



LES
TURNER
ALS
FOUNDATION

Strategic priorities to guide our next three years 2024-2026

These strategic priorities outline the initiatives we will undertake and the investments with which we will commit to advance and to realize our mission and vision.



Fund ALS Research

We are funding groundbreaking ALS research initiatives at the Les Turner ALS Center at Northwestern Medicine. By investing in pioneering studies and clinical research, we aim to accelerate the discovery of effective treatments and ultimately find a cure for this devastating disease. Our commitment to funding ALS research is unwavering, as we believe that scientific breakthroughs are the key to a future free from ALS.



Enhance Quality of Life for People Living with ALS

We are improving the lives of people living with ALS, their families, friends, and loved ones. Our strategic plan prioritizes initiatives that provide comprehensive support, resources, and services to enhance the quality of life for people living with ALS. This includes offering multidisciplinary care, assistive technology, and emotional support, ensuring that those facing ALS lead fulfilling lives despite the challenges posed by this devastating disease.



Increase Our Leadership in the ALS Community

We are expanding our influence and leadership within the ALS community. This priority involves strengthening partnerships, fostering collaboration, and advocating for policies that benefit people living with ALS. By uniting stakeholders, raising awareness, and driving change, we aim to lead the way in shaping a brighter future for those impacted by ALS.



The Les Turner ALS Foundation: Our Story

The Les Turner ALS Foundation was founded in 1977 by the family and friends of Les Turner, a Chicago business owner who had been diagnosed with ALS the previous year at the age of 36. At a time when information and research on ALS was almost nonexistent, Les Turner's brother-in-law Harvey Gaffen and his wife Bonny, along with their friends and family, set out to raise funds to provide vital research and resources to people living with ALS and their families.

Les passed away in 1978, but this extraordinary group of founders went on to establish what is now the longest-serving independent ALS organization in the U.S.

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

Our Vision is a world free of ALS.



Enabling Investments



These investments provide both the essential conditions and opportunities required for our strategic priorities to be effectively realized and underscore the importance of measuring the impact of our investments.

- Empower the Foundation staff, board, and volunteers
- Develop a transformative funding model
- Foster diversity, equity, accessibility, and inclusion
- Embrace digital transformation
- Measure and evaluate the impact of our investments and initiatives

Priorities:

Fund ALS Research



By 2027, we will increase our funding commitment to ALS research, ensuring that we continue to lead the way in supporting innovative studies and clinical research, bringing us closer to finding a cure for ALS.

To get there, we will:

- **Attain ALS Center of Excellence** status by investing in state-of-the-art research facilities, fostering collaboration with world-class researchers, and enhancing the reputation of the Les Turner ALS Center at Northwestern Medicine.
- **Enhance the Les Turner Symposium on ALS** by extending its impact, disseminating the research of ALS experts, featuring the researchers and programs of the Les Turner ALS Foundation and Center through speakers and poster sessions, and facilitating meaningful networking opportunities to promote advancements in the field of ALS research.
- **Augment clinical research** at the Lois Insolia Clinic at the Les Turner ALS Center at Northwestern Medicine by expanding funding for clinical research, forging collaborations with pharmaceutical companies, and actively involving a larger number and more diverse set of people living with ALS in research initiatives.

Priorities:

Enhance the Quality of Life for People Living with ALS



By 2027, we will significantly enhance the quality of life for people living with ALS through a comprehensive range of support services, effective therapies, and improved accessibility to resources, ensuring they experience greater health and dignity throughout their journey with the disease.

To get there, we will:

- **Enhance existing support for people living with ALS** by developing comprehensive mental health support programs, increasing educational resources, and providing guidance on clinical research.
- **Provide assistance with financial and insurance-related matters** by offering personalized financial guidance, insurance support, and estate planning assistance, as well as expanding equipment loans to those in need.
- **Strengthen the Lois Insolia Clinic at the Les Turner ALS Center at Northwestern Medicine** by improving care coordination between clinic staff and the Les Turner ALS Foundation Support Services team, aligning goals for high-quality care, and expanding the clinic network to include both established and underserved communities.

Priorities:

Enhance the Quality of Life for People Living with ALS *continued*



By 2027, we will significantly enhance the quality of life for people living with ALS through a comprehensive range of support services, effective therapies, and improved accessibility to resources, ensuring they experience greater health and dignity throughout their journey with the disease.

To get there, we will:

- **Expand our library of educational content and resources** by developing tools, guides, webinars, and other resources to empower people living with ALS and their caregivers with knowledge and support while actively seeking their input.
- **Empower primary care physicians and allied professionals** by developing train-the-trainer programs aimed at enhancing the capabilities of healthcare professionals in providing ALS care.

Priorities:

Increase Our Leadership in the ALS Community



By 2027, we will solidify the Les Turner ALS Foundation as a recognized and influential leader in the ALS community, working collaboratively with stakeholders to drive positive change and innovation in the fight against ALS.

To get there, we will:

- **Proactively cultivate relationships with media outlets and legislative authorities**, establishing a robust media presence, actively participating in advocacy efforts, and engaging in collaborative partnerships with policymakers to address the needs of people living with ALS.
- **Position ourselves as the charity of choice for donors dedicated to advancing ALS research and supporting people living with ALS** by creating compelling funding opportunities, ensuring transparent financial stewardship, and effectively communicating the tangible impact of donations on our mission.

Enabling Investments:

Measuring Our Progress

By 2027, we will make investments that support a path to our goals.

To measure our progress, we will:

- **Empower our team:** Measure the effectiveness of our investments in professional development, training, and support for staff and volunteers to enhance their skills, foster innovation, and maximize our collective impact.
- **Develop a transformative funding model:** Assess the success of diversifying revenue sources, implementing new fundraising strategies, and building donor relationships to create a sustainable funding model adaptable to changing ALS community needs.
- **Embrace digital transformation:** Gauge the impact of technology investments on enhancing communication, stakeholder engagement, and operational efficiency, enabling us to reach a broader audience and better serve people living with ALS.

Measuring Our Progress *continued*



By 2027, we will make investments that support a path to our goals.

To measure our progress, we will:

- **Foster diversity, equity, accessibility, and inclusion (DEI):** Evaluate progress in removing barriers, promoting diversity, and improving accessibility to ensure our programs and services cater to the diverse ALS community. Additionally, implement DEI initiatives within our foundation's staff and practices to create an inclusive and equitable workplace, reflecting our commitment to diversity and inclusion at all levels of our organization.
- **Measure and evaluate the impact of our investments and initiatives:** Assess and analyze the outcomes of our investments and initiatives to ensure they align with our strategic priorities and effectively contribute to our mission and vision.



In the pursuit of our mission to combat ALS and support those affected by it, we are reminded of the incredible strength, resilience, and unity within our community. Together, we envision a future where ALS is no longer a devastating diagnosis, where hope shines brighter than ever, and where the possibilities for a cure are boundless. Let our unwavering commitment and collective efforts propel us toward a future filled with hope, progress, and a world free from ALS. Together, we can make it happen.

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Laura Freveletti
Chief Executive Officer
Les Turner ALS Foundation
5550 W Touhy Avenue
Suite 302
Skokie, IL 60077-3254