions (with the rare exception of some of those with a history of severe allergic reactions).

### Should caregivers or loved ones get the COVID-19 vaccine? If so, how soon and will it be safe?

The COVID-19 vaccines will be distributed and allocated based on a tiered system. It is uncertain when the vaccine will be available for individuals such as caregivers, but caregivers and loved ones should begin to develop and discuss a vaccination plan with their care team.

### Can the vaccine have negative effects on treatments for lymphoma?

There is no evidence (or expectation) that the vaccine will have any impact on lymphoma therapy, nor should lymphoma patients have an increased risk of side effects. Of note, COVID-19 vaccines are NOT “live virus” vaccines (which would be a type that in some cases may not be appropriate for lymphoma patients).

### Does medication or treatment for lymphoma affect the efficacy of the vaccine?

Lymphoma and lymphoma therapies can be associated with a diminished immune system. An immune response to the vaccine, which then also acts against the virus if infection occurs, is the key way vaccines provide protection. It is expected that certain lymphoma therapies, particularly rituximab (Rituxan) and obinutuzumab (Gazyva), may diminish the immune response to vaccines due to their effects on normal B cells. This observation has been noted in some patients with other vaccines. It is possible that chemotherapy and other treatments, including targeted therapies, may also affect immune responses to vaccines. However, since lymphoma patients (and other patients receiving cancer therapies) were generally not included in clinical trials of COVID-19 vaccines, we do not presently know if or how much lymphoma treatments would affect the efficacy of a vaccine. It may also be that some patients might have a diminished immune response, but that the vaccine may nonetheless provide some meaningful but lower efficacy. These issues are under active study by researchers and likely depend on the details of the nature and timing of lymphoma therapies relative to vaccination. In general, it seems appropriate for lymphoma patients to receive COVID-19 vaccinations when available, given the possibility of at least some efficacy, but it is a good idea to speak with one’s physician/healthcare provider for specific guidance on this issue.

### Does the vaccine have side effects?

Thus far, it has been rare to experience any severe side effects as a result of either vaccine. You may experience mild reactions after receiving the vaccine that are in keeping with similar symptoms after receiving a flu shot. The most common side effect is soreness at the injection site. Other reactions may include fatigue, headache, muscle aches, joint aches and less commonly, fever. These

reactions are temporary and may be a sign that your body is building immunity. It is important that any individuals with a history of severe allergic reactions alert the medical team prior to receiving a vaccine, as such reactions can occasionally occur with COVID-19 vaccination. In general, given the risk of exposure to COVID-19 in the community and the potential for severe consequences of infection (including in patients with lymphoma), it is felt that the benefits of vaccination far outweigh the risks.

### How effective is the COVID-19 vaccine?

The Pfizer and Moderna vaccines demonstrated 95 percent efficacy in clinical trials. Studies thus far suggest that receiving two doses of the vaccines is important for achieving the immune response to provide lasting protection. Even in those of us who are vaccinated, however, following social distancing protocols, handwashing and using masks remain important to maximize safety and avoid the spread of infection. ○

## 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.

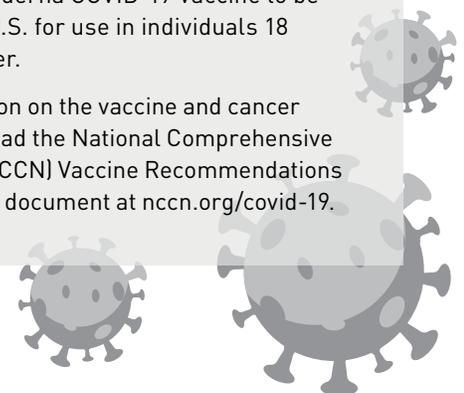
### PFIZER-BIONTECH COVID-19 VACCINE

**December 11, 2020** — the first emergency use authorization (EUA) for a vaccine for the prevention of coronavirus disease 2019 (COVID-19) in individuals 16 years of age or older. The EUA allows Pfizer-BioNTech COVID-19 Vaccine to be distributed in the U.S.

### MODERNA COVID-19 VACCINE

**December 18, 2020** — an emergency use authorization (EUA) for the second vaccine for the prevention of coronavirus disease 2019 (COVID-19). The EUA allows Moderna COVID-19 Vaccine to be distributed in the U.S. for use in individuals 18 years of age or older.

For more information on the vaccine and cancer community, download the National Comprehensive Cancer Network (NCCN) Vaccine Recommendations for Cancer Patients document at [nccn.org/covid-19](https://www.nccn.org/covid-19).





TAMMY WEITZMAN, LICSW

Seattle Cancer Care Alliance

# PATIENT PERSPECTIVES

## MANAGING STRESS AMID A PANDEMIC

A lymphoma diagnosis can be challenging to cope with at any time, but the current pandemic has only increased stress, anxiety and depression for many lymphoma patients. While at times this can all be overwhelming, there are many ways to manage this stress to help patients feel more at ease.

Clinical social worker Tammy Weitzman, LICSW of the Seattle Cancer Care Alliance, addresses the challenges of dealing with a lymphoma diagnosis with a special emphasis on the additional concerns of accessing treatment during a pandemic and managing anxiety and depression as a lymphoma patient.

### **What are the mental health needs of lymphoma patients?**

Adjusting to news of a lymphoma diagnosis can be an ongoing process. It's not unusual for patients to experience many different emotions even throughout a single day. Many find that they experience feelings of shock/disbelief, as if this isn't really happening to them. Feelings of anxiety and sadness/depression are very common. Worry about beginning treatment and fear of the unknown are commonplace. It is important to be able to validate a patient's experiences and feelings as well as normalize them in the context of this setting. Listening attentively

to patients and offering prompt evidence-based clinical interventions to help support patients and their loved ones through their journey can be immensely helpful to them.

### **How has COVID-19 exacerbated the stress and anxiety that is often associated with receiving a lymphoma diagnosis?**

During this pandemic it remains important to have every possible resource accessible to help support you during this incredibly challenging time. For many people diagnosed with cancer, treatment continues as usual during the pandemic. Many are fearful of catching the

virus and being compromised due to their already fragile immune system. News headlines can be debilitating. COVID-19 has significantly increased anxiety because the fear is that COVID-19 can end one's life. Leaning into strategies such as Behavioral Activation (a therapeutic intervention that aims to help people engage more often in enjoyable activities and improve their problem-solving skills) and mindfulness stress reduction techniques can be very powerful and helpful. Practicing these interventions helps balance anxiety, as you continue to learn to adapt to this pandemic in daily life. We have the control to be proactive in what exists in the today, in the present moment. The ability to control outcomes has never belonged to us. Balancing the present moment with the future is where the work is.

### What are some tips and exercises that lymphoma patients can do to manage this stress?

Many patients with lymphoma and other cancers find it helpful to engage in mindfulness-based strategies and activities to cope with and manage the demands of their illness, such as yoga, tai chi and breathing techniques. Tapping into the common meditation apps such as Headspace and Breathe Insights has helped many patients manage their distress.

### What can family members, friends and caregivers do to help ease lymphoma patients' anxiety and depression during COVID-19?

One of the most effective strategies for many of my patients has been to utilize technology (Zoom, FaceTime, etc.) with their loved ones. This increases connection and decreases the sense of isolation for many patients who are stuck at home or in the hospital.

### Caregivers also experience a unique set of challenges and stress during their loved ones' care. What are some things they can do to manage stress?

Caregivers often rush through the caregiver role without the ability to care for themselves. They need to remember several logistics in their head and are often the point of contact for a patient. It's helpful for caregivers to consider the following tips:

- Be mindful of your pace. Slow down!
- Engage in meditation relaxation-based strategies
- Check in with yourself daily
- Appreciate the positives — think of three good things in your life
- Find pockets of restorative time — start with 10 minutes a day and build from there
- Offer yourself compassion and permission to set clear boundaries for yourself

### What mental health resources are available for lymphoma patients, survivors and caregivers to help them during this difficult time?

I encourage patients, survivors and their loved ones to ask their healthcare teams what mental health resources are available to them at their treatment centers. They often offer free resources to their patients to help them along their journey. There are also several other organizations that offer services to individuals who have been impacted by cancer, including the National Alliance for Caregiving, where patients and their loved ones have access to clinical social workers who can provide individual/family supportive counseling and offer resources in their local community. 🕒

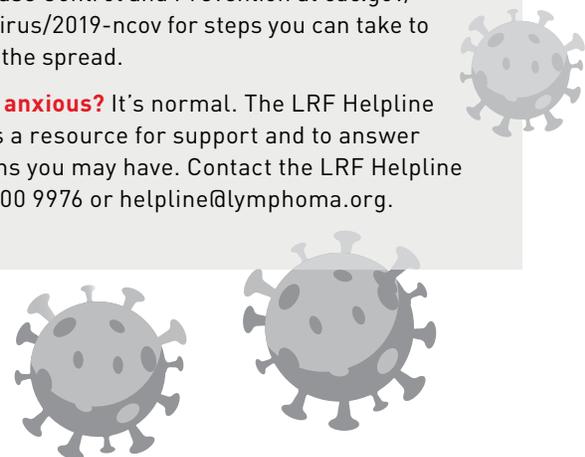
## CURRENT UPDATES ON COVID-19

The health and safety of the lymphoma community is LRF's top priority. We are taking proactive measures to help patients, survivors and their loved ones during the COVID-19 pandemic. Visit the COVID-19 Learning Center at [lymphoma.org/covid19](https://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 free fact sheets and watch COVID-19-specific webinars at [lymphoma.org/covid19](https://lymphoma.org/covid19) to stay informed.

The most important thing you can do to prevent the spread of COVID-19 is to **practice good hygiene and social distancing**. Visit the Centers for Disease Control and Prevention at [cdc.gov/coronavirus/2019-ncov](https://cdc.gov/coronavirus/2019-ncov) for steps you can take to prevent the spread.

**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](mailto:helpline@lymphoma.org).



# BEST SHOT



When Chris Gorelik received news that his central nervous system lymphoma would leave him with months to live, he sought a second opinion and took a chance on a new treatment protocol — to give him a fighting chance to see his children grow up.

Chris Gorelik's first diagnosis of lymphoma started in 2010. Initially, he found himself fighting to stay awake and sleeping as much as 18 hours a day. As a single father of two young children, Gorelik needed as much energy as possible, but his efforts to increase his energy were not working. After numerous doctor visits and tests, he received news that a tumor was growing on his kidney. It was later confirmed he had diffuse large B-cell lymphoma (DLBCL).

"I remember my doctor coming into the room, looking very grim, to tell me I had cancer. But quite frankly, my first reaction was that I was relieved to finally know what was wrong with me," says Gorelik. "I was even more relieved when I learned my cancer was DLBCL, because of how effective the treatments are."

DLBCL is an aggressive or fast-growing type of non-Hodgkin lymphoma (NHL). DLBCL affects B-lymphocytes, which are one type of white blood cell. These lymphocytes make antibodies to fight infections and are an essential part of the lymphatic system. DLBCL is the most common type of NHL worldwide, accounting for 18,000 newly diagnosed cases in the United States each year.

Presently, the most widely used treatment for DLBCL is the combination therapy known as R-CHOP (rituximab [Rituxan], cyclophosphamide [Cytoxan], and prednisone). The R-CHOP regimen is usually given in 21-day cycles (once every 21 days) for an average of six cycles. However, the length and number of cycles given can vary based on the patient's disease and health status.

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**"The most difficult part of my diagnosis was telling my children, who were 12 and 10 years old at the time."**

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"The most difficult part of my diagnosis was telling my children, who were 12 and 10 years old at the time," says Gorelik. "Fortunately, we had been working with a family therapist since 2004. To say she was instrumental in helping our family navigate through some difficult times is a massive understatement."

With the family therapist's help, Gorelik was successfully able to communicate with children Madeline and Maxwell throughout his illness. "The best advice our therapist gave us was that there was no need for my kids to participate in my illness or even be a part of my care. They could just be kids, doing kids things. In fact, they shouldn't even be given any slack from their daily routine because of my illness," says Gorelik. "They should still be held to family standards, attend class, do homework on time, complete their chores, have playdates and go to all their extracurricular activities." This helped the children for many reasons, and it also helped Gorelik as it took a great deal of emotion out of everyday life decisions.

Gorelik's therapist also gave him a mantra, "If I do what the doctor says and I don't do anything stupid, I'll be fine." This mantra, according to Gorelik, helped his entire family, especially when he had to go off to the ER with an infection or leave for a week for a new chemotherapy treatment. Gorelik would tell the children this mantra and it calmed everyone down right away. It also helped him make the right decisions when he felt too tired to complete tasks from his doctor. "In my mind, a big part of beating cancer is doing what the doctor tells you and not doing anything stupid!" Gorelik jokingly says.

Unfortunately, one year after completing treatment for DLBCL and in remission, he began to feel soreness and stiffness on the right side of his body. During an appointment with an acupuncturist to help with his body stiffness, the right side of his face went completely numb.

"The right side of my face just fell. The acupuncturist looked at me and said, 'You need to go to the ER right now.' So, I drove myself to the ER," says Gorelik. "When I walked in, a nurse took one look at me and immediately pulled me through the lobby past a dozen other waiting patients and brought me in to see a doctor. Regrettably, the doctor misdiagnosed me with Bell's palsy. This resulted in prescribing me the standard treatment for Bell's palsy, a high dose of steroids, which masked the real issue."

Three weeks following the ER doctors' protocol of steroids, Gorelik's symptoms became so bad he was no longer able to move his right leg and was unable to walk. The pain was incredible. After several tests, he was finally diagnosed correctly with central nervous system lymphoma (CNS).

*Continued on the next page*

“Looking back, I would’ve benefited greatly having an advocate to help me navigate through this illness. I was essentially going through this alone while raising two children at the same time,” says Gorelik. “Throughout all of it, I never thought to call my hematologist or even let any of my other doctors know I had been to the ER and diagnosed with Bell’s palsy. Just doing this would have saved me countless hours of pain and confusion. It seems crazy to me now that I failed to reach out to any one of my primary physicians. However, it does demonstrate how one’s thinking becomes distorted and clouded when going through an illness. It’s important to have someone there to double-check your thinking during times like these.”

Gorelik also said that this does not mean an advocate should do everything for the patient. “I believe one of the most helpful things for me was the fact that I was responsible for making all my appointments and travel arrangements for my treatments, keeping track of my

medicines and ensuring the care of my children. This forced me to stay alert and connected to the world. Sometimes an advocate can do too much, but it’s important to remember, sometimes the best help is to do nothing at all. It is finding the right balance that makes an advocate most effective.”

CNS lymphoma is an aggressive form of NHL in which malignant (cancer) cells form in the brain’s lymph tissue and/or spinal cord. It may develop in the brain, spinal cord, eye or leptomeninges (two of the membranes surrounding the brain and spinal cord). The main symptoms of CNS lymphoma are focal neurological deficits (i.e., problems with nerve, spinal cord or brain function), but headaches, vomiting, confusion, seizures, personality changes and blurred vision can also occur.

Dealing with a more severe cancer and poorer prognosis, Gorelik set out to accomplish specific goals. “Survivorship for me at that point meant getting my kids to college.

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**“Looking back, I would’ve benefited greatly having an advocate to help me navigate through this illness. I was essentially going through this alone while raising two children at the same time...”**

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*Chris with his family  
(left to right: Brittany,  
Jennifer, Bryanna,  
Maxwell and Madeline)*

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“The sureness that I was on the right path saw me through many days and nights of what otherwise would have been much scarier.”

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I thought if I can hang on long enough to get them to college, they would be okay,” says Gorelik. “I had to figure out how to stay with them long enough to do this. After this decision, it really never again occurred to me I was going to die. I can’t explain why except to say that the children were an awfully great incentive!”

Through a connection with a friend, Gorelik was able to obtain referrals to three oncologists specializing in CNS. Gorelik decided on one doctor offering a different protocol outside the standard treatment. “It was a leap of faith, absolutely — to try a different treatment protocol, especially in my condition. But what encouraged me to try this treatment was my confidence in the referrals and the fact that this particular doctor had such an air of tenacity and reassurance. The sureness that I was on the right path saw me through many days and nights of what otherwise would have been much scarier.”

Gorelik’s new treatment protocol required him to receive 17 milligrams of methotrexate every three weeks. After almost one year of this treatment, Gorelik was given a new chemo “cocktail” that he describes as the most physically difficult part of his protocol. This was followed by an autologous stem cell transplant. Two years ago, and five years after his stem cell transplant, Gorelik

finally received the news that he is cancer-free.

Since then, Gorelik continues to be active, playing low-impact sports that allow him to stay healthy without agitating some of the prolonged symptoms and side-effects acquired from his lymphoma and aggressive treatments, like seizures and hemophilia. He also uses his story to connect with others in the lymphoma community as an LRF Ambassador, and spoke at a TED Talk titled “How to help a friend with cancer.” He’s even remarried and has a large, happily blended family. His daughter graduated from the University of Alabama one year ago, and his son is currently a junior at the University of Southern California.

“I remember the day I helped my daughter move into her dorm. A typical college move-in day — tons of parents with their kids, everyone whizzing around from dorm room to dorm room, boxes everywhere,” recalls Gorelik. “After all was squared away, I hugged my daughter and said goodbye. When I left her room, miraculously, the entire hallway was empty, not a soul but me. It was at that moment on my way to the elevator when it hit me. I raised my fists over my head and quietly said to myself, ‘I did it. I got her to college.’ No exclamation points. Just a silent moment of pure triumph.” ○

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

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# UPCOMING EVENTS



<b>New York Lymphoma Rounds</b> — <i>Virtual</i> .....	<b>2.23</b>
<b>Ask the Doctor About Lymphoma Program</b> — <i>Virtual</i> .....	<b>2.24</b>
<b>Philadelphia Lymphoma Rounds</b> — <i>Virtual</i> .....	<b>2.25</b>
<b>Rare Disease Day: Cutaneous T-cell Lymphoma and the African American Community</b> — <i>Facebook Live</i> .....	<b>2.28</b>
<b>East Coast Lymphoma Workshop</b> — <i>Virtual</i> .....	<b>3.20</b>
<b>Team LRF Houston Walk: Research Update and Kickoff Event</b> — <i>Virtual</i> .....	<b>3.23</b>
<b>Team LRF Dallas Walk: Research Update and Kickoff Event</b> — <i>Virtual</i> .....	<b>3.24</b>
<b>Team LRF Nebraska Walk: Research Update and Kickoff Event</b> — <i>Virtual</i> .....	<b>3.25</b>
<b>Team LRF Minnesota Walk: Research Update and Kickoff Event</b> — <i>Virtual</i> .....	<b>3.30</b>
<b>Team LRF New York Walk: Research Update and Kickoff Event</b> — <i>Virtual</i> .....	<b>3.31</b>
<b>Walk On! America</b> — <i>Virtual</i> .....	<b>6.4</b>
<b>Neighborhood Lymphoma Walks</b> — <i>Nationwide</i> .....	<b>6.5-6</b>

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



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When you include the Lymphoma Research Foundation (LRF) in your estate plan, you are investing in the most promising research that has the greatest potential to dramatically improve the lives of those impacted by lymphoma.

Thank you for ensuring LRF can serve those touched by this disease well into the future and, ultimately, eradicate lymphoma.

To learn more, contact Kate LeBoeuf at **646 531 5184** or **[kleboeuf@lymphoma.org](mailto:kleboeuf@lymphoma.org)**, or visit **[lymphoma.org/legacy](http://lymphoma.org/legacy)**.

