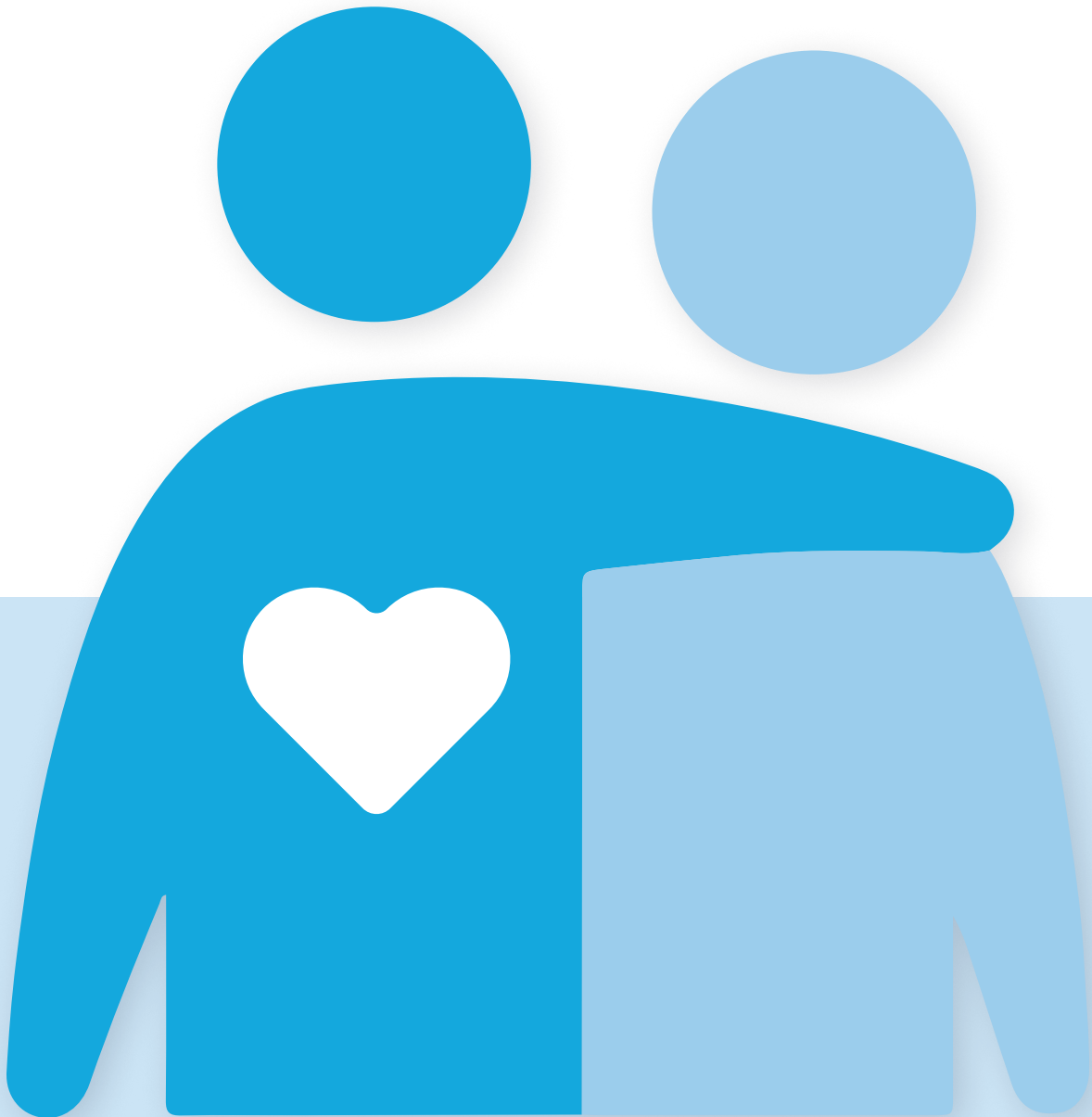


Leptomeningeal Cancer Foundation

Theo's Legacy: Finding answers. Offering hope.



Fostering Hope by Fostering Community

2025 IMPACT REPORT

Fostering Hope by Fostering Community

Vision:

A world where no one suffers or dies from leptomeningeal cancer

Mission: To improve quality and extend quantity of life of all people diagnosed with leptomeningeal cancer by:

- Accelerating breakthrough research into meningeal biology and the prevention and treatment of leptomeningeal cancer
- Providing support, navigation and education for all those affected by and treating the disease
- Raising awareness of the dire clinical situation and urgent need for funding in this space

Letter from Founder and President



Losing our son Theo to leptomeningeal cancer and then diving in to help others has felt somewhat like losing my most precious person in a fire and then running back into the fire with buckets of water, attempting to save thousands of people from a burning building. It would be easier to walk away and work on healing my own trauma. But when hundreds of thousands of people are dying of this terrible disease, how can we walk away? I joined forces with some of the most intelligent, empathetic and committed individuals – the members of our scientific advisory board, some of who were involved in Theo’s care – and along with the strong community of patients, caregivers, and volunteers, started building greater awareness of this heartbreaking disease.

In just over a year, we have reached every state in the United States and nearly 40 countries. Being the first and only organization focusing on leptomeningeal cancer, we quickly learned that our existence was long overdue. Our educational tools are accessed daily, our webinars are shared in private cancer groups, and healthcare providers are reaching out to us to get involved with our work. We had no idea how many people needed support, education and community. And now we are here to fill that gap.

Our accomplishments in this first year are only possible because of the kindness and dedication you have shown us and your belief and faith in us to make a difference. We move into our 2nd year motivated and ready to improve the outcomes for patients around the world – increasing access to experts through the launching of a virtual tumor board, presenting investigator awards and grants for basic and translational science to support research, forming a Corporate Council and a Partnership Network to deepen our collaborative efforts, and continuing to educate and support patients and caregivers.

As I reflect upon LMCF’s first year, I am grateful for the generous and steadfast support we have received from patients and their families, friends of the foundation, advocates, researchers and clinicians. I am deeply moved by how much this community cares about one another and the commitment everyone has to our shared mission of finding answers to improve the quality of life and extend the number of days, months and hopefully years for all those with leptomeningeal cancer.

*With deep gratitude,
Helaine Bader*

Financial Snapshot

\$200k+
GRANTED
350+
UNIQUE DONORS

Every dollar donated helped us build out our educational tools, spread awareness to patients, caregivers and physicians around the world, and demonstrate the urgent need for research and funding.

Your generous contributions helped us advance the mission of our foundation and amplify messages of hope to all corners of the world:

- Building our website
- Presenting at conferences and meetings
- Producing webinars
- Supporting patients and caregivers

In 2026, we are launching the ambitious **20 for 20 campaign, a \$20 million global effort** in honor of Theo's 20th birthday to transform the future of leptomenigeal cancer. This investment will fuel our priorities for the next 5 years. We will mobilize leading experts, expand access to life-extending care, support patients and caregivers, and accelerate discoveries that move us closer to a cure.

Our Impact in 2025

In 2025, we focused on patient education, community engagement, advocacy partnerships and healthcare provider collaboration. Our impact was immediate and our reach was global.

Because we exist, patients and caregivers now have:

- a website to find information on the disease, the diagnostic pathway, treatment options, expert physicians, and relevant clinical trials.
- webinars on topics of concern for patients and caregivers.
- a place to reach out for advice, support, community and hope.

Because we exist, clinicians now have:

- a resource to refer their patients to.
- a central hub to meet, collaborate, share ideas, and ask for support.
- a community of advocates to tap into.



“When my husband passed, one of his wishes was to donate to a cancer foundation. With leptomenigeal cancer being rare and challenging, we wanted to shed some awareness and help fund research for this cancer. We chose Leptomenigeal Cancer Foundation because the goals are directly aligned with what we felt was needed in the LMC community. Having a tribute page with his name and story is a huge bonus.”

– Kelly Kriezinger

Timeline

- 2024** **No organizations** focusing on leptomeningeal cancer.
- 2025** The Leptomeningeal Cancer Foundation was formed. We are the **first and only** foundation focusing on this heartbreaking disease.
- 2026** We are launching initiatives to expand access to patients around the U.S., provide virtual support to caregivers, form collaborations to advance research, create an educational platform for healthcare providers, and align leaders across industry, academia, diagnostics, clinical care and advocacy around a shared mission.



“When my mom was diagnosed with leptomeningeal disease, there was a lot of uncertainty and fear about treatment options. The information provided by the Leptomeningeal Cancer Foundation turned our confusion into clarity and gave us hope.”

– Dana Alizakhova, Caregiver

Understanding Leptomeningeal Metastases (LM)
It's More Common than You Think – Talk to Your Doctor

What is LM?
Leptomeningeal Metastases (LM), also known as Leptomeningeal Disease (LMD), happen when cancer spreads to the leptomeningeal fluid (CSF) and tissues that surround your brain and spinal cord (the leptomeninges).
• CSF flows through a space that contains important structures like cranial and spinal nerves.
• The two layers of tissue are called the arachnoid and pia mater, and these tissues help protect your brain and spinal cord.

How common is LM?
• 5%-10% of all people who have cancer develop LM.
• There are an estimated 132,000 new cases of LM in the U.S. each year.

Leptomeningeal Metastases
Cancer cells can enter the leptomeningeal space through blood vessels, lymph vessels and along nerves in the brain and spine.

MRI Scans of the Brain with LM
Diffuse These brain scans show how LM can appear. Cancer cells can appear as diffuse flaring in the CSF or spread across the brain or nodular (in a mass or lump). Often, these cancer cells do both.
Nodular

Most Common Cancers Leading to LM
Breast, Lung, Melanoma, Brain & Spine, Gastro-Intestinal, Blood

Most Common LM Symptoms
Headaches & dizziness, Confusion, Seizures, Nausea & vomiting, Vision changes, Facial drooping, Weakness in extremities, Numbness or tingling.
You may have one or more of these symptoms. These symptoms may come and go or get worse over time.

LM is underdiagnosed, making early detection with advanced diagnostics critical.

Diagnostic tools: CSF analysis, MRI imaging of the brain and spine, physical and neurological exam
Treatment options: Chemotherapy, targeted therapy, immunotherapy (given by IV or directly into the CSF), radiation therapy

There is hope! Clinical trials, advancements in CSF diagnostics and new targeted therapies offer promise for improving outcomes.

For more information about LM, visit tmcancer.org

Educational Content

- LMCancer.org website, evolving daily with relevant content and new advances
- Webinar Series: 8 webinars with more than 4000 viewers
 - Episode 1: Melanoma & Leptomeningeal Spread
 - Episode 2: Radiation Therapy & Leptomeningeal Cancer
 - Episode 3: Understanding Palliative & Hospice Care
 - Episode 4: Clinical Trials in Leptomeningeal Cancer
 - Episode 5: Leptomeningeal Metastases & Lung Cancer
 - Episode 6: Diagnosis and Treatment of LM in Europe
 - Episode 7: Leptomeningeal Spread and Breast Cancer
 - Episode 8: A Conversation on Caregiving
- Educational poster for physicians (created in partnership with Plus Therapeutics)

Social Media:

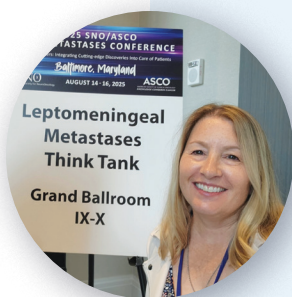
Facebook
1.3 million views | 7500 content interactions

LinkedIn
210k impressions | 300 content interactions

Partnerships and Collaborations

Collaboration is at the core of LMCF's approach. In our first year, we began building a collaborative ecosystem of leading academic institutions, clinicians, researchers, advocacy organizations, and industry partners united by a shared commitment to improving patient outcomes. Together, we are bridging gaps across research, care, and education by aligning efforts, reducing silos, and fostering innovation to accelerate discovery and expand access to critical resources. These partnerships not only strengthen a connected, global community, but also create the infrastructure needed to drive meaningful, measurable change for patients and caregivers worldwide.

In 2026, we are establishing more formal relationships by creating a Corporate Council and the LM Partnership Network. We will work with companies focused on innovative diagnostic tools and treatments, and advocacy organizations engaged in various types of cancers.



In 2025, LMCF was invited to participate in The Society for Neuro-Oncology/American Society of Clinical Oncology Leptomeningeal Metastases Think Tank. As the first patient advocacy organization ever invited, we shared insights, experiences and challenges from a patient's perspective to add to the discussion for developing a practical and adaptable blueprint for patient-centered LMD programs across various institutions. This framework will allow for better treatment access for patients, earlier and accurate diagnosis, and multidisciplinary therapeutic options including clinical trials. The Think Tank included a core group of key opinion leaders in LMD and offered us the opportunity to connect with clinicians and researchers, establishing LMCF as an essential source of education and support, and an expert voice in the LMD patient and caregiver experience.



“As a provider and research scientist in leptomeningeal cancer, I am fabulously happy that Helaine and her team founded LMcancer.org. As the first organization for leptomeningeal disease (LMD), they are making an amazing impact for patients and their families around the world. Finally, in the “black hurricane” of LMD that patients and families experience, there is a beacon that provides information, support, and hope; a guiding light during dark times. The Leptomeningeal Cancer Foundation is transforming our field and improving the care of patients and families affected by this disease.”

– Peter Forsyth, MD, Department Chair
of Neuro-Oncology
H. Lee Moffitt Cancer Center & Research Institute

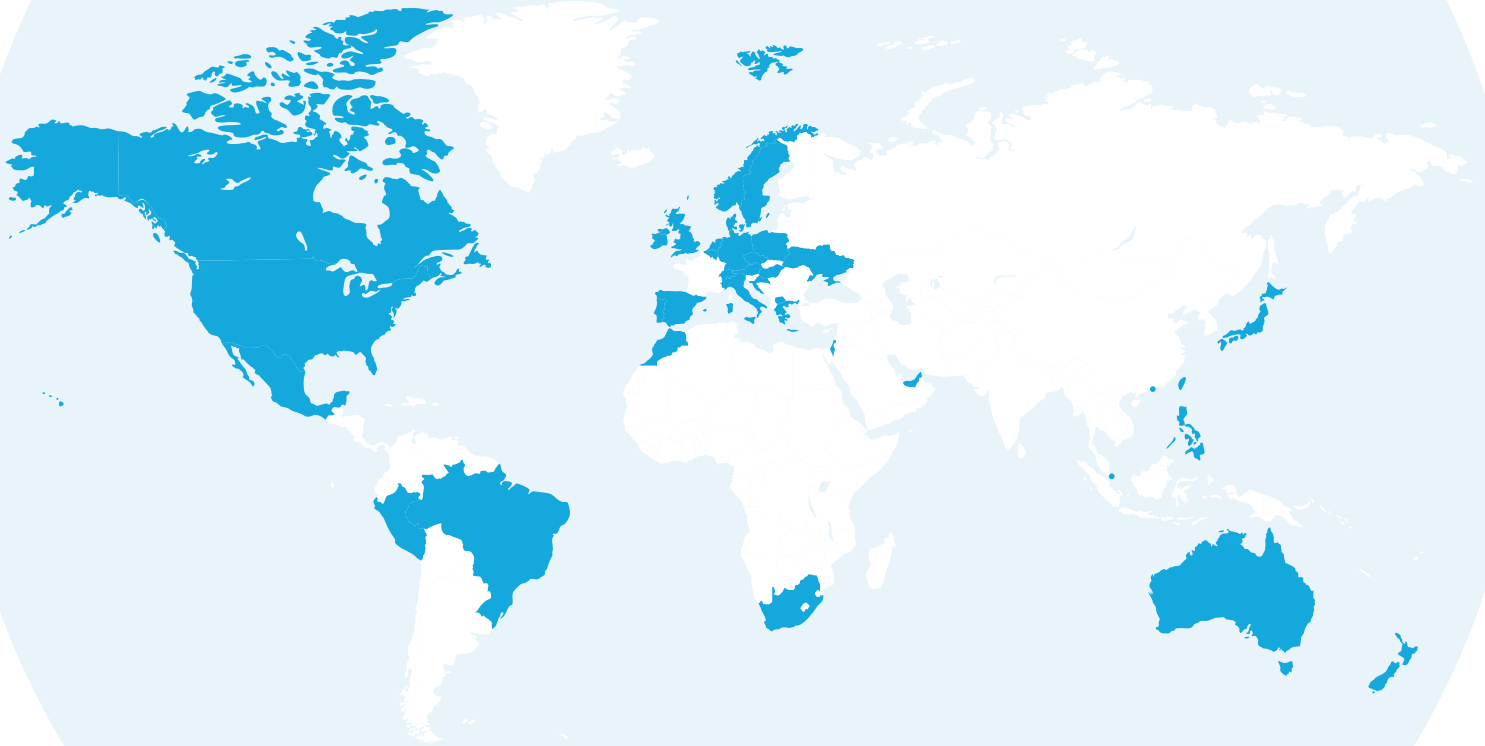


“The Leptomeningeal Cancer Foundation has been incredibly helpful since being diagnosed. Not only is the website a wealth of knowledge on trials and real patient stories, but the webinars that the Foundation has hosted have been the most helpful. Talking to doctors and other patients has helped me learn advocacy, exactly what is going on when it comes to LMD, symptoms, best options for treating the disease and so much more. I direct anyone who reaches out to me who has LMD to the Foundation's website.”

– Heather Curley, Patient

Building our Footprint

Leptomeningeal cancer - and the ways to fight it - know no geographic boundaries. We are expanding awareness around the world by working with global experts in several countries and reaching a broad and diverse audience through our social media channels, newsletters, webinars and website. We have reached all states in the U.S. and 37 countries around the world.



- AUSTRALIA
- AUSTRIA
- BELGIUM
- BRAZIL
- CANADA
- CHINA
- CROATIA
- CZECHIA
- DENMARK
- ENGLAND
- GERMANY
- GREECE
- HUNGARY
- IRELAND
- ISRAEL
- ITALY
- JAPAN
- KOSOVO
- MEXICO
- MOROCCO
- NETHERLANDS
- NEW ZEALAND
- NORTH MACEDONIA
- NORWAY
- PERU
- PHILIPPINES
- POLAND
- PORTUGAL
- SINGAPORE
- SOUTH AFRICA
- SPAIN
- SWEDEN
- SWITZERLAND
- TAIWAN
- UKRAINE
- UNITED ARAB EMIRATES
- WALES



“LMCF has put a spotlight on leptomeningeal cancer by raising awareness, educating patients and families on what to expect, and connecting the right interdisciplinary experts to begin working on a cure. We contribute in honor of Theo and all the others that have lost their lives to this disease, knowing Helaine and the LMCF team are making a huge impact and bringing hope for the future.”

– *The Post Family*

Bold Plans for 2026

In 2026, we will build on our momentum and deepen our commitment to expanding equitable access for patients, catalyzing research collaborations, increasing awareness and educational resources, and providing meaningful support to caregivers and care partners navigating diagnosis and treatment.

Harnessing Thought Leadership: In collaboration with leading experts around the country, we will launch the Leptomeningeal Metastasis Virtual Tumor Board. The tumor board will convene experts in neuro-oncology, radiation oncology, medical oncology, neurosurgery, and neuroradiology and help address the challenges that patients and clinicians face when trying to access and understand treatment options and clinical trials. These challenges are compounded by the lack of treatment guidelines, as well as the need to act quickly given the fast progression of the disease. The VTB is being formed in honor of patients around the world who struggled to find answers and died from leptomeningeal disease.

Deepening Partnerships and Collaborations: We are establishing more formal relationships by creating a Corporate Council and the LM Partnership Network. By working with companies researching CNS-penetrant targeted therapies and innovative diagnostics, we can provide patient-centered input and engage in active collaboration through the research and development lifecycle. Working with advocacy organizations allows us to connect with patients with various cancer diagnoses, coordinate on educational and awareness outreach strategies, amplify awareness of expanded diagnostic and therapeutic options, and offer renewed hope for potential advances in patients with leptomeningeal metastases.

Advancing Research: As part of our goal to advance research, we are working with physician-scientists to support and encourage collaborative LM research through science and fellowship awards to junior and senior investigators and grants to advance projects on the basic biology of LM, correlative analyses of current and completed clinical studies, and trials focusing on the prevention and alleviation of cognitive impairment and treatment side effects. We also are planning our 2027 Forbeck Forum, an invitation-only international gathering to foster collaboration between neurobiologists, immunologists, and cancer biologists and identify opportunities for new therapeutic approaches.

Campaign for Change: We are launching our ambitious 20 for 20 campaign, a \$20 million global effort in honor of Theo's 20th birthday to transform the future of leptomeningeal cancer. This investment will lay the groundwork for truly making a difference in the uncharted landscape of leptomeningeal cancer, fueling our priorities for the next 5 years. We will mobilize leading experts, expand access to life-extending care, support patients and caregivers, and accelerate discoveries that move us closer to a cure. At its core, 20 for 20 is about changing what patients are told at diagnosis, from uncertainty and limitation to possibility and hope, ensuring that no patient is ever told there is nothing more we can do.

A Call to action



Imagine being told you have cancer spread throughout your brain and spine and there's nothing that can be done. Doctors can't tell you if you'll make it weeks or months. **We must do better.**

The future of leptomeningeal cancer care and research depends on what we do next. Together, we can accelerate breakthroughs, expand access to expert care, and ensure that no patient faces this diagnosis without support or options. **Join us by investing, partnering, or sharing our mission, and be part of transforming what is possible for patients and families around the world.**

lmcancer.org

Scientific Advisory Board



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H. Lee Moffitt Cancer Center & Research Institute



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Neuro-Oncologist, Stanford Cancer Center
Clinical Professor, Neurology and Neurological
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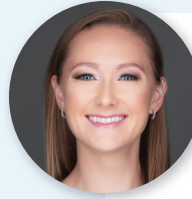
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Division of Cancer Medicine
The University of Texas MD Anderson Cancer Center



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Director, Leptomeningeal Program
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H. Lee Moffitt Cancer Center and Research Institute



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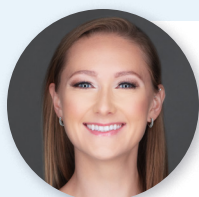
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Stanford University School of Medicine



Inna Smalley, PhD
Board Member
Associate Member
Moffitt Cancer Center



“Theo’s seventeen years weren’t enough - for him, his family, or his friends. He should be here with us, off at college somewhere in this world. We give to LMCF with hope and intent for a day when research finds a way to eradicate this awful disease and spare others the devastating heartbreak of years lost to the ‘weren’t enoughs.’”

– Carrie and Dylan Hartley



“LMD is a devastating complication that can occur from any type of primary cancer, but is often overlooked by cancer support groups. The new Leptomeningeal Cancer Foundation has filled the void by joining patients, caregivers, clinicians, and researchers across disciplines to accelerate basic and translational science research, advocate for trial access and provide much needed support for the treatment journey. Finally, there is a place for us to share our knowledge and hope for a better future for all our patients with LMD.”

– Seema Nagpal, MD, Neuro-Oncologist
Stanford Cancer Center

Amplifying Patient and Caregiver Voices

In 2018, there was very limited information on leptomeningeal cancer. I am so thankful that people now have the option of learning about LMD on the Internet through the Leptomeningeal Cancer Foundation.

The LM cancer Foundation has been a wonderful source of information since my dad passed. I just wished I had them when I was in the trenches with my loved one or at diagnosis.
Thank you

Your organization is amazing and you should be listened to and taken seriously as you are our voice and are leading the way for leptomeningeal to be recognized and for a cure to be found.

Thank you for doing this. It's this foundation that helped my mom and me. I would have been so alone and afraid if it wasn't for y'all.
I'm so grateful.



**Leptomeningeal
Cancer Foundation**

Theo's Legacy: Finding answers. Offering hope.

Fostering Hope by Fostering Community