

Hope and help for people with ALS.

lesturnerals.org

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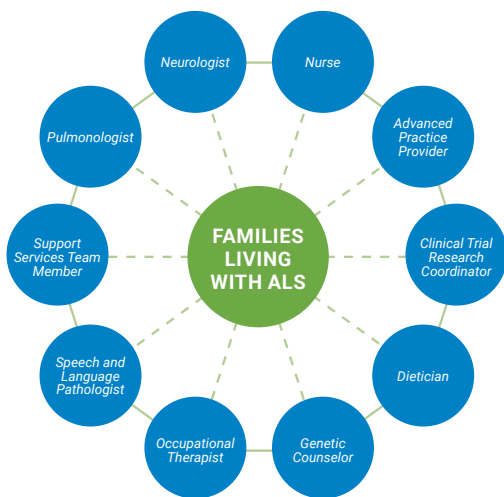
## Multidisciplinary Care

THE LOIS INSOLIA ALS CLINIC AT THE LES TURNER ALS CENTER AT NORTHWESTERN MEDICINE

ALS is a disease that affects a person's health in many complex ways and managing the disease requires multiple specialists.

These include **neurologists** who concentrate in treating the brain, spinal cord and nerves, **pulmonologists** who assess a patient's respiratory status and help maximize respiratory function, **dieticians** to assess nutritional needs, **occupational therapists** to recommend adaptive equipment and ways to manage daily activities like eating, dressing and hygiene and **speech pathologists** to help maintain speech and swallowing function.

And that's only a few of the experts people living with ALS need.



Can you imagine having to make separate appointments and office visits for each of these specialties and trying to meet with each of them on a quarterly basis? The thought alone is exhausting.

That's why, in 1986, we established one of the country's first multidisciplinary clinics to help people living with ALS, the Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine.

Multidisciplinary care brings together, in one location, all the experts needed to fully support a person diagnosed with ALS. At our Clinic, each patient works with a team of experts that provide coordinated, patient-centered care.

And while we established this model over 30 years ago, this is now considered the gold standard model of care for individuals with complex medical needs.

During a typical visit to our Clinic, a patient and their loved ones visit with the expert members of our clinic staff to discuss their treatment and answer questions in the comfort of one room. Rather than move the patient around to see their various specialists, our specialists go to them.

Making multidisciplinary care even more impactful is the teamwork approach. Each patient's care team works together to share information and make sure all aspects of the disease are being discussed and supported, both physically and emotionally.

And, at the Les Turner ALS Foundation, that care doesn't stop at the end of your Clinic visit. To ensure a person living with ALS is supported along every step of their journey with the disease, we make sure each individual's care team includes the social workers and nurses that make up our Support Services Team.

This free service provides visits to people living with ALS between Clinic appointments in the comfort and privacy of their homes to provide ongoing support and to enhance the continuity of care. Important information from these meetings may be confidentially shared with the patient's clinical care team so each member is always up-to-date on each patient's unique journey and needs.

The benefits of multidisciplinary care are huge. People living with ALS who participate in a multidisciplinary clinic generally report a high level of satisfaction with their care, stay healthier longer and have improved health care outcomes.

We are committed to the total care and support of people with ALS, their families and caregivers and our multidisciplinary approach ensures we can do just that. We know ALS is hard. Receiving the quality care you need shouldn't be.

MAKE AN APPOINTMENT AT THE LOIS INSOLIA ALS CLINIC AT NORTHWESTERN, CALL 312.695.7950

LEARN MORE ABOUT THE FOUNDATION'S SERVICES AND MULTIDISCIPLINARY CARE, CALL 847.679.3311

# Letter from the CEO

Dear Friends,

If you're anything like me, you're probably asking yourself how it's already the end of November. Here at the Foundation, we've made tremendous progress this year in increasing our support services programs, bringing new clinical trials to the Lois Insolia ALS Clinic and seeing the fruits of our investment in ALS research.

*Throughout this newsletter, you'll read a lot about the various ways in which our work is making a real impact in the ALS community.*

From our esteemed multidisciplinary approach to clinical care, to disease-changing clinical trials, to the unparalleled support we give to people with ALS and their caregivers, to the countless people working tirelessly to raise money through fundraisers like the ALS Walk for Life and the Chicago Marathon, we have a community of people who are committed to supporting each family facing ALS in the Chicagoland community every step along their journey with the disease.

I want to call attention to a special group of individuals who are instrumental to our mission. Next to this letter, you'll notice a blue box entitled "Leadership."

These leaders are the members of our Board of Directors. Our Board is made up of 21 leaders from the business and civic worlds in Chicagoland. This passionate group of volunteers gives their time, talents, treasure and leadership skills to provide strategic direction to the Foundation. While some of our members have been with us for many years, we've added nine new directors since last year who bring new passion and skills to our tenured board.

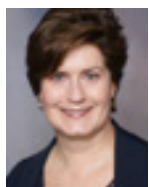
Each member of our Board of Directors has been personally touched by ALS through a family member or a friend and knows what the journey with ALS is like. And they are driven by a deep commitment to our mission of advancing scientific research and supporting every person living with ALS, and those they love, every step of the way.

*Thank you to this amazing group of individuals for their wisdom, guidance and leadership.*

And thank you to you, dear reader, for your commitment to the Les Turner ALS Foundation, where we ensure each and every family facing ALS in the Chicagoland area has the support and care they need. We know you have many choices for your charitable giving, and we honor your partnership with us.

Thank you for being a part of our family. My heartfelt wishes to you and your families for a wonderful holiday season.

Together towards a cure,



Andrea Pauls Backman  
Chief Executive Officer

## Les Turner ALS Foundation Leadership

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# Introducing the First-Ever ALS Platform Trial

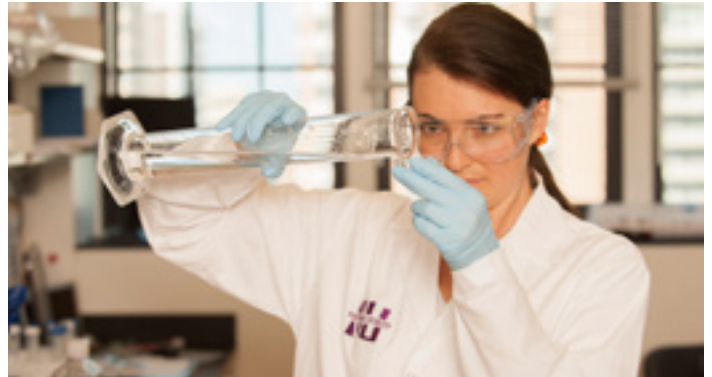
*The Sean M. Healey & AMG Center at Massachusetts General Hospital (Healey Center) is launching the first-ever ALS platform trial aimed at more rapidly advancing the development of ALS treatments, the HEALEY ALS Platform Trial.*

We are proud to share our Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine has been selected as a participating site, with enrollment of patients to begin in 2020.

A “platform trial” is a clinical trial that tests and evaluates multiple potential treatments for a disease at the same time. In addition, because different treatments are tested using a shared framework, data from participants

in all placebo groups can be pooled. This increases the chance of each individual participant to receive active treatment versus placebo, unlike in traditional trials.

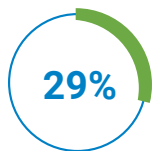
The benefits of the “platform trial” approach to drug development have already been tested and proven successful in the cancer field. “This design optimizes chances for people to receive active treatment, provides answers faster and ensures we keep learning about the disease,” shares Merit Cudkowicz, MD, MSc, Director of the Healey Center.



## National Family Caregivers Month

*November 1 marked the beginning of National Family Caregivers Month, a nationally recognized event to honor and celebrate those who support aging parents, ill spouses or other loved ones with disabilities.*

According to the National Family Caregivers Association, more than 65 million people, or 29% of the US population, provide care for a family member or friend who is chronically ill, disabled or aged during any given year. And these caregivers spend an average of 20 hours per week providing care for their loved one.



For those of us in the ALS community, we know just how vital caregivers are. The support caregivers provide is priceless. And though it comes with much love and many moments of joy, sometimes it can be really hard.

As new therapies and technologies have allowed people living with ALS to live longer, the need for caregiving has increased. Similar to other neurological conditions such as Alzheimer’s, multiple sclerosis and Parkinson’s disease, caregiver burden is high and the risk of burnout is great.

Since 2012, the Les Turner ALS Foundation has offered respite grants designed to provide short-term relief for families living with ALS, thanks to a generous annual gift from a family that knew firsthand just how hard caregiving can be. Respite care provides the primary caregiver with some time away from their care duties. This promotes well-being for both the caregiver and person living with ALS and helps prevent caregiver burnout. Since 2013, we have provided 136 respite grants to families living with ALS.

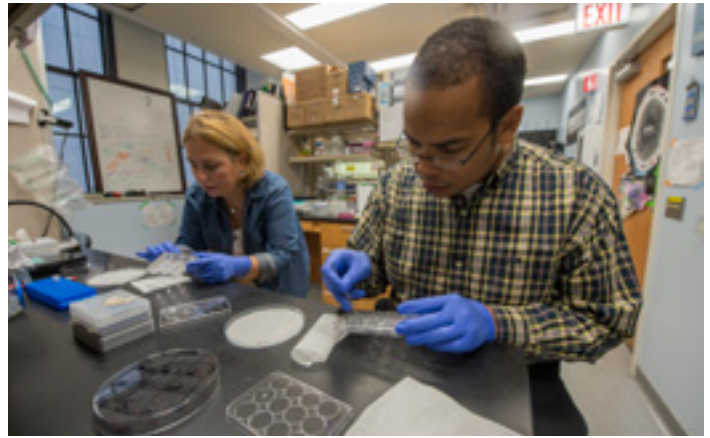
**So to all of the caregivers who are part of our Les Turner ALS family, know that although November is only 30 days long, we cherish you each and every day of the year. Words can’t even begin to express our gratitude and thanks for your amazing dedication and heart. Thank you for all you do to help people living with ALS!**



As one of just fifty-four selected sites across the country, Senda Ajroud-Driss, MD, Director of the Lois Insolia ALS Clinic, explains what this means for our Chicagoland ALS community, “We are really excited to participate in this innovative design for Phase 2 clinical trials in ALS. We are hoping this new initiative will shorten the time it takes to do traditional clinical trials, broaden patient access to trials and help us better understand this disease.”

To support people living with ALS through a clinical trial, our Clinic has an on-staff Clinical Trial Research Coordinator. Among many other responsibilities, our coordinator shares with patients information about trials at the Clinic, screens prospective participants, organizes medical records needed for the study and generally supports a trial participant through the process.

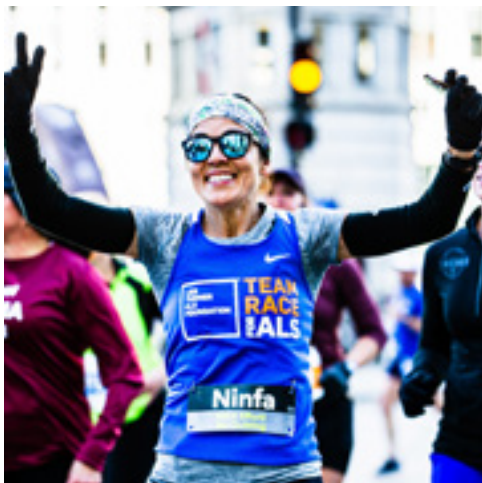
The Healey Center issued a call for the best therapeutic ideas ready to enter the HEALEY ALS Platform Trial and received an outstanding response with almost 30 applicants from 10 countries. A group of expert ALS scientists chose the top five therapeutic ideas ready to enter the platform trial. The platform trial will launch with three therapies first, with plans to add two more shortly afterward.



“We are thrilled to partner with leading organizations around the country to bring this innovative and potentially disease-changing, trial model to our Center at Northwestern Medicine and to our Chicagoland area families.” shares Les Turner ALS Foundation CEO, Andrea Pauls Backman.

*“Our vision is to see a world free of ALS. This trial takes a giant leap toward making that vision a reality.”*

# Chicago Marathon



Ninfa Queyquep

It's estimated that less than 1% of the world's population will run a marathon in their lifetime. That's what makes finishing a marathon even more impressive for the 29 members of our Team Race for ALS who ran the Bank of America Chicago Marathon this year, including someone who always goes the extra mile (or 26.2!) for her patients, the Director of our Lois Insolia ALS Clinic at Northwestern Medicine, Dr. Senda Ajroud-Driss.

These incredible marathoners run for those who can't, plain and simple. And many of them know first-hand just how true that statement is.

For Ninfa Queyquep, it was her journey with ALS after her husband Eric was diagnosed in 2009 that inspired her to run.

*“I personally have seen the challenges someone living with ALS goes through,” says Ninfa. “If I’m physically struggling in a run or workout, I think of how minimal that is compared to the daily struggles of a person living with ALS.”*

As if running 26.2 miles wasn't enough, our runners also set a new Team Race for ALS fundraising record, **raising over \$54,000 to support our Les Turner ALS family!** “Every mile and every dollar is helping those battling ALS striving to move forward through their daily lives,” shares Ninfa.

“It truly makes those living with ALS feel that they are not alone. We are fighting for them. It makes you proud to wear the Team Race for ALS shirt at the Marathon. You are running with your heart from mile 0.0.”



Manny Favela, Cindy Favela, Blas Bolivar

REGISTRATION FOR THE 2020 BANK OF AMERICA CHICAGO MARATHON IS OPEN. IF YOU'D LIKE TO RUN WITH TEAM RACE FOR ALS NEXT OCTOBER, PLEASE EMAIL [EVENTS@LESTURNERALS.ORG](mailto:EVENTS@LESTURNERALS.ORG).



# ALS Walk for Life

On Sunday, September 15, we hosted our 18th annual ALS Walk for Life at Soldier Field. What started as a rainy morning turned in to a truly spectacular day. Numbers are hard to estimate, but we feel confident saying this was one of the highest turnouts for a Walk we've ever had!

Over 7,000 of you came out to Walk for Hope, Walk for Help and Walk for Life! And together, we've raised over \$735,000 (and counting!) to support people living with ALS and their families across Chicagoland.

Our Walk is like one big family reunion where we welcome teams, new and old who, in one way or another, have been affected by ALS: mothers, fathers, sons, daughters, grandparents, aunts, uncles, cousins, friends, neighbors. You are all part of our family, and we are so thankful for all you do to support people living with ALS.

WE ALWAYS SAY THE WALK IS ONE OF OUR FAVORITE DAYS OF THE YEAR. EVEN WHEN OVERWHELMED WITH EMOTION, TO LOOK AROUND AND SEE 6,999 OTHER PEOPLE FIGHTING THE SAME BATTLE YOU ARE IS NOTHING SHORT OF AWE INSPIRING. **THANK YOU.**

*FUNDRAISING FOR THE WALK STAYS OPEN UNTIL DEC 31. MAKE A DONATION AT [ALSWALKFORLIFE.ORG](http://ALSWALKFORLIFE.ORG).*







YOU CAN BE PART OF  
HELPING FIND A CURE FOR  
ALS. GIVE TODAY BY VISITING  
[HELPCUREALS.ORG](http://HELPCUREALS.ORG).

## Terri & Eloise

*It's the end of the year and time to start thinking about your annual gift to support people living with ALS.*

Dear Friends,

I'm a mother to two small children, a wife and a daughter. I am also the sole caregiver for my mom and my inspiration, Eloise, who was recently diagnosed with ALS.

Within a month of her diagnosis last January, we had packed up the family home in St. Louis and moved Mom and her two dogs to our home in Glen Ellyn.

*My fiercely independent mother was now dependent on me for most of her needs.*

We were shocked and devastated to hear the letters ALS. We felt lost and alone. But then we discovered the Les Turner ALS Center at Northwestern Medicine and we found reasons for hope and much needed answers. Words cannot express how much the Les Turner ALS Foundation means to my family.

Please give today so others living with ALS know you care and can receive the support they need.

Forever Grateful,  
Terri, Eloise and the Gravonski family