

All Together Now

2021 Annual Report

LES
TURNER
ALS
FOUNDATION



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Our Mission

To provide the most comprehensive care and support to people living with ALS and their families so they can confidently navigate the disease, and advance scientific research for the prevention, treatment and cure of ALS.

Nobody in our community fights ALS alone.

That's at the core of who we are as an organization. For many of us, the fight against ALS is personal. It carries the name of a parent, a partner, a close friend, or someone else who meant the world to us – someone, we vowed, who would never be alone with this terrible disease.

Two years ago, people around the world were separated and often isolated by a global pandemic. But in 2021, we found new ways to come back together. This report describes how, through your support, the Les Turner ALS Foundation carried out that mission – how your donations, sponsorships, and volunteer commitments made it possible to create this community with a remarkable sense of belonging, care, and above all else, hope.

You made it possible to reach more people than ever before with personalized support visits, support groups, and educational resources. You opened doors to clinical trials and funded new research pilot grants. You brought the compassion and determination of this community to people living with ALS beyond Chicagoland, across the country and around the world.

And as we've come back together, we've had the opportunity to learn more from the people we serve – what they want and what they need, and how we can be more available to them, in the ways that mean the most to them.

As our Manager of Support Services Cara Gallagher notes, “We have watched the magic of friendships develop and recognized that individuals can find a common thread not only because of loss, but because of the impact ALS has on a family, which differs from most diseases. We have provided safety and comfort for those who have lost loved ones and find rebuilding their lives challenging and frightening.”

There will always be change. As time passes, there will be more families who are shaken by an unexpected diagnosis and the hard truths of this disease. But one thing will always be true. We're all in this fight together. Now and every day.



Ken Hoffman
Board Chair



Andrea Pauls Backman
Chief Executive Officer



Providing Care & Support

Our collective reach to people living with ALS has never been greater than it was in 2021.

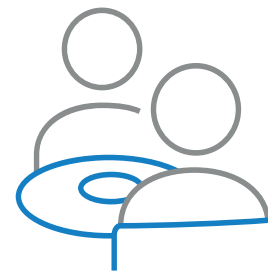
At the **Lois Insolia ALS Clinic** at the Les Turner ALS Center at Northwestern Medicine, visitors receive care from a multidisciplinary team with extensive experience in diagnosis and treatment of ALS. During visits, people with ALS and their loved ones meet with several members of the ALS care team to discuss treatment and answer any questions including assessment, care planning, education, clinical trials and other healthcare needs.



Overall clinic volume was up **17%** over 2020.



The clinic offered **15** clinical trials and research studies, including the HEALEY ALS Platform Trial.



Our experienced Support Services team of nurses and social workers **more than doubled** its personalized visits over the same time in 2020.



Participation in our support groups **nearly doubled**, offering virtual access for people living with ALS and their families, as well as new bereavement and caregiver support groups.

Adapting and Thriving

“The pandemic forced us to find new ways to reach those we serve without losing the intimate nature of the support we offer. In 2021, we began to realize the many benefits of remote work and how it allowed us to reach more people with ALS and their families, working more efficiently and effectively.”

“Our virtual visits have allowed for family members out of the area to take part and feel more supported. In addition, virtual support groups have allowed those that would otherwise not be able to attend in person to be a part of these very helpful groups. Although there were certainly some negatives that the pandemic created, our resiliency as a Foundation stood up to the test of time and came out ahead.”

- KAREN RALEY STEFFENS, RN, CHPN, CCM
ALS SUPPORT SERVICES COORDINATOR



“As telehealth and virtual visits increased, so did the ease to provide increased collaboration and continuity of care for individuals living with ALS. As a palliative social worker, I was easily able to participate in joint Zoom visits with Julie Stowell RN, the Les Turner ALS Support Services coordinator, while I was in the individual’s home or also in a remote location. Julie and I were able to coordinate care needs on an ongoing basis with Zoom, while also reinforcing resources available such as the My ALS Decision Tool, need-based grant programs, and medical equipment and communication needs.”

- ROCHELLE WALWER, LCSW

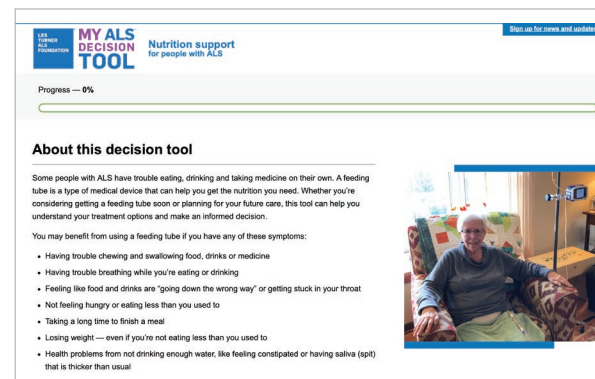
Building Confidence & Hope

In 2021, we awarded \$1,456,667 in grant dollars to the Les Turner ALS Center at Northwestern Medicine, funding research toward more effective treatment and cures for ALS as well as world-class multidisciplinary patient care at the Lois Insolia ALS Clinic.



Launched in 2021, the new My ALS Decision Tool™ empowers people with ALS to make **early and informed decisions** about their care for improved health outcomes.

This unique **interactive resource** was developed by the Les Turner ALS Foundation in collaboration with people living with ALS, caregivers, advocates, researchers and clinicians. It takes you through the thought process needed to make complex medical decisions and puts people living with ALS in control of their treatment.



Our monthly ALS Learning Series webinars have **over 5,000 views** since the series was launched in fall 2020.

In tandem with **six new information guides**, these educational materials are part our mission to help people with ALS navigate the disease with confidence.



Research

M Northwestern Medicine®
Feinberg School of Medicine

Les Turner ALS Center

Led by Dr. Robert Kalb, the Center funded several ambitious research projects and then laid the groundwork to launch a new **Research Pilot Grant Program** for 2022 that would award the most promising early-stage ALS Research Projects to a broad group of scientists and increase the Center’s commitment to research by **16%**.



GRANT TITLE	PRIMARY INVESTIGATOR
Identification of new genes for Familial ALS	Teepu Siddique, MD, DSc
Investigating how mislocalized proteins contribute towards neurotoxicity in C9orf72-based ALS	Evangelos Kiskinis, PhD
Defining the mechanisms by which NEK1 genetic variants associated with ALS lead to motor neuron degeneration	Evangelos Kiskinis, PhD
Relationship between ARF GTP’ases and genetic forms of ALS	Robert G. Kalb, MD
Mechanistic Insight into Proteasome impairments evoked by DPRs	Robert G. Kalb, MD



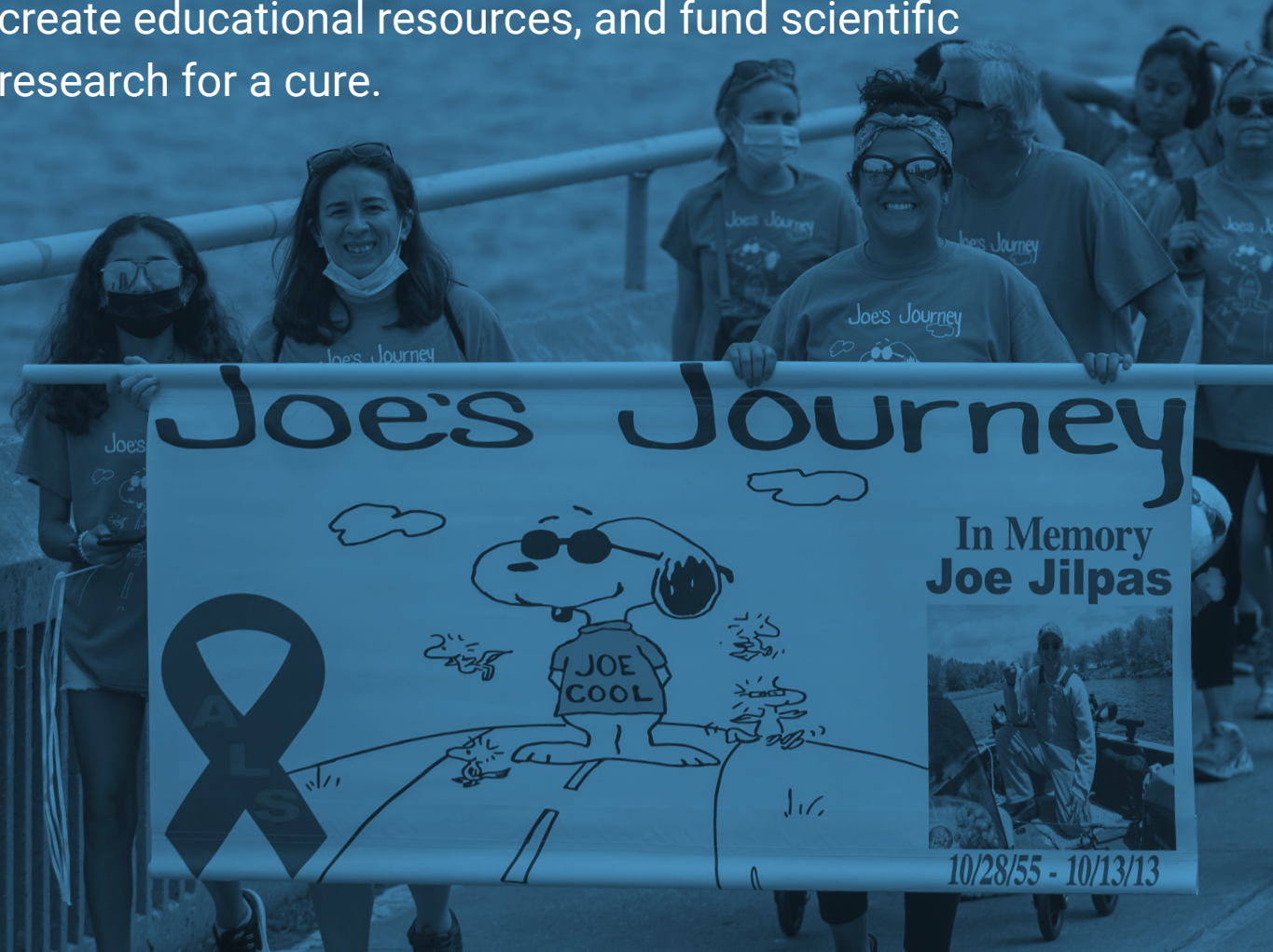
“The most common genetic form of ALS is due to a mutation in the C9ORF72 gene. As part of a collaboration with

Dr. Todd Lamitina at the University of Pittsburgh, we undertook a genetic screen for genes required for toxicity of the mutant form of C9ORF72. As we reported recently in the Proceedings of the National Academy of Science, the genetic architecture of C9ORF72 toxicity is complex. Our focus on a single gene, called SPOP, shows that manipulating the expression and function of SPOP is able to suppress C9ORF72 toxicity. Ongoing work focuses on extending these observations to mouse models of C9ORF72 disease and a more in-depth study of the mechanism of SPOP action.”

- ROBERT KALB, MD
DIRECTOR, LES TURNER ALS CENTER
AT NORTHWESTERN MEDICINE

Creating Community

Our live events create a sense of community by connecting old friends and new. They also raise funds to provide comprehensive care and support to more people living with ALS than ever before, create educational resources, and fund scientific research for a cure.



In March, our first all-virtual Hope Through Caring Gala went before the cameras to raise over \$485,000.



In July, we lined up at the home of the Chicago White Sox and at locations around the country for the Strike Out ALS 5K & 1 Mile Run, Walk and Roll, which raised \$55,000.



In September, our signature annual event brought 3000 people together at Soldier Field and along the lakefront to celebrate and honor friends and loved ones who are living with ALS or have passed away from the disease. The ALS Walk for Life raised \$552,000.

There's no end to the ingenuity of a community determined to create a world free of ALS.

Other fundraising events in 2021 included the annual Tag Days fundraising drive during ALS Awareness Month in May, the Team Race for ALS at the Bank of America Chicago Marathon in October, the All In for ALS Casino Night hosted by the Young ProfessionALS Group, and many more.

Thank you to all our fundraisers, sponsors, and participants!



Young ProfessionALS Group

Members of the Young ProfessionALS Group share a common interest in finding a cure for ALS. While most members have a connection to the disease, anyone interested in supporting the Foundation and its mission is welcomed. The group meets to socialize, support one another, and discuss new ways to raise awareness.

Proceeds from the YPG's popular fundraising events – such as their NCAA bracket challenge, bar crawl and All in for ALS Casino Night – directly benefit the Foundation. Members also give support by participating in the Foundation's yearly events and volunteering.

“During my mother's battle with ALS, the Les Turner Foundation and the ALS community provided both her and my family incredible support,” said Ryan McGarvey. “I was inspired by this support and wanted to become a part of it. In my three years in the group, it's been incredibly fulfilling to help raise money and awareness for a cause I am very passionate about. Not only that, but it is fulfilling doing it alongside individuals who also understand what it is like to have a loved one battle ALS.”

To learn more, contact co-Chairs Laura Kunberger and Ryan McGarvey at YPG@lesturnerals.org.



ACT for ALS

In July 2021, the Les Turner ALS Foundation joined 19 other advocacy organizations in calling on the U.S. House of Representatives to pass the ACT for ALS Act.

This legislation would create a program to convene and coordinate drug development stakeholders in rare neurodegenerative diseases; commission an action plan from the Food and Drug Administration to advance therapeutic development, regulatory science, and policy dissemination; and create two new grant programs with the goal of accelerating development and access to promising new therapies.

In December 2021, President Joseph R. Biden signed the ACT for ALS into law – a tremendous victory for the ALS community.

Champions

Chicago Bears Super Bowl champion Steve ‘Mong’ McMichael was diagnosed with ALS in January 2021. Besides playing for the Bears and arguably the most dominant defense in NFL history, he was also a professional wrestler and could squat 720 lbs. Steve’s personality hasn’t changed, but his motor skills have declined due to ALS.

Despite that, Steve said, “I’d do it all over again. Even if it means that you’re going to get ALS at 63 years old. The journey is the reward – not the destination.”

Steve receives support from the Les Turner ALS Foundation and his many friends and former teammates, including former Bears tackle and longtime Les Turner ALS Foundation spokesperson Keith Van Horne. He is especially grateful for his wife, Misty.

Since his diagnosis, Steve has reflected on his life and embraced both the good and the bad. “I see the compassion in people – that’s when God is smiling. Every man lives but not every man really lives. And I’ve lived 10 lives.”

At the 2021 ALS Walk for Life, we presented Steve with the first **ALS Courage Award** to celebrate his courage on and off the field.



Our Generous Supporters

The Les Turner ALS Foundation is grateful for every donation, regardless of the amount. The following list of donors represents gifts of \$1,000 and above.

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Please consider making a donation online at lesturnerals.org. To make a bank transfer, a stock donation, or other types of contributions, contact Steve Schapiro at schapiro@lesturnerals.org or 847.679.3311.

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\$1,000 - \$4,999

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Why I Give

“I have the unfortunate and unique perspective of both losing my father to ALS and owning a home respiratory company that provides ventilators and support services to the ALS community. My family and my company give to the Les Turner ALS Foundation to help support research efforts in finding new treatments and one day a cure, as well as to assist those currently struggling with ALS and their family struggling beside them.”

- BRIAN DACY

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Gratitude Group

Our Gratitude Group was formed in August 2021 to personally welcome and thank new donors. Led by Beverly AbiAntoun, Joe Collins, Susan Footlik, Wendy Formanski, Ina Turner Jones, Holly Kahan, Diana Pisone, and Mary Roemer, each volunteer has a special connection to ALS and the desire to give back.

In their handwritten notes, Gratitude Group members often share personal stories about how the Foundation has helped them and their family members.

“My husband Dave was diagnosed with ALS in 2010 and passed away in 2015. I volunteer for this group because I am forever grateful for the Foundation and all that they did to help my family,” said Mary Roemer. “ALS is a family disease, and the Foundation knows the importance of patients and their families. If it hadn’t been for the guidance of the Foundation and our caregiver, we would have run out of gas on the road of life. Today, I can give back what was given to me, and a handwritten note is so meaningful and personal.”

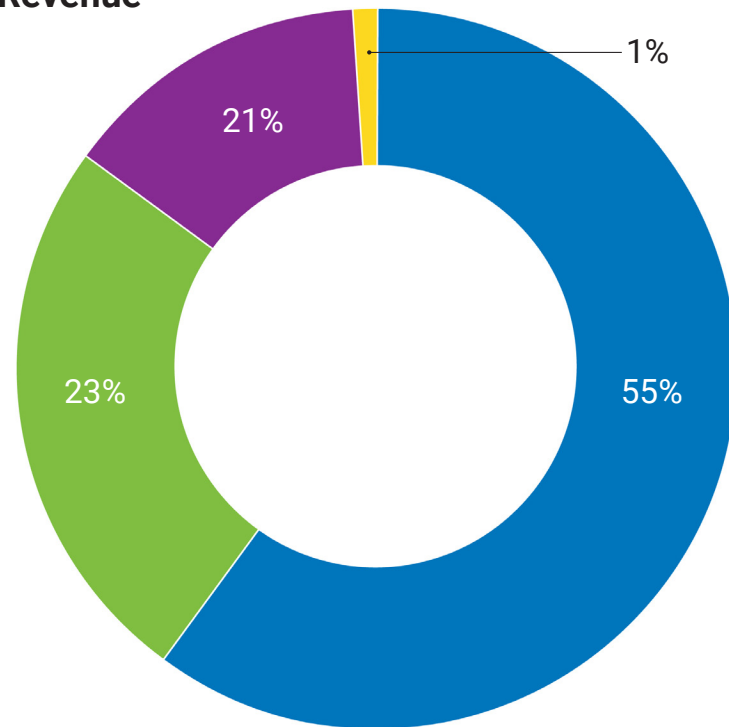
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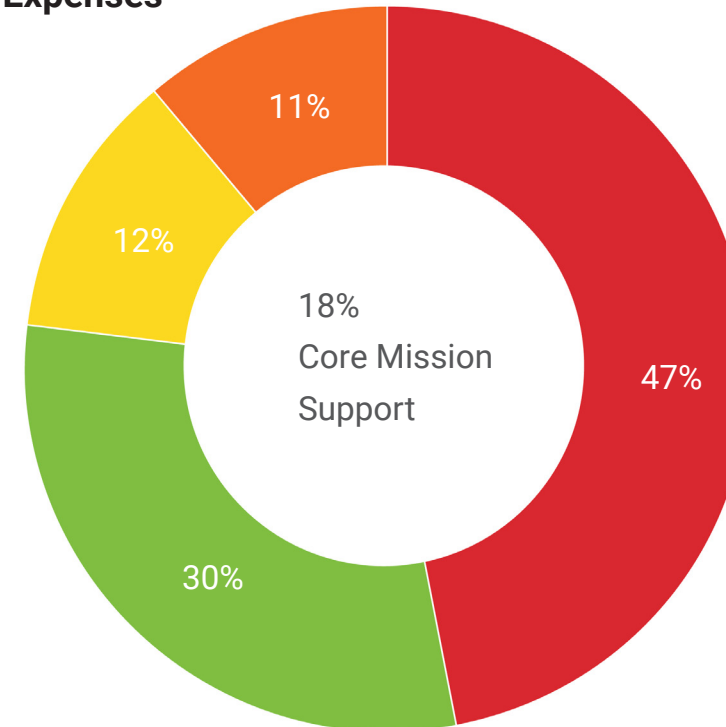
Financial Impact

Revenue



\$1,734,198	■ Individuals, Corporations, Foundations
715,481	■ Fundraising Events (Net)
662,752	■ Grants and Contracts
7,789	■ Investments
\$3,120,220	Total Revenue

Expenses



\$1,181,000	■ Research / Endowment
771,739	■ Support Services
550,984	■ Core Mission Support
300,000	■ Lois Insolia ALS Clinic
279,267	■ Education
\$3,082,990	Total Expenses

Independent Auditors

Wipfli



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Support Group Facilitators

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Anne Lidsky, PhD
Ileane Mindel, RN

Walking Together

Lori Hoover, an Air Force veteran, was diagnosed with ALS in 2019. At the Les Turner ALS Center at Northwestern Medicine, she met with clinicians and Julie Stowell, RN, one of our support services coordinators. In search of support and answers, Lori especially appreciated the help from Julie.

“When I was first diagnosed, Julie suggested I join the Wheaton Support Group,” said Lori. “Julie has helped me so much with everything. Without her assistance, I would not have known what to do and where to get started.”

Lori was excited to be back in person with the ALS community at the 2021 ALS Walk for Life with her team, Lori’s Legion. Although Lori relies on mobility equipment to get around, she was so happy to return to the Walk for Life that she decided on something special for the finish line.

“My nephew asked me if I wanted to walk across the finish line, so he and my younger son helped me cross the finish line on my feet,” she said, smiling. “I guess the biggest thing that has come out of having ALS is knowing that I have so much support. My family is very close, and we’ve just become closer.”



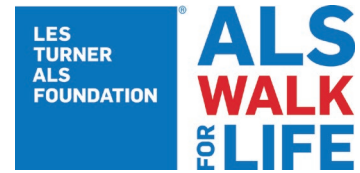


Upcoming Events



**Strike Out ALS 5K
and 1 Mile Run, Walk & Roll**
Guaranteed Rate Field
Thursday, July 21, 2022

[REGISTER](#)



ALS Walk for Life
Soldier Field
Saturday, Sept. 24, 2022

[REGISTER](#)



Team Race for ALS
2022 Bank of America
Chicago Marathon
Sunday, Oct. 9, 2022

[REGISTER](#)

Thank you for your continued support of the Les Turner ALS Foundation. Together, we will see a world free of ALS.



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