



LYMPHOMA EPIDEMIOLOGY of OUTCOMES

NEWSLETTER

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WELCOME TO LEO

Thank you for participating in the Lymphoma Epidemiology of Outcomes Cohort Study (LEO). LEO is the first national study of its kind to study factors that affect how long and how well people diagnosed with lymphoma live. In 2016, an estimated 72,580 people in the US will be diagnosed with non-Hodgkin lymphoma (NHL). NHL survival rates have been increasing since the mid-1990s thanks to improved strategies for treating and supporting cancer patients. These trends have led to an increase in the number of NHL survivors, which was estimated to be more than 540,000 in 2012. We developed LEO to address the current and long-term unmet health needs of this growing patient population. LEO builds on an existing study started at the Mayo Clinic and University of Iowa. LEO plans to enroll a total of 12,900 newly diagnosed NHL patients at 8 centers (Mayo Clinic, University of Iowa, Emory University, UT MD Anderson Cancer Center, Washington University in St. Louis, Weill Cornell University, University of



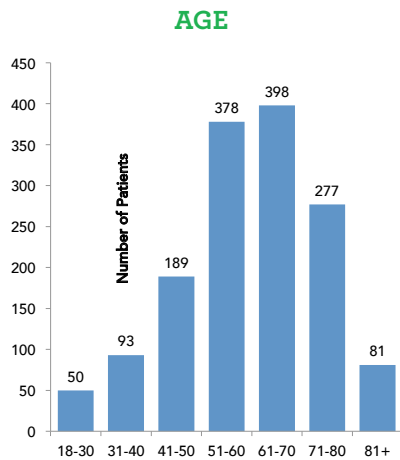
Dr. Christopher Flowers



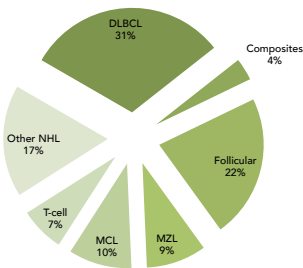
Dr. James Cerhan

Rochester Medical Center New York, University of Miami). The study team will review the pathology of tumors for newly diagnosed patients, and they will build a NHL tumor bank that contains pathology samples, tumor DNA and RNA, and blood samples. We will collect data from participants' medical records on their medical history, treatments, and outcomes. We will also use surveys to collect information directly from participants, such as family history, health behaviors and quality of life. The overall goal of LEO is to build a large and diverse cohort study to support a broad research agenda. Specific research questions will be aimed at identifying new clinical, epidemiologic, genetic, tumor, and treatment factors that significantly influence NHL survivorship. Your participation in LEO will help us to understand these factors and use this knowledge to improve survival and quality of life following a diagnosis of lymphoma. We appreciate your support of LEO.

LEO Year One Accrual and Figures

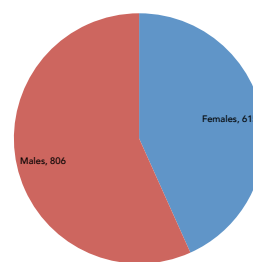


TYPE OF LYMPHOMA*

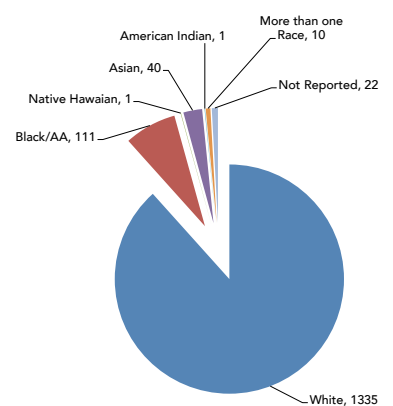


* DLBCL: Diffuse Large Cell Lymphoma, MZL: Marginal Zone Lymphoma, MCL: Mantle Cell Lymphoma.

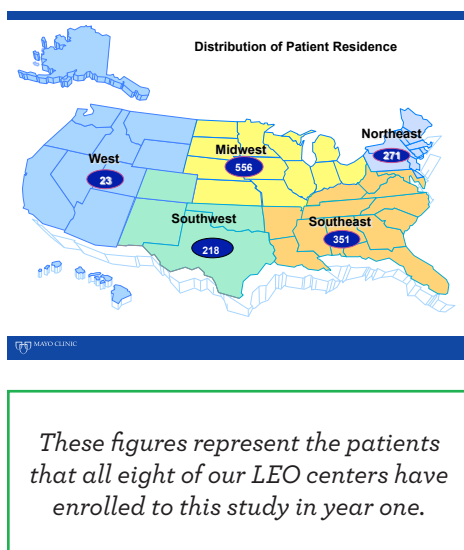
GENDER



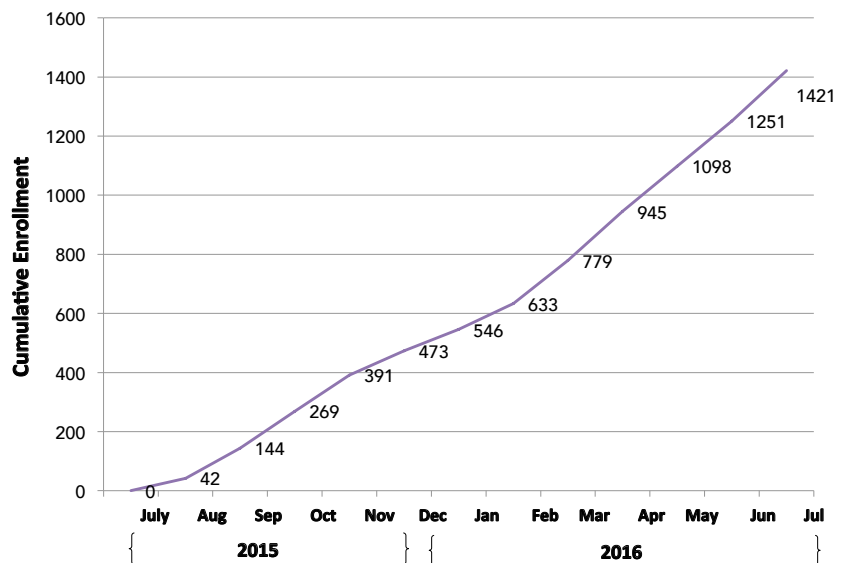
RACE



PATIENT RESIDENCE DISTRIBUTION



CUMULATIVE ENROLLMENT



Lymphoma Facts

- Lymphomas include both Hodgkin and non-Hodgkin lymphomas.
- Non-Hodgkin lymphomas (NHLs) are a group cancers of the blood that develop from white blood cells called lymphocytes. Lymphocytes are part of the immune system and help protect the body against infections.
- There are many subtypes of NHL, and each subtype may have different causes and need different treatments. As a result, patients with NHL need different types of care.
- There are over 50 kinds/subtypes of lymphoma.
- 72,580 cases of non-Hodgkin lymphoma are estimated to be diagnosed in the US in 2016, which ranks it as the 6th most common form of cancer.
- Lymphoma is often undiagnosed because it remains dormant in many patients.

Meet our Investigators

THE UNIVERSITY OF TEXAS MD Anderson ~~Cancer Center~~[®]



Dr. Loretta Nastoupil

Participating in LEO (Lymphoma Epidemiology of Outcomes) was incredibly important to me as I took on a new position at the University of Texas MD Anderson Cancer Center in the fall of 2013. I could not envision a more critical project to the understanding of lymphoma including exploring potential risk factors and critically reviewing outcomes to shape the future for our patients with lymphoma. Being new

to MD Anderson, I was nervous about launching a large scale, prospective, observational study, focused on patient outcomes as this was different from our typical clinical trials. I knew the expertise of the existing Mayo-Iowa MER (Molecular Epidemiology Resource) and had great admiration for the leaders of this group, so I was confident I could generate the same enthusiasm for this important project within my home institution. After all, we all have the same goal, eliminate cancer.

To be successful, I needed a team of professionals that would feel as passionate about this project as I did, and be motivated to find solutions to the problems we did not yet know existed. Launching a new research project always exposes the limitations or reservations of a department. This project would be unique in that it extended far beyond the walls of our institution and could serve as an example to others regarding the potential advantages of tapping into external resources. Within our first year, we have generated a team that is highly committed to the success of this project and to the outcomes of our patients. This is personal, everyone on my team has an intimate relationship with cancer and know too well how it can shape lives. Just like our patients, we want to know why lymphoma happens and how can we stop it. Through LEO, we hope to answer these questions and be a vital part of making cancer history.

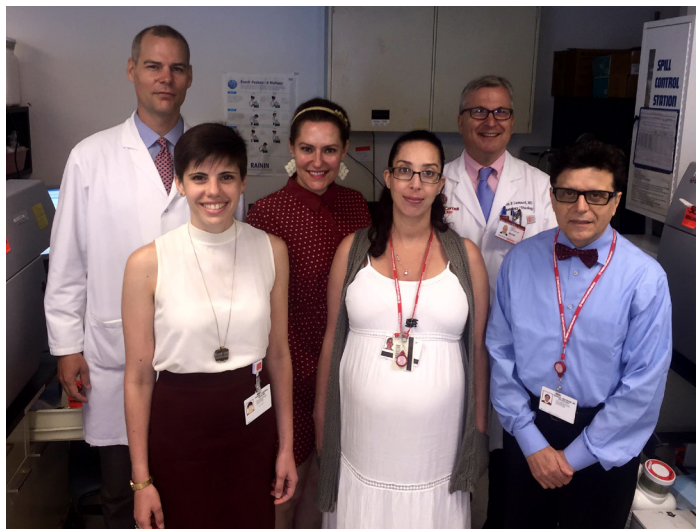


Dr. Brian Link

Iam really pleased to be representing the University of Iowa team in the LEO project. The readers may be aware that the LEO project is in many ways an expansion of a project referred to as MER (Molecular Epidemiology Resource) - a joint effort begun over a decade ago between researchers at the Mayo Clinic and the University of Iowa with a passion for learning better options for managing patients with lymphoma. This

expansion to eight centers for LEO excites us because we expect to learn the answers to our questions faster with more participants. LEO's Hawkeye team includes laboratory researchers such as Drs. George Weiner and Gail Bishop, pathology specialists led by Dr. Sergei Syrbu, the doctors caring for lymphoma patients such as myself and Dr. Umar Farooq, and we all rely heavily on the group of research assistants led by Ashley McCarthy and Angela Merriss. The University of Iowa has been recognized as a Specialized Program of Research Excellence in Lymphoma since 2002, and this year I am seeing lymphoma patients who have been under my care for 20 years – something neither of us would have predicted when we first met! Iowa has been home to all my ancestors since leaving central Europe in the mid 19th century and I take pride in helping make sure Iowans have access to the best lymphoma care possible and will now benefit quickly from new findings discovered as the LEO project moves forward.

LEO Centers



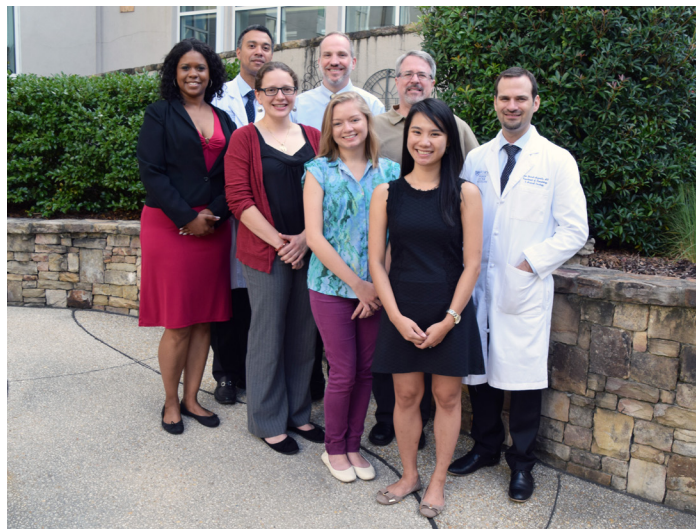
Cornell Medical College

Front row (L to R): Hannah Campbell, Sharon Barouk-Fox, Dr. Giorgio Inghirami
Back row (L to R): Dr. Peter Martin, Tricia Ellis, Dr. John Leonard



EMORY

WINSHIP
CANCER
INSTITUTE



EMORY Winship Cancer Institute

Front row (L to R): Barbara Copeland, Monique Farone, Jaque Payne, Anh Phan
Back row (L to R): Dr. Christopher Flowers, Dr. Kevin Ward, Dr. David Jaye, Dr. Leon Bernal-Mizrachi



Iowa

Front row (L to R): Dr. Brian Link, Dr. Sergei Syrbu
Back row (L to R): Ashley McCarthy, Freda Sell, Janice Cook-Granroth



University of Miami

(L to R): Tania Rodriguez, Dr. Izidore Lossos, Dr. Francisco Vega, Neslihan Yorukoglu





Mayo Clinic

Front row (L to R): Dr. Thomas Haberman, Julianne Lunde, Dr. James Cerhan, Dr. Andrew Feldman
 Second row (L to R): Mathew Holets, Terri Berndt, Lindsay Emanuel, Katelyn Cordie, Dr. Carrie Thompson
 Third row (L to R): Christine Allmer, Amy Eisenberg, Christina Stenzel
 Back row (L to R): Katie Reed, Bayly Bucknell, Tammy Rattle, Matthew Maurer, Sara Borgschatz



URMC

(L to R): Don Burns, Dr. Patrick Reagan, Rick McDowell, Dr. Richard Burack, Dr. Carla Casulo,
 Dr. Jennifer Kelly, Lindsey Caines, Dr. Jonathan Friedberg



Washington University

(L to R): Ann Marie Harrington, Dr. Brad Kahl,
 Dr. Kenneth Carson, Dr. Kiran Vij

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(L to R): Bianca Bowden, Jiffin John, Sandy Ashkar, Dr. Loretta Nastoupil, Lisa Thomas, Jolene Li



LaCrosse

(L to R): Deb S. Schultz, Dr. Jonathan Ticku, Jo Kaseno

Meet Our Investigators *(continued)*



Dr. Carrie Thompson

Cancer survivorship is a broad term that encompasses all effects of cancer and its treatment from the time of diagnosis moving forward. The LEO investigators are keen on understanding survivorship, not only surveillance for lymphoma, but the psychosocial impact of the disease and treatment, quality of life, interaction with the health care system, and other medical conditions that may be experienced by

patients. The team of LEO investigators studying survivorship is diverse: lymphoma physicians, psychologists, and epidemiologists. We have designed comprehensive questionnaires that address these survivorship issues for participants to complete every 3 years. We appreciate your time in providing this information! Studying these important survivorship issues will help health care providers take the best care of lymphoma patients possible, not just during treatment, but throughout their lifetime.



Dr. Richard Burack

Pathology is a branch of medical science primarily concerning the cause, origin and nature of a disease. What pathologists do with tissue sample from tumors is crucial to discovering why lymphoma happens. There is a team of 8 pathologists on the LEO project; one pathologist at each of the 8 LEO sites. Every month, the pathologists review the tissue samples (also called 'specimens') from the tumors of hundreds of recently

diagnosed patients who volunteered to be part of the LEO project. I am one of the pathologists looking for the specimens that can teach us the most about your disease. What are we doing with your specimens? First, we review all the information that was used for your diagnosis to ensure that the information fits a standard format that all 8 LEO sites have agreed to use. Standardizing our process is critical since the LEO project will eventually have tens of thousands of participants. Next we examine the "slides", which are extremely thin pieces of your tumor (and I mean thin: 500 of these thin pieces stacked together would be the thickness of a penny). Each thin slice of your tumor is stuck to glass and dyed...imagine a stained glass window. What are we looking for? The specimens that are most likely to teach us about your disease are the ones that contain more of the tumor and less of your normal tissue. Once we find these informative specimens, we ship them to the central LEO site. At the central site, another team of pathologists uses a small needle (just like is used for typical shots) to pluck a representative and even smaller microscopic sample from your specimen. They return the rest of the specimen back to the original LEO site. This microscopic sample of pure tumor is cataloged at the central LEO site. It is then available for long term studies. The power of LEO is that so many patients have not only volunteered to provide information about themselves by answering surveys, but that so many tumor specimens are being stored. In the near future, we will be able to look for associations between the information from the surveys (like family histories and health behaviors) and characteristics of lymphoma tumors from the specimens.

Meet Your Patient Advocate

What is a Patient Advocate?

A patient advocate is an individual or a group of individuals who focus on supporting and educating patients, survivors and caregivers. Typically advocates are concerned with a specific group of disorders and ensure that the patients' rights, privacy and confidentiality are protected.

LEO Goals

- Support research that finds new and better ways to improve the length and quality of life of people living with non-Hodgkin lymphoma.
- Create a bank of blood and tissue specimens.
- Collect clinical and risk factor data from participants at enrollment and over time.
- Follow patients over time to determine possible causes, optimal treatment, and survivorship of NHL.

PATIENT ADVOCATE *Ben Haines*

My name is Ben Haines. I live in Minneapolis and have been married for almost 24 years to a woman named Janice. Back in 1997, she was diagnosed with 'incurable' non-Hodgkin Lymphoma, low grade, indolent, Stage IVb. She is alive and doing well today thanks to the great lymphoma doctors. I am simply a caregiver. It is not about me, it is about the patients and the doctors and the teams who support the entire process.

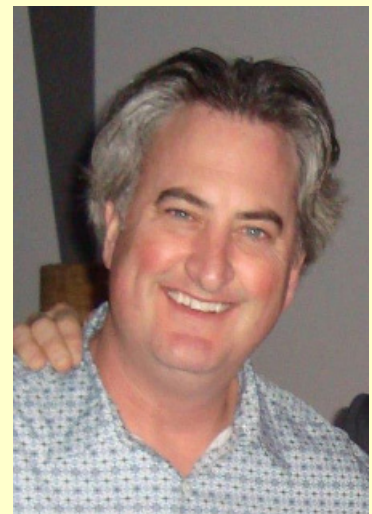
I am now 19 years into my patient advocacy. We wear many hats from fundraising to helping the doctors, including the hematologists and the epidemiologists. My profession is turning data into information for large companies like Target, Carlson, and Allianz. I enjoy what I do, but don't like the bureaucracy. It is the same with my volunteering for my patient advocacy. Sometimes it is easier for advocates to talk about the tough stuff in what is wrong with cancer care today. Also, it is really easy for me to help support the doctors and their teams working behind the scenes to save lives. With this effort, epidemiologists are gathering important information, thanks to the incredible willingness of patients like you, to help not only you but others.

This is no different than what I have done from my profession, figuring out exactly what toothpaste, or hotel room you

need, but in this case the knowledge saves or extends lives.

So, while I have never been a patient, I can tell you, rest assured, these people are smart as I get to work behind the scenes. Side by side, as they talk 'shop' constantly, working tirelessly for you. So all of you with lymphoma can have more time, time to worry about the mundane like toothpaste, rather than your mortality.

LEO is near and dear to my heart, I am so grateful to be your patient advocate.



Ben Haines

Frequently Asked Questions

Who is the research team?

The LEO research team consists of investigators, study coordinators, lab technicians, pathologists, statisticians, clinicians, patient advocates and students who all work together to collect, store, and analyze data, and specimens. The research teams at all 8 centers work closely together to ensure the continued success of this cohort.

How long is this study?

There is no end date for this study. Please know that you are able to leave this study at any point by contacting the study team at your medical facility.

Does the biopsy tissue used by the study compromise the availability of tissue which may be needed for clinical purpose?

No, participating in this research study will not compromise the availability of tissue for diagnostic purposes.

Will participating in LEO affect my cancer treatment?

No. Participation in the LEO study will not impact your cancer treatment or affect your medical care in any way.

Will my ID and personal information be shared?

None of your identifying personal information will be shared.

How will the LEO study benefit me?

While there is no direct benefit to you for participating in LEO, the information you provide will help us gain a better understanding of disorders of the blood and lymphatic system. Our goal is to have the information you provide help us find ways to improve patient care and quality of life for individuals diagnosed with lymphoma in the future.

I'm not getting treatment for my diagnosis. Can I still participate?

Yes. The LEO study is currently recruiting patients who have been diagnosed with newly diagnosed with lymphoma within the last 6 months. Patients are eligible to participate regardless of their treatment status.

Contact Us

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