

PULSE

PLAYING THE LONG GAME IN LYMPHOMA RESEARCH

Lymphoma research is not a field for those looking for instant gratification, but Dr. Ari Melnick has never taken a sprinter's approach to finding cures for lymphoma.

page 8

Ari Melnick, M.D.

Weill Cornell
Medical College

USING THE POWER OF SOCIAL
MEDIA TO SUPPORT THE LRF MISSION

page 6

UPDATES FROM 2019 AMERICAN SOCIETY
OF HEMATOLOGY ANNUAL MEETING

page 12

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 and chronic lymphocytic leukemia (CLL) research, awareness and education.

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

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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 be made at any age.

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

lymphoma.org/legacy

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TABLE OF CONTENTS



[FEATURES]

Using the Power of Social Media to Support the LRF Mission

6

In our increasingly interconnected world, people are using Facebook to support nonprofits—how can you make the biggest impact?

Playing the Long Game in Lymphoma Research

8

Lymphoma research is not a field for those looking for instant gratification, but Dr. Ari Melnick has never taken a sprinter's approach to finding cures for lymphoma. He is more of a marathoner.

The Toxic Cost of Cancer

20

"Financial toxicity" describes problems a patient faces related to the cost of medical care. Despite advances in treatments, several studies show that cancer patients and survivors are more likely to experience financial toxicity than people without cancer.

The Promise and Hope of Family

24

Nick Howe never expected a lymphoma diagnosis or pursuit of a family to lead him to find 10 half-siblings and participate in one of the first CAR T-cell therapy clinical trials.



[DEPARTMENTS]

Community Impact

4

Philanthropy in Action

From the Field

12

2019 American Society of Hematology Annual Meeting Updates

U.S. Food and Drug Administration Updates

Living with Lymphoma

16

Patient Perspectives

IN-PERSON EDUCATION PROGRAMS



Upcoming In-Person Education Programs:

- 2.20 Ask the Doctor**
Philadelphia, PA
- 2.25 Ask the Doctor**
Charlottesville, VA
- 3.7 Lymphoma Workshop**
Washington, DC
- 3.15 Ask the Doctor**
Portland, OR
- 3.18 Ask the Doctor**
Dallas, TX
- 3.28 Lymphoma Workshop**
Needham, MA
- 4.14 Ask the Doctor**
Tucson, AZ
- 4.23 Ask the Doctor**
Seattle, WA

Due to the rapid advancement and tremendous progress made in the study of lymphoma, the Lymphoma Research Foundation (LRF) hosts in-person patient education programs around the country, including 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

As a friend of the Lymphoma Research Foundation (LRF), I am excited to share with you the inaugural issue of *Pulse*, the Foundation's newest publication.

Pulse represents the most significant news and updates from across the field of lymphoma and chronic lymphocytic leukemia research. Our new magazine will also explore the latest trends and research on the patient and caregiver experience. We welcome your feedback—and suggestions—as we develop new stories and exclusive content for members of the lymphoma community.

In this issue we profile one of the foremost translational scientists in the world, LRF Scientific Advisory Board member Ari Melnick, MD, from New York-Presbyterian Hospital/Weill Cornell Medicine. Dr. Melnick describes how he is working to decode the lymphoma cell with an aim to achieve a cancer-free future. He also shares why supporting the next generation of lymphoma scientists is more critical than ever before if we are to achieve his goal of a world without lymphoma.



This issue also features stories on two critical issues facing our community: clinical trials and the financial toxicity associated with medical expenses. The Foundation offers numerous resources to patients and their caregivers to address these urgent topics, which are also highlighted in these important pieces.

We also share exciting updates from the largest scientific conference for lymphoma researchers and clinicians in the world, the American Society of Hematology Annual Meeting & Exposition. Lymphoma Research Foundation grantees and scientific advisors, supported by Foundation funding, presented pivotal data that will inform the development of new therapies across the spectrum of lymphoma subtypes. Many of these studies will be highlighted during LRF patient education programs throughout 2020.

Philanthropic funding is often the first step toward new discoveries and understanding the patient experience. These discoveries are a testament to the impact of your support, and you will read how LRF researchers have translated new insights into a better understanding of lymphoma, advanced new treatments and explored the needs of patients and their caregivers. We are grateful for the partnership of LRF donors and volunteers, and those who participate in Lymphoma Walks, the Lymphoma Research Ride or other fundraising events and campaigns, all of which can make a significant difference, enabling innovative ideas to take root and grow.

I hope you enjoy reading this installment of *Pulse* and will look forward to future issues as we explore the latest in lymphoma research and patient care. As Dr. Melnick reminds us, the future holds great promise, and together I am certain we will one day achieve our shared mission to eradicate lymphoma. Thank you for supporting this important work.

Sincerely,

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

Meghan Gutierrez
Chief Executive Officer

PHILANTHROPY IN ACTION



Walk participants at the 2019 Arizona Lymphoma Walk

2019 ARIZONA LYMPHOMA WALK

On October 20, 2019, 1,000 members of Team LRF gathered at the Phoenix Zoo for the Arizona Lymphoma Walk. The Phoenix lymphoma community enjoyed a day of fun and camaraderie as they walked in honor and memory of all those impacted by a lymphoma diagnosis. Together, they raised more than \$55,000 in support of the Lymphoma Research Foundation's mission.

LRF Scholar Allison Rosenthal, DO, of Mayo Clinic, Arizona served as the event's Grand Marshal and spoke about the importance of lymphoma awareness, fundraising and research. Additionally, Dr. Rosenthal, along with her entire team, *Team Mayo Clinic Lymphomies*, were the 2019 Walk series' largest team in the country, boasting over 300 members. Linda Allen was honored with the 2019 Vanguard Award for her long-standing commitment to the Arizona lymphoma community. Linda and her family walk in honor of her husband Max.

2019 SWIRL: ORANGE COUNTY

One hundred and fifty guests attended *Swirl: OC "Whiskey, Wine & All That Jazz"* on October 24, 2019. The event, held at Seven-Degrees in Laguna Beach, Calif., featured a curated selection of wine and whiskey from Swirl Series Founding Sponsor, Southern Glazer's Wine & Spirits.

LRF expanded *Swirl: A Wine Tasting Series* to Orange County in 2018 with the help of dedicated volunteers and *Swirl: OC* co-chairs, A.J. and Michelle Manas. This year's event raised \$95,000 in support of LRF's mission.



Michelle and A.J. Manas (third and fourth from right) and family at 2019 Swirl: OC

EMPOWERING THE LYMPHOMA COMMUNITY FOR GIVINGTUESDAY

GivingTuesday, which takes place the Tuesday following Thanksgiving, is a global generosity movement that unleashes the power of people and organizations to transform their communities and the causes that matter to them most. This year, the Lymphoma Research Foundation focused its GivingTuesday campaign on empowering the lymphoma community to find their path to a cure.

Thanks to a generous donor, all gifts to LRF's GivingTuesday campaign were matched up to \$15,000— and through the collective power of giving, the Foundation raised more than \$80,000 to inspire hope for a brighter future for all those impacted by lymphoma.



Northeast Rod Run

2019 NORTHEAST ROD RUN

Each year, T.J. Ragucci brings together hundreds of muscle car enthusiasts through his fundraising event **Northeast Rod Run**. During the first weekend of October, these aficionados cruise through the scenic highways of the Northeast, all while raising funds for lymphoma research.

After T.J.'s girlfriend Hollie was diagnosed with Hodgkin lymphoma, he turned his passion for cars into a meaningful fundraiser in support of the Lymphoma Research Foundation. The 2019 Northeast Rod Run event raised over \$23,000 through LRF's *Fundraise Your Way* platform, bringing their four-year total to over \$65,000. 🕒

Show Your Love for a Lymphoma Patient This February, Support LRF's Patient Aid Program

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

LRF's Patient Aid Program seeks to help patients in need by helping them cover out-of-pocket expenses associated with their care.

Show your love for a lymphoma patient by making a donation to LRF's Patient Aid Program, to make their journey a little easier.

Visit lymphoma.org/showlove to learn more.

USING THE POWER OF SOCIAL MEDIA TO SUPPORT THE LRF MISSION

In our increasingly interconnected world, people are using social media to support nonprofits—how can you make the biggest impact?

When the first-ever telethon was hosted in 1949, the idea of pledging charitable donations over the phone was new, but caught on quickly—helping nonprofits raise billions of dollars for their cause. Who knew the “social” giving of yesteryear would become the high-speed, super-connected network it is today?

According to Fast Company, online giving—donations for charities made through websites, social media and apps—is growing quickly. Donations made online rose 17 percent between 2016 and 2019, to over \$34 billion. Some 8.5 percent of all U.S. charitable donations, including grants from foundations and gifts from people and companies, are made through websites, social media and apps.

SOCIAL MEDIA RISING

With seven out of 10 people using at least one social media account, social media has become a one-stop shop for connecting with friends and family and supporting nonprofits. Last year, nonprofits received more than \$125 million via Facebook on GivingTuesday, the Tuesday following Thanksgiving and Black Friday that is devoted to giving back to charity. This year, GivingTuesday—which has become a global day of social giving—raised more than \$500 million online and \$1.97 billion across all mediums, according to its website.

Facebook is a rising destination to celebrate birthdays and support users’ charities of choice. According to Facebook, the platform has raised more than \$2 billion through its giving tools for nonprofits and personal causes since 2015, half of which came from the birthday fundraising program, which launched in 2017.

For the Lymphoma Research Foundation, Facebook is an exciting frontier and is making it easier for supporters to join the Team LRF *Fundraise Your Way* program, connect with their existing network of friends and family, and fundraise.

Facebook has raised more than **\$2 billion** for nonprofit and personal causes through its giving tools



“We’ve seen such immense support through Facebook, and it keeps growing,” says William White, Director of Peer-to-Peer Fundraising at the Lymphoma Research Foundation. “It not only helps existing supporters fundraise with us more easily and effectively, but it also connects the Foundation to new supporters.”

The Team LRF *Fundraise Your Way* program allows anyone to support LRF in a way that makes the most sense for them. With the assistance of a Team LRF staff member, fundraisers can turn their time, talent and connections into raising funds and awareness for LRF. Since utilizing Facebook as a fundraising tool, *Fundraise Your Way* has seen an increase in social fundraising by 362 percent between 2017 and 2018.

Between 2017 and 2018, Facebook giving for the Lymphoma Research Foundation increased by 362%



INTEGRATION IS KEY

Starting this year, using Facebook as a platform to raise funds for Team LRF Lymphoma Walks, the Lymphoma Research Ride or a do-it-yourself fundraiser will be easier than ever. Through integration with the Foundation’s peer-to-peer fundraising platform, supporters can connect their individual fundraising page with a Facebook Fundraiser in a few clicks.

“We’re excited to have this new feature as part of our Team LRF program,” says White. “What easier way to connect with friends and family to support your cause? You speak with them and share memes and videos with them on Facebook every day. Now there is a more direct way to share with them that you’re participating in a local Lymphoma Walk or cycling at the Lymphoma Research Ride.”

TIPS FOR A SUCCESSFUL LRF FACEBOOK FUNDRAISER

1.

START SMALL, BUILD UP

Set an initial goal of \$250 and make incremental increases of \$250 every time the goal is met. This will give your donors a sense that they are **really helping to reach incremental goals**, rather than their gift not having an impact.



2.

DONATE TO YOUR FUNDRAISER OR START WITH A MATCH

Show your friends that you believe in your fundraiser by making the first donation to your page. You can also write on your page, **describing your commitment to match dollar-for-dollar up to a total of your choosing.**



3.

SPREAD THE WORD

Most Facebook fundraisers that fail are not successful because people do not know about them! No matter the method, passive fundraising doesn’t work as well as active fundraising. **Invite as many Facebook friends as possible and share the fundraiser often** with a personalized message so friends will see it in their News feed.



4.

SHOW APPRECIATION

Regardless of the fundraising appeal, donors should receive some acknowledgment. Each time a friend gives to your fundraiser, **tag them in a post thanking them.** This will also help spread the word about your fundraiser, because their friends will see the post.



PLAYING THE LONG GAME IN LYMPHOMA RESEARCH

“The long view is that you need to develop mechanisms to help patients.”



Playing the long game is not a new concept for Lymphoma Research Foundation Grantee and Scientific Advisory Board (SAB) member Ari Melnick, MD, of NewYork-Presbyterian/Weill Cornell Medicine. Lymphoma research is not a field for those looking for instant gratification, but Dr. Melnick has never taken a sprinter’s approach to finding cures for lymphoma. He is more of a marathoner.

When you look around Dr. Melnick’s office on the Upper East Side of Manhattan, you can’t help but notice a gigantic model replica of the Millennium Falcon from *Star Wars*. Dr. Melnick approaches research with the same patience and attention to detail that it seemingly took to put together that model, and with an equally innovative view of the future.

FROM DANCE TO HEMATOLOGY

Born in Argentina, Dr. Melnick spent most of his adolescent and young adult life with a love of dance—even directing his own dance company. However, his true passion always lay in medicine and understanding the nature of disease. This passion led him to attend medical school in Argentina and later move to the United States for clinical training in internal medicine.

“I had read in one of my pathology textbooks about a hospital in New York [Mount Sinai Hospital] where certain diseases were being discovered, and so I thought, ‘Wow, that must be the best place to go,’” says Dr. Melnick.

“I felt that hematology presented an opportunity to have a deeper understanding of medicine at the molecular level.”



Dr. Melnick with LRF grantee, Lorena Fontan-Gabas, PhD; Dr. Melnick sponsored Dr. Fontan-Gabas' LRF Fellowship

He completed his clinical training in internal medicine and decided to pursue a specialty in hematology/oncology. “I became very interested in hematology because it is, and perhaps always has been, the most molecularly advanced area in all of medicine,” he says. “I felt that hematology presented an opportunity to have a deeper understanding of medicine at the molecular level.”

Starting his career as an oncologist, Dr. Melnick worked to support patients and their families during a despairing time in their lives—a job that he found to be both tough yet rewarding. “[At the time] we weren’t able to cure many patients, but we could at least be there for them, as someone who they could rely on,” he says.

However, after years of diagnosing patients and treating them with chemotherapy “recipes,” he felt that there had to be a better way to have an impact on patients with cancer. “A patient would come in with a potential cancer. You get a biopsy, you figure out what tissue it corresponds to, do a series of tests to determine disease stage, and then there’s a recipe for what chemotherapy to give—it all felt medieval,” says Dr. Melnick.

Dr. Melnick realized that in order to make a significant change in the way patients were treated, there would first need to be a better understanding of how these diseases work. His thought was that if he could discover the molecular basis causing cancer to occur, that he could then produce much more powerful and less toxic treatments that could eradicate it. “I was fascinated with understanding the disease and disease mechanism, and thought understanding this could help us achieve more targeted treatments,” he adds.

“I was fascinated with understanding the disease and disease mechanism, and thought understanding this could help us achieve more targeted treatments.”

He made the decision to switch gears from clinician to researcher, with the willingness and drive to devote his career to developing mechanisms that could treat cancers at their source. “I was okay with the idea that I may never have a direct impact on a patient, because the top priority is to understand what cancer is, which is required in order to then successfully cure it,” he says.

BREAKTHROUGH AND VALIDATION

A few years later, Dr. Melnick experienced a breakthrough in his lab that would completely validate his choice to enter the field of lymphoma research. He and his team discovered the mechanism through which a master regulatory protein called B-cell lymphoma 6 (BCL6) drives lymphoma: “[The protein] is acting like the airport marshallers who stand on the runway with lights to direct planes to their proper

[FROM THE FIELD]

docking sites,” says Dr. Melnick. “Its main function is to bind to thousands of genes where it brings in cellular machinery to control these genes.” He reasoned that by defining the precise biochemical mechanism through which this occurs, it would be possible to develop BCL6 inhibitors. The problem was that no one had ever developed a drug that was able to target a master regulatory protein like BCL6, which was thought to be “undruggable.”

Dr. Melnick’s team used this information to develop inhibitors that could block the ability of lymphoma cells to use BCL6. They began by creating biochemical decoys and, much to their surprise, the decoys completely wiped out any trace of lymphoma cells. “It was a validation that I didn’t expect,” he says. “I didn’t think that could happen in less than 20 years, and we made it happen in six months.” The decoys worked effectively as BCL6 inhibitors—a major turning point in Dr. Melnick’s research and an impetus for the research he still conducts today.

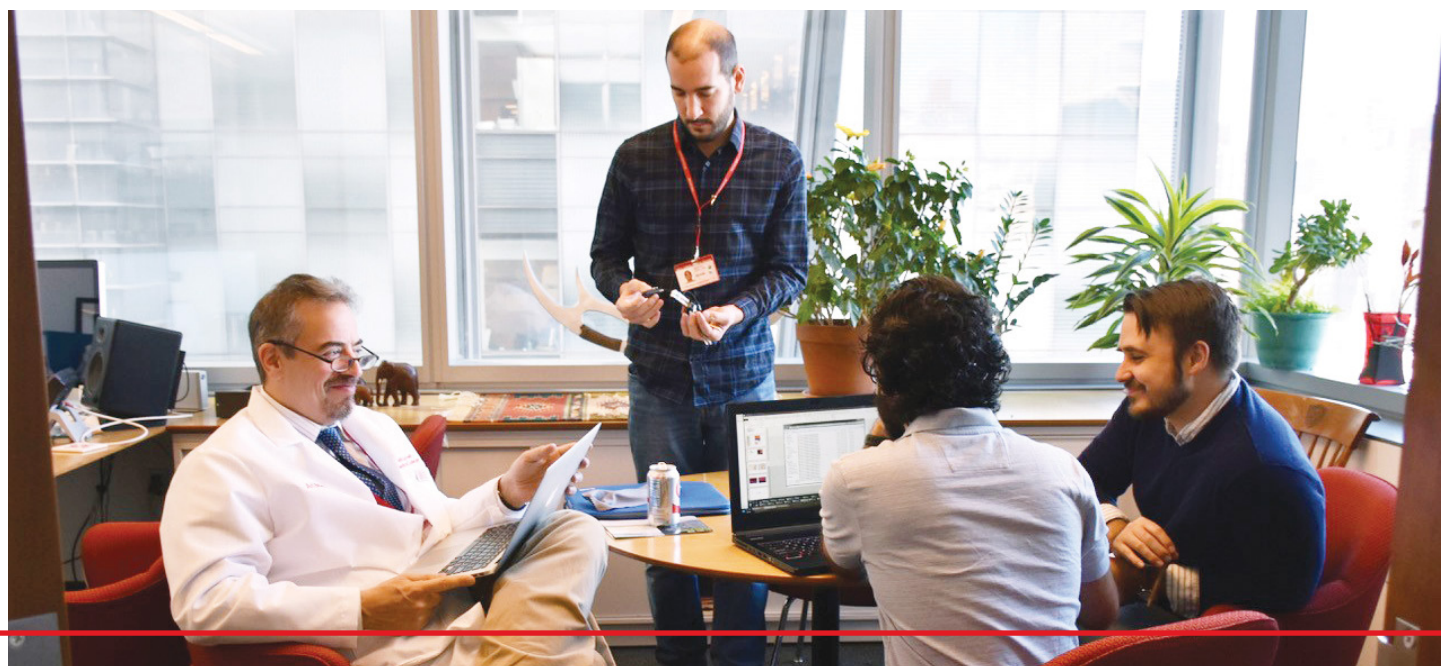
DIVERSITY IS STRENGTH

A key element to the success of Dr. Melnick’s lab is the collaborative, friendly and warm environment that he works hard to maintain. He feels strongly that the researchers in his lab work collaboratively, and finds that better science is done when people work together as a team. He and his colleagues even participate in team-building activities to foster creativity and encourage brainstorming. “Playing games actually helps brainstorming be more effective,” he says. Dr. Melnick also believes in the importance of diversity and multiculturalism throughout his team. “Science is a wonderful field because

it is inherently so cosmopolitan. One of the beauties of science is that it provides a basis for people to cross cultural and ethnic barriers and discover their shared humanity,” he says. He believes diversity can inspire better, more impactful research and presents the researchers an opportunity to explore their work through multiple different lenses.

“Mentoring is not about telling people what to do, but rather, enabling them to take advantage of their inner strengths and passion for science and improving the lives of people with cancer.”

Mentoring the next generation of lymphoma researchers is also of the utmost importance to Dr. Melnick, and he says it is one of his favorite parts about his job. “Mentoring is not about telling people what to do, but rather, enabling them to take advantage of their inner strengths and passion for science and improving the lives of people with cancer,” he says. As if mentoring the researchers in his lab wasn’t enough, Dr. Melnick has also volunteered as mentoring



Dr. Melnick with his research team members including LRF grantee Martin Rivas, PhD (standing); Dr. Melnick sponsored Dr. Rivas' LRF Fellowship



Dr. Melnick in his research lab

faculty for LRF's Lymphoma Clinical Research Mentoring Program (LCRMP), the first and only early-career mentoring program focused exclusively on clinical researchers in lymphoma. He has sponsored four LRF Postdoctoral Fellowship grantees as well. Dr. Melnick relishes in the "aha moments" that come out of his lab and says that seeing his mentees make scientific discoveries based on their own ideas and initiative is a main driver of satisfaction and happiness of his profession.

LOOKING TOWARDS A CANCER-FREE FUTURE

Currently, Dr. Melnick and his team are developing ways to identify the master regulatory proteins that can "reprogram" the immune system to form lymphomas and dissect out their molecular mechanisms of action. "It's very rewarding because it gives you a dramatic insight into the incredible ways in which the immune system works, the complex and intricate process of lymphomagenesis and most importantly, the ability to develop ways to better treat these tumors," he says.

Though the pace of science can sometimes be "dizzying" for Dr. Melnick, he also sees much promise for the future and believes that recent technological and conceptual advances represent a "new frontier" for researchers. "For the first time, we're able to study lymphomas from a holistic, systemic standpoint," says Dr. Melnick. "From lymphoma cells, to the cells that help them, to the cells that are supposed to stop them—at the single cell level—we can actually see it all happening."

Given the rapid and accelerating pace of discovery, Dr. Melnick underlines that it is difficult to predict how rapidly these new advances will translate to the clinic, although one thing that has always been clear to him is the reason he began doing research in the first place. "Nature is stranger and more exciting than humans can imagine, so when you see it unfold, it is invariably stunning and beautiful," he says. Yet for Dr. Melnick, it all harkens back to his time as a clinician when he would meet with families whose lives had been impacted by cancer.

As a researcher he feels a palpable responsibility to ensure a brighter future for patients, survivors and their loved ones. He obtains the most satisfaction from meeting patients who have benefited from a discovery that he participated in and experiences great joy from seeing people who have gone through treatment and have come out on the other side healthy and without toxicity. "The moments that really make it worth all the pain and sacrifice is when you realize that you've figured something out and see how it can play out in medicine and improve the lives of cancer patients," he says. "There is nothing like that." ○

LRF'S IMPACT ON EARLY-CAREER SCIENTISTS

In 2014, LRF sought to establish a program that would train the most talented early-career clinicians in oncology and support them as they pursue careers in the field of lymphoma research. The resulting program, the Lymphoma Clinical Research Mentoring Program (LCRMP), is a first-of-its-kind education and mentoring program for junior scientists—LRF Scholars—who wish to focus on lymphoma clinical research.

Already, the LCRMP has surpassed expectations, with a 100 percent retention rate in the first five years of its existence. All Scholars participating in the program's first five grant classes are still studying blood cancers, and 97 percent are studying lymphoma specifically.

We seek to partner with forward-thinking philanthropists and foundations to help fund cutting-edge science and foster the early careers of the next generation of lymphoma researchers.

If you are interested in funding a Lymphoma Research Foundation Scholar in your name, the name of a loved one or the name of a healthcare provider or caregiver, **please contact LRF's Development Team at development@lymphoma.org.**

2019 AMERICAN SOCIETY OF HEMATOLOGY MEETING UPDATES

The Lymphoma Research Foundation (LRF) returned to the American Society of Hematology (ASH) Annual Meeting and Exposition, with nearly 70 LRF-affiliated scientists presenting more than 100 abstracts at this year's conference.

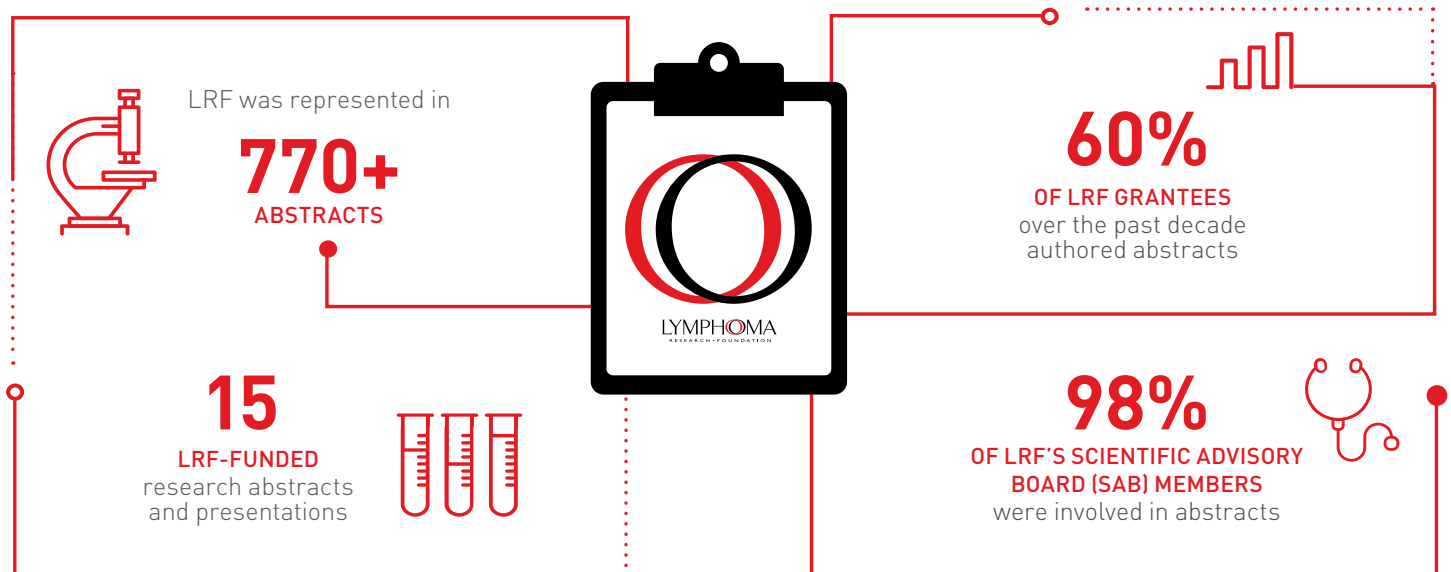
Widely regarded as the premier event in malignant and non-malignant hematology, the ASH Annual Meeting, held from December 7-10, 2019 in Orlando, Fla., provided a critical forum for leading hematologists/oncologists to present their findings to over 30,000 of their peers. Among the distinguished scientists invited to present, nearly 50 percent of LRF Scholars—participants in LRF's Lymphoma Clinical Mentoring Program—presented abstracts at the 2019 ASH Annual Meeting.

In addition to the Lymphoma Research Foundation's representation through presentations, more than 60 percent of LRF grantees from the past decade were authors on abstracts selected for this year's meeting alone. In addition, LRF is represented in more than 770 abstracts through grantees, Lymphoma Rounds Steering Committee members, Mantle Cell Lymphoma (MCL) Consortium members, LRF staff, and current and former SAB members.

The 2019 ASH Annual Meeting also featured 15 abstracts and presentations stemming from LRF-funded research.

“The fact that we have 98 percent of LRF's current Scientific Advisory Board (SAB) members involved in abstracts at this year's ASH Annual Meeting speaks to the caliber of world-leading scientists we have steering LRF's research investment and patient education.”

—Andrew D. Zelenetz, MD, PhD, Chair of the LRF Scientific Advisory Board



New CAR T-Cell Therapy for Relapsed/Refractory Mantle Cell Lymphoma Shows High Complete Remission Rates



Michael Wang, MD

Treatment with the CAR T-cell therapy KTE-X19 resulted in a complete remission rate of 67 percent and response rate of 93 percent for patients with relapsed/refractory mantle cell lymphoma (MCL), according to findings presented by LRF Mantle Cell Consortium member Michael Wang, MD, of The University of Texas MD Cancer Center.

The 69 patients included in the study cohort received conditioning chemotherapy, with 68 receiving KTE-X19. The therapy was successfully manufactured for 96 percent of the patient cohort and administered to 92 percent. During the manufacturing process, patients were allowed to bridge therapy (defined as therapy that assists patients to another stage of therapy or past a challenging period) for progressive disease. These therapies include ibrutinib (Imbruvica), acalabrutinib (Calquence) or dexamethasone, but not chemotherapy. Patients also received 3 consecutive days of conditioning chemotherapy five days prior to T-cell infusion.

Of the patients who reached a complete remission, 78 percent remained in remission at the time of the analysis. Of the first 28 patients treated in the trial, 43 percent remained in remission, suggesting high durability of response.

Based on the findings of the trial, a biologics license application (BLA) to the U.S. Food and Drug Administration (FDA) for KTE-X19 in relapsed/refractory MCL was filed. Prior to the BLA application, KTE-X19 received a breakthrough therapy designation from the FDA.

This study included contributions from Scientific Advisory Board (SAB) member John Timmerman, MD, of UCLA Jonsson Comprehensive Cancer Center; LRF grantee John Pagel, MD, PhD, of Swedish Cancer Institute; Lymphoma Clinical Research Mentoring Program (LCRMP) Scholar Patrick Reagan, MD, of University of Rochester/James P. Wilmot Cancer Institute; Mantle Cell Lymphoma Consortium member Ian Flinn, MD, of Tennessee Oncology; and former SAB member Andre Goy, MD, of John Theurer Cancer Center/Hackensack University Medical Center.

Lenalidomide Plus Obinutuzumab Achieves 100 Percent Response Rate in Rituximab-Refractory Indolent Non-Hodgkin Lymphomas



Nathan Fowler, MD

The combination of lenalidomide (Revlimid) and obinutuzumab (Gazyva) reported at 100 percent overall response rate in patients with relapsed (disease that reappears or grows again after a period of remission) indolent non-Hodgkin lymphoma (NHL) that was refractory (lymphoma does not respond to treatment) to rituximab (Rituxan).

Presented by former Scientific Advisory Board (SAB) member Nathan Fowler, MD, of The University of Texas MD Anderson Cancer Center at the ASH Annual Meeting, the trial evaluated the combination in 66 patients (57 with low-grade follicular lymphoma [FL], five with small lymphocytic lymphoma [SLL] and four with marginal zone lymphoma [MZL]). Patients needed to have indolent disease that had not transformed and must have received at least one prior therapy to be eligible.

Patients with MZL and SLL showed an overall response rate of 88 percent; and patients with FL showed an overall response rate of 100 percent, all with no progressive disease.

Dr. Fowler noted in his presentation that correlative studies are ongoing to predict patients who are at risk for early relapse with the combination. In addition, he concluded the need for larger randomized studies to determine if this combination therapy is superior to lenalidomide plus rituximab.

This study included contributions from LRF grantees Paolo Strati, MD, and Jason Westin, MD, of The University of Texas MD Anderson Cancer Center.

New Therapy Shows Promising Results for Patients Who Relapse After or Are Resistant to CAR T-cell Therapy



Stephen Schuster, MD

An immunotherapy that uses a patient's own T-cells, altered to specifically attack cancer cells and then reintroduced to the patient, CAR T-cell therapy has shown promising early results for aggressive lymphomas that have proven resistant to other therapies.

However, for patients who experience CAR T-cell failure, further treatment options are very limited or non-existent. At a plenary session, Philadelphia Lymphoma Rounds Steering Committee chair Stephen Schuster, MD, of the Abramson Cancer Center, University of Pennsylvania, presented results of a study of mosunetuzumab, a single-agent bispecific antibody that binds both CD3 T-cells and CD20 on B-cells.

The cohort included 270 adult patients with relapsed/refractory non-Hodgkin lymphoma (NHL), including 85 patients with indolent NHL (mostly patients with follicular lymphoma [FL]) and 180 patients with aggressive NHL (mostly patients with diffuse large B-cell lymphoma [DLBCL] or FL), who had received an average of three prior therapies. Nearly one-quarter of enrolled patients with NHL who had relapsed or failed to respond to CAR T-cell therapy achieved complete remission following the administration of mosunetuzumab.

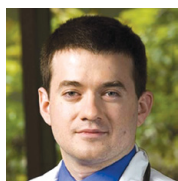
In the overall group of 67 patients with indolent NHL, the overall response rate was 63 percent and the complete remission was 43 percent. The Corresponding groups of 124 patients with aggressive NHL experienced an overall response rate of 37 percent and complete remission of 19 percent.

Most notable in the study was the durability of the complete remission to mosunetuzumab, with nearly 83 percent of patients with indolent NHL and nearly 71 percent of patients with aggressive NHL maintaining their complete remission up to a period of 25 and 16 months off treatment, respectively.

Dr. Schuster noted that studies are ongoing with single-agent mosunetuzumab and combinations.

This study included contributions from Scientific Advisory Board (SAB) members Nancy Bartlett, MD, of Washington University Medical School, and Laurie Sehn, MD, MPH, of British Columbia Cancer; and LRF Mantle Cell Consortium member Lihua Elizabeth Budde, MD, PhD, of City of Hope.

Study Suggests 90 Percent of Patients with Limited-Stage DLBCL Can Skip Radiation Therapy



Daniel Persky, MD

According to study results presented by past LRF Arizona Lymphoma Workshop Chair Daniel Persky, MD, of the University of Arizona in Tucson, almost 90 percent of the patients had negative PET scans after completing three cycles of chemotherapy, suggesting that the vast majority of patients with newly diagnosed limited-stage diffuse large B-cell lymphoma (DLBCL) can forego radiotherapy.

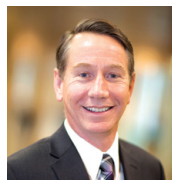
The study was based on results of the Southwest Oncology Cooperative Group (SWOG) S0313 trial that found adding ibritumomab tiuxetan consolidation to three cycles of CHOP showed an overall survival estimate of 91 percent; and on the BC Cancer Agency's study that reported PET-driven treatment after three cycles of R-CHOP showed a three-year time to progression rate of 60 percent and overall survival of 83 percent for patients with positive scans treated with radiation therapy.

The study cohort included 132 patients with early-stage DLBCL, including 98 patients with DLBCL, 19 with high-grade B-cell lymphoma, four with "double hit" high-grade B-cell lymphoma, and two with T-cell or histiocyte-rich large B-cell lymphoma. Nine patients did not have histology confirmed by central review. After an average follow-up of 4.5 years, five patients had disease progression and 13 had died (two patients of lymphoma and 11 of other causes). Progression occurred in three patients who received only R-CHOP, one who had a positive PET scan but declined radiation therapy, and one who stopped treatment after the first cycle of R-CHOP.

Overall, the study showed an estimated five-year progression-free survival of 87 percent and overall survival of 90 percent in patients. Patients who received no radiation had a progression-free survival of 89 percent and overall survival of 91 percent, and most deaths were unrelated to lymphoma.

This study included contributions from Scientific Advisory Board (SAB) members Nancy Bartlett, MD, of Washington University Medical School; Jonathan Friedberg, MD, MMSc, of University of Rochester/James P. Wilmot Cancer Institute; Brad Kahl, MD, of Washington University School of Medicine; John P. Leonard, MD, of NewYork-Presbyterian Hospital/Weill Cornell Medicine; and Sonali Smith, MD, of The University of Chicago. This study also included LRF grantees Paul Barr, MD, of University of Rochester/James P. Wilmot Cancer Institute; Steven Park, MD, of Levine Cancer Institute; and Debbie Stephens, DO, of University of Utah/Huntsman Cancer Institute. Also contributing to the study were Former SAB member Richard I. Fisher, MD, of Fox Chase Cancer Center; and Lisa Rimsza of Mayo Clinic, Scottsdale.

Nivolumab Study Halted in Peripheral T-cell Lymphoma Due to Hyperprogressive Disease



Steven Ansell, MD, PhD



Gita Thanarajasingam, MD

Results from a phase II study of nivolumab (Opdivo), a checkpoint inhibitor, in patients with relapsed/refractory peripheral T-cell lymphoma (PTCL) was halted due to the high number of patients with hyperprogressive disease, the moderate activity of the drug, and short duration of response, according to a study presented at 2019 ASH. Hyperprogressive disease is defined as dramatic progression within one cycle of treatment.

The trial enrolled 12 patients (six with angioimmunoblastic T-cell lymphoma, three with PTCL, not otherwise specified; one with ALK-negative anaplastic large cell lymphoma [ALCL]; one with enteropathy-associated T-cell lymphoma; and one with hepatosplenic gamma delta T-cell lymphoma). A total of 11 patients had stage 4 disease, 11 had extranodal involvement, and six had prior autologous stem cell transplant. All patients received at least one cycle of nivolumab.

Overall, four patients had a response to single-agent nivolumab, which included two complete responses and two partial responses. Patients had a median progression-free survival of 2.7 months and a median overall survival of 6.7 months.

The study authors noted that these findings likely reflect the distinct biology of PTCL and should be considered when designing future studies using checkpoint inhibitors in these diseases.

This study included contributions from Scientific Advisory Board (SAB) member Steven Ansell, MD, PhD; LRF Lymphoma Clinical Research Mentoring Program (LCRMP) Scholar Gita Thanarajasingam, MD; and former SAB member Thomas Witzig, MD, of Mayo Clinic, Rochester.

Whole Exome Sequencing for Follicular Lymphoma Reveals Distinct Genetic Subgroups



Sandeep Dave, MD, MS

Follicular lymphoma (FL) is one of the most common types of lymphoma [WS8]. Because FL can present in several different ways in the human body and frequently transforms from indolent to aggressive disease, there are major challenges to identifying associated genetic alterations or clinical outcomes. Based on the observed mutational rates in FL, an international study investigated more than 1,000 cases with a goal to delineate the genetic alterations that underlie histologic grade and clinical outcome.

The study, presented by Scientific Advisory Board (SAB) member and LRF grantee Sandeep Dave, MD, MS, of Duke University, performed DNA and RNA sequencing on paired normal and tumor specimens from 1,042 patient tissue samples with newly diagnosed FL. The researchers used a technique called whole exome sequencing, which analyzes all the protein-coding regions of genes (the exome) in a given type of cell. They also analyzed other key biomarkers and genetic pathways relevant to lymphoma, including immunoglobulin, T-cell receptor and CD3 loci, likely breakpoint regions, long noncoding RNAs and microRNAs. For viral detection, the study targeted viruses thought

to contribute to the development of lymphoma, including Epstein-Barr virus (EPV), human papillomavirus (HPV), human immunodeficiency virus (HIV), hepatitis B and C, Kaposi's sarcoma-associated herpesvirus, human T-lymphotropic virus and Merkel cell polyomavirus.

The sequencing of the samples revealed over 100 genes mutated with a frequency of at least two percent, confirming that FL does have a wide variety of genetic differences from patient to patient. Nearly 100 percent of cases had a mutation in at least one chromatin-modifying gene, with the most frequently mutated genes being *KMT2D*, *BCL2*, *IGLL5* and *CREBBP*. The study also identified frequent mutations in the *SPEN*, *BIRC6* *SETD2*—which is believed to be a new discovery in these genes. Genetic data such as this will help researchers to develop new diagnostic and prognostic tools for the different varieties of FL as well as new targeted therapies.

This study included contributions from Scientific Advisory Board (SAB) members Eric Hsi, MD, of Cleveland Clinic, and Christopher Flowers, MD, MS, of MD Anderson Cancer Center; and LRF grantees Richard Burack, MD, PhD, of University of Rochester, and Matthew McKinney, MD, of Duke University School of Medicine. ©

For more updates from 2019 ASH, visit lymphoma.org/research-news and listen to the 2019 American Society of Hematology Annual Meeting webinar at lymphoma.org/webinars.

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.

PEGFILGRASTIM-BMEZ (ZIEXTENZO)

November 5, 2019 — approved as a long-lasting supportive care biosimilar to pegfilgrastim (NEULASTA). Pegfilgrastim-bmez is indicated to decrease the incidence of infection, as manifested by febrile neutropenia (low white blood cell count with a fever) for patients with nonmyeloid malignancies (i.e. lymphomas and lymphocytic leukemias) who are receiving myelosuppressive anti-cancer therapy (i.e. chemotherapy).

ZANUBRUTINIB (BRUKINSA)

November 14, 2019 — approved for adult patients with mantle cell lymphoma (MCL) who have received at least one prior therapy.

ACALABRUTINIB (CALQUENCE)

November 21, 2019 — approved for adult patients with chronic lymphocytic leukemia/small lymphocytic lymphoma (CLL/SLL).



PATIENT PERSPECTIVES

Study Explores Unmet Needs of Lymphoma Patients and Caregivers

Due to an increase in new and effective treatments, outcomes among lymphoma patients have improved, with a 10-year survival rate reported to be higher than 50 percent for many subtypes. With more patients living with and after a lymphoma diagnosis, the need to understand all aspects of survivorship and long-term quality of life has become a priority among researchers and patients alike.

Given the growing need for patient-centered care and lymphoma survivorship research, a group of lymphoma, public health and patient advocacy experts—including Lymphoma Research Foundation Scientific Advisory Board member Christopher Flowers, MD, MS, of The University of Texas MD Anderson Cancer Center, and LRF Chief Executive Officer Meghan Gutierrez—conducted a research study with lymphoma survivors and caregivers to identify gaps in care and how best to address them.

“It is well recognized among providers that the perspectives of patients and caregivers are very important in planning the ways that we deliver care and the areas that we focus on for research in lymphoma,” says Dr. Flowers. “However, very little research has been done asking patients and caregivers about these perspectives.”

The study explored topics most important to people with lymphoma. These included communication with healthcare providers; survivorship; treatment-related side effects; and the role and needs of caregivers.

“Due to advances in treatment that have resulted from our investment in research, more people than ever before are surviving—in fact thriving—for years, even decades, after being diagnosed with lymphoma,” says Gutierrez. “But even with these advances, we know that survivors often experience side effects or other complications from their treatment, and so we need to better understand how LRF can support this growing group of lymphoma survivors.”

Patients and caregivers who participated in the study described receiving an overall lack of information regarding their diagnosis, research opportunities and treatment decisions from their healthcare team. Furthermore, participants described a feeling of disconnect with their team and an inability to receive compassionate care.

I feel sometimes they don't understand that you're talking to someone whose life has just changed for the worst, and you need to be as sympathetic and kind and compassionate as you can.

—Study Participant

SELF-ADVOCACY MATTERS

Knowing as much as possible about your lymphoma subtype, treatment options and their potential effects can empower you to take charge of your health and communicate with your physician. Being a self-advocate and an active participant in your healthcare can be a positive experience and may help restore any sense of control you may have felt was lost following your diagnosis. Many patients feel better when they actively participate in their care.

BASIC TIPS FOR SELF-ADVOCACY:

- 1 DON'T BE AFRAID TO ASK YOUR DOCTOR**
Ask your doctor or nurses questions about your care.
- 2 LEARN MORE ABOUT YOUR SPECIFIC SUBTYPE OF LYMPHOMA**
Ask your doctor for information and visit reliable websites, such as the Lymphoma Research Foundation's lymphoma.org.
- 3 TAKE ADVANTAGE OF SUPPORT SERVICES**
Ask your doctor about counseling, support groups, nutritional counseling, fitness classes and other services offered at your doctor's office, cancer center or hospital.

Consider joining the Lymphoma Support Network, a nationwide buddy program that matches patients and caregivers with people who have had similar experiences.

For information about the program, call the LRF Helpline at 800-500-9976 or email helpline@lymphoma.org.




Caregivers felt a disconnect as well, with many describing a feeling of being overlooked and unappreciated by the clinical care team. “Caregivers never get the day off,” says Gutierrez. “They are responsible for numerous aspects of a patient’s treatment and care, and so we need to understand more about the effects of a lymphoma diagnosis on their quality of life and the needs that they have, both during active treatment and after treatment is completed.”

“In general, patients are quite interested in participating in clinical research, but found it difficult to determine where to go for more information ...

– Dr. Christopher Flowers

The study also revealed that patients and caregivers desire a holistic focus to not only treat their lymphoma, but also to address the emotional, mental health and other health-related needs that come with navigating their disease.

The clinical implications of the study results reveal the need for clinicians to establish a trusting and patient-centered relationship by providing clarity and guidance on care plans and clinical trial opportunities; consider other cancer-related factors like the patients’ emotional health; and consider caregivers by providing supportive resources.

“In general, patients are quite interested in participating in clinical research, but found it difficult to determine where to go for more information about whether a study was the right choice and wanted more resources for helping with clinical decisions,” says Dr. Flowers. “In particular, our study indicated that caregivers are often overlooked in the process of caring for the patient. Even as an oncologist and an expert in the field, my personal experiences as a caregiver match what the caregivers in this study told us.” 

The original article, “Patients and Caregiver Perceptions of Lymphoma Care and Research Opportunities: A Qualitative Study” was published in Cancer on October 29, 2019.



USING EMOJIS TO MONITOR PATIENTS' HEALTH

Researchers at Mayo Clinic, Rochester, recently shared the results of an initial study using emojis to help patients measure their overall well-being during treatment. The study's lead author, Carrie A. Thompson, MD, of Mayo Clinic, Rochester, (who serves as speaking faculty for several LRF patient education programs, including Ask the Doctor About Lymphoma and the Minnesota Lymphoma Workshop), used two scales—a mood scale and an ordinal scale—featuring a total of 10 emojis.

The expressions, ranging from smiling faces to frowns, were used to help patients express their current mood. The research is being used to determine how patients manage treatment, as well as ways doctors could track their patients' progress using mobile technology.



SWIRL: MIAMI BEACH

A Wine Tasting Event

Wednesday,
March 18, 2020

6:30 – 9:30 PM

La Gorce Country Club – Miami Beach, FL

For more information,
visit lymphoma.org/swirlmiami

or contact Rebecca Rausch,
Senior Manager of Distinguished Events, at
646-465-9106 or rtausch@lymphoma.org.



THE TOXIC COST OF CANCER

Cancer is one of the costliest conditions to treat today in the United States. With outcomes among patients with lymphoma improving, managing costs related to the diagnosis and treatment of their disease is a major concern.

In 2005, Anita Jones noticed dry patches of skin developing on her face, including her neck and nose. Months later, after having seen three different dermatologists, the then 47-year-old from New York was diagnosed with lymphoma. “My dermatologist told me it was lymphoma, but when he said it, I never thought it was cancer,” says Jones. Jones was diagnosed with cutaneous T-cell lymphoma (CTCL), a rare and incurable type of non-Hodgkin lymphoma that appears on the skin. Symptoms for CTCL include skin patches, plaques, tumors or a reddening of the skin called erythroderma. Many patients with CTCL may experience an initial misdiagnosis due to CTCL skin lesions mimicking the look of other skin conditions like eczema, psoriasis and dermatitis.

Because it is a rare disease, management of CTCL is usually done at centers with expert experience treating it or in partnership with such centers. The treatment is highly tailored for each patient, but may include a combination of skin-directed treatments such as topical corticosteroids, topical chemotherapy, skin radiation therapy and ultraviolet light, among others.

Jones immediately underwent intense skin radiation therapy for 30 days to eradicate the lesions on her face. She was elated to learn that the procedure removed the patches but, because Jones' disease was chronic, they quickly came back.

After nearly six years of frequent skin radiation therapy and chemotherapy, Jones eventually maxed out her sick time, paid time off and medical leave. She made the decision to retire early from employment at her local police department, where she worked for 20 years. "When I finally had to retire, I felt terrible. I didn't know what to do," she says. "I didn't know how I was going to sustain my treatments on a fixed income. I started counting pennies—I mean looking for pennies in my house to pay for travel to treatment."

Jones, now 61, still undergoes frequent treatments for her CTCL, which includes a combination of chemotherapy for a period of six months, as well as phototherapy three times a week. She struggles to cover the costs to and from treatment, co-pays for medication and other cost-of-living expenses. "Due to the radiation on my face, I have glaucoma, and the cost of the medication is \$300 per month," says Jones.

"So what do I do? I sometimes take \$150 from rent to pay half of my medication, or stretch one month of medication to two months to pay for travel to my treatments. It's like robbing Peter to pay Paul."

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Unfortunately, Jones' story is not unique. Cancer is one of the most expensive medical conditions to treat in the United States. Lymphoma patients may receive multiple types of treatments, are frequently hospitalized and/or incur a variety of ancillary costs that add up. According to a study

TIPS FOR MANAGING COSTS RELATED TO TREATMENT

Lymphoma treatment can be expensive, even with insurance, and keeping track of tests, treatments, paperwork, bills and other records may seem overwhelming. Here are some tips to help manage costs related to treatment:

① UNDERSTAND YOUR EXPENSES

- **Be aware of your expenses from the beginning** to have a foundational understanding of your total cost related to treatment.
- **If you plan to participate in a clinical trial**, it's important to understand the difference between patient care costs and treatment costs.
- **Talk with your medical institution's billing office** or financial counselor before starting treatment to learn about payment options such as payment plans, reduced rates and patient assistance.

② UNDERSTAND YOUR HEALTH INSURANCE

- **Speak with your health insurance provider** to understand which tests, treatments and drugs are covered under your policy.
- **Learn about your co-pays, deductibles and other costs** and whether they are due up front and how much they cost.

③ SPEAK WITH YOUR DOCTOR

- **If there are tests or procedures not covered by your insurance policy**, ask your doctor to write a letter stating why it is needed to submit to your health insurance provider.
- **If you think the costs of care could be a burden for you**, speak with your healthcare team or social worker so they can consider other treatment options or refer you to an organization that can offer financial assistance.

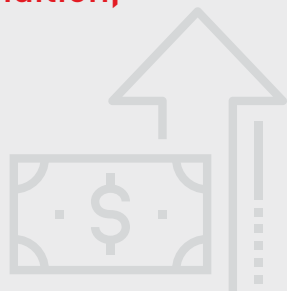
For questions regarding financial assistance, call the LRF Helpline at 800-500-9976 or email helpline@lymphoma.org.



published in the *Journal of American Medical Association* (JAMA), 39 percent of cancer patients experienced higher-than-expected financial burden from cancer care costs, averaging \$703 per month out of pocket. In fact, cancer survivors usually report higher out-of-pocket spending than people who have not had cancer.

“Financial toxicity” describes problems a patient faces related to the cost of medical care. And this problem seems to be getting worse for cancer patients as treatments and survival rates improve. “The cost of care has steadily climbed for anyone with a serious medical condition, as well as the cost of drugs related to cancer,” says Joanna Morales, Chief Executive Officer at Triage Cancer.

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Compared to 10 years ago, patients are receiving more expensive chemotherapy, immunotherapy and other new types of treatment. In addition, many patients may receive newer treatments until disease progression, which could last for several years. Copayments for prescription drugs covered by health insurance may be more for higher-priced drugs or brand name drugs (versus generic drugs) and may increase over time. These copayments and coinsurance for drugs, coupled with other costs not covered by insurance such as transportation to and from treatment and cost-of-living expenses, may cause financial toxicity.

“The cost of health insurance coverage has also gone up,” says Morales. “People have focused on purchasing health insurance or choosing options with the lowest monthly premiums, which often have the highest out-of-pocket costs. And because most people don’t understand how out-of-pocket maximums work, this is where we see patients take the greatest hit.”

Because of debt burdens like inadequate health insurance, high copayments for prescription drugs and ancillary costs related to treatment, the effects of financial toxicity are detrimental to patients’ quality of life and their ability to maintain their health.

“Data shows people with inadequate health insurance—with high deductibles and copays—are not going to get medical care because they simply cannot afford to pay those costs,” says Morales. “This is certainly true with prescription drugs. If a patient walks into a pharmacy and the copay is higher than they can afford, more often than not they are walking out of that pharmacy without their medication.”

Even for many patients with full-time employment and adequate health insurance, financial toxicity is a possibility. Having cancer may make it difficult for patients to do the physical and mental tasks required for their job. Many may miss time at work or not be able to work at all. Many patients and caregivers contacting the Lymphoma Research Foundation (LRF) for financial assistance and referrals often cite their inability to work consistently or living on a fixed income as reasons for seeking help.

“There are a number of reasons people have provided during their request for financial assistance, including that they are retired and living off Social Security, or they do not have insurance or they have insufficient coverage,” says Izumi Nakano, Associate Director of Support Services at LRF. “However, the number one reason many request financial assistance is because of their inability to work due to treatment.”

100% of LRF’s Patient Aid Program is privately funded by individual supporters and foundations who want to pay it forward and help lymphoma patients in need.

LRF’s Patient Aid Program assists patients currently in active treatment who are in need of financial assistance to cover the costs associated with care.

Through the LRF Helpline, eligible patients receive a one-time financial grant, and all patients receive referrals to additional financial assistance programs. The Patient Aid Program is entirely privately funded by individual supporters and foundations who want to pay it forward and help lymphoma patients in need.

TAKING A HOLISTIC APPROACH TO GIVING

In June 2012, Steven Eichberg was diagnosed with indolent follicular lymphoma. While researching patient support resources, he discovered the Lymphoma Research Foundation. He was drawn to the dual focus on patient support services and innovative research. “LRF helps on both ends of the spectrum—getting patients to the right doctors for treatment and funding cutting-edge research for new treatments to eventually lead to a cure,” says Eichberg. The support provided by the LRF Helpline and *Focus on Lymphoma* mobile app was invaluable in guiding Eichberg and his wife Jean to the best care. “We appreciate the instrumental role LRF plays in pointing patients in the right direction to ensure they get the services and support they need,” he says.

That’s why the Eichbergs decided to take a holistic approach to giving and split their gifts between LRF’s patient support programs like the Lymphoma Support Network and Patient Aid Program, and research. “We give to complete the circle, and help patients better understand what lies ahead, whether they need treatment or not,” Eichberg adds.



Steven Eichberg

“Whether it’s \$5 or \$5,000, being a part of the LRF family is money well spent helping others receive the best care and finding a cure.”

Often, the financial implications of a cancer diagnosis are overlooked and for many become an additional stress and a real factor in making treatment decisions. At a time when patients should be focused on self-care and healing, many find themselves concerned with insurance co-pays and out-of-pocket expenses. In supporting LRF, Eichberg knows he’s helping others and himself. “When you need it, LRF will be there with something for you,” he says. “Whether it is the steady guide of peer support through the Lymphoma Support Network, the trained staff through the LRF Helpline, their award-winning app or cutting-edge research.”

“The program offers hope to those in need of support,” says Nakano. “A lymphoma diagnosis is difficult and stressful enough to have to deal with, but the additional pressure of not being able to afford treatment-related expenses in addition to other normal life expenses can be devastating.”

Since the inception of the Patient Aid Program, LRF has awarded more than 3,500 grants, but the need continues to rise each year. “The need for the program has risen over the past several years, where now, nearly 5,000 calls and emails to the LRF Helpline are a need for financial assistance,” says Nakano.

LRF’s Patient Aid Program has awarded more than 3,500 grant awards to date.

Although the need for financial assistance programs like LRF’s is still great, there are ways patients and caregivers can work to mitigate costs related to treatment. According to Morales at Triage Cancer, the most important way to mitigate debt burden is finding adequate health insurance and understanding how to navigate health insurance coverage.

This includes understanding the appeals process if insurance denies a claim to avoid paying out of pocket for care. Understanding one’s employment rights and wage replacement options like disability should also be considered.

“I always encourage people to think as broadly as possible when talking about financial toxicity,” says Morales. “The cost of care is a very important conversation. But a major reason why financial toxicity is so hard to address is because there are a variety of factors that contribute to it—and there isn’t just one solution. People should understand all the risk factors so they can be addressed and lower the financial burden as much as possible.” ○

THE PROMISE AND HOPE OF FAMILY



Nick Howe never expected a lymphoma diagnosis or pursuit of a family to lead him to find 10 half-siblings and participate in one of the first CAR T-cell therapy clinical trials.

At 28 years old, Nick Howe never imagined a morning cup of coffee with his mother would change his life forever. Howe, who hails from Nebraska, was explaining to his mother that starting their family had not been easy for him and his wife Rachel. “The conversation moved into a discussion of various reproductive treatments,” he says. “I told her I would rather adopt.”

His mother was shocked by his dismissal. “She asked me, ‘What if I were to tell you the reason why you and your sister are here today is because of a donor?’” adds Howe. Once Howe grasped onto the reality of what his mother had said, he walked her back to her office and immediately went home to tell his wife what had happened.

After a few agonizing moments, Rachel processed the news. “She told me knowing how hard my parents worked to bring me into her life made her love me even more,” says Howe. “I gave a huge sigh of relief. And honestly at that moment, everything made sense to me.”

Three years later, Howe, now 31, and his wife were still struggling to start their family. Howe also began to experience a variety of severe health issues, including liver and kidney failure, and the loss of 55 pounds within the span of a couple of months. “I was in immense pain, both physical and emotional, and was anything but my jovial self,” he says.



Nick Howe with his wife, Rachel, and their daughter, Julia

After some time in the hospital, he was finally diagnosed with diffuse large B-cell lymphoma (DLBCL) and was told to start treatment immediately.

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

Presently, the most widely used treatment for DLBCL is the combination therapy known as R-CHOP (rituximab [Rituxan], cyclophosphamide [Cytoxan], doxorubicin [Adriamycin], vincristine [Oncovin], and prednisone). The R-CHOP regimen is usually given in 21-day cycles (once every 21 days) for an average of six cycles. However, the length and number of cycles given can vary based on the patient’s individual disease and health status. In certain cases, 14-day cycles may be used, and for limited-stage disease (stage I or II), 3-4 cycles may be used followed by radiation.

Before starting his first round of R-CHOP, Howe’s doctor asked if he and his wife were planning to start a family, because this treatment could potentially result in infertility. As many young people facing a lymphoma diagnosis must do, the Howes quickly needed to make several additional medical appointments in order to secure their chances of having a family in the future. “I couldn’t have done any of this without the unconditional support of my wife, who carried us both when I was unable to stand on my own,” says Howe.

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Only hours into Howe’s first round of treatment, the Howes received a call from their fertility doctor telling them that they would be able to help them start a family. “I never cry, but at that moment I did,” says Howe. “We still might have a chance to become parents. It was exactly the news we needed to hear in order to get through that tough first night of chemo.”

Following that first night of chemotherapy, Howe’s journey was fraught with challenges and setbacks. He endured two more years of anti-cancer treatments, including chemotherapy, immunotherapy, multiple clinical trials and an autologous stem-cell transplant (a procedure in which stem cells are collected from the patient).

After his autologous stem-cell transplant failed, Howe relapsed in less than 100 days, and his doctors began preparing him to undergo an allogeneic stem-cell transplant. This treatment relied on Howe finding a donor who was a complete genetic match. There was also a possibility of developing various long- and short-term side effects. His doctors began testing his immediate family, including his sister, as possible stem cell donors. With none resulting in a complete match, Howe remembered his life-changing conversation with his mother three years ago. That memory quickly impacted his search for a donor. “Shortly after my conversation with my mother, I began a search for my half-siblings,” he says. Through that search, he identified and connected with 10 half-siblings. One of them would be the person who Nick calls his “Hail Mary.”

Weeks prior to learning about his relapse, Howe connected with one of his siblings, a half-brother who happened to be a healthcare professional working at the same medical institution where Nick was being treated. Surprisingly, with little knowledge of one another or any real connection aside from sharing DNA, Howe and his half-brother quickly created an unbreakable bond and later learned that he was the match that could potentially save his life.

At the same time, an additional treatment called chimeric antigen receptor (CAR) T-cell therapy became available in the United States. CAR T-cell therapy is a treatment in which engineered molecules called chimeric antigen receptors (CARs) recognize and destroy antigens present

on the surface of lymphoma cells. T-cells are first removed from the patient and then genetically modified to produce CARs. The genetically engineered CAR T-cells are grown in the laboratory until they number in the billions and are then infused back into the patient.

At the time of Howe’s relapse, CAR T-cell therapy was in the clinical trial phase, meaning that it was still being tested in people. Having participated unsuccessfully in clinical trials before, Howe was nervous about participating in another trial with this new therapy. Faced with the difficult decision between an allogeneic stem-cell transplant or CAR T-cell therapy, Howe decided to adopt the mindset of exploring the trial for the greater good. “I decided to adopt the mindset of being an astronaut,” he says. “Like an astronaut, I had an obligation to my fellow man to discover the unknown in hopes of finding something that would save not just my life, but also the lives of the lymphoma patients who would come after me.”

“I decided to adopt the mindset of being an astronaut. Like an astronaut, I had an obligation to my fellow man to discover the unknown in hopes of finding something that would save not just my life, but also the lives of the lymphoma patients who would come after me.”



Ultimately, Howe decided to undergo CAR T-cell therapy, wanting more than to just do well himself and defeat his lymphoma, but also to participate in a clinical trial so that all who followed would have a better chance at life. This was especially true since he would be only the fifth person in the world to be treated with this type of therapy as part of the clinical trial.

In the months leading up to the clinical trial, not knowing what the outcome would be, the Howes decided to live for today and take the next steps toward becoming parents. “There were risks involved, but there was also hope in family,” says Howe.

When the day came to begin CAR T-cell therapy, Howe spent seven days each in inpatient and outpatient observation, for side effects monitoring and data recording. He was shocked to learn he only experienced minor vertigo, “It all seemed too good to be true,” he says.

Three weeks after receiving treatment, he and his wife were elated to find out his treatment was a success and he was clear of any disease. Shortly after, they welcomed their daughter, Julia, into the world. He credits his strength through his journey to his wife, his mother, his siblings and to the promise of a family.

“People always ask me, ‘Nick, how should I interact with someone I care about who has cancer?’” he says. “My answer is simple: give them a future. Give them exploration and something to look forward to. We all need a future to survive for.”



QUESTIONS TO ASK ABOUT CLINICAL TRIALS

Have you ever wondered how treatments for lymphoma are developed? Clinical trials are research studies that involve people. Each study answers scientific questions and tries to find better ways to treat a disease. Clinical trials may also compare a new treatment to a treatment that is already available. Clinical trials are available for most types of lymphoma at every stage of disease. If you would like to learn more, or if a clinical study is being recommended by your healthcare team, below are some general questions you can ask to learn more:

1. **WHAT IS THE PURPOSE OF THIS CLINICAL TRIAL?**

2. **WHY ARE YOU RECOMMENDING THIS CLINICAL TRIAL TO ME?**

3. **WHO IS SPONSORING THIS TRIAL (THE NATIONAL CANCER INSTITUTE, A CANCER CENTER, A PHARMACEUTICAL/BIOTECHNOLOGY COMPANY)?**

4. **WHO HAS REVIEWED AND APPROVED THIS CLINICAL TRIAL?**

5. **DOES THIS CLINICAL TRIAL INCLUDE THE USE OF A PLACEBO (SUGAR PILL)?**

6. **HOW LONG WILL THE STUDY LAST? WHERE WILL IT TAKE PLACE?**

7. **WHAT ARE THE RISKS INVOLVED?**

8. **WHAT ARE MY RESPONSIBILITIES DURING THE CLINICAL TRIAL?**

9. **WHAT KINDS OF TESTS, PROCEDURES OR TREATMENTS WILL BE PERFORMED? HOW MANY AND HOW OFTEN?**

10. **WHAT ARE THE SIDE EFFECTS?**

11. **WILL I BE ABLE TO SEE MY OWN DOCTOR DURING THE CLINICAL TRIAL?**

12. **WHAT COSTS WILL I BE RESPONSIBLE FOR?**

13. **WHAT HAPPENS IF MY HEALTH GETS WORSE DURING THE CLINICAL TRIAL?**

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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.

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TUNE INTO LRF'S NEW *LIVING WITH LYMPHOMA* PODCAST

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.



UPCOMING EVENTS



Update on Peripheral T-cell Lymphoma, Webinar	2.10
Ask the Doctor, Philadelphia, PA	2.20
Ask the Doctor, Charlottesville, VA	2.25
Lymphoma Workshop, Washington, DC	3.7
Ask the Doctor, Portland, OR	3.15
Swirl: A Wine Tasting Event, Miami Beach, FL	3.18
Ask the Doctor, Dallas, TX	3.18
Lymphoma Workshop, Needham, MA	3.28
Dallas Lymphoma Walk, Dallas, TX	4.4
Ask the Doctor, Tucson, AZ	4.14
Houston Lymphoma Walk, Houston, TX	4.18
Ask the Doctor, Seattle, WA	4.23
Nebraska Lymphoma Walk, Ashland, NE	4.25



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

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It's easy to rally your community and start a Facebook Fundraiser in support of the Lymphoma Research Foundation (LRF).



Join Team LRF Today

Raise awareness and funds to support LRF's mission of eradicating lymphoma serving those touched by this disease.

STEP 1

Visit LRF's Facebook page at, facebook.com/lymphomacommunity and click the "create a fundraiser" button.

STEP 2

Name your campaign, select your goal amount and end date, and let your friends know why you're fundraising for LRF.

STEP 3

Share your fundraising campaign with friends, family, and your community on Facebook