LES TURNER ALS FOUNDATION™

Hope and help for people with ALS.

lesturnerals.org

July 2018 ●

Community

The Newsletter of the Les Turner ALS Foundation

Legacies That Live On

In 2010, Mary Roemer's life drastically changed. What were supposed to be golden years with her husband, Dave, were uprooted when he was diagnosed with ALS. Trying to come to terms with their "new normal," Mary found one of our monthly support groups.

The support group introduced Mary and Dave to other families going through a similar situation and to the care, expertise and guidance of the Les Turner ALS Foundation.

Eager to get further involved, the Roemers considered attending the ALS Walk for Life. It had been about a year since Dave's diagnosis and they weren't sure it was a good idea. As Mary remembers fondly, they couldn't have been more wrong. The day was "hopeful and affirming" and has become one of Mary's most cherished memories.

Though Dave passed away in 2015, the Roemer family's commitment to supporting the Les Turner ALS Foundation and people living with ALS was just getting started. The family has made it their mission to honor Dave by doing all they can to support the Foundation that took such personal care of him while he was alive.

> *"The Les Turner ALS Foundation is a lifeline, not only to people living with ALS but to families and caregivers."*
>
> *–Mary Roemer, caregiver to her late husband, Dave*

From trivia nights, wine and cheese parties, to boat cruises and even a cheerleading clinic, the Roemer family has put on countless fundraising events both here and in Boston where some of the family lives. "ALS is often described as an orphan disease. It's up to the people who are family and friends to support the Foundation," said Mary.

Mary still attends her local support group and serves on our Support Services Committee as a non-board member. This committee oversees all of the Foundation's extensive support services for people living with ALS, their families and caregivers and directs the work of our medical and support professionals to best serve the medical, research and educational needs of those with ALS. Being engaged in so many ways keeps Mary motivated in her desire to raise needed funds for advancements in care and an eventual cure.

Mary's drive and passion has passed on to the next generation. This year at the 2018 ALS Walk for Life, two of Mary's grandsons are taking the lead to co-captain their Walk team, Pop Squad.

Just as the Foundation was there for Mary and her family through their journey with ALS, the Roemer family continues to pay it forward and carry on Dave's legacy. "Once you're in the Les Turner ALS Foundation family, you're in it for life."

Letter from the CEO

Andrea Pauls Backman

Dear Friends,

Over forty years ago, a family sat in a doctor's office and was given the news their beloved husband and father, Les Turner, had a fatal disease, ALS. They looked around and they were alone.

There wasn't a clinic or nurses or social workers. There weren't laboratories doing research. There weren't support groups to connect them to others going through the same thing. There was nowhere to turn for help.

But, the Turners had each other, they had determination and they had their friends and family. These friends and family, headed by Harvey and Bonny Gaffen, built a Foundation that embodies the true spirit of family and offers all the resources the Turners had wished for.

They created a Foundation that exists to care for those affected by the disease, answers their questions, supports them and their loved ones and provides hope through scientific research.

Thirty years after Les was diagnosed, I sat in a doctor's office with my beloved mother as she received the same diagnosis. In the three decades that had passed, the way the disease would affect my mother's body and the terminal nature of ALS had not changed.

What had changed is that we found the Les Turner ALS Foundation, *an instant family that understood what we were going through and the help we needed.* Through our family's difficult journey, we were given support to help us feel less lost, less alone and less hopeless.

A lot has happened since our founding over 40 years ago. What started as an act of love for one man by his family and friends has grown to become the leading provider of care and support for those affected by ALS in Chicagoland, and a globally recognized organization conducting vital research in search of a cure.

Despite how much we've changed, one thing remains the same: *we're committed to supporting each person living with ALS, and those who love them, every step of the way.*

Together towards a cure,

Andrea

Andrea Pauls Backman

Les Turner ALS Foundation Leadership

Affiliations

Les Turner ALS Research and Patient Center at Northwestern Medicine

Community Health Charities of Illinois

International Alliance of ALS/MND Associations

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Upcoming Events

Friday, September 28
Northwestern Medicine's First Annual Updates in the Diagnosis and Management of ALS

Saturday, September 29
ALS Walk for Life, ALSWalkforLife.org
Soldier Field, Chicago, IL

Sunday, October 14
ALS News You Can Use Educational Conference
Hyatt Rosemont, Rosemont, IL

Monday, November 12
Les Turner Symposium on ALS and NeuroRepair
Prentice Women's Hospital, Chicago, IL

THE RHODE TO A CURE

> *"Everyone from the Les Turner ALS Foundation is there to support you in any way needed."*
>
> *–Jennifer Rhode*

When Jennifer Rhode, an avid outdoorswoman, first started noticing symptoms of muscle weakness, the 33 year old chalked it up to getting out of shape. After seeing multiple doctors, Jennifer was diagnosed with ALS at Mayo Clinic in July of 2017.

Immediately, she began looking into local clinics in the Chicagoland area and called Judy Richman, our Director of Support Services and Education. **"When I spoke with Judy I knew I wanted to connect with the Les Turner ALS Foundation. She was so compassionate and helpful," said Jennifer.**

Soon after being diagnosed, Jennifer learned about our ALS Walk for Life. With just three months to prepare, she got to work with her family and rounded up a team for the annual event. Held every September, the ALS Walk for Life brings together families and friends for a walk along Chicago's lakefront and through iconic Soldier Field.

"I wasn't sure what to expect, but it was a great day for the entire family, and everyone had a blast. It felt like everyone came together for a common goal, and it was very uplifting."

The tremendous community support received by Jennifer's team, The Rhode to a Cure, is one of the reasons they decided to be our Team Chair for the 2018 ALS Walk for Life.

"The outpouring of support and generosity has been overwhelming and I love that we can bring that with us to the Walk." As Walk Team Chair, Jennifer and her team will provide helpful tips and encouragement to all registered participants throughout the summer leading up to event day.

At its heart, the ALS Walk for Life is a big family reunion, as thousands of participants gather and form teams in honor or memory of their loved ones. That sense of family is just one of the things Jennifer is looking forward to, along with "all of the positivity and camaraderie. It's so fun for everyone, including the kids. We also have connected with another family, so it will be nice to see them there."

Jennifer and her team hope that, "people take away the fact that they are not alone. **Everyone from the Les Turner ALS Foundation is there to support you in any way needed. Everyone is behind you, is supporting you and fighting for a cure. It's an indescribable feeling."**

To start your own team and join Jennifer and The Rhode to a Cure, visit alswalkforlife.org.

Financial Highlights

In 2017, the Les Turner ALS Foundation invested more than $2M in ALS support services, research and education. Core mission support includes critical functions such as strategic planning, infrastructure and development (fundraising) to ensure that our programs continue to grow and are sustainable for the future. The growth and effectiveness of our work depends on a solid core at the center of our organization. Investing in our infrastructure ensures efficiency and is absolutely necessary for long-term success. We are committed to operating at the highest level of financial integrity and caring for the ALS community in Chicagoland in the most effective and compassionate way possible.

Phase 3 Clinical Drug Trial at Les Turner ALS Center at Northwestern Medicine

Our Les Turner ALS Center at Northwestern Medicine effectively connects the worlds of research and patient support to ensure the best care is provided and the brightest minds are working to find a cure.

Unlike other organizations, our Center brings together researchers, clinicians and support services enabling advancements achieved at our clinic to influence research conducted in our labs and vice versa. We believe it's imperative for scientists and patient care providers to work together to develop therapies, provide the best care possible and move us closer to finding a cure.

Working with partners across the country as a national ALS community, we are pleased to share the Center is part of a Phase 3 clinical drug trial. The Center is one of 100 sites selected for the study, for a total of about 450 enrolled participants.

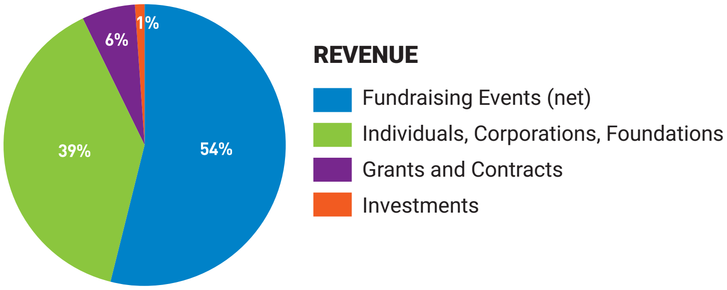
The drug being tested, OMD-109 (oral levosimendan), is being used in more than 60 countries as a short term treatment for severe chronic heart failure. However, scientific evidence suggests OMD-109 may improve respiratory and skeletal muscle function for the symptomatic treatment of ALS. The drug trial is sponsored by the Finnish pharmaceutical firm, Orion.

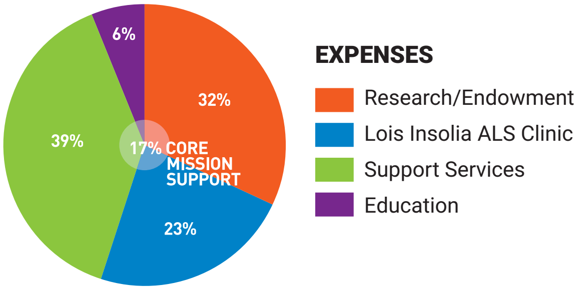
Previous stages of the OMD-109 trial showed a short IV infusion of the drug improved neuromechanical efficiency of the diaphragm by 21% in healthy volunteers.

According to the FDA, "Researchers design Phase 3 studies to demonstrate whether or not a product offers a treatment benefit to a specific population. Sometimes known as pivotal studies, these studies involve 300 to 3,000 participants. Phase 3 studies provide most of the safety data. In previous studies, it is possible that less common side effects might have gone undetected. Because these studies are larger and longer in duration, the results are more likely to show long-term or rare side effects."

Phase 3 studies take time to conduct and review, so it's possible we won't hear news of the study's results for two to three years. However, if the study shows positive results, the likely next step is to present the drug to the FDA for review and, ultimately, approval as a treatment for ALS.

It's important to note this treatment would not change the fact that motor neurons die in people living with ALS. OMD-109 could, however, treat the symptom of muscle weakness and could potentially slow progression and provide a longer, better quality of life for people diagnosed with ALS.





FUND RAISE YOUR WAY

You asked for it and we heard you! We're excited to introduce our brand new community based fundraising program built just for you. Fundraise Your Way (FYW) gives you the opportunity to raise money for people living with ALS by creating an online fundraiser or by planning your own fundraising event.

Whether you're collecting donations to celebrate a birthday or planning a golf outing, you can turn your special occasions, hobbies or athletic aspirations into ways to raise money to help people living with ALS.

And if planning your own event is too much work, we have plenty of events you can join!

So, how do you want to fundraise?

OPTION 1:

Create an Individual Online Fundraiser

Create a simple, online fundraising page and encourage your friends and family to donate in support of your special initiative. Do you have a wedding or birthday coming up? Celebrating a bar or bat mitzvah? Ask for donations instead of gifts. Use special events and occasions to motivate your network to support people living with ALS.

OPTION 2:

Plan an Event

This option is for any idea where people need to purchase a ticket or RSVP to attend. Let your imagination run wild in planning your dream event and our event staff will be here to provide support and make sure your event is successful. Examples include golf outings, trivia nights and theatre or music outings.

OPTION 3:

Attend an Existing Event

We get it, life is busy. Luckily for you, we already have several events for you to join where we do all the heavy lifting. Simply join in on the fun by raising money for an existing event throughout the year. The ALS Walk for Life on Saturday, September 29 is a great place to start.

To get started on your fundraiser or talk with one of our events team professionals about some of your ideas, email events@lesturnerals.org or call 847 679 3311.

Support for Young Adults

LAURIE B. FIELDMAN, MS, LCSW

CARA GALLAGHER, MA, LPC

ALS is a disease that affects the whole family. From the person living with ALS to their spouses, caregivers and children, each one experiences the disease differently. Just as every member of a family is unique, so is our care for them.

This spring, we launched our Young Adult Virtual Support Group, a brand new program specifically designed for the young adult children of people living with ALS. "This is our first all-virtual support group that allows busy young adults the opportunity to connect with others who understand what it's like to have a loved one with ALS. It specifically addresses the needs and issues of those who have a family member with ALS," said our Director of Social Services and support group leader, Laurie B. Fieldman, MS, LCSW. The group is co-led by Support Services team member Cara Gallagher, MA, LPC.

While the support group may be offered in a new format, it shares the same goals as our existing groups. "It is our goal that these participants have the same feeling of camaraderie and support that our in-person group members experience," said Laurie.

The Young Adult Virtual Support Group connects the third Tuesday of each month at 7:00pm. If you are interested in attending or know someone who might be, please email Laurie B. Fieldman at lfieldman@lesturnerals.org.

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One Latte a Week...

Lots of us enjoy a good cup of coffee or tea to start our day. But did you know for the cost of one latte a week you can make a difference in the life of someone living with ALS? By becoming a monthly donor, we can count on you to be a vital source of support and hope not just today, but all year long. It's the easiest way to give because once you make that commitment we take care of the rest.

Your donation is secure, flexible and automatic. Just give and forget about it! You choose the amount you wish to give each month and you can change, or cancel, your pledge at any time.

A monthly gift is easy for you and it means we can continue to provide personalized, compassionate support to people living with ALS. The needs of people living with ALS are ongoing, and with your monthly gift, you can support them every step of the way.

One latte. Just $5. When you make a monthly gift of any amount, you become part of something meaningful. You become a loyal part of the Les Turner ALS family. Please give today.

To learn more about becoming a monthly donor, visit lesturnerals.org or call 847 679 3311.

"I'm a monthly donor to the Les Turner ALS Foundation because the Foundation cared for my grandmother during her fight with ALS. The Foundation was there for my family, and my small donation every month helps to make sure they can be there for many other families every day."

–Daniel, age 25