

Moments » Momentum

2022 Annual Report

LES
TURNER
ALS
FOUNDATION[®]



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How do moments become momentum?

As we celebrate 45 years of dedicated service to the ALS community, we reflect on the remarkable journey that has brought us to this milestone. From its humble beginnings as a project initiated by the loved ones of one courageous person facing ALS, the Les Turner ALS Foundation has evolved into a beacon of hope and support for tens of thousands of people and their families who have been touched by this challenging diagnosis.

Our theme for this annual report, “Moments to Momentum” speaks to the essence of our journey. Momentum is not a singular force; it is a collective surge of energy generated by countless moments of dedication, compassion, and collaboration.

As we take the helm of this extraordinary organization, we are reminded of the incredible leaders who preceded us. Ken Hoffman, whose transformative eight-year tenure as President of the Foundation’s board concluded in 2022, and Andrea Pauls Backman, who distinguished herself as our CEO until earlier this year, have left an indelible mark. They ensured that our mission would always be grounded in the needs and aspirations of the ALS community.

One of the driving forces behind our momentum is the unwavering commitment of those who have shared their ALS journey with us. In 2022, we welcomed two people living with ALS to our board of directors and added five people living with ALS and caregivers to our support services committee. Their insights, needs, and concerns remain at the forefront of our decision-making processes, shaping our funding priorities and objectives. Our momentum, indeed, emanates from those we serve.

Momentum also arises from the shared vision we hold – a world free of ALS. In 2022, we witnessed the approval of two new treatments aimed at slowing the progression of this relentless disease. These approvals were made possible through the collaboration of people living with ALS who participated in clinical trials conducted at the Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine, fueled by the generosity of donors who support the Les Turner ALS Foundation.

Moreover, the first genetic mutation linked to cause ALS, SOD-1, was co-discovered at the Les Turner ALS Center in 1993. It underscores

the importance of sustained dedication and perseverance in our pursuit of life-changing discoveries. Moments of resilience eventually transform into enduring momentum, shaping the future of ALS treatment and care.

Throughout our journey, we have tragically lost many individuals to ALS, each leaving an indelible mark on our hearts. Their enduring legacy fuels our resolve to press forward. Their love and memory are a source of strength, propelling us toward our mission.

So, how do moments become momentum? The answer is clear: Together, as the Les Turner ALS Foundation.



Erin R. Cohn
Erin Reardon Cohn
Board Chair



Laura Freveletti
Laura Freveletti
Chief Executive Officer



Led by Those We Serve

ALS has affected Frank Granata's ability to do many of the things that he loves, like cooking meals for his family, golfing, and especially riding his custom chopper motorcycle. But Frank won't let ALS stop him from doing everything. He works out at the gym five to six times per week using a customized regimen from Shirley Ryan AbilityLab, an affiliated rehabilitation partner of the Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine.

"Currently, ALS is primarily affecting the fine motor skills in my upper body and breathing," says Frank. "I spend my time working out the muscles that still respond to help optimize the motor functions I have remaining, so that I can have some sense of independence for as long as possible."

The Foundation is providing Frank and his family with comprehensive care and support.

"The support services team is truly amazing," Frank says. "Everyone I have worked with is highly skilled, genuine, personable, and sincerely concerned about my well-being. They have listened to every detail that I have given them and tried to find a way where they can be of service or refer me to someone that could further assist me."

In 2022, Frank joined the Foundation's Board of Directors to share his insight and perspective on living with the disease. He also delivered opening remarks at the Les Turner Symposium on ALS, offering valuable insights on that occasion as well.



"When you have ALS, you have to keep your sense of humor. It's easy for me to think about the things that I was able to do prior to my diagnosis, but it could easily lead me down a path of self-pity or anger. You don't know what's next, so you might as well just roll with the punches and have a laugh or two along the way."

— FRANK GRANATA

Ensuring Comprehensive Care and Support

At the Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine, patients 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.

With backgrounds in nursing, social work, and speech-language pathology, our support services team collaborates with ALS care teams to address the needs of people living with ALS and their families. We provide emotional support and guidance; offer solutions for challenges of daily living, home safety and equipment; provide guidance on Social Security Disability Insurance, Medicare and Medicaid; and much more.

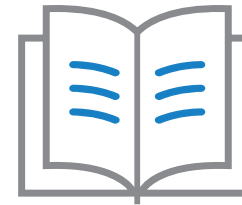




Our ALS support services coordinators provided nearly 4,000 care coordination meetings for people living with ALS, up 20% over 2021.



Our ALS Learning Series webinars have had nearly 10,000 views since launch in fall 2020; in 2022, experts discussed home modifications, financial planning, Medicare and more.



We published three new, best-in-class ALS information guides on the impact of ALS on children, the importance of caregiver self-care, and maintaining relationships and physical intimacy while living with the disease.



Nearly 60 people per month found solace and shared experiences in our support groups.



We offered 19 clinical trials and research studies, including the HEALEY ALS Platform Trial, and three expanded access programs, which provide access to experimental drugs or medical treatments that are not yet approved by regulatory agencies or are not readily available on the market. These programs are subject to ethical and regulatory oversight to ensure patient safety.



We distributed 106 needs-based grants to help cover the cost of equipment, respite care and transportation for people living with ALS and caregivers.



“I am grateful for the Les Turner ALS Foundation’s Walter Boughton Grant because it allows me to enter my home using the wheelchair lift. It allows me to get in and out of my home using either my walker or wheelchairs. It has given me independence.”

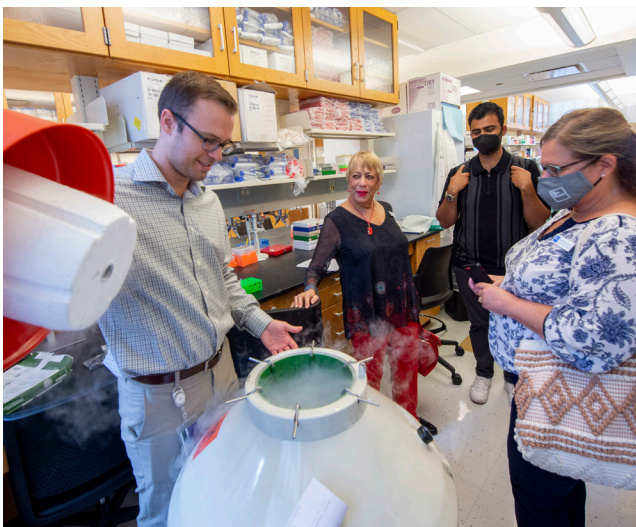
– JANIE GOBELI



Accelerating Leading-Edge Research

In 1979, with an initial donation of \$50,000, we embarked on a pioneering journey by dedicating one of the world's first laboratories solely devoted to ALS research at Northwestern Medicine. Little did we know that this humble beginning would evolve into a momentous movement.

Today, the Les Turner ALS Foundation stands as a beacon of hope, tirelessly working to make a significant and meaningful difference in the lives of people living with ALS and their families. We have become a global role model for ALS organizations, and our partnership with Northwestern Medicine has flourished.



Our partnership has been a testament to shared values, resilience, and unwavering dedication. Over the years, we have raised over \$70 million, with most of these funds contributing to the remarkable growth of Northwestern Medicine's ALS research and care initiatives. This extraordinary collaboration has withstood the test of time, and it is a legacy we will always hold dear. The mission of the Les Turner ALS Center at Northwestern Medicine remains resolute: to forge a future

free of ALS. Under the visionary leadership of Dr. Robert G. Kalb, the Joan and Paul Rubschlager Professor and Chief of the Division of Neuromuscular Medicine, it has grown to encompass over 70 members spread across Northwestern University's Chicago and Evanston campuses. Together, we harness diverse expertise across scientific disciplines, generating new insights and groundbreaking advances in the relentless battle against ALS. This momentum is a testament to our enduring commitment and dedication to turning moments of hope into a future without ALS.

In 2022, we funded several ALS basic science research pilot grants at the Les Turner ALS Center, increasing our funding to research by 36% over the previous year. This basic science research seeks to understand the fundamental biological, genetic, and physiological mechanisms underlying the development and progression of ALS.

Analysis of Ataxin2 Targets as Mediators of Amyotrophic Lateral Sclerosis

Ravi Allada, MD

Genetic Modifiers of Familial ALS

Erik Andersen, PhD

Characterizing the Metabolite Changes in Lysosomal and Mitochondrial Compartments in ALS

Navdeep Chandel, PhD
and Evangelos Kiskinis, PhD

C9orf72 Expansion Alters Innate Immune Function and Contributes to Neurodegeneration in ALS

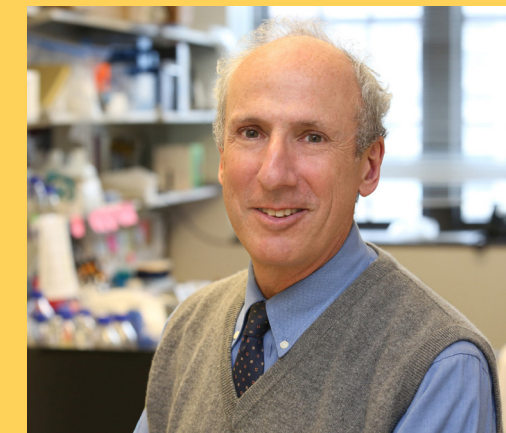
David Gate, PhD

Personalized Medicine Program

Robert Kalb, MD

Developing a Multiplex iPSC-based Platform for Interrogating Sporadic ALS Disease Mechanisms

Evangelos Kiskinis, PhD



“In combination with our robust clinical research program, the results from the research labs will be well positioned to be translated into tangible new therapies for ALS.”

— DR. ROBERT KALB



United to Create a World Free of ALS

We're grateful beyond words to everyone who attended, organized, sponsored, and raised funds and awareness at events in 2022. Countless people came together as one community, determined to create a world free of ALS.

At the Hope Through Caring Gala, we bestowed the Harvey and Bonny Gaffen Advancements in ALS Award upon Joshua Cohen and Justin Klee, co-founders and CEOs of Amylyx Pharmaceuticals. Their dedicated efforts to develop innovative treatments for ALS were celebrated. Additionally, we honored Dr. Lisa Wolfe of the Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine, a trailblazer in the field of respiratory medicine for neuromuscular disease, with the prestigious Hope Through Caring Award for her outstanding contributions.

Events are the lifeblood of our mission. They are not just gatherings; they are the heartbeats of our community, the fuel that keeps our momentum going. Throughout the year, these events become the canvas upon which we paint our stories of hope, determination, and unity.

In September, Soldier Field welcomed thousands of compassionate souls who joined the Les Turner ALS Walk for Life. This grand event stands as a testament to our commitment. It's where we come to honor the courage of those living with ALS and to cherish the memory of those who've left us. It is, without a doubt, the largest ALS gathering in the entire Midwest.

Our Young ProfessionALS Group works year-round, organizing a series of engaging events and meetups that build bridges within our community. These gatherings aren't just about fundraising; they're about forming connections that empower us all.

Then, in November, the Les Turner Symposium on ALS takes center stage. This symposium unites clinicians, researchers, and people living with ALS, creating an environment where insights are shared and the latest advancements in ALS treatment are discussed.

These events serve as beacons guiding us forward. Not only do they bring our ALS community together, but they also play a pivotal role in elevating awareness and generating the essential funds required to fuel comprehensive care and groundbreaking research.

From the spirited participants who converged at Sox Park for Strike Out ALS to the resilient souls who conquered the Chicago Marathon with Team Race for ALS, and the generous hearts behind community-organized fundraisers like the Sun Mechanical and Matt Creen Golf Outings, we extend our heartfelt gratitude to everyone who joined our events in 2022.





Driving Progress: Advocacy in Action

Until recently, there was only one drug approved by the FDA to slow the progression of ALS. Then, in 2017, another drug called Radicava was approved. And then, in 2022, two more drugs, Radicava ORS and Relyvrio, were added to that list, with several more joining the pipeline.

What changed?

Change is happening because the ALS community demands it. When consideration of a promising new treatment stalled in March, we spent the summer helping organize and lead collaborative efforts across ALS organizations to demand accelerated approval. At the FDA Advisory Committee meeting in September, we spoke on behalf of families of people who were lost to ALS during that delay.

Behind every new drug are clinical trial participants. Our Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine hosted clinical trials for both Radicava ORS and Relyvrio, the drugs that were approved in 2022.

Thanks to the people living with ALS who participated in clinical trials, researchers had the evidence to move those new drugs forward. And a long-term vision is being realized. Years ago, the first genetic mutation linked to cause ALS, SOD1, was co-discovered at the Les Turner ALS Center at Northwestern Medicine.

In 2022, thanks to that discovery – and to the donors who supported that research – the first treatment for a genetic form of ALS went before the FDA for evaluation.

In 2022, we provided leadership for the new ALS Strategic Plan developed by the National Institutes of Health and National Institute of Neurological Disorders and Stroke, and we worked with other organizations to demand federal action on issues like the outdated Supplemental Security Income system. We also worked with the ALS Association, I AM ALS, and Muscular Dystrophy Association to increase federal funding to nearly \$200 million for ALS research and programs.

Throughout the year, we worked in partnership with the ALS community to accelerate therapy development and increase access to treatments, equipment, and clinical research. We collaborated with advocates, academia, biotech industry, government agencies, and nonprofit organizations on clinical research, expanded-access programs, health literacy, and healthcare operations.



Our Generous Donors

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

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In 2022, 3,310 new donors made first-time contributions, becoming part of a strong and rapidly-growing base of support for our programs.

Please consider joining them by making a donation online at lesturnerals.org. To make a bank transfer, a stock donation, or other types of contributions, contact Steve Schapiro, Chief Philanthropy Officer, at sschapiro@lesturnerals.org or 847.679.3311.

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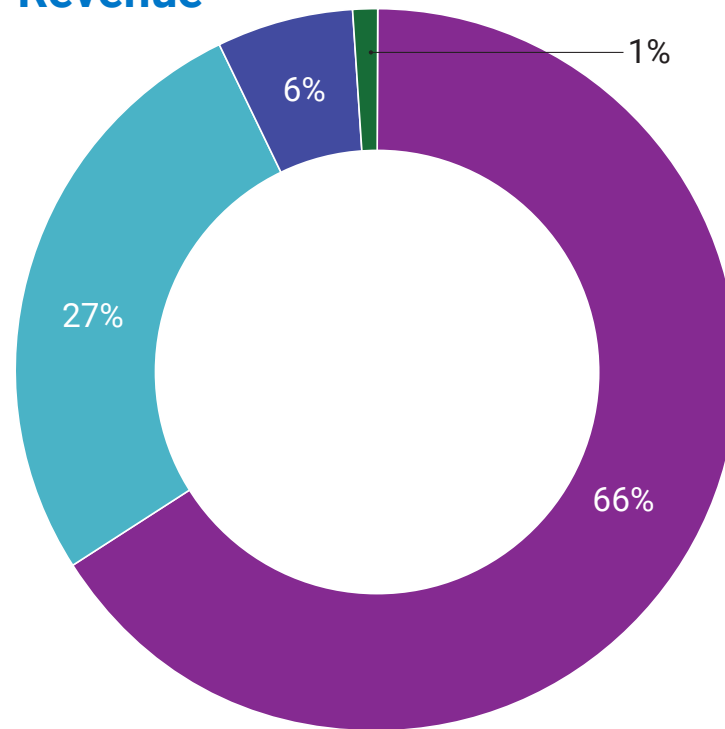
Monthly donations offer a flexible and impactful way to support our mission. We understand that donors have diverse preferences, and monthly giving allows you to choose a giving frequency that suits you best. Whether you opt for monthly, annual, or another interval, your support is invaluable. Monthly donations provide a steady and predictable cash flow, allowing us to plan effectively and be there for the ALS community when they need us most. Thank you for considering the giving option that aligns with your preferences and for being a vital part of our mission's success.

"The Les Turner ALS Foundation was our family's lifeline during my husband's five-year journey with ALS," says Mary Roemer. "Because Dave often asked for ALS research updates, I enrolled in the Foundation's monthly giving program to honor his memory and help ensure the research and compassionate care continue for people living with ALS."

To learn more, visit lesturnerals.org/sustainers.

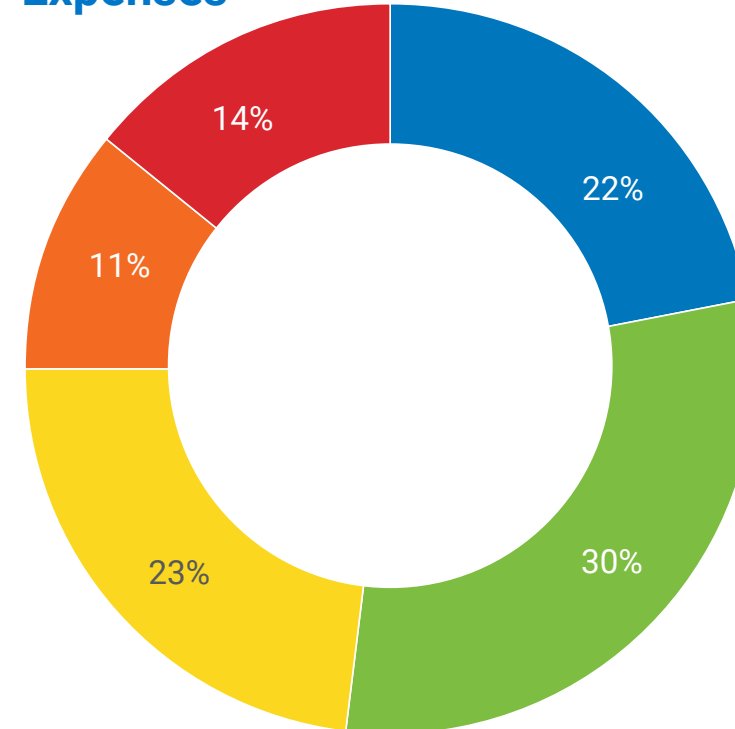
Financial Insights

Revenue



\$1,762,725	Individuals, Corporations, Foundations
715,542	Fundraising Events (Net)
153,121	Grants and Contracts
28,645	Investments
\$2,660,033	Total Revenue

Expenses



\$600,000	Les Turner ALS Center at Northwestern University Feinberg School of Medicine (Research)
849,641	Support Services
625,445	Core Mission Support
310,000	Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine
401,038	Education
\$2,786,124	Total Expenses

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Wipfli



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Special thanks to Andrea Pauls Backman, Emily Cerbone, Christina Esparza-Cassidy, Karen Gianni, Madeline Hardy, Deb Marron, and Julie Stowell for their staff contributions in 2022.

Moments of Extraordinary Love and Adventure

Despite her ALS diagnosis, Eloise Nilges was committed to living to the fullest. Her daughter Terri helped arrange for her to receive treatment at the Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine, and then the family set out to make the most of every moment together.

“My mom was known as ‘Grandma Weezie’ to her two grandkids,” says Terri. “She loved being a grandma and was always up for an adventure! We took her and our two kids to Disney World. My mom had always wanted to go with her grandkids and at the time she was still able to go on the rides with them.”

Shortly after that trip, Eloise underwent a procedure for a feeding tube. Feeling more energetic due to better hydration and nutrition, Eloise set off with Terri and her husband for a European getaway that included Paris, Rome, and Florence.

When they returned, the family reached out for assistance in obtaining mobility equipment and a communication device. Julie Stowell, RN, one of the Foundation’s ALS support services coordinators, provided much-needed knowledge and support.

“As my mom’s disease really started progressing, we would have been lost without Julie,” says Terri. “Julie was always able to communicate the next steps with my mom in the most compassionate and understanding ways. Even when the conversations were beyond difficult, she always had a caring and calming presence.”

Since Eloise passed away, her family has continued to receive guidance and grief support.

“The Foundation was there for us at every turn,” says Terri. “I will be forever grateful to the Les Turner team!”





Annual Events



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November

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Thank you for being a vital part of our journey. Your support has fueled our momentum, turning moments of hope into progress. As we move forward, we invite you to stay involved in our events, share in our mission, and consider continuing your generous support. Together, we can create more moments of impact and bring us closer to a future without ALS.

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