

PULSE

BRIDGING THE GAP IN ADOLESCENT AND YOUNG ADULT LYMPHOMA RESEARCH

The adolescent and young adult (AYA) oncology field is an underserved population compared to pediatric and adult oncology, but Dr. Kara Kelly is helping to bridge the gap and improve patient care.

page 12

THE NEW RESEARCH REPORT

IN THE BUSINESS OF GIVING BACK

page 6

MEET THE 2020 LYMPHOMA CLINICAL MENTORING PROGRAM SCHOLARS

page 16



PULSE

A Publication for Friends of the Lymphoma Research Foundation

LYMPHOMA
RESEARCH • FOUNDATION

Pulse is a publication of the Lymphoma Research Foundation, providing the latest updates on the Foundation and its focus on lymphoma research, awareness and education.

The Lymphoma Research Foundation is devoted to funding innovative lymphoma research and serving the lymphoma community through a comprehensive series of education programs, outreach initiatives and patient services.

FOUNDATION LEADERSHIP

Michael Werner

Chair, Board of Directors

Andrew D. Zelenetz, MD, PhD

Chair, Scientific Advisory Board

Meghan E. Gutierrez

Chief Executive Officer

Editor

Kinya Harte

Associate Editor

Nichole Musumeci

Editorial Assistant

Penelope Andujar

Contributors

Amy Jin

Christina Kazhe

Michael Werner

Editorial Board

Jesse Brown

Victor Gonzalez

Kyle Haines

Gary D. Jaworski, PhD

Sarah Quinlan

Rebecca Rausch

Traci Scott Karro

Whitney Steen

William White

CONTACT US

Lymphoma Research Foundation

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

Tel: 212 349 2910

Fax: 212 349 2886

Email: LRF@lymphoma.org

lymphoma.org

LRF Helpline

800 500 9976

Helpline@lymphoma.org

Contact the Editor

For more information or to share comments, please email editor@lymphoma.org.

Pulse ©2020 Lymphoma Research Foundation

Commit to Your Future Impact Today

Planned Giving: An Option for All

A planned gift is a commitment to making a gift in the future. Often, this means including an organization as a beneficiary to part of your estate, investment accounts, or other assets.

A planned gift of any size can have a demonstrable impact on the lymphoma community and can result in favorable tax benefits to the donor.

To learn more, contact Gary D. Jaworski at 212-349-2799 or gjaworski@lymphoma.org

LYMPHOMA
RESEARCH • FOUNDATION

lymphoma.org/legacy

TABLE OF CONTENTS

[FEATURES]

In the Business of Giving Back

Corporate social responsibility is a cornerstone of many companies and has become an increasingly important business practice; many companies are joining LRF to support the lymphoma community.

Bridging the Gap in Adolescent and Young Adult Lymphoma Research

Adolescent and young adult (AYA) lymphoma patients and survivors face unique medical and psychosocial challenges when it comes to care. Dr. Kara Kelly is helping to bridge the gap and improve patient care for this underserved population.

Meet the 2020 Lymphoma Clinical Research Mentoring Program Scholars

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

An Emerging Cancer: Survivors Advocate for Women's Health and Awareness

Breast implant-associated anaplastic large cell lymphoma (BIA-ALCL) is impacting women globally — leaving many questions for both patients and providers.

[DEPARTMENTS]

Community Impact

Philanthropy in Action

Advocacy Matters

Op-Ed: America Needs Nonprofits Now More Than Ever

From the Field

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

Living with Lymphoma

Patient Perspectives
Five Mindfulness Tips to Get Through COVID-19 and Beyond



6

12

16

25



4

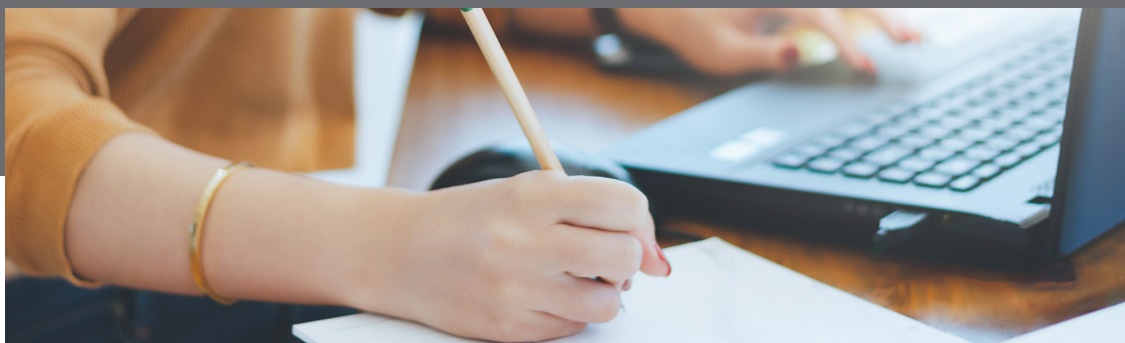
10

20

28



VIRTUAL EDUCATION PROGRAMS



Upcoming Virtual Education Programs:

6.24

Update on Immunotherapy
Webinar

7.8

Update on Adolescent and
Young Adult Lymphoma Webinar

7.16

Virtual Washington, DC Lymphoma
Workshop

7.21

Update on Mantle Cell Lymphoma
Webinar

7.30

Virtual Seattle Lymphoma
Workshop

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

Whether you are newly diagnosed, want detailed information about your lymphoma subtype, are looking for ongoing support, or seeking help with long-term survivorship, LRF is here to help.

Visit lymphoma.org/programs to register and learn more.

WELCOME TO PULSE

Your health and safety are our priority, especially during these unprecedented times.

As we continue to learn and live through the current pandemic, we want you to know that the Lymphoma Research Foundation (LRF) is here for you. We remain committed to being a resource for lymphoma patients, survivors and their loved ones, providing the most up-to-date and evidence-based information about lymphoma and connecting them to the support and resources they need. We have been hard at work developing COVID-19-specific educational programming and resources for the lymphoma community, including webinars, fact sheets and social media live chats with experts. For the latest information on COVID-19 and how it affects the lymphoma community, visit lymphoma.org/covid19.



This issue of *Pulse* is an extension of our support efforts and features articles on COVID-19, including how LRF is advancing new programs, mindfulness and meditation tips, and instruction on the best way to monitor your health during this time.

In this issue we also profile one of the world's most prominent pediatric and adolescent lymphoma clinical investigators, LRF Scientific Advisory Board member Kara Kelly, MD from Roswell Park Comprehensive Cancer Center/University at Buffalo Jacobs School of Medicine. Dr. Kelly describes for us how she is working to bridge the gap between pediatric and adult oncology to better understand and address the unique needs of adolescent and young adult (AYA) cancer patients and survivors. In recognition of Women's Health Month and Cancer Survivors Month, this issue features stories on emerging issues in lymphoma including breast implant-associated anaplastic large cell lymphoma (BIA-ALCL) and late-term side effects for AYA cancer survivors.

Finally, in the face of this global health emergency, which has shut down scientific research labs across the country, we are excited to introduce you to the 2020 LRF Lymphoma Clinical Research Mentoring Program (LCRMP) Scholars. The LCRMP is a first-of-its-kind education and mentoring program for junior scientists who wish to focus their careers on lymphoma clinical research. Since the creation of the LCRMP five years ago, every Scholar participating in the program is still studying blood cancer, and 97 percent are studying lymphoma specifically. Continued investment in innovative research is a top priority for the Foundation, as is keeping the best and brightest scientists in the field of lymphoma research.

The support you have given to the Foundation has been instrumental in allowing us to fund this new class of Scholars. Thank you for your part in helping the Foundation fund life-saving research and support all those affected by this blood cancer.

Sincerely,

A handwritten signature in black ink, appearing to read 'Meghan Gutierrez', with a stylized flourish at the end.

Meghan Gutierrez
Chief Executive Officer

PHILANTHROPY IN ACTION: ADJUSTING TO THE NEW NORMAL TO CONTINUE TO SERVE THE LYMPHOMA COMMUNITY

In the blink of an eye, COVID-19 swept the world and disrupted the way we interact, communicate, conduct business and live. While life as we knew it transformed, businesses scrambled to adjust to the “new normal” and find alternative ways to connect with their consumers. Nonprofit organizations were no exception, as they too felt the pressure of continuing to serve some of the most vulnerable populations within their communities, while reimagining funding and programming in an isolated environment.

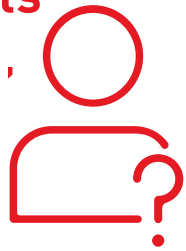
Nonprofits whose missions do not specifically address COVID-19-related needs have faced an added obstacle of raising awareness, while continuing to provide resources to those who need them. For many individuals, nonprofits serve as their trusted resource for accurate and up-to-date information. As the pandemic began to unfold, nonprofits such as the Lymphoma Research Foundation (LRF) quickly responded by coming up with new and creative ways to meet the needs of the lymphoma community.

PIVOTING TO VIRTUAL EDUCATION

With no traveling or public gatherings permitted, COVID-19 forced many businesses to undergo a dramatic digital transformation in an instant. Since the onset of the pandemic, the world has seen companies including the likes of Microsoft, the American Society of Clinical Oncology, and Facebook pivot traditional in-person conferences to virtual programs. The Lymphoma Research Foundation’s in-person educational programs are vital tools to educate and interact with the lymphoma community. In a matter of just one month, the LRF Helpline witnessed a 93 percent

increase in requests for lymphoma information, resources and support due to the coronavirus outbreak.

The LRF Helpline witnessed a **93% increase in requests** for lymphoma information, resources and support due to the coronavirus outbreak.



“Hearing the latest information on COVID-19, lymphoma treatment options and research helps patients cope during these challenging times,” says Sarah Quinlan, Senior Director of Programs and Strategy at the Lymphoma Research Foundation. “Each day can present new obstacles, especially for those living with lymphoma, and we want to support patients by giving them access to medical experts.”

As an immediate response to COVID-19, LRF hosted a webinar featuring LRF Scientific Advisory Board (SAB) member John P. Leonard, MD (Weill Cornell Medicine), who shared information on what lymphoma patients need to know about the virus. LRF also hosted its first Virtual Ask the Doctor About Lymphoma and Lymphoma Workshop educational programs, bringing these hallmark educational events into the safety of people’s homes.

“As a global community, we are all learning to pivot many aspects of our lives and are adjusting to the new normal,” says Quinlan. “LRF continues to strive to meet the evolving needs of patients and their loved ones during the pandemic.”

SUPPORTING THE MOST VULNERABLE

To further support the lymphoma community during COVID-19, LRF sought to address the added financial burden related to the virus. Aside from the already overwhelming costs that are often associated with cancer, many people contacting the LRF Helpline reported that COVID-19 made the issue worse. According to a survey by the American Cancer Society, 4 in 10 cancer patients in active treatment said COVID-19 was having a notable effect on their ability to afford their care, due mostly to reduced work hours.

LRF's Patient Aid Program is a cornerstone resource for people undergoing treatment for lymphoma. The program provides limited financial assistance to lymphoma patients to help cover the cost of out-of-pocket expenses associated with their care.

4 in 10 cancer patients in active treatment said **COVID-19** was having a notable effect on their ability to afford their care...

“Receiving a lymphoma diagnosis can be overwhelming and, coupled with the financial burden often associated with cancer treatment, can be devastating,” says Quinlan.

In direct response to this increased need, LRF expanded its Patient Aid Program to create a COVID-19-specific financial

assistance grant program, helping those impacted financially by coronavirus and lymphoma. During the first week the grant program opened, the LRF Helpline received over 100 inquiries.

“No patient should have to choose between paying for necessities and potentially life-saving treatments, and LRF hopes that this program ensures they don't have to,” says Quinlan.

SOCIALLY DISTANCED FUNDRAISING

COVID-19 also had a significant impact on nonprofits' ability to fundraise. Organizations were challenged to create virtual fundraising events that could help engage donors while social distancing.

The nonprofit rating organization Charity Navigator reported a 237 percent increase in people giving to nonprofits through their site as compared to the year prior, and a 30 percent increase in the average donation — showing that many individuals were still eager to give back despite the economic uncertainty presented by COVID-19.

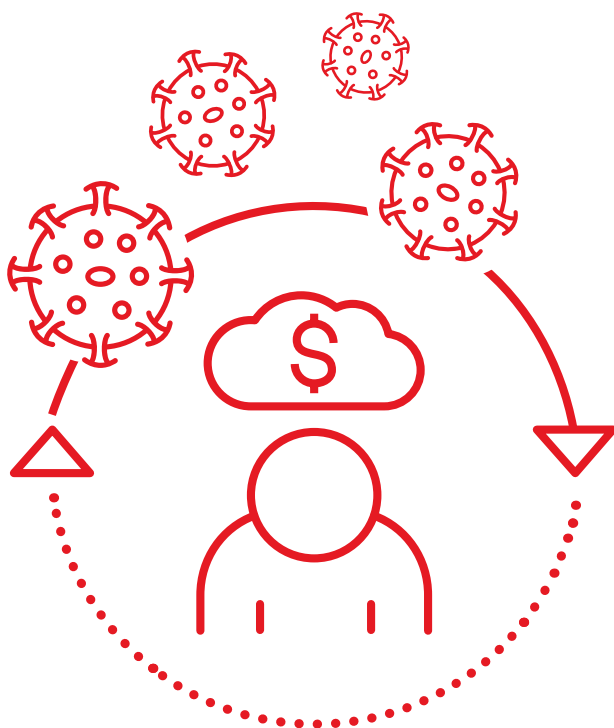
When it became clear that coronavirus would impact public gatherings, LRF's distinguished events and peer-to-peer fundraising teams began to rethink LRF's signature fundraising events, including *Swirl: A Wine Tasting Event* and Team LRF Lymphoma Walks.

Swirl: A Wine Tasting Event offers attendees the opportunity to taste and enjoy a collection of wines, participate in a silent auction and raise money to support LRF's mission. In an effort to bring this event into the comfort of people's homes, the traditional in-person event was pivoted to a virtual tasting series, *Swirl: America*. The event will feature a mixology demonstration along with exciting remarks from LRF spokesperson and chief investigative reporter for *Inside Edition*, Lisa Guerrero.

The national Team LRF Lymphoma Walk series raises critical funds for lymphoma research programs and provides an opportunity for the lymphoma community to come together for a special day of celebration. “LRF's Lymphoma Walk is an event that my family and friends look forward to participating in each year,” says longtime Houston Lymphoma Walk participant Dexter Neal. “When I realized there was a chance that it wouldn't happen this year because of COVID-19, I was extremely disappointed.”

LRF began planning its first-ever Facebook Live fundraising rally *Rally On! America* as a pivot to its Lymphoma Walks and bring the lymphoma community together during a time of social distancing.

“*Rally On!* gives me an opportunity to interact with my fellow survivors and other members of the lymphoma community, which has even more meaning during this global pandemic,” says Neal. “Lymphoma patients and their loved ones are lucky to have LRF to support and comfort them during these most difficult times.” ○



IN THE BUSINESS OF GIVING BACK



Lewis Kweit (top row, 4th from left) with fundraising Team Kweit at the 2019 New York Lymphoma Walk. Kweit provides pro bono legal services to LRF through his law firm Akin Gump Strauss Hauer & Feld

Corporate social responsibility is a cornerstone of many companies and has become an increasingly important business practice. Being a socially responsible company helps businesses “do good” while building credibility among their customers and employees. While many companies rely on monetary donations to give back to causes, some businesses find it more impactful to make in-kind contributions — donations of goods, services or time.

In 2019, corporations donated over \$20 billion to nonprofit organizations

According to Double the Donation, corporate philanthropy increased by more than 15 percent between 2013 and 2017 and is estimated to continue growing. In fact, in 2019, corporations donated over \$20 billion to nonprofit organizations. Many organizations, such as the Lymphoma Research Foundation (LRF), have long-standing partnerships with businesses that support LRF’s mission by giving back through goods and services. This allows organizations to free up time and money towards serving their communities.

PHILANTHROPIC PRINTING*

J Squared Press Inc., a commercial printing company based in the New York City area, has been a longtime supporter of LRF and many other nonprofits. J Squared Press's owner and president, Eric Mendelson, has been in the printing business for over 36 years, after acquiring the company from his uncle. Mendelson takes great pride in his work and his ability to use his company to support causes that are important to him, sharing, "My company's commitment to supporting our nonprofit clients is what sets us apart in the printing industry."

J Squared Press's partnership with LRF stems from a very personal connection that Mendelson has to lymphoma. His youngest son, Jordan, was diagnosed with diffuse large B-cell lymphoma (DLBCL) at the age of 23. Overwhelmed like many parents of cancer patients, Mendelson searched for support and found the LRF Helpline. Shortly after, he introduced LRF to his printing company. "After speaking with the staff at LRF, I fell in love with their kindness and warmth," says Mendelson. "It became more like family."

When J Squared Press began its partnership with LRF, Mendelson came up with an idea that would help him give more than high-quality printing services. In addition to keeping the cost of his printing services low, he donates a portion of the cost of each printing project back to LRF. Through this business model, J Squared Press has donated over \$6,450 to support the lymphoma community since 2017. "As long as I can do what I am doing and maintain a relationship — I don't need to get rich on this work, it's



From left: Eric Mendelson with son Josh, wife Debbi and son Jordan at the 2019 New York Lymphoma Walk

When I was on the phone and needed help, the Lymphoma Research Foundation helped me through tears and rough days. Now we have the opportunity to help other people like LRF helped us.

– Eric Mendelson, J Squared Press

time to give back," he says. "Continuing to give LRF my support makes me happy."

Mendelson and his family not only give back through business, but also through various personal capacities as well. In 2019, the Mendelson family raised hundreds of dollars for the New York Lymphoma Walk, and his son Jordan helps to raise awareness through his participation as an LRF Ambassador. "When I was on the phone and needed help, the Lymphoma Research Foundation helped me through tears and the rough days," says Mendelson. "Now we have the opportunity to help other people like LRF helped us." Mendelson says that he sees his company's partnership with LRF as a lifelong one.

LAWYERS FOR LYMPHOMA

Pro bono work is conducted by many law firms in order to provide a service to their community that would otherwise not be available due to limited resources. In fact, the American Bar Association requires attorneys to complete 50 hours of pro bono work each year. Akin Gump Strauss Hauer & Feld (Akin Gump) is a law firm that goes above and beyond the national requirement.

Akin Gump is the largest lobbying law firm in the United States, with over a thousand attorneys across the globe. The firm's attorneys have devoted more than 100 pro bono hours to clients per year and have received countless awards for pro bono work — LRF being among the many nonprofits that the firm supports.

A 20-year-partner of Akin Gump, Lewis Kweit connected LRF to the firm due to a personal connection to lymphoma. Kweit's wife, Karen, was diagnosed with Hodgkin lymphoma when she was 20 years old. As a result of her

[COMMUNITY IMPACT]

journey with lymphoma, she wanted to help others who have been diagnosed.

When she passed in 2017 due to a heart attack, Kweit decided to continue her legacy and began supporting a nonprofit focusing on lymphoma. “Upon her passing, I picked up the torch, and that was my connection,” he says. While in search of an organization, he came across LRF. “I felt that because LRF is solely focused on lymphoma and I was impressed with their research, I wanted to get involved with the organization,” Kweit says.

Through Kweit’s support, his firm has given LRF access to a team of lawyers who specialize in contract law, including intellectual property specialists, to assist LRF with its research grant contract process. “Through my law firm, we have resources that could be very helpful to LRF, and I thought it was a great way to support the organization outside of raising money or writing checks,” he says.

Many of the services that Akin Gump provides for LRF include reviewing and updating research contracts and ensuring that the Foundation is updated on new state laws and institutional policies that require attention, an important factor, as LRF funds research across the country.

Kweit also supports LRF beyond his pro bono work with his law firm. Since 2017, Kweit’s fundraising team at the Team LRF New York Lymphoma Walk has raised nearly \$60,000 and is one of the top fundraising teams at the Walk. He brings this culture of giving back in his office by encouraging his colleagues to donate to the organization, and a few of them even joined his team to walk. Kweit’s efforts to raise funds in his late wife’s memory will leave a lasting legacy.

I felt that because LRF is solely focused on lymphoma and I was impressed with their research, I wanted to get involved with the organization...

— Lewis Kweit, Esq., Akin Gump Strauss Hauer & Feld



Lewis Kweit and a team member at the 2019 New York Lymphoma Walk

BENEFICENCE THROUGH BEVERAGES

In-kind donations are not limited to reduced pricing or the provision of free services; they can also take on the form of donated goods. Many companies like Southern Glazer’s Wine & Spirits (SGWS) use this model of philanthropy. SGWS is the largest wine and spirits distributor in the United States and Canada. SGWS Executive Vice President of Commercial Operations Kevin Fennessey made the connection between LRF and SGWS in 2013 in an effort to support LRF’s mission. Fennessey was looking for an opportunity to give back after his wife was diagnosed with breast cancer. “We know there is no direct correlation between her cancer and lymphoma, however we saw that there was a real need for support in this particular type of cancer,” says Fennessey.

In 2013, he secured SGWS’ support as the Founding Sponsor of LRF’s signature fundraising series, *Swirl: A Wine Tasting Event*. The event, held in six cities throughout the country, provides an opportunity for attendees to enjoy a collection of rare and highly sought-after wines and spirits provided by SGWS. While their main contribution to *Swirl* is the in-kind donation of beverages, Fennessey, who is also a member of the LRF Board of Directors, emphasized that when it comes to this event, SGWS is “all hands-on deck.” With the help of SGWS, the *Swirl* series has raised over \$1.2 million to support the LRF mission.

“The *Swirl* series is a perfect event for SGWS to support as it educates attendees about the great wines SGWS distributes while, of course, raising money and awareness for LRF,” says Fennessey. “SGWS is always looking for ways to develop the series and bring it to other cities.” Fennessey’s passion

“With the help of Southern Glazer’s Wine & Spirits, the Swirl series raised over \$1.2 million to support the LRF mission.”

for giving back has always been supported by SGWS, as the company encourages its employees to support causes that are important to them. Through a program called *Voluncheers*, SGWS strives to support local and regional organizations across North America by devoting time and resources to those who need them most. “Southern Glazer’s Wine & Spirits supports many businesses and encourages its employees to do the same. They really are a company that strives to be the fabric of the community,” he says.

Companies like Akin Gump Strauss Hauer & Feld, J Squared Press, and Southern Glazer’s Wine & Spirits have made it their mission to make a difference. Whether it is integrating philanthropic culture into the workplace like SGWS or donating vital services like Akin Gump and J Squared Press, businesses are giving back, improving the state of the world and presenting the courage necessary to achieve a shared goal. The Lymphoma Research Foundation is grateful for the philanthropic partnerships of Eric Mendelson, Lewis Kweit,



Kevin Fennessey (middle) with Charlie Madden (left) and Mike Evans of Southern Glazer’s Wine & Spirits

Kevin Fennessey and other partners for their critical support of LRF’s mission to eradicate lymphoma and serve those touched by this disease. ○

If you or your business would like to learn more about partnership opportunities, please contact development@lymphoma.org.

*Eric Mendelson of J Squared Press has pledged to donate a portion of the proceeds of any new business that results from this article to the Lymphoma Research Foundation.

COVID-19 LEARNING CENTER

The well-being of people with lymphoma and their caregivers is the top priority of the Lymphoma Research Foundation. People with cancer who are in active cancer treatment or have been previously treated for cancer, older patients, and people with other chronic medical conditions may be at higher risk should they contract COVID-19.

LRF’s COVID-19 Learning Center provides members of the lymphoma community with up-to-date information on the novel coronavirus and LRF educational programming and events. Recognizing that members of the lymphoma community may require additional education materials and services at this time, we want to encourage anyone in need of support to contact the LRF Helpline at 800-500-9976 or helpline at lymphoma.org.

Visit the COVID-19 Learning Center at lymphoma.org/covid19.



OP-ED:

AMERICA NEEDS NONPROFITS NOW MORE THAN EVER

The COVID-19 pandemic has brought the country to a crawl. Lawmakers and consumers alike are rightly worried about the economic security of shuttered bars, restaurants, and retail locations. But many have largely ignored the nation's charities.

COVID-19 has the potential to devastate nonprofit organizations, which provide essential services to vulnerable populations, fund biomedical research, support education, and employ millions of Americans. Social distancing and donor uncertainty prevent these organizations from hosting crucial fundraisers and food drives, recruiting volunteers, and in some cases, delivering their services to those in need.

On May 15, 2020, Senators Amy Klobuchar (D-MN), Brian Schatz (D-HI), Ron Wyden (D-OR) and Sherrod Brown (D-OH) introduced a bill called the Work Opportunities and Resources to Keep Nonprofits Well (WORK NOW) Act to support nonprofit organizations during the COVID-19 pandemic. These funds will help maintain vital services and protect a vital pillar of our economy.

Over 1 million nonprofits employ more than 12 million people in the United States and contribute \$1 trillion to the economy each year.

COVID-19 has disrupted the nation's nonprofits just when many citizens need them most. The American Red Cross — which provides 40 percent of the nation's blood supply — has had to cancel 7,000 blood drives since March 1, resulting in 200,000 lost donations. Such a severe shortage of blood puts lives at risk. Hospitals need a constant flow of donations to treat cancer patients, trauma victims, and others.

Many of the 3.3 million Americans who recently filed for unemployment will soon turn to The Salvation Army for food, shelter, and financial assistance. But COVID-19 has forced The Salvation Army to close many of its donation centers and retail stores.

Feeding America has seen a sharp decline in volunteers. The organization is one of many hunger relief organizations scrambling to retain staff and keep their shelves stocked in the face of a sinking economy. Seattle-based Food Lifeline has gone from 18,000 to 20 volunteers, just as it expects demand for its services to double. The organization no longer has the capacity to sort food donations and has resorted to purchasing pre-packaged boxes of food.

COVID-19 has also dealt a severe blow to America's cancer research nonprofits. The Lymphoma Research Foundation has postponed all in-person programs events, including free patient and professional education programs and fundraising events, at least through the fall, to protect the patients who attend these events and who are at higher risk for severe complications from the novel coronavirus.

With hospitals canceling non-essential visits, lymphoma patients will rely on the Lymphoma Research Foundation to provide information to manage their disease.



With hospitals canceling non-essential visits, cancer patients will rely on organizations like the Lymphoma Research Foundation to provide information about how to manage their disease. And since cancer patients are particularly vulnerable to COVID-19, they'll look to nonprofit organizations like LRF for support and ways to stay healthy throughout the pandemic.

Finally, Partnership With Native Americans (PWNA) provides essential services for those living on remote reservations. Native Americans are extremely susceptible to COVID-19 due to overcrowded housing, higher rates of diabetes and respiratory illness, and limited healthcare options. Nearly 50 percent of grandparents raise their grandchildren, putting themselves at risk of contracting the virus. And tribal communities often live in food deserts. The Navajo Nation, for instance, spans three states and has only 13 grocery stores.

PWNA, one of the largest nonprofits serving Indian Country, is still making critical deliveries of food, water, sanitizer, toilet paper and other essentials to hundreds of tribal communities, even those with travel restrictions and shelter-in-place orders. But as COVID-19 increases demand, PWNA's warehouse supplies are running low.

By providing emergency funds to nonprofit organizations, both large and small, Congress could help the economy as well as vulnerable Americans. Over 1 million charitable nonprofits employ more than 12 million people in the United States and contribute \$1 trillion to the economy each year. Sustaining these groups through our present crisis will help lessen the economic turmoil wrought by COVID-19. Now more than ever, we need our nonprofits. ○

About the Authors



Michael Werner

is a long-standing Board member of the Chicago Council on Global Affairs.

Michael Werner serves as Chair of the Lymphoma Research Foundation's Board of Directors and is a lymphoma survivor. He is the Founder and CEO of Chicago-based Home Experience, LLC, a digital and services company enhancing the home ownership experience. Werner is the former President and CEO of Globe Union Group, Inc., and



Christina Kazhe

Christina Kazhe serves as Chair of the Partnership With Native American's Board of Directors and specializes in protecting the interests of Native Americans, such as tribal sovereignty, legal and public policy and federal recognition. Founder of The Kazhe Law Group, she holds a Juris Doctor from Boalt School of Law at UC Berkeley and a Bachelor's in Human Development and Native American Studies from the University of California, Davis. Kazhe is a member of the Navajo Nation and affiliate to the Mescalero Apache Tribe.

This opinion editorial was published in the "International Business Times" on May 10, 2020, and updated to include in this edition of "Pulse."



Dr. Kara Kelly with colleague Douglas McDaniel, DACM, Dipl. Ac. (NCCAOM), L.Ac., at Roswell Park Comprehensive Cancer Center, treating a patient

BRIDGING THE GAP IN **ADOLESCENT AND YOUNG ADULT LYMPHOMA RESEARCH**

“Adolescent and young adult patients need advocates to help make sure they’re able to experience improvements in care just like everyone else.”

Lymphoma is a disease that does not discriminate. It impacts both young and old with equal intensity. It does not show preference to the elderly or otherwise infirmed and it is gender neutral. So, when Kara Kelly, MD, an oncologist and researcher at Roswell Park Comprehensive Cancer Center, decided to go into the field of pediatric oncology, she was fulfilling an ongoing need within the field of cancer research and care.

Each year, nearly 70,000 adolescents and young adults (AYA) are diagnosed with cancer; and lymphoma, the most common type of blood cancer, accounts for nearly 1 in 5 cancer diagnoses among young people. Since this is a historically underserved population, Dr. Kelly is working tirelessly to ensure that AYA patients have advocates within the lymphoma community.

FOCUSING ON YOUNG ADULTS

While attending medical school at the University at Buffalo, Dr. Kelly participated in a pediatric rotation that sparked her interest in working with younger patients. She was excited at the prospect of making an impact on the lives of children that would, in essence, change their lives forever.

“I really liked the ability to work with patients and their entire families throughout their journey, and the pediatric field is a rather supportive one, so I enjoyed working in that environment,” says Dr. Kelly, who is also Chair of the Roswell Park Oishei Children’s Cancer and Blood Disorders Program.

Dr. Kelly thought she would pursue a career in general pediatrics, but as she began to learn more about the field, she realized if her patients’ cases became complicated, she would need to refer them to sub-specialists to continue their care. “I really liked taking care of those more complex patients,” she says. “One of the great things about pediatric oncology is that you get to take care of patients, see them through their care, and learn from them to improve treatments for people in the future.”

“One of the great things about pediatric oncology is that you get to take care of patients, see them through their care, and learn from them to improve treatments for people in the future.”

After deciding to pursue a career in pediatric oncology, Dr. Kelly completed her residency and fellowship at Children’s Hospital of Philadelphia. During her residency, she worked with an international leader in pediatric lymphoma who exposed her to the field of hematological malignancies and research. “I remember being intrigued by the research side of the field,” she recalls. “We unfortunately can’t save everyone, but the fact that I could contribute to our collective knowledge to hopefully cure more patients was really attractive to me.”

Dr. Kelly took her first faculty position at Columbia University Medical Center. Early on in her career, Dr. Kelly’s mentor at Columbia gave her an opportunity to lead a trial on Hodgkin lymphoma (HL) through the Children’s Oncology Group (COG). The study tested a moderate dose-intensive treatment regimen, BEACOPP (bleomycin, etoposide, doxorubicin,

cyclophosphamide, vincristine, procarbazine and prednisone), for adolescents and young adults (AYA) with advanced-stage disease. The treatment regimen had a disease-free survival rate of 94 percent and an overall survival rate of 97 percent — an exciting step forward in Dr. Kelly’s career.

“That was a pivotal moment for me,” she says. “It got me excited to work in the field of lymphoma and proved that what I was doing directly benefited patients.”

UNDERSTANDING THE UNIQUE NEEDS OF THE AYA COMMUNITY

As she continued in the field of AYA oncology, Dr. Kelly discovered that treating younger patients came along with unique medical and psychosocial needs that impacted their care. The National Cancer Institute (NCI) defines the adolescent and young adult cohort as individuals between the ages of 15 and 39. Due to the complexity and disparity of this age group, Dr. Kelly says there are many factors to consider when building treatment plans for AYAs. Factors such as body image, long-term side effects and fertility make it even more challenging for physicians to put together treatment plans for AYA patients.

“There is a multitude of factors that impact this age group, and therefore an optimal treatment for AYA patients, particularly with lymphomas, has yet to be identified,” says Dr. Kelly.

“There is a multitude of factors that impact this age group, and therefore an optimal treatment for AYAs, particularly with lymphomas, has yet to be identified.”

Since youth and maturity levels of AYAs have significant effects on their ability to manage their diagnosis and treatment, Dr. Kelly noticed that many younger patients struggle with adhering to treatment and following through with their care plans. This is especially true of those in the 15-30 age range. While Dr. Kelly recognizes that this could be due to the transitional stage that many patients in this age group are experiencing, she also believes that increased research and advocacy could help to address these needs.

“We need to bring attention to this group and make people aware of some of the challenges that they face and some potential solutions to be able to help move things forward,” says Dr. Kelly.



As a clinician and researcher, Dr. Kelly found that while outcomes for the adult and pediatric cancer populations were improving, outcomes for AYA patients were not. “The adolescents and young adults are a group that’s been lost in that transition between pediatric and adult care,” she says. “They need advocates to help make sure they’re able to experience improvements in care just like everyone else.”

“AYAs need advocates to help make sure they’re able to experience improvements in care just like everyone else.”

Dr. Kelly attributes gaps in improvements to a variety of unanswered questions about AYAs, including understanding the biology of different cancers, age-appropriate care delivery and adjusting outreach and care plans for this demographic. Dr. Kelly noted that while great strides have been made in caring for AYAs, clinicians and scientists are still at the “tip of the iceberg” from a biological and research perspective. Dr. Kelly believes that a greater emphasis and investment in AYA research would allow them to have a much broader understanding of both the disease as well as the psychological and social impact on the patient.

WORKING COLLABORATIVELY TOWARDS ONE GOAL

Dr. Kelly attributes much of the recent successes in adolescent and young adult research to collaborations between the pediatric and adult oncology communities. She says that many

of her collaborative work is a result of her involvement with the Lymphoma Research Foundation (LRF), which has advocated for an increased focus on AYA-specific research like hers. Due to her ability to network with her colleagues, Dr. Kelly helped to develop the first collaborative clinical trial by the National Cancer Institute for Hodgkin lymphoma.

“This trial was the first time that the pediatric groups and adult groups sat down together and came up with a design that was appropriate for the adolescent young adult age group,” says Dr. Kelly.

Dr. Kelly believes that increased collaboration between the pediatric and adult oncology fields will help to bring attention to adolescent and young adults and improve the care that is delivered to them. To facilitate continued conversations about AYAs, Dr. Kelly, a member of LRF’s Scientific Advisory Board, helped LRF establish its first-ever AYA Lymphoma Consortium as part of its AYA initiative *Erase Lymphoma*. The goal of this consortium is to convene multi-industry experts to identify and address what is needed for adolescent and young adult lymphoma patients regarding research, education and advocacy.

“I help to bring experts together from many different areas to hopefully reduce our tendency to work in silos,” she says. “We need to keep AYA lymphoma at the forefront so that we can ensure improvements in the future.”

The LRF AYA Lymphoma Consortium hosted its inaugural conference in 2019, drawing many attendees from the pediatric and medical oncology fields, researchers, the Food and Drug Administration (FDA), and pharmaceutical industry — groups that rarely get the opportunity to work together, according to Dr. Kelly. She says that allowing these professionals to step out of their normal work helps to bring new ideas forward and accelerate the pace of research.

A BRIGHTER FUTURE FOR YOUNG ADULTS

While Dr. Kelly feels there has been much progress in adolescent and young adult lymphoma over the past decade, she still feels that there is more to be done. Dr. Kelly hopes that increased research and collaboration will continue to improve survival rates and, more importantly, maintain their quality of life post-cancer.

“Our therapies still have a lot of side effects both in the short term and potentially the long term,” she says. “I just want to be able to do better for my patients — that is what’s driving me.”

While many challenges still exist for AYAs with lymphoma, Dr. Kelly feels there are many reasons to be hopeful, including LRF’s very patient-centered approach to improving outcomes.

“You have to put in the effort to try to connect with them and understand where they’re coming from, and then hopefully, you can help reduce their suffering.” ○

GIVING: THE NEXT GENERATION



“It’s important to support causes you’re passionate about, and if you don’t have the financial means to give, volunteering your time is just as powerful.”

— Lauren

In 2017, Lauren was diagnosed with diffuse large B-cell lymphoma (DLBCL) at 23 years old. As is common among adolescents and young adults (AYAs), Lauren experienced a series of misdiagnoses before learning she had lymphoma. It was then she decided to push for additional testing at her urgent care center. “Over time, I was feeling worse, and I knew it was time for me to advocate for myself,” says Lauren. “With my mother, I asked the doctors to do blood work because I knew something was wrong.” After that, I took the steps to get a biopsy.” Once she had an accurate diagnosis, she was able to receive life-saving care.

Throughout her life, Lauren’s grandparents instilled in her the importance of supporting organizations she is passionate about. Her passion for helping others who shared a similar journey is what led her to find the Lymphoma Research Foundation.

“My grandparents encouraged us to find charities whose mission really spoke to us,” says Lauren. “While in treatment, I decided to research charities with a focus on lymphoma and found LRF.”

She was drawn by LRF’s mission and impressed by its high charitable ratings for funding patient programs and research. She decided then that LRF would be the charity she would support. Since connecting with LRF, she has donated to support research programs and support services, connected with other survivors, including young adults her age, participated in the annual Team LRF New York Walk and shared her story on stage at the Annual LRF Gala. “I’m always thinking about more ways to get involved with LRF, especially speaking with other patients to provide support. Knowing that I can use my story and experience to help others is incredibly rewarding,” she says.

LATEST U.S. FOOD AND DRUG ADMINISTRATION (FDA) APPROVALS FOR THE TREATMENT OF LYMPHOMA

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. To receive real-time FDA updates for the treatment of lymphoma, download the Focus on Lymphoma app for free in the Apple App and Google Play Store.

PEMBROLIZUMAB (KEYTRUDA)

April 28, 2020 — approved as a new dosing regimen of 400 mg every six weeks across all currently approved adult indications, in addition to the current 200 mg every three weeks dosing regimen. Pembrolizumab is currently approved for refractory classical Hodgkin lymphoma (HL), or patients who have failed at least three prior therapies; and for the treatment of adult and pediatric patients with refractory primary mediastinal large B-cell lymphoma (PMBCL) or those who have relapsed after two or more prior lines of therapy.

IBRUTINIB (IMBRUVICA) PLUS RITUXIMAB (RITUXAN)

April 21, 2020 — approved the combination treatment for adult patients with previously untreated chronic lymphocytic leukemia/small lymphocytic lymphoma (CLL/SLL).

MEET THE 2020 LYMPHOMA CLINICAL MENTORING PROGRAM SCHOLARS

The Lymphoma Research Foundation's Lymphoma Clinical Research Mentoring Program (LCRMP) is a first-of-its-kind education and mentoring program for junior scientists who wish to focus on lymphoma clinical research.

The primary goal of the LCRMP is to retain its talented participants — called LRF Scholars — in the field of lymphoma by providing mentoring and education programming and fostering research collaboration among expert faculty and the grantees. With a 100 percent retention rate in the first five years of its existence, the LCRMP has proven to be an invaluable resource for the next generation of lymphoma clinical researchers.

Led by the 2020 LCRMP Co-chairs Brian Link, MD (The University of Iowa) and Kerry Savage, MD (BC Cancer, Vancouver), the new class of LRF Scholars is pursuing research projects covering a diverse range of lymphoma subtypes including new treatment paradigms for rare diseases like cutaneous T-cell lymphoma (CTCL) and nodular lymphocyte predominant Hodgkin lymphoma (NLPHL), and more common subtypes like follicular lymphoma (FL) and diffuse large B-cell lymphoma (DLBCL).

The new class of LRF Scholars is pursuing research projects covering a diverse range of lymphoma subtypes.



PAMELA ALLEN, MD

**EMORY UNIVERSITY/WINSHIP
CANCER INSTITUTE**

Patients with advanced-stage cutaneous T-cell lymphoma (CTCL) have a median survival of less than five years and often experience debilitating itchy red skin. Patients with CTCL may be treated with extracorporeal photopheresis (ECP), which isolates white blood cells and exposes them to light. While ECP has a high response rate in CTCL, it can take up to six months to work and is less effective for patients with an abundance of cancer cells in their blood. Dr. Allen proposes an experimental study that combines ECP and a monoclonal antibody called mogamulizumab for the treatment of newly diagnosed and relapsed advanced-stage CTCL. Mogamulizumab can induce rapid responses even in patients with high tumor burden in the blood. While mogamulizumab works fast, the duration of response is often less than a year; ECP has a longer response rate. Dr. Allen predicts the combination of these therapies will produce more rapid and longer-lasting responses than either can achieve alone.

Dr. Allen is an Assistant Professor in the Department of Hematology and Medical Oncology at Emory University School of Medicine. She began pursuing clinical research in lymphoma during her hematology/oncology fellowship at Northwestern University. She has written two clinical trials assessing the outcomes in female lymphoma patients undergoing fertility prevention, as well as assessing immunotherapy for the treatment of Hodgkin lymphoma. Once she completed her Master of Science in Clinical Investigation, she joined Winship Cancer Institute at Emory University to focus on immunotherapy as a treatment for lymphoma.

For her LRF research project, Dr. Allen hopes to increase positive responses to therapy and reduce the debilitating symptoms that patients suffer from this disease. Dr. Allen says that through LRF she can, “continue growing my network of colleagues to collaborate on future opportunities for clinical trial investigations, participate in cooperative groups, and apply to career development awards” to advance her work in clinical research.



JAMIE FLERLAGE, MD

ST. JUDE CHILDREN'S RESEARCH HOSPITAL, INC.

Nodular lymphocyte predominant Hodgkin lymphoma (NLPHL) is a rare subtype of Hodgkin lymphoma (HL) that tends to grow more slowly than HL and requires different treatment. Dr. Jamie Flerlage says, "While it is almost 100 percent curative, the treatment regimens utilized vary greatly in their toxicity, both short and long term, with little data to support the use of one regimen over another."

By collaborating internationally, Dr. Flerlage hopes to generate statistically significant data to help better inform the treatment of this rare disease.

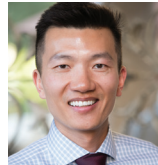
Her LRF research project's focus is to reduce late side effects in HL survivors through novel frontline therapies.

Dr. Flerlage is an Assistant Member of the Leukemia/Lymphoma Division at St. Jude Children's Research Hospital, Inc. She obtained her MD at Albany Medical College and is currently leading the St. Jude-Stanford-Dana Farber consortium to develop frontline treatment strategies. Dr. Flerlage's hope for the future is to "be a leader in the field of pediatric Hodgkin lymphoma and continue to find novel ways to cure the disease with limited late effects." She hopes to have a better understanding of the genetics of the disease and a better comprehension of the development of HL through learning the late effects of survivors.

Her passion for lymphoma research derives from a personal experience of watching a loved one's journey with cancer. Dr. Flerlage says that this experience has kept her motivated and curious. "While this disease is curable, I will constantly ask how we can do it better all around the world," she says.

97%

of Scholars are still studying lymphoma



BOYU HU, MD

UNIVERSITY OF UTAH/HUNTSMAN CANCER INSTITUTE

Gene mutations and chromosomal alterations found in relapsed/refractory chronic lymphocytic leukemia (CLL) make the disease more resistant to currently approved therapies and prone to earlier relapses. While these gene changes are advantageous to the leukemia's growth and proliferation, they also create new dependencies in the leukemia that can be directly targeted for therapeutic benefit. Dr. Boyu Hu's LRF research project is an investigator-initiated clinical trial, examining the use of talazoparib (Talzenna) and venetoclax (Venclexta) to directly target these vulnerabilities in relapsed/refractory CLL. If this targeted combination therapy is found to be safe and effective, it would be the first treatment in CLL to directly use biomarkers within the disease as predictors of response. "The spectrum of the diseases within lymphoma makes the field very interesting to perform research. On one hand, we have patients who are cured with conventional chemotherapy and on the other, we have patients who have absent or short responses to treatments," says Dr. Hu. "This heterogeneity in the diseases can be partially explained by gene mutations within each lymphoma that give the lymphoma a survival advantage."

Dr. Hu is an Assistant Professor in the Department of Internal Medicine at the University of Utah/Huntsman Cancer Institute. His interest in lymphoma research led him to work with Dr. William Wierda, MD, PhD, and other researchers during his fellowship training at the University of Texas MD Anderson Cancer Center. Together, they have described the genetic landscape within CLL and its effects on the disease course and survival outcomes. Throughout his time as a researcher, Dr. Hu has had the opportunity to showcase his findings at multiple international conferences and has published his work in multiple high-impact journals.

Dr. Hu's goal is to become an independent clinical investigator and clinical trialist. "The panel of physicians and researchers that LRF has assembled as my mentors are internationally recognized experts in lymphoma and clinical trial research who will help ensure the proper design, execution and analysis of my proposed clinical trial. Furthermore, they will be instrumental in my career development into an independent clinical investigator."



CHRISTINA LEE, MD

WEILL CORNELL MEDICAL COLLEGE

It has become increasingly apparent that normal immune cells are important in disease progression and therapy resistance in lymphoma. Studies from a clinical trial of two targeted therapies, ibrutinib (Imbruvica), and the CDK4/6 inhibitor palbociclib (Ibrance), in patients with mantle cell lymphoma (MCL) reveal the immune system may play a crucial role in improving treatment response.

Dr. Christina Lee's LRF research project evaluates the safety and preliminary effectiveness of combining CDK4/6 inhibitors and immunotherapy in patients with indolent non-Hodgkin lymphoma. Correlative studies, including immune profile monitoring and genomic analyses, will be performed in hope of improving the understanding of the lymphoma immune microenvironment. Dr. Lee hopes this study will lead to the development of novel drivers, predictive markers, and more rational therapies for patients with lymphoma.

Dr. Lee is a current hematology/oncology fellow at Weill Cornell Medicine. It was during her first year at Weill Cornell that she developed a strong interest in lymphoma. "While rotating through the lymphoma inpatient service and clinics, I became fascinated by the complexity of the disease, with its many distinct subtypes and intricate interplay with the immune system," she says. Dr. Lee then joined the laboratory of three-time LRF grantee Selina Chen-Kiang, PhD, to study the immune-mediated mechanisms of drug resistance in MCL. During her time in Dr. Chen-Kiang's lab, Dr. Lee found that treatment response was associated with an oligoclonal expansion of cytotoxic T-cells and that relapsed or progressive disease correlated with increased tumor PD-1 expression.

Dr. Lee plans to take these findings back to the clinic and propose a phase Ib clinical trial investigating the safety and preliminary efficacy of dual CDK4/6 inhibition with immune checkpoint blockade in patients with non-Hodgkin lymphoma. She looks forward to collaborating with her mentor, LRF Scientific Advisory Board member Peter Martin, MD (Weill Cornell Medicine), to help guide her research. "The LCRMP, in addition to my mentors and training environment, will provide me with the necessary intellectual and professional support to complete and implement my proposed clinical research study as well as successfully design and administer future studies, with the ultimate goal of improving the care of patients with lymphoma," she says.



RAPHAEL ERIC STEINER, MD

**UNIVERSITY OF TEXAS MD ANDERSON
CANCER CENTER**

Primary mediastinal large B-cell lymphoma (PMLBCL), a type of diffuse large B-cell lymphoma (DLBCL), affects predominantly adolescents and young adults and is usually treated with chemo-immune therapy with or without radiotherapy. While most patients are cured with such frontline therapies, these modalities can be toxic, and the outcome of patients with relapsed or refractory disease treated with secondary chemotherapy/autologous stem cell transplantation is generally poor. However, a recent study indicated that PMLBCL patients with disease resistance to at least two different lines of treatment showed impressive response to the combination of immune therapies brentuximab vedotin and nivolumab.

Dr. Raphael Eric Steiner's LRF research project is a clinical trial for untreated PMBL patients with brentuximab vedotin (Adcetris) and nivolumab (Opdivo) used alone and combined with chemotherapy, with the intent to increase the rate of cure and decrease acute and long-term toxicities. Dr. Steiner hypothesizes that this new regimen could further decrease the relapse rate of untreated PMBL patients, allow for less toxic chemotherapy, use less cycles of chemotherapy for early responders, and avoid use of radiotherapy.

Dr. Steiner is an Assistant Professor in the Department of Lymphoma & Myeloma at the University of Texas MD Anderson Cancer Center. He received his MD and completed his Internal Medicine/Family Practice Residency and Medical Oncology fellowship in Switzerland. "Lymphoma medicine and research received all my attention because of its wide range of clinical and multisystemic presentations, potential for cure in many cases, exciting translational ties and long-term patient-physician relationship," he says. This interest in lymphoma brought him to the United States in 2016 for a Lymphoma/Myeloma fellowship at the University of Texas MD Anderson Cancer Center.

Dr. Steiner aims to further develop his clinical research activity focused on aggressive B-cell lymphomas and Hodgkin lymphomas and be promoted to Associate Professor in the Lymphoma/Myeloma department at MD Anderson Cancer Center. "I gained priceless knowledge from the LCRMP, notably about excellence in design of trials, mentoring and career development, countless pearls of wisdom that I will cherish for a lifetime and am sharing to residents and fellows," Dr. Steiner says.



CHRISTOPHER STROUSE, MD

THE UNIVERSITY OF IOWA

Follicular lymphoma (FL) is typically an indolent, or slow-growing, form of non-Hodgkin lymphoma that accounts for 20 to 30 percent of all cases of non-Hodgkin lymphoma. Patients diagnosed with FL can typically expect to live with their lymphoma for years, if not decades. Thus, when coming up with a treatment plan for patients with FL, it is important to weigh the desired effects on the patient’s lymphoma without the undesired effects on the patient’s quality of life.

Dr. Christopher Strouse’s LRF research project will investigate whether follicular lymphoma patients who are exposed to less cycles of bendamustine (Bendamustine) have a better quality of life.

Dr. Strouse is a current hematology and medical oncology fellow at the University of Iowa. He received his MD from the University of Wisconsin. His goal is to become an expert in the clinical care of patients with lymphoma by researching methods to improve current or future treatments. “I hope to be able to have several relationships with a new generation of researchers,” he says. “Through the mentorship from the LCRMP, I hope to gain insight into the unanswered questions doctors and their patients with lymphoma face, and how to perform research that will provide meaningful answers to these questions.”



ABI VIJENTHIRA, MD

UNIVERSITY HEALTH NETWORK

Lymphoma is the most common blood cancer in Canada, and diffuse large B-cell lymphoma (DLBCL) has the greatest incidence in older patients compared to all other lymphomas. Older patients are at risk for “frailty,” a multi-dimensional syndrome of loss of reserves that gives rise to vulnerability. Dr. Abi Vijenthira’s LRF research project will look at how frailty affects survival in older patients with DLBCL. The project will also look at whether frailty predicts survival even when adjusted for other prognostic factors in lymphoma.

Dr. Vijenthira is a hematology/oncology senior resident (PGY-6) at the University Health Network. She received her MD at the University of Ottawa and her fellowship in hematology/oncology at the University of Toronto. She says that she is “passionate about clinical research specifically in the areas of improving the experience and outcomes of older patients with lymphoma, innovations in care delivery, and comparative effectiveness analysis in areas with varied clinical practice in lymphoma.” Her interest stems from the complexity of the disease, from both the patient and research perspectives.

Dr. Vijenthira notes that the LCRMP, “will help not only current research proposals, but also future ones, as I will be able to integrate what I have learned.”

To learn more about the Lymphoma Research Foundation’s research programs, visit lymphoma.org/research. Applications for the expanded 2021 LCRMP will be accepted through Sept. 9, 2020. Visit lymphoma.org/grants to learn more.

100%

of Scholars published lymphoma-specific research since being accepted in the LCRMP



50%

of Scholars received additional federal research funding, a critical part of contemporary scientific training and career development



79%

reported collaboration with expert mentors as a primary benefit of the LCRMP

100%

of Scholars reported the LCRMP contributed to their career advancement





Dr. Ann S. LaCasce speaking at the 2018 Lymphoma Research Foundation New England Lymphoma Workshop

WHERE ARE THEY NOW?

ANN S. LACASCE, MD, MMSC

Ann S. LaCasce, MD, MMSc is an Associate Professor of Medicine, lymphoma specialist and the Director of the Dana-Farber/Partners CancerCare Fellowship in Hematology/Oncology at the Dana-Farber Cancer Institute. She is also a member of the Lymphoma Research Foundation (LRF) Scientific Advisory Board (SAB).

WHEN DID YOU BECOME INTERESTED IN LYMPHOMA?

I became interested in lymphoma during my first year of medical school. Our hematology course was directed by Dr. Jane DesForges, who was a lymphoma physician and

former president of the American Society of Hematology (ASH). As a woman looking to begin my career, I was truly inspired by Dr. DesForges. I also found the study of lymphoma fascinating from many perspectives — the pathologic appearance and biology, as well as the clinical management and broad range of ages of the patients.

WHEN DID YOU FIRST GET INVOLVED WITH THE LYMPHOMA RESEARCH FOUNDATION AND IN WHAT CAPACITY?

I first became involved with LRF when I was fortunate to be awarded a Clinical Investigator Career Development Award (CDA) through the Foundation's research program.

The grant I received provides funding to advanced fellows or junior faculty members to facilitate their transition to independent clinical researchers.

WHAT RESEARCH/PROJECT DID YOU PURSUE WITH YOUR LRF GRANT?

My project examined the impact of adding bortezomib (Velcade) to standard therapy in patients with primary mediastinal large B-cell lymphoma (PMLBCL). This was based on data showing the importance of the NfKappaB pathway in the disease. The overall goal was to improve chemotherapy to limit the number of patients who would require radiation. Unfortunately, the study closed early due to poor accrual, but I learned an enormous amount in the process.

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

The funding provided critical protected time during my early career, allowing me to work on several projects. These projects were key to my development and were essential at the outset of my career.

“The funding I received from LRF was my introduction to the Foundation, which has been integral to my growth as a researcher and a clinician over the years.”

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

I was very fortunate to be elected to LRF’s Scientific Advisory Board (SAB) and have collaborated with the Foundation in several capacities. I have participated in multiple LRF programs, including in-person patient education programs as speaking faculty, the Foundation’s professional education program, Lymphoma Rounds, and one of LRF’s research programs, called the Lymphoma Clinical Research Mentoring Program (LCRMP). Additionally, the mentorship I have received from other members of the SAB has been invaluable to my career, and on a personal level, I have made many close friends in the lymphoma community.

HOW ARE YOU HELPING TO MENTOR THE NEXT GENERATION OF LYMPHOMA SCIENTISTS?

I participate in LRF’s LCRMP — an outstanding program for fellows and junior faculty — where I network with and teach the LRF Scholars. In 2017, I even had the pleasure of co-chairing the program with a fellow SAB member, Sonali Smith, MD (The University of Chicago) — whom I admire and respect enormously. The Scholars were outstanding, and watching their careers evolve over the years has been gratifying. Another wonderful part of the program is the faculty, all of whom are leaders in the lymphoma space. I feel that I have learned just as much as the Scholars each time I have participated in the program.

WHAT IS YOUR EXPERIENCE BEING A LEADER IN THE FIELD AND HELPING TO USHER IN THE NEXT GENERATION IN YOUR ROLE AT DANA-FARBER CANCER INSTITUTE?

In 2011, I took over as Program Director for the Dana-Farber Mass General Brigham Fellowship in Hematology/Oncology. We have the largest program in the country and train the next generation of leaders in research and clinical care. Two of our recent fellows, Jennifer Crombie and Reid Merryman, are now faculty at Dana-Farber, chose to focus on lymphoma in their careers, and have participated in LRF’s LCRMP.

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

As the only nonprofit organization devoted to exclusively funding research for all lymphomas, it provides critical support to the research community. The funding allows the most promising lymphoma researchers to advance their careers and ultimately helps improve patient outcomes.

The funding allows the most promising lymphoma researchers to advance their careers and ultimately helps improve patient care and outcomes.

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

I am currently working on trials in early-stage Hodgkin lymphoma and primary mediastinal large B-cell lymphoma, mainly through the cooperative groups. ○

PATIENT PERSPECTIVES

A study reveals new information related to mortality and chronic health conditions in long-term survivors of early adolescent and young adult cancers



Each year, nearly 70,000 adolescents and young adults (AYAs) between the ages of 15 and 39 are diagnosed with cancer in the United States. Of that 70,000, one in every five diagnoses is lymphoma.

Although nearly 80 percent of adolescents and young adults will survive more than five years after their cancer diagnosis — many with the potential of living a long life — they remain at risk of developing long-term and sometimes severe side effects or dying prematurely due to the health-related effects from their previous cancer treatments.

Every 1 in 5 adolescents and young adults' cancer diagnosis is lymphoma.



A team of expert researchers in pediatric and adolescent and young adult oncology, including LRF AYA Lymphoma Consortium and Scientific Steering Committee member Tara Henderson, MD (The University of Chicago), conducted a retrospective cohort study to evaluate outcomes among survivors of adolescent and young adult cancer (ages 15-20) and survivors diagnosed younger than 15 years by comparing both groups to siblings of the same age.

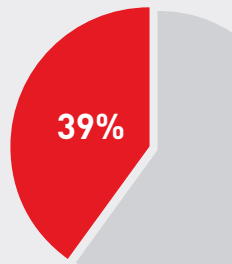
The research is the result of the Childhood Cancer Survivor Study (CCSS), the first retrospective study to characterize long-term health outcomes in a large cohort of cancer survivors diagnosed and treated in adolescence and early adulthood and compare their outcomes to childhood cancer survivors and the general public.

THE FINDINGS

The researchers analyzed results from 11,608 5-year cancer survivors (5,804 early-adolescent and young adult cancer survivors and 5,804 childhood cancer survivors) at 27 academic institutions in the United States and Canada between 1970 and 1999; and 3,806 randomly selected siblings were included as the control group to represent the general population.

Among the 5,804 5-year AYA cancer survivors, approximately 23 percent died due to subsequent cancer, cardiovascular disease, pulmonary disease or medical causes other than recurrence or progression of their primary cancer or external causes. Furthermore, the study showed that early-adolescent and young adult survivors were more than 1½ times likely to die from a recurrence or progression of their primary cancer. The researchers discovered this was most prominent in leukemia and Hodgkin lymphoma survivors.

By age 45, 39% of early-adolescent and young adult cancer survivors developed a severe health condition, the study reveals.



The majority of early-adolescent and young adults that were part of the chronic health condition analysis (4,804) were diagnosed with lymphoma (Hodgkin lymphoma, 35 percent; and non-Hodgkin, 10 percent). By age 45, 39 percent of early-adolescent and young adult survivors developed a severe health condition. Compared with siblings of the same age, early-adolescent and young adult survivors were more likely to develop any chronic health condition, regardless of severity.

GAPS IN CARE FOR THE ADOLESCENT AND YOUNG ADULT CANCER COMMUNITY

Poorer outcomes for adolescent and young adults diagnosed with Hodgkin lymphoma between the ages of 17 and 21 compared to those diagnosed before 17 have previously been reported. In the study, the researchers note that greater mortality risk due to the late recurrence or progression of early-adolescent and young adult cancer

survivors may be due to known factors that contribute to poorer outcomes for this community, including delays in diagnosis, lack of health insurance, little to no compliance to treatment, follow-up and transition to long-term follow-up care and disease biology.

The Lymphoma Research Foundation's AYA initiative *Erase Lymphoma* aims to identify and fill the gaps in need and care for this community. Founded in 2015 with the support of The Paul Foundation, the AYA initiative has funded research with an aim to improve outcomes for AYA lymphoma patients and convened some of the world's leading pediatric and adult oncologists, lymphoma researchers, regulatory officials and industry representatives through its AYA-specific scientific workshops. The 2019 LRF AYA Lymphoma Scientific Workshop examined the biological, clinical, epidemiological, and health services issues like those mentioned in the CCSS study, which cause unique complications in both caring for and conducting research on this patient population.

“To better understand the nature of the disparities that impact young people with blood cancer, the Lymphoma Research Foundation established a first-of-its kind AYA Lymphoma Consortium in 2019 to engage and support patients, survivors, researchers and clinicians,” says Meghan Gutierrez, Chief Executive Officer at the Lymphoma Research Foundation. “The Consortium’s work will include a focus on the needs of AYA cancer survivors and seek to prioritize the unique needs and challenges of this underserved — and understudied — patient population.”

The researchers of the CCSS study suggest that guidelines for risk-based long-term follow-up care, such as the Children’s Oncology Group Long-Term Follow-Up (COG LTFU) Guidelines and the National Comprehensive Cancer Network Guidelines are appropriate for early-adolescent and young adult cancer survivors. The researchers also suggest a new model be developed for cross-communication and collaboration between primary care physicians and oncologists for risk-based follow-up care for adolescent and young adult cancer survivors. ○

The original article, “Late Mortality and Chronic Health Conditions in Long-Term Survivors of Early-Adolescent and Young Adult Cancers: A Retrospective Cohort Analysis from the Childhood Cancer Survivor Study” was published in “The Lancet Oncology” on February 14, 2020.

TOGETHER WE CAN #ERASELYMPHOMA

A cancer diagnosis is unexpected, especially for adolescents and young adults (AYAs) in their teens, 20s and 30s.

The Lymphoma Research Foundation (LRF) is dedicated to **assisting young lymphoma patients and survivors with addressing the unique medical, psychosocial and access challenges** they may encounter by providing support, resources and programs.

For more information visit, lymphoma.org/AYA

RESOURCES FOR AYAS:

- Peer-to-Peer Support
- Lymphoma Facts & Guides
- Digital Education & Tools
- In-Person Education & Networking Programs
- LRF Helpline



FOLLOW-UP CARE AFTER LYMPHOMA TREATMENT

Although no standardized guidelines currently exist for all lymphoma subtypes on how often survivors should be monitored for cancer recurrence and late health effects from treatment, there are some general rules to help stay healthy.

HEALTH SCREENINGS

Based on the type of treatments a survivor has received, the doctor may recommend specific health screenings at an earlier age than currently recommended for the general population. For example, due to the increased risk of secondary breast cancer from radiation therapy, the American Cancer Society and the Children's Oncology Group recommend that women who received radiation therapy to the chest area between the ages of 10 and 30 should have clinical breast examinations every six months and yearly mammograms and magnetic resonance imaging (MRI) screenings beginning at age 25 or eight years after the completion of the radiation therapy, whichever comes first. Other health screenings the doctor may suggest include:

- Pap tests
- Colorectal screenings
- Prostate exams
- Bone density scans
- Thyroid function tests

ESTABLISHING A FOLLOW-UP CARE PLAN

After treatment completion, the hematologist/oncologist will set up a follow-up care schedule based on the survivor's specific type of lymphoma and other factors such as age and overall health status. Generally, survivors will have follow-up visits with their oncologist every few months for two to

three years following remission to ensure no lymphoma recurrence and to monitor the occurrences of long-term and late treatment side effects.

Ideally, the hematologist/oncologist should work in conjunction with the survivor's primary care physician from the time of diagnosis onward. To ensure that all health concerns, including mental health issues such as depression, are being met, survivors should maintain an ongoing relationship with their primary care physician during lymphoma treatment. Once a long-term remission is achieved, it is still critical for the hematologist/oncologist to work collaboratively with the primary care physician to monitor or manage any long-term or late effects.

KEEPING TRACK OF YOUR CARE

Even when uniform guidelines are established for cancer survivors' follow-up care, as an individual patient, the disease course may be very different from that of other patients. To ensure that long-term health needs are addressed, survivors should keep a detailed medical history of their lymphoma journey, including but not limited to:

- Type (subtype) of lymphoma
- Date of diagnosis
- A list of types of treatments received and the location and doses of radiation therapy given
- Pathology reports and copies of imaging studies
- Any treatment complications
- Types of side effects experienced and frequency
- The doctor's recommendations for follow-up visits and how to maintain optimal health
- Future scheduled visits

For questions regarding survivorship and follow-up care, contact the LRF Helpline at 800-500-9976 or helpline@lymphoma.org.

AN EMERGING CANCER: **SURVIVORS ADVOCATE FOR WOMEN'S HEALTH AND AWARENESS**

In January 2015, Michelle Forney started to experience intense pain and itching of her right breast. Several years earlier, she had undergone breast enhancement surgery using textured implants. Understanding that implants could present complications, she immediately made an appointment with her primary care physician, who invited a dermatologist to examine her.

“I was going to my physician pretty frequently, and every time I'd ask, ‘What's going on with me?’” says Forney. “Every time, I would receive a different diagnosis. ‘Oh, you have shingles’ and get treated for six months, then ‘Oh you may have a virus,’ then get treated for a year. Nothing was helping.”

For two more years Forney endured pain, itching and other symptoms. She received two mammograms and even presented her symptoms to her plastic surgeon, where she received a third diagnosis of low-grade capsular contracture and received a fee schedule to remove and replace her implants.

She knew things were getting serious when her right breast started to swell and grew approximately 30 percent larger than her left. “My plastic surgeon suggested I have my implants removed and replaced. By that time my health really started to decline — I was constantly fighting a cold, I was fatigued, my eyesight was worsening — but financially, a removal was not an option for me.”

Running out of options, she decided to visit her OB-GYN and was referred to a breast care specialist. From there, she received a series of tests that finally revealed her diagnosis of a cancer she'd never heard of before: breast implant-associated anaplastic large cell lymphoma (BIA-ALCL).

“My plastic surgeon suggested I have my implants removed and replaced. By that time my health really started to decline — I would constantly be fighting a cold, I was fatigued, my eyesight was worsening — but **financially, a removal was not an option for me.**”



AN EMERGING CANCER

Not to be confused with breast cancer, BIA-ALCL is a type of T-cell non-Hodgkin lymphoma called anaplastic large cell lymphoma (ALCL). According to hematologist/oncologist Lauren Pinter-Brown, MD (UCI Health), ALCL accounts for 20 percent of all T-cell lymphoma cases in the United States and is the third most common type of T-cell lymphoma. BIA-ALCL is considered a type of ALCL because of its similar molecular makeup.

“After someone has had a breast implant, in this case textured implants, a person may experience swelling of the breast,” says Dr. Pinter-Brown. “There is fluid that accumulates on the outside of the implant that is extracted for examination. It’s found that the cells in that fluid mimic or look like the cells in ALCL.”

In most cases, BIA-ALCL is found in the scar tissue and fluid near the implant, but in some cases, it can spread throughout the body. The main symptoms of BIA-ALCL are persistent swelling and the presence of a mass or pain in the area of the implant. In most patients, BIA-ALCL is treated successfully with surgery to remove the implant and surrounding scar tissue, and sometimes treatment with chemotherapy and radiation therapy.

There has been a causal link to textured breast implants, both silicone and saline. Because textured implants are less common than smooth, experts agree the risk of developing BIA-ALCL is low; however, this type of lymphoma is considered serious and can lead to death, especially if not treated promptly. To date, there have been no cases or causal link between BIA-ALCL and smooth implants.

Jennifer Cook never thought the textured implants she received in 2010 would lead to a cancer diagnosis. Especially since her plastic surgeon was a leader in the field and enrolled her in an early study to determine if textured implants were an improvement from other types. “On the consent form, I remember there being a section that addressed cancer, and it stated that there was no scientific evidence linking implants to any type of cancer,” says Cook.



In 2011, the U.S. Food and Drug Administration first identified a possible link between breast implants and ALCL.

The link between textured breast implants and the disease was first reported in 1997, and the U.S. Food and Drug Administration (FDA) first identified a possible link between breast implants and ALCL in 2011. Although there have been several studies, and an announcement from the nation’s main source of drug and medical device information, many — the general public and medical community, alike — have never heard of this disease.

For Cook, a chance encounter with her students prompted her to research implants’ link to cancer. She took the students to see a student play about bullying and self-esteem and heard a line that really struck her. “In the course of the play, there was a line that referenced plastic surgery. One of the characters in the play said ‘I would never do that! Haven’t you heard breast implants cause cancer?’” recalls Cook. “At first, I thought the students were just saying something reckless for shock value. It couldn’t have been true, I would’ve known it.”

Cook performed a search online for implants’ link to cancer with the expectation of not finding any evidence and using that as a teachable moment for her students to be careful about sharing information that isn’t true. She was surprised to find the FDA’s 2011 announcement linking breast implants to ALCL. Five years later, she noticed a lump in the upper part of her left breast. She immediately consulted two surgeons to talk about, and be evaluated for, BIA-ALCL. But like Forney, she was having difficulty getting answers, and her symptoms started to get worse.

“Before I was officially diagnosed, I started seeing my symptoms change. My breast was increasing in size and I knew I needed to get treated immediately,” says Cook. “The plastic surgeon I reached out to didn’t understand my symptoms and thought I was unhappy with my implants and wanted my health insurance to pay for a removal. I was just alarmed by his dismissal.”

ADVOCATING FOR WOMEN’S HEALTH

During an FDA advisory committee meeting in 2019 to hear testimony from a panel of patients, plastic surgeons and oncologists about the safety of implants, it was reported that there are more than 500 BIA-ALCL cases worldwide (304 in the U.S.) and 34 deaths.

Forney and Cook took part in conversations with the FDA, including a joint meeting with patient advocates in 2018 to bring light to this emerging cancer and the need to inform women of BIA-ALCL and other implant-related issues. Both have made it their mission to raise awareness and connect with as many women impacted by this blood cancer as possible to provide support and information so they can be their own health advocates.

“It’s important for everyone to be their own health advocate,” says Cook. “You know your body and you are the best person to communicate to doctors what is going on with you and really push for additional tests or a second opinion.”

More than 400,000 women received implants in 2018.

The impact of BIA-ALCL could be much greater than presently reported. According to the American Society of Plastic Surgeons 2018 Plastic Surgery Statistics Report, more than 400,000 women received implants. A simple search on Facebook found several community groups dedicated to BIA-ALCL, with more than 2,000 members sharing their journey and symptoms connected to the disease. Flourney and Cook are administrators for one of the Facebook groups and are Breast Implant Lymphoma Advocates (BILA) on the BILA information site, biaalcl.com.

“When I was diagnosed, I went searching on the internet to learn as much as I could about the disease. That’s when I found the Facebook group and became very active with the other women,” says Cook. “I thought, *Okay, I could be one in a million and was very unlucky, or this could be something that is happening to lots of women. I wanted to help.*”

In response to the FDA’s request for a recall following its advisory committee meeting and subsequent Medical Device Report (MDRs) reporting worldwide cases of BIA-ALCL and BIA-ALCL-related deaths, Allergan, the manufacturer of BioCell textured implants, voluntarily removed millions of its textured implant products from the global market.

Since the recall, the Lymphoma Research Foundation’s Helpline has received numerous calls and emails from women seeking more information about textured implants, BIA-ALCL and guidance on what they should do if they experience symptoms. Many expressed concerns about their particular implant and if they were part of the voluntary



Patient advocates, including Michelle Forney and Jennifer Cook (third and second from right), met with the FDA in September 2018 to discuss BIA-ALCL and other implant-related issues

recall. Some inquired as to whether their diagnosis of lymphoma (whether it was ALCL or another subtype) may be connected to their implants.

“BIA-ALCL remains an obscure diagnosis for many patients and clinicians alike, so raising awareness about this lymphoma is paramount,” says Victor Gonzalez, Associate Director of Support Resources and Strategic Partnerships at the Lymphoma Research Foundation. “People who contact the LRF Helpline often express frustration at the lack of detailed information and confusion about what steps to take when it comes to this disease, so making sure patients are informed of their options is important to ensure the best possible health outcomes.”

Since their diagnoses, Forney and Cook have received treatment for their lymphoma and stay on top of their follow-up PET/CT scans to monitor recurrence. Although they are happy with the steps being taken to protect women’s health, they both shared that there is still more work to do in educating the public and medical community on this disease, improving the relationship between patient and doctor and removing the stigma around plastic surgery.

“We’ve heard so many stories from women who encountered so many roadblocks before they got answers,” says Forney. “A roadblock when you’re speaking with a medical professional that never heard of this disease; a roadblock with health insurance because many women need a referral to get tested; and a roadblock from the guilt you feel from public judgment. It’s an emotional rollercoaster.” 🌀

FIVE MINDFULNESS TIPS TO GET THROUGH COVID-19 AND BEYOND

Mindfulness is the practice of paying attention to the present moment without judgment. That may sound simple, but its ability to provide us with agency, perspective, and compassion can give us exactly what we need in these uncertain times.

Feeling anxious about COVID-19 or any disease is completely normal — especially when navigating a lymphoma diagnosis. Processing your daily experience, in addition to the state of the world, is a feat in and of itself. It can be bewildering, scary, and overwhelming all at the same time.

Mindfulness is the practice of paying attention to the present moment without judgment. That may sound simple, but its ability to provide us with agency, perspective, and compassion can give us exactly what we need in these uncertain times. Follow these tips below to manage anxiety and stress and live a more mindful life.

① PRACTICE RADICAL ACCEPTANCE

We can spend precious energy resisting our new reality, which can contribute to our struggle, fatigue, and suffering. If you can radically accept your state of affairs, you'll be able to stop expending energy fighting what is.

Say to yourself, "This is where we are now. I am here. This is today. Some things are outside of my control, such as a, b, and c. I radically accept them, so that I can deal with them, move forward, and focus on what is within my control."

You may also direct your radical acceptance towards uncertainty. Say to yourself, "I radically accept that I don't know what might happen today or tomorrow. I will do my best, and that is all I can do."

② BE YOUR OWN BEST FRIEND

When we go into survival mode, one thing we may lose is connection to our own needs, especially our emotional ones. Don't let this happen. Befriend yourself. Gently ask yourself: "What do you need today? What do you need right now?" One framework to help identify your needs is *Maslow's Hierarchy of Needs*.

Now that you hear your own needs, respond as you would to a best friend — without judgment, and with tenderness,



love, and generosity. This is called self-compassion. Just like your friend, you are allowed to have an irrational response or be scared. Be kind to yourself and give yourself the leeway and flexibility to be accepted exactly as you are. Then, see if you can express these needs in a healthy way. Set boundaries where you need to with others, with the news and media, and with social media.

This practice of self-compassion and self-care is the foundation for your ability to care for others. After you have attended to your own needs, see if you can direct your focus and generosity to others. That might be as simple as reaching out to a friend to ask how they are today, smiling at someone over video conference or in the kitchen, or simply silently sending a loving-kindness wish to someone, “May you be happy.”

3 GIVE SPACE TO YOUR EMOTIONS

Whether we like it or not, and whether it’s convenient or not, we are emotional beings. Take time to process your feelings, because what you resist persists. Fear can be immensely uncomfortable, but it cannot kill you. Call on your courage and your curiosity. And remember, emotions are data. What is your fear or anxiety here to tell you?

When you feel an emotion such as sadness or fear, try to get out of your head and into your body. What does sadness feel like in your body? What sensations accompany it? Is it cool or hot? Is it a tingling in your hands or in your shoulders? Keep asking yourself, “Where do I feel this emotion?” Then see if you can sit with these physical sensations without listening to the stories of the mind. Remember that everything is changing all the time, and even the most uncomfortable emotions will eventually pass.

Try to remember that we are not our thoughts or emotions. Try saying to yourself, “Sadness is here,” instead of “I am sad.” This is how we observe our emotions, which gives us time to pause and choose our response. Victor Frankl,

survivor of the holocaust and author of *Man’s Search for Meaning*, summarizes this beautifully: “Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom.”

Remember, you’re not alone. Feeling scared, overwhelmed, or angry are fundamental to the human experience. We all feel these emotions; it’s OK, and they will pass.

4 STAY PRESENT IN THIS MOMENT

Our minds are often in the past or in the future. We can be trapped reliving an experience like a bad movie on repeat or imagining a doomsday future. The problem is, you can’t experience an emotion in the past — you can only experience it now. (Want proof? Try having an emotion in the past!)

So, when you catch your mind in the past or the future, stop and take a breath. Feel your toes in your socks, look at the time, and say to yourself, “It is 1pm on Thursday. I am in my bedroom.” Then do something different, like walk to another room or take a sip of water. You can also simply try repeating the word “now” to yourself as a mantra. I do this when I’m jogging and getting winded. As painful as each step is, “now” helps me focus on the current step I’m taking, rather than the longer mile I’m attempting to finish. I find that we can bear anything for one moment.

5 LAUGH

Laughter has been shown to be good for us physiologically, psychologically, and socially. Tap into this powerful medicine now. Spend your time finding things that make you laugh and share them with others. Laughter can be a wonderful break to help release tension. That’s right, I’m actually suggesting you spend time on TikTok or YouTube. Give yourself a good laugh and see how it makes you feel.

For more mindfulness tips, listen to LRF’s *Living with Lymphoma* podcast episode “Mindfulness and Meditation” featuring Amy Jin. *Living with Lymphoma* is available on Spotify, Apple Podcast, Google Podcast, Stitcher and at lymphoma.org/podcast. 

About the Author



Amy Jin

Amy Jin is a mindfulness-based leadership coach and inspirational speaker. She works with mission-driven entrepreneurs and executives, helping them lead consciously. A passionate advocate for women, she is the co-host of “Straighten Your Crown,” a podcast for female founders. Her life’s mission is to reduce human suffering, and her mantra is to lead with heart.



BE WELL: HOW TO CHECK FOR A FEVER

A fever is the body's way of warning you that something is off and can be a sign that your body is trying to fight an illness or infection. For COVID-19 and other viruses like the cold and flu, a high fever can be a symptom.

The Centers for Disease Control and Prevention (CDC) considers a person to have a fever when a temperature measures 100.4° or more. Here are tips to check your temperature effectively:

WHAT KIND OF THERMOMETER SHOULD I USE?

The type of thermometer to use depends on age. For adults, oral and ear thermometers can be used. Forehead thermometers are another option, although most are substantially more expensive than an oral thermometer.

WHAT'S THE BEST WAY TO CLEAN A THERMOMETER?

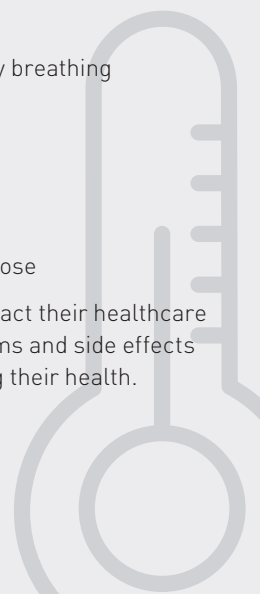
Always clean the thermometer before and after use with cool, soapy water or rubbing alcohol. Ear thermometer tips can be wiped with alcohol. Check the directions on the packaging to see how the manufacturer advises how to properly clean the device.

WHEN SHOULD I SEE A DOCTOR ABOUT MY FEVER?

The CDC recommends seeing a doctor if experiencing one or more of the following:

- Temperature higher than 101° that lasts more than two days or fails to respond at least partly to treatment
- Temperature higher than 103° under any condition
- Headache with stiff neck
- Severe coughing or vomiting
- Pain taking a deep breath or difficulty breathing
- Facial pain
- Skin rash
- Unexplained bruising or bleeding
- Persistent diarrhea
- Yellow or green discharge from the nose

Lymphoma patients are advised to contact their healthcare team if they experience severe symptoms and side effects or have questions regarding monitoring their health.



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 Izumi Nakano and Victor Gonzalez from the Foundation's Helpline as they explore various survivorship topics.

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

SCIENTIFIC ADVISORY BOARD

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

2019-2020 MEMBERSHIP

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

SONALI M. SMITH, MD
Chair-Elect
The University of Chicago

RANJANA ADVANI, MD
Stanford University School of Medicine

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

STEPHEN ANSELL, MD, PHD
Mayo Clinic, Rochester

NANCY BARTLETT, MD
Washington University Medical School

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

CATHERINE BOLLARD, MD, MBCHB
George Washington University
Children's National Medical Center

JAMES CERHAN, MD, PHD
Mayo Clinic, Rochester

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

**BRUCE D. CHESON, MD, FACP,
FAAAS, FASCO**
Past Chair, 2010-2012

MORTON COLEMAN, MD
Chair, Medical Affiliates Board
NewYork-Presbyterian Hospital
Weill Cornell Medicine

SANDEEP DAVE, MD, MS
Duke University

KIERON M. DUNLEAVY, MD
George Washington University
GW Cancer Center

KOJO S.J. ELENITOBA-JOHNSON, MD
University of Pennsylvania
Perelman School of Medicine

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

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

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

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

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

STEVEN M. HORWITZ, MD
Memorial Sloan Kettering Cancer Center

ERIC D. HSI, MD
Cleveland Clinic

BRAD S. KAHL, MD
Washington University School of Medicine

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

ANN S. LACASCE, MD
Harvard Medical School
Dana-Farber Cancer Institute

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

BRIAN K. LINK, MD
University of Iowa

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

PETER MARTIN, MD
Weill Cornell Medicine

ARI MELNICK, MD
NewYork-Presbyterian Hospital
Weill Cornell Medicine

LINDSAY MORTON, PHD
National Cancer Institute

OWEN O'CONNOR, MD, PHD
Columbia University Medical Center

LAURA PASQUALUCCI, MD
Columbia University
H. Irving Comprehensive Cancer Center

BARBARA PRO, MD
Robert H. Lurie Comprehensive Cancer
Center of Northwestern University

KANTI R. RAI, MD
Hofstra Northwell School of Medicine

KERRY J. SAVAGE, MD
British Columbia Cancer

LAURIE SEHN, MD, MPH
British Columbia Cancer

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

EDUARDO M. SOTOMAYOR, MD
George Washington University
GW Cancer Center

CHRISTIAN STEIDL, MD
British Columbia Cancer

JOHN M. TIMMERMAN, MD
UCLA Jonsson Comprehensive Cancer Center

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

HANS-GUIDO WENDEL, MD
Memorial Sloan Kettering Cancer Center

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

FOUNDING CHAIR

JOSEPH R. BERTINO, MD
Rutgers Robert Wood Johnson Medical School
Rutgers Cancer Institute of New Jersey

SWIRL: AMERICA

An At Home Tasting Event

Thursday,
June 25, 2020
6:00 PM – 7:00 PM ET

The Lymphoma Research Foundation (LRF) is excited to expand its signature event series, Swirl: A Wine Tasting Event, to a virtual event, **Swirl: America, An At Home Tasting Event**. Please join LRF for the inaugural Swirl: America event hosted by award-winning television journalist, Lisa Guerrero, and featuring an entertaining mixology session with Robby Haynes, co-founder of Apologue Liqueurs.

For more information visit lymphoma.org/swirlamerica or contact Rebecca Rausch, Senior Manager of Distinguished Events at (646) 465-9106 or r-rausch@lymphoma.org.

UPCOMING EVENTS



Update on Immunotherapy Webinar	6.24
<i>Swirl: America</i>	6.25
Update on Adolescent and Young Adult Lymphoma Webinar	7.8
Virtual Lymphoma Workshop, <i>Washington, DC</i>	7.16
Update on Mantle Cell Lymphoma Webinar	7.18
Virtual Lymphoma Workshop, <i>Seattle, WA</i>	7.30
Virtual Ask the Doctor About Lymphoma	8.4



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.

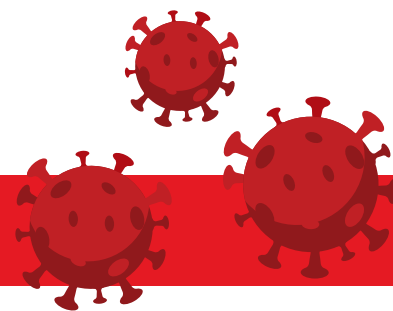
LYMPHOMA

RESEARCH • FOUNDATION

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

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

REGULAR UPDATES ON COVID-19



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

Need to know how COVID-19 is impacting the lymphoma community? Download our fact sheet, call LRF's Helpline (800-500-9976) and listen to COVID-19-specific webinars to stay informed at lymphoma.org/covid19.

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

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