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2023 Annual Report

LES  
TURNER  
ALS  
FOUNDATION

# Caring Cure Quality of Life Empowerment

“ I would not have survived the diagnosis without the Les Turner ALS Foundation’s support services team. It was overwhelming from the start, and any question I had, they had an answer. The last thing you want to do after the emotional stress of handling the diagnosis is to think logistics. A huge weight has been lifted and to be able to breathe after the diagnosis, it’s a true gift. ”

– FROM 2023 EXPERIENCE OF CARE SURVEY





# Committed to **Caring**

Since 1977, our mission has been 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.

Our donors make that work possible. Their compassion and dedication inspire us every day, and we can't thank them enough.

**2023**



**4,231** care coordination meetings provided  
Up 6% from the year before



**14** clinical trials and studies offered  
**4** expanded access programs



**60** support group participants per month  
Including new 'Newly Diagnosed' support group



**121** needs-based grants delivered  
Including technology, home renovation,  
transportation, and caregiver support



"Utilizing iPSC technologies to investigate disease mechanisms in ALS"



**M** Northwestern  
Medicine

## Committed to a **Cure**

In 2023, we funded over **\$1 million in ALS research grants** and clinic and endowment support at the Les Turner ALS Center at Northwestern Medicine, led by Dr. Robert G. Kalb. These grants are intended to support investigators who are new to the ALS community, bringing fresh ideas and insights into the field.

### 2023 ALS Research Grants

**Analysis of Ataxin2 Targets as Mediators of Amyotrophic Lateral Sclerosis**  
Ravi Allada, MD

**Characterizing the Metabolite Changes in Lysosomal and Mitochondrial Compartments in ALS**  
Navdeep Chandel, PhD  
Evangelos Kiskinis, PhD

**C9orf72 Expansion Alters Innate Immune Function and Contributes to Neurodegeneration in ALS**  
David Gate, PhD

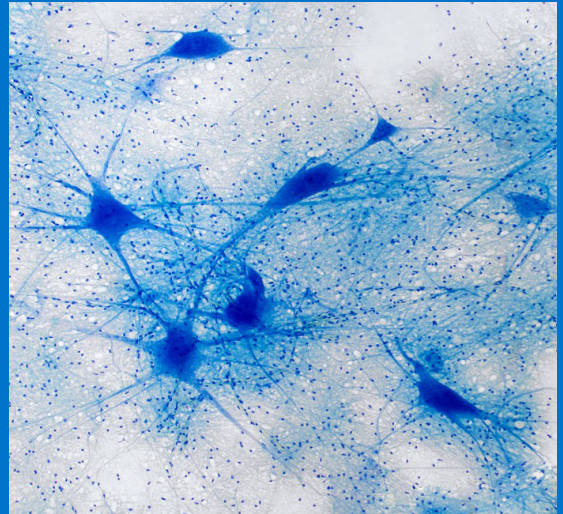
**Personalized Medicine Program**  
Robert Kalb, MD

**Developing a Multiplex iPSC-based Platform for Interrogating Sporadic ALS Disease Mechanisms**  
Evangelos Kiskinis, PhD



## Clinical Trials Lead to Treatment Breakthrough

One of the greatest challenges in combatting ALS is that the causes of the disease remain little understood. One of the first answers came in 1993 when the first genetic mutation linked to cause ALS, SOD-1, was co-discovered at the Les Turner ALS Center. That led to the first-ever treatment for a genetic form of ALS, Qalsody, which was approved by the FDA in 2023. That drug was studied and tested at our Lois Insolia ALS Clinic, which is led by Dr. Senda Ajroud-Driss.



## Revealing the Mechanisms of the Disease

NEK1 is known to be a significant genetic cause of ALS. However, until now, it hasn't been known how mutations in the gene disrupt the function of motor neurons and cause them to degenerate and die. In 2023, scientists led by Dr. Evangelos Kiskinis at the Les Turner ALS Center discovered how mutations in NEK1 lead to ALS – and pointed the way forward to new therapeutic targets for the disease.





## Committed to **Quality of Life**

In 2023, the American College of Chest Physicians released a **new clinical practice guideline on respiratory management of patients with neuromuscular weakness**. We represented the ALS community in the development of these evidence-based recommendations, which include mouthpiece ventilation, transition to home mechanical ventilation, salivary secretion management, and airway clearance therapies. Dr. Lisa F. Wolfe, pulmonologist at the Lois Insolia ALS Clinic, was one of the authors.

Through leadership within organized medicine, we hope to help standardize and improve the respiratory care provided to people living with neuromuscular diseases, including ALS, across the United States.

When the Centers for Medicare and Medicaid Services (CMS) opened a comment period on **Medicare coverage of power seat elevation systems in power wheelchairs**, we organized support and lobbied in favor of coverage. We know that power seat elevating devices are important to the people we serve because they facilitate safer transfers from wheelchairs, improve reach and independence, and aid in communication by making it possible to talk at eye level, especially in crowds and noisy environments.

In 2023, CMS announced that Medicare will formally cover wheelchair seat elevating systems for many types of power wheelchairs. We applaud the decision and are proud to have advocated for it.



## Committed to Empowerment

In 2023, we hosted **eleven ALS Learning Series webinars with 4,473 views**, gathering experts on nutrition, exercise, tracheostomy, and other essential topics to inform and interact with our community.

We also hosted the **13th annual Les Turner Symposium on ALS**, uniting speakers from research and industry with people living with ALS to discuss the latest developments in treatment and care.

**Our online resources continue to set the standard in ALS education.** We launched the groundbreaking My ALS Decision Tool™ on Genetic Testing for People Living with ALS and began translating our complete set of ALS guides into Spanish in order to reach more people in need.

Our website and online ALS resources have seen a **314% increase in pageviews** since 2019 – providing answers and encouragement to people from more than **175 countries** worldwide.



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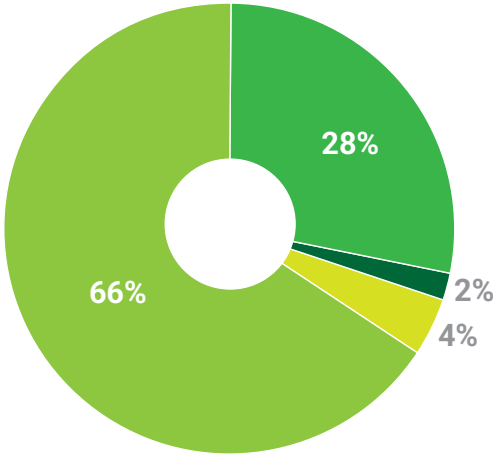
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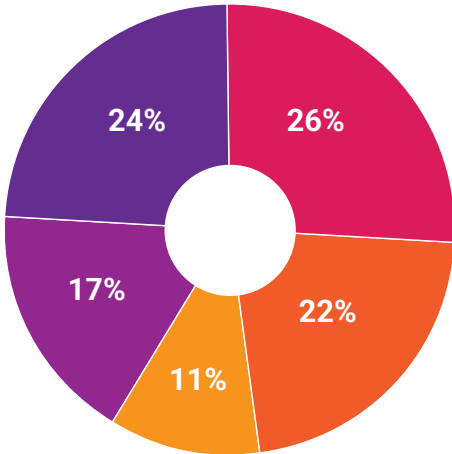
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# 2023 Financials



## Revenue

\$1,781,787	Individuals, Corporations, Foundations
755,756	Fundraising Events (Net)
42,500	Grants and Contracts
102,365	Investments
<b>\$2,682,408</b>	<b>Total Revenue</b>



## Expenses

\$820,000	Les Turner ALS Center at Northwestern University Feinberg School of Medicine (Research)
861,953	Support Services
718,217	Core Mission Support
375,000	Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine
580,770	Education
<b>\$3,355,940</b>	<b>Total Expenses</b>

## Summary

Total Revenue: \$2,682,408  
 Program Expenses: \$2,637,723  
 Management Expenses: \$269,128  
 Fundraising Expenses: \$449,089  
 Total Expenses: \$3,355,940  
 Ending Net Assets 12/31/2023: \$3,286,760

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