

# Community

The Newsletter of the Les Turner ALS Foundation

Hope and help for people with ALS.

lesturnerals.org

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## MEETING THE CHALLENGE OF ALS DURING COVID-19

LES TURNER ALS TEAM NOT SKIPPING A BEAT AS SERVICES, EVENTS GO VIRTUAL

Perhaps it would be understated to say that these past several months have been unexpected and stressful for everyone. For those facing the day-to-day challenges of ALS, the many uncertainties and unanswered questions brought upon by the COVID-19 pandemic can be simply overwhelming. True to our mission, the Les Turner ALS Foundation put a plan into motion, ensuring each family impacted by ALS in the Chicagoland area continues to be supported at every step.

“Our commitment and number one goal as a Foundation is to support all our families living with ALS through this outbreak,” said Foundation CEO Andrea Pauls Backman. “While we’ve had to alter the ways we do our work as a team, we haven’t skipped a beat in providing essential services and care to those that rely upon us daily.”

Our in person programming has moved to a virtual format for the foreseeable future, which includes:

- Support visits from our ALS Support Services Coordinators are now conducted via teleconference and phone calls.
- Our four monthly in-person support groups are now being conducted virtually through videoconferencing.
- Appointments at the Lois Insolia ALS Clinic at Northwestern Medicine are largely done via telehealth, with some in-person appointments available.

“The silver lining of the pandemic is that we have been able to use telehealth to provide multidisciplinary care to our patients,” said Senda Ajroud-Driss, MD, director of the Lois Insolia ALS Clinic. “It was very easy to implement, and the patients have been very receptive and

good at juggling all the virtual platforms. Telehealth has allowed us to see our patients in their physical environment and to also provide care to patients living far away, even out of state, who we would not have been able to see if we were doing face to face visits.”

In March, we established the Les Turner ALS Foundation COVID-19 Emergency Relief Fund which provides immediate help to people living with ALS to cover the cost of basic needs such as sanitizing cleaner, food delivery, groceries and ALS-related costs such as surgical masks, gloves, respiratory supplies and over-the counter medications. In order to apply for a \$250 grant, individuals must attend the Lois Insolia ALS Clinic at Northwestern Medicine.

Equipment pick-up and drop-off at our Skokie office has been paused, but our Support Services Coordinators will work with each person individually to meet their equipment needs.

Another major change for 2020 is that our signature community events are now virtual, including the ALS Walk for Life, which is annually one of the largest ALS gatherings in the country. This year’s ALS Walk for Life has moved from its regular home at Soldier Field to the web and will culminate with a Facebook Live celebration on the morning of Saturday, September 26.

We recently held two successful virtual events, our Strike Out ALS 5k and One Mile Run, Walk & Roll on July 16 and our Celebration of Life on July 18. As always, we’re not skipping a beat!

**VISIT  
LESTURNERALS.ORG**

For more COVID-19 information and resources

# Letter from the CEO

Dear Friends,

*As we face these extraordinary and challenging times together, we continue to support each person living with ALS and their families every step of the way. The way we do our work may have changed for the time being, but our dedication remains to provide you the essential services you rely upon, including all ALS clinical services and research activities.*

We have ramped up support visits from our ALS Support Services Coordinators and support groups, moving these services to a virtual format through video streaming technology. In March, clinic visits at the Lois Insolia ALS Clinic at our Les Turner ALS Center at Northwestern Medicine moved to telehealth, although some in-person appointments are currently available.

*Similarly, our signature community events for the year, including the ALS Walk for Life, have also gone virtual for the remainder of 2020.*

There are lots of fun ways for you and your team to host smaller Walk events in your local community ahead of our livestreamed celebration on September 26. As always, our events team is just an email or phone call away to help you maximize your fundraising efforts.

We know our ALS community is more committed than ever, as we saw from our record-setting Hope Through Caring Gala in February at the Radisson Blu Aqua Hotel, which raised over \$950,000 to advance ALS scientific research, clinical care and support in Chicagoland. We are grateful to two men living with ALS, Ed Rapp, recipient of the Harvey and Bonny Gaffen Advancements in ALS Award, and Matt Creen, recipient of the Hope Through Caring Award, and all of you who made this memorable evening the success it was.

Finally, with COVID-19 causing us to adapt our lives, our current fundraising is being impacted as well. As a result, we have initiated a new monthly giving program, "Sustainers for Sustainability," in which your minimum monthly gift of \$25 will be doubled, thanks to the generosity of the Foglia Family Foundation. More details can be found on the back page.

As we remember the sudden loss of our board member, Meg Rooney, I wish you and your loved ones health and safety in this difficult time. As always, we are here for our families, and for you, no matter what, until we all live in a world free of ALS.

Together towards a cure,



Andrea Pauls Backman  
Chief Executive Officer

## Les Turner ALS Foundation Leadership

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**Andrea Pauls Backman**

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**Community Health Charities of Illinois**

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**IN MEMORY**  
In Meg and John's memory, our long-running south side Chicago support group will be renamed the Rooney Family Memorial Support Group.

# Marching On

*Meg Rooney's involvement with the Les Turner Foundation began in 1999, when her mother-in-law Mary was diagnosed with ALS, and continued through her husband John's battle with the disease. Following his death in 2016, she joined the Foundation's Board of Directors. She died on May 17, 2020 of complications due to stomach cancer.*

Our mom did not die of ALS, but she certainly lived with it.

She handmade our Team Rooney signs for the first-ever ALS Walk for Life, which came about two years after our grandma died. We still use those signs today. She made the green tie-dyed shirts we wore for that first walk, too. We outgrew those shirts long ago, but Team Rooney marches on.

Until May 17, we all marched behind her. She led our family through our dad's journey with ALS, caring for him and showing the rest of us how to live with grace in the face of tragedy. She summoned her immense strength to guide us through times of sorrow and helped us find joy through all of it.

And as she led us, she would have been the first to admit she would have been lost without the Les Turner ALS Foundation. She relied on the tremendous

care and expertise our entire family received, to say nothing of the vast system of support and countless friendships we forged through the Foundation.

So, when the time came for her to be able to give back, she leapt at the opportunity. From organizing Tag Days on the south side and volunteering at events like the Strike Out ALS 5k to joining the Foundation's Board of Directors and religiously attending our local support group, she cherished each moment she spent giving back to the Foundation that has given our family so much.

Though both of our parents are gone now, we remain committed to keeping them alive by staying close to the people and causes they held dear. In other words, Team Rooney continues to march on.

*Ned, Jack, and Dan Rooney*



*John and Meg Rooney*



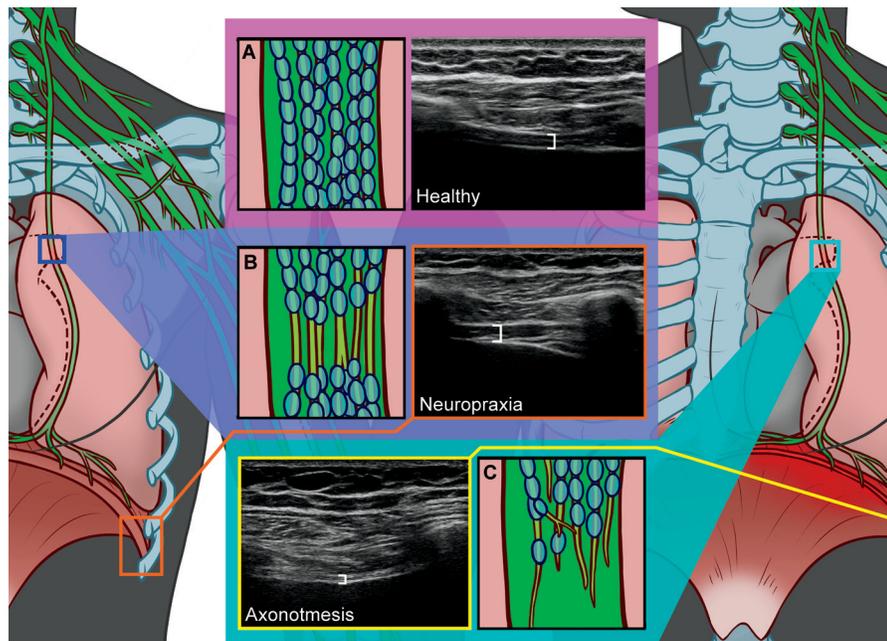
*Ned, Jack, Meg, and Dan Rooney*

# Progress through Perseverance

*For our community, the multidisciplinary care at the Lois Insolia ALS Clinic and innovative ALS research have always been essential. Despite new and challenging times, the extraordinary members of our Les Turner ALS center continue their work to support people and families living with ALS every step of the way.*

Members of our Les Turner ALS Center at Northwestern Medicine, including Drs. Lisa F. Wolfe and Colin Franz, are finding ways to support those affected by COVID-19.

At the onset of the pandemic, concern for non-invasive ventilation (NIV) was high as we all did our part to “flatten the curve.” The importance of NIV, especially for those with neuromuscular conditions, is one Lisa F. Wolfe, MD, Associate Professor in Medicine and longtime pulmonologist and legislative advocate at our Lois Insolia ALS Clinic, knows well. She co-developed “Care Recommendations for the Home-Based Ventilation Patient Undergoing Therapy for Known or Suspected Respiratory Viral Infection With COVID-19” with the CHEST Foundation. These recommendations ensure that clinicians across the country and the world have guidance to support individuals living with ALS during the pandemic.



Graphical representation of the two types of phrenic nerve damage and their corresponding diaphragm findings on ultrasound.



Dr. Wolfe (left) was at the forefront of advocating, with support by the Foundation, for the removal of NIV from Medicare’s competitive bidding program. The competitive bidding process would have limited the independence of people living with ALS by reducing their access to therapy providers and devices, possibly even restricting them to non-portable devices. Thanks to Dr. Wolfe’s leading efforts, along with other advocates and organizations, NIV was successfully removed from the 2021 competitive bidding program earlier this year.

Furthermore, the pandemic ushered in new ways of conducting research and care. Our team at Northwestern quickly adapted to continue their work without sacrificing months and years of progress.

“We saw this shutdown coming a couple weeks in advance,” shared Colin Franz, MD, PhD, Assistant Professor in Physical Medicine and Rehabilitation and clinician at our Lois Insolia ALS Clinic (right).



Dr. Franz shifted his teams’ duties to those that could be accomplished remotely, such as planning and designing experiments, analyzing data, and writing papers and grant applications.

One such grant application, a “trailblazer” grant, involves “assembling brain and nerve-muscle tissues that we generate from human stem cells. We call these “assembloids,” explained Dr. Franz. A colleague at Northwestern is in the process of making a machine that Dr. Franz and his team will use to measure the neuromuscular circuits of these assembloids. This approach, currently studying the effects of neurotrauma, would be relevant to ALS and other neuromuscular diseases.

The world of ALS research and clinical support continues to adapt to the changing environment. However, what hasn’t changed is the work at our Les Turner ALS Center at Northwestern Medicine, ensuring the best care continues to be provided and the brightest minds are working to find a cure.

SAVE THE DATE

10th Annual

## Les Turner ALS Foundation Symposium on ALS

*Celebrating Research, Patient Care and Education*

**Northwestern Medicine**  
Feinberg School of Medicine

Les Turner ALS Center

VIRTUAL EVENT

**Monday, November 9**

KEYNOTE SPEAKER

**Sabrina Paganoni, MD, PhD**  
Co-Director, MGH Neurological  
Clinical Research Institute (NCRI)

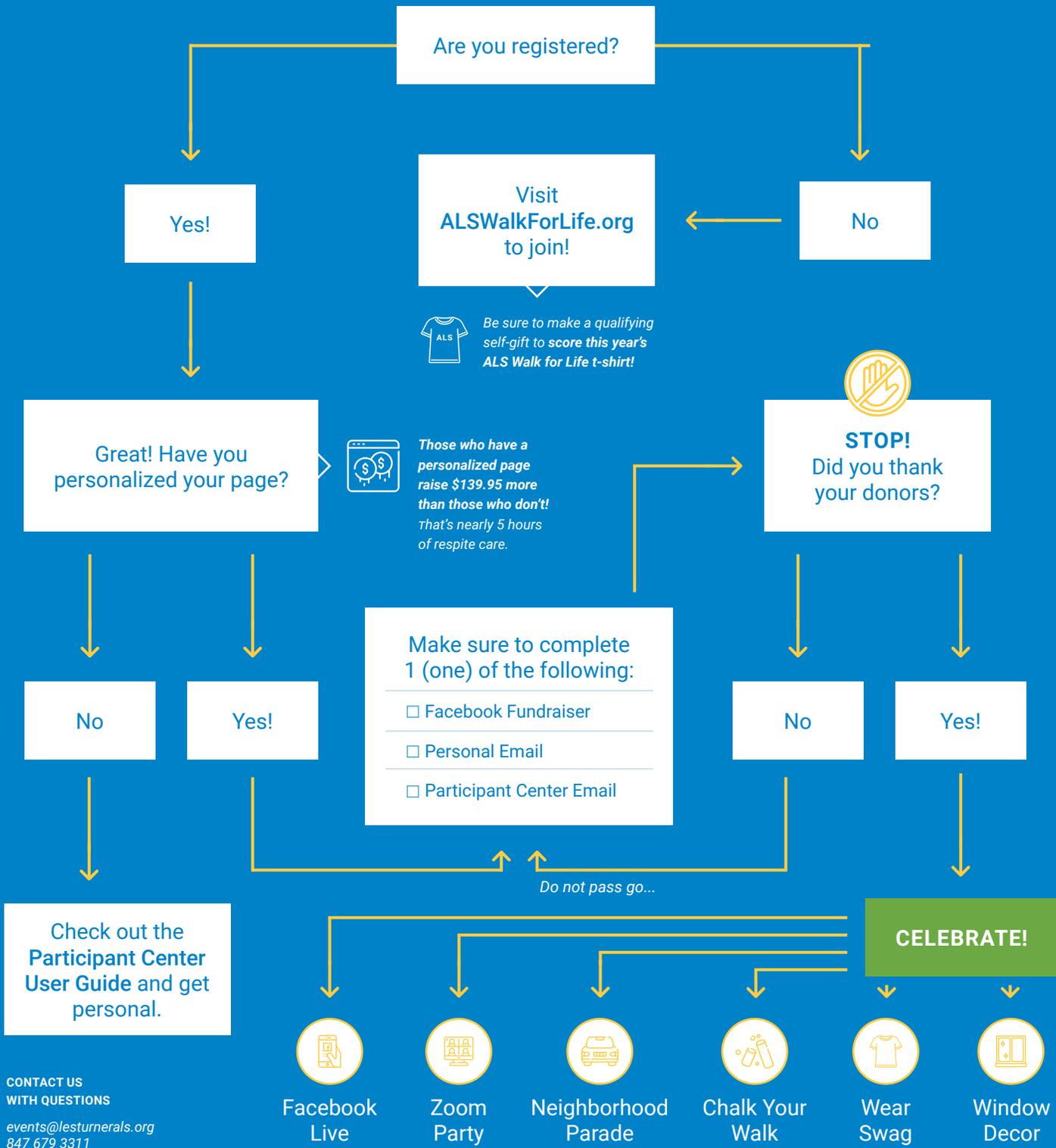
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More event details and registration  
will be available in mid-August



# Have you registered for the 2020 ALS Walk for Life?

SATURDAY, SEPTEMBER 26, 11AM, ALSWALKFORLIFE.ORG



CONTACT US WITH QUESTIONS  
events@lesturnerals.org  
847 679 3311

THANK YOU TO OUR 2020 ALS WALK FOR LIFE SPONSORS!





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MONTHLY DONOR CHALLENGE

# Double *your* Impact

*Become a Sustainer for Sustainability*

ALS is unrelenting, so we're doubling our impact, but we need your help! The COVID-19 pandemic has affected all our lives in unpredictable ways. It has also impacted the Foundation's fundraising and revenues, which are needed to ensure no person with ALS goes without individualized support services and that our clinical and research programs can continue to do their unparalleled work.

Between now and August 31, if you make a new monthly gift of at least \$25, it will be doubled thanks to the generosity of the Foglia Family Foundation. Your sustaining monthly gift will help us move closer toward our shared vision of a world free of ALS by providing care and support to those impacted by the disease and advancing critical research across the Chicagoland area.

**THE TIME TO ACT IS NOW!** *Double your Impact*  
*through August 31, 2020*  
LESTURNERALS.ORG/SUSTAINER

**CONTACT US WITH QUESTIONS** Steve Schapiro *Director of Development* [sschapiro@lesturnerals.org](mailto:sschapiro@lesturnerals.org)  
847 745 6021

*Thank you for your support during this critical time.*