

Hope and help for
people with ALS.

lesturnerals.org

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Senda Ajroud-Driss, MD, Director of our Lois Insolia ALS Clinic at Northwestern Medicine, is among the presenters expected to participate in ALS Learning Series programs in 2021

NEW MONTHLY ALS LEARNING SERIES LAUNCHES

Education is a lifelong process, and new and emerging delivery systems have enabled us to learn in reimagined ways. Recognizing these innovations, the Foundation has embarked on re-tooling our ALS education resources to ensure we share crucial information with those who need it most. With input from our most knowledgeable experts, people living with ALS, we've created our new online ALS Learning Series to provide information, insights and education to those living with ALS and their family members as well as other caregivers and providers.

Lisa Kinsley, MS, CGC, senior genetic counselor at Northwestern University's Department of Neurology, kicked off the new monthly online learning series on November 17. Her webinar covered genetics basics as well as the inheritance patterns of both sporadic and familial ALS and the process

for genetic testing for both symptomatic and pre-symptomatic familial ALS patients. Lisa has worked with hundreds of ALS families as a valued member of our Lois Insolia ALS Clinic at Northwestern Medicine for 10 years.

"Progress in gene discovery and technology has made genetic testing more complex and more helpful for ALS patients with questions about their own diagnosis," said Lisa. "It's an honor for me to kick off the Foundation's new education series with this important topic that can help individuals interpret family history, assess risk and offer recommendations for appropriate genetic testing options in the future."

A recording of her webinar can be viewed on our website at lesturnerals.org.

Our next ALS Learning Series program takes place on **Tuesday, December 8**, and features Benjamin Joslin, CCRC, clinical research project manager at Northwestern University's Feinberg School of Medicine, who will give a general overview of ALS clinical trials and how individuals can participate in a trial at our Lois Insolia ALS Clinic.

Other upcoming series topics include telemedicine, multidisciplinary care, basic science research and respiratory care. The program format will range from informational webinars to interactive Q&As with people living with ALS, the Foundation's Support Services team and clinicians from our Lois Insolia ALS Clinic at Northwestern Medicine, as well as regular blog posts on our website.

"The ALS landscape is ever-changing, and we know our Les Turner ALS family is always eager for the latest information, scientific insights and data to guide them in their journey with the disease. We are excited to bring this new education series to the larger ALS community and, with it, more interaction, engagement and support for people and families living with ALS."

— **LAUREN WEBB, LCSW**
Director of Support Services and Education



Letter from the CEO

Dear Friends,

When someone is first diagnosed with ALS, it can feel as though life has changed in the blink of an eye. You may begin asking questions you've never had to grapple with before and find yourself overwhelmed by new concerns.

This year, we have all had a taste of what it feels like to have our lives changed seemingly overnight. We, too, found ourselves asking different questions and were concerned about unfamiliar challenges. Yet, for those of us in the ALS community, we knew who to turn to for guidance - our Les Turner ALS community living with ALS. People living with ALS are the embodiment of courage, adaptability and resiliency. In this time, they have been our guiding lights, showing us the way. They have remained the spirit of what we do, allowing us to respond with flexibility, keeping our mission front-of-mind.

As such, we look back on a year of hard-fought "firsts." **For the first time in the Foundation's history, we held almost all our educational programs, support groups and fundraising events virtually (and successfully!), including our ALS Walk for Life.** We began enrollment of the first-ever ALS clinical platform trial, the HEALEY-ALS trial, at our Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine. We launched a new online ALS Learning Series to inform, educate and ultimately empower our Les Turner ALS family and beyond. We expanded our monthly giving program to ensure our sustainability in otherwise uncertain times.

The determination, creativity and commitment of our Les Turner ALS family, our Board of Directors, our Les Turner ALS Foundation staff, and the greater ALS community allows us to look back not only on a year of "firsts" but on a year of advances and successes. Plain and simple, we could not have done it without you and your dedication.

I wish you and your loved ones health and happiness as we head into the holiday season, which will look different this year. With your help, we look to the new year with clear eyes and a renewed eagerness and responsibility to meet these challenges for you and your family until we have created a world free of ALS. Be well and stay safe.

Together towards a cure,



Andrea Pauls Backman
Chief Executive Officer

Les Turner ALS Foundation Leadership

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Editorial

Jeremy Barewin

Hallie Kobylski

Layout

Bri Allen

Design

“We are so grateful to be able to experience the ALS Walk for Life in this kind of light”

— TERRI GAVRONSKI
Captain, Weezie's Warriors



Walking, Reimagined

2020 ALS WALK FOR LIFE RECAP

Over the past 19 years, the ALS Walk for Life has welcomed members of our Les Turner ALS family far and wide to join us in a day of celebration, hope and love. For the first 10 years, we gathered at Montrose Harbor on the shores of Lake Michigan. And in recent years, we've taken to the Stadium Green outside of Chicago's iconic Soldier Field. This year, we came together across our screens with long-time hosts Phil Schwarz of ABC7 Chicago and Melissa McGurren of 101.9 The Mix, energized with the same joy and festivity we've come to know and appreciate.

Though we could not gather in-person, our Les Turner ALS family made our first-ever virtual walk something special. Thanks to you, countless ALS Walk for Life celebrations took place in the streets, living rooms, backyards and even forest preserves across the country.

Together, we exceeded our fundraising goal, raising over \$540,000 to support our ALS research and care programs as well as people and families living with ALS across Chicagoland. Plus, our Facebook Live celebration has been viewed by nearly 10,000 people online, making this one of our largest ALS Walk for Life gatherings ever.

Thank you to everyone who remains committed to walking for hope, walking for help and walking for life! This is a year none of us will ever forget!



“We formed a team for the ALS Walk for Life as a way to give back to the Les Turner ALS Foundation because without their knowledge, support and kindness, we would be truly lost in the face of this disease.”

— ROSIE RILEY
Person living with ALS
Captain, Rosie's Riveters

"While we missed being with everyone at Soldier Field, our social distancing Walk was a great success."

— ANONYMOUS
From post-event survey



Make a Plan

WAYS TO GIVE

As we reflect on our blessings this time of year, please consider a gift to the Les Turner ALS Foundation so our shared vision to create a world free of ALS becomes a reality. Gifts are accepted online (debit, credit, ACH), by mail or by phone.

We know that giving is not a "one size fits all" scenario. As such, the Foundation accepts a variety of gift types.



DONOR ADVISED FUND

Allows you to make your charitable donation in a way that works best for you



HONOR OR MEMORIAL

Donation in memory or in honor of a loved one



MATCHING GIFTS

Gifts made by employers that match employee contributions



PLANNED GIVING

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SUSTAINING GIFTS

Gifts made on a monthly or recurring basis



WORKPLACE GIVING

Deduction right from your paycheck

Learn more at
LESTURNERALS.ORG

CONTACT US
WITH QUESTIONS

Steve Schapiro, Director of Development
sschapiro@lesturnerals.org / 847 745 6021



Hope Through Caring Gala

SAVE THE DATE | MARCH 20, 2021

We are excited to announce two award winners at our first virtual Hope through Caring Gala, taking place on March 20, 2021:



Steve Gleason
Harvey and Bonny Gaffen Advancements in ALS Award



Bob Ives
Hope Through Caring Award

Both Steve and Bob have distinguished themselves in their dedication to furthering ALS research, treatments and support, working tirelessly in the fight against ALS – *all while living with ALS.*

Steve Gleason is a very worthy recipient of our Harvey and Bonny Gaffen Advancement in ALS Award. He played for the NFL's New Orleans Saints from 2000-2008. In January 2011, he was diagnosed with ALS. With his mission to show that people living with ALS can not only live but thrive after their diagnosis, Steve, along with his wife, Michel, formed the non-profit group, Team Gleason, to help him accomplish those goals. Steve's inspiring story and mission have been told countless times throughout the media and in a documentary released in 2016.

As an advocate on the national stage, Team Gleason has brought ALS to the forefront. In 2018, the Steve Gleason Enduring Voices

Act was signed into law to ensure the availability of life-sustaining communication devices for those in need. Steve is also a founder of Answer ALS, a global project dedicated to developing and implementing a unified strategy to stop ALS, in which the Foundation is a partner.

Our Hope Through Caring Award honoree, Bob Ives, has lived with PLS, a slower progressing form of ALS, since 2014. As an engineer and business owner, Bob has never backed down from a challenge. His tenacity was formed as a young lieutenant in the Army during the building of the Berlin Wall and the Cuban Missile Crisis. Both these traits have served him well since his diagnosis. Bob and his wife, Mary, are active in our Chicago Support Group, and are dedicated donors to the Foundation's Research and Support Services programs.

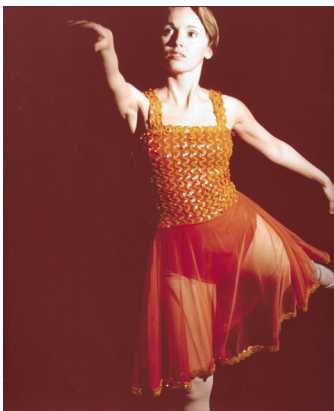
Join us on March 20—it will be a night to remember!

INDIVIDUAL TICKETS AND OTHER SPONSORSHIP PACKAGES FOR THE VIRTUAL HOPE THROUGH CARING GALA WILL BE AVAILABLE FOR PURCHASE IN JANUARY 2021 AT HOPETHROUGHCARING.ORG.

DIANE'S STORY

"It really boils down to mom's quality of life, which she has been able to maintain thanks to the Les Turner ALS Foundation. We're grateful for everything they do for us."

— THE POSPESHIL FAMILY



Music and the arts have been driving forces for Diane Pospeshil and her family. For 25 years, they ran a dance studio in Buffalo Grove, Illinois, where they were a fixture of the community, teaching an array of classes to children and adults alike.

When Diane was diagnosed with ALS in 2018, things changed drastically. Her son Matt went from business partner to caregiver overnight and turned to the Les Turner ALS Foundation to help his mom and their family navigate the many unknowns brought about by the diagnosis.

While the studio has since closed its doors, Diane's passion for dance continues, and she lives it through her family every day.

"ALS has affected my mom's ability to dance, but it has not stripped her of the things she loves most!"

— MATT POSPESHIL

ANNUAL GIVING

It's the end of the year and time to start thinking about your annual gift to help people living with ALS, like Diane, through support services, clinical care and research.

Read Diane's full story online and be part of helping find a cure for ALS by giving today.

[HELPCUREALS.ORG](https://www.helpcureals.org)