We are the
Les Turner
ALS Foundation
Letter from Board Chair and CEO

Dear friends,

You are receiving this report because you have helped change the life of someone living with ALS today or someone to be diagnosed tomorrow, and we thank you. Because of you, we are the leader in comprehensive ALS care in Chicagoland, allowing thousands of people affected by ALS to count on us.

2019 was a year marked by growth, innovation and collaboration. We expanded our expert clinical care team at our Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine and greatly expanded our clinical trial program. We funded six novel research pilot grants as part of our robust and long-standing ALS research program. We are a proud partner in Answer ALS, the largest ALS research study in the world, which finished its enrollment in 2019. And, along with Hope Loves Company, we co-sponsored Camp HLC Chicago for children impacted by ALS.

As you will see in our first-ever, digital annual report, our focus on care, support and novel scientific research to unlock the mystery of ALS has never strayed. With your help, we continue to move closer to our shared vision of a world free of ALS. We have always believed that our mission is best told through the eyes of those we serve; families and individuals living with ALS. These are the heroes that inspire and inform our work.

As we write this, we find the country and the world in the throes of the COVID-19 pandemic, which has affected all of us: our ALS families, how we deliver our support services and how we conduct our ALS research and clinical care. Our primary concern, always, is the health and safety of our extended Les Turner family, of which you are an essential part. We will expand on this very important topic in this report, to include our response to the pandemic and measures we have implemented to ensure we are never more than a phone call away.

Wishing all of you and those you love safety and good health in these troubling times.

Together toward a cure,

Ken Hoffman
Board Chair

Andrea Pauls Backman
Chief Executive Officer
Mission in Action

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

Our vision is to create a world free of ALS

HOW WE DO IT
Hope Through Scientific Research
Our Les Turner ALS Center at Northwestern Medicine effectively connects the worlds of research and patient support to ensure the best care is provided and the brightest minds are working to find a cure.

A Local Community of Support
Over the last 43 years, we’ve built a local community that feels like family. Together, we encourage and empower each other throughout our journey with the disease and beyond.

Individualized Care for People and Families Affected by ALS
We provide a personalized approach – preparing people living with ALS for their difficult journey, listening to and addressing the needs they have right now and will have in the future.

Our Values in Action
Kindness
Our grant programs for our families help with respite care, transportation, equipment, assistive communication devices and other needs.

Tenacity
We fund innovative research at our Les Turner ALS Center at Northwestern Medicine to make sure people living with ALS are provided truly comprehensive care.

Individuality
Each person living with ALS is unique, just like our approach to support and clinical care.

Expertise
We continue to grow our expert clinical care team at our Les Turner ALS Center at Northwestern Medicine to make sure people living with ALS are provided truly comprehensive care.

Collaboration
We issued 1.26M in grants to I AM ALS, under our fiscal sponsorship agreement, to support ALS awareness. We are a proud partner of Answer ALS. We also co-sponsored Camp HLC Chicago, along with Hope Loves Company, for children impacted by ALS.

Mission in Action
I am grateful to the Les Turner ALS Foundation. Investing in basic science is a solid path to identifying meaningful therapeutic intervention strategies for ALS and I am thankful to the Foundation and the patients that support this vision.”

— EVANGELOS KISKINIS, PHD
In 2015, the Les Turner ALS Foundation, in partnership with Northwestern Medicine, embarked on a campaign to raise $10 million to create a one-of-a-kind ALS Center in Chicago that would unite research and patient care, with another $9 million in expendable funding over 10 years pledged by the Foundation. Thus, the Les Turner ALS Center at Northwestern Medicine was formed, bringing together all ALS disciplines under one umbrella and enabling enhanced collaborations between researchers and clinicians to provide a full spectrum of treatment to ALS patients while facilitating the development of new therapies for ALS.

CURRENT ALS RESEARCH PROJECTS

Robert G. Kalb, MD, Joan and Paul Rubschlager Professor of Neurology and Director of our Les Turner ALS Center at Northwestern Medicine, provides an excellent update on the research being done at the Center on an episode of the Better Edge podcast.

<table>
<thead>
<tr>
<th>Grant Title</th>
<th>Primary Investigator</th>
</tr>
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<tbody>
<tr>
<td>Translating Research and Implementation for ALS (TRIALS)</td>
<td>Senda Ajroud Driss, MD</td>
</tr>
<tr>
<td>Identification of new genes for Familial ALS</td>
<td>Teepu Siddique, MD, DSc</td>
</tr>
<tr>
<td>Investigating how mislocalized proteins contribute towards neurotoxicity in C9orf72-based ALS</td>
<td>Evangelos Kiskinis, PhD</td>
</tr>
<tr>
<td>Defining the mechanisms by which NEK1 genetic variants associated with ALS lead to motor neuron degeneration</td>
<td>Evangelos Kiskinis, PhD</td>
</tr>
<tr>
<td>Relationship between ARF GTPases and genetic forms of ALS</td>
<td>Robert G. Kalb, MD</td>
</tr>
<tr>
<td>Mechanistic Insight into Proteasome impairments evoked by DPR's</td>
<td>Robert G. Kalb, MD</td>
</tr>
</tbody>
</table>

Over the past 43 years, we have discovered that a significant percentage of ALS is due to a mutation in a single gene.”

— ROBERT G. KALB, MD
Clinic and Clinical Trials

MULTIDISCIPLINARY CARE AT THE LOIS INSOLIA ALS CLINIC

Our Lois Insolia ALS Clinic at our Les Turner ALS Center at Northwestern Medicine is one of the first multidisciplinary ALS clinics in the country. We use a multidisciplinary approach to patient care that provides high quality care that is convenient for families. People with ALS who participate in a multidisciplinary clinic generally report a high level of satisfaction with their care, stay healthier and have improved health care outcomes. Our team is dedicated to the total care and support of people with ALS, their families and caregivers.

2019 HIGHLIGHTS

The Lois Insolia ALS Clinic is Chicagoland’s largest and most comprehensive clinic for people living with ALS.

Added to our Team at the Clinic

- two neurologists
- two advance practice nurses
- one genetic counselor
- one nurse resource coordinator
- one research coordinator
- two pulmonologists
- two advance practice nurses
- six neurologists
- one nurse resource coordinator
- medical assistants
- respiratory therapists
- occupational therapists
- speech-language pathologists
- dietitians
- nurses
- one research coordinator

Total Clinic Team Now Includes
As an active member of NEALS, in 2019, the Clinic was selected to join the Phase 2 HEALEY ALS Platform Trial, the first multi-center platform trial in ALS organized by the Healey ALS Center at Massachusetts General in Boston, along with 53 other sites around the country. This is a very exciting trial for the ALS community. Five targeted therapies will be evaluated over time with the same group of patients, allowing for fewer patients to receive a placebo. Platform trials have proven to be an effective way to trial cancer drugs and is being used in ALS for the first time.

Senda Ajroud-Driss, MD, Director of the Lois Insolia ALS Clinic, and her clinical research staff enrolled 57 people in Answer ALS, the single largest coordinated and collaborative effort to end ALS in the history of the disease. Answer ALS is building the most comprehensive clinical, genetic, molecular and biochemical assessment of ALS and makes the data and research tools freely available to researchers to help bring an end to this disease.

Our annual Les Turner Symposium on ALS and NeuroRepair, organized by the Foundation and Hande Gedikler, PhD, featured prominent ALS researchers and clinicians from our Les Turner ALS Center at Northwestern Medicine and other institutions sharing their discoveries and insights with other researchers, patients and families.
In 2019, our Les Turner ALS Foundation family grew by leaps and bounds, helping us raise more money, support more people living with ALS, provide more services and educate more people about how to understand, treat and cope with ALS. Each one of you is a unique, irreplaceable member of our family, supporting and inspiring us every step of the way as we come closer to a world free of ALS.

**Our Les Turner ALS Family**

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Event Attendees</td>
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<tr>
<td>Donors</td>
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<td>Social Media Followers</td>
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<td>Volunteers</td>
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<tr>
<td>People Living with ALS</td>
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<tr>
<td>Staff Members</td>
<td>16</td>
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<tr>
<td>Board of Directors Members</td>
<td>21</td>
</tr>
<tr>
<td>Les Turner ALS Center at Northwestern Medicine Staff Members</td>
<td>75</td>
</tr>
</tbody>
</table>

**INDIVIDUALIZED CARE**

We provide a personalized approach to treatment and care. The coordinated care between our Support Services team and clinicians allows us to collectively treat every aspect of the disease and support people living with ALS every step of the way.

**In 2019 we provided**

- 1,785 visits from our ALS Support Services Coordinators to the homes of people living with ALS in between Clinic appointments, providing expert guidance, comfort and a continuum of care
- 506 people living with ALS and their families with comfort through our support groups facilitated by the experts on our Support Services team throughout Chicagoland
- 2,174 attendees with ALS community education through our research symposium, professional in-services, ALS provider medical conference and other programs
- $96,989 grant dollars to people living with ALS and their families through our four grant programs: Walter Broughton Foundation Support Services Grant, Dan Nelson ALS Respite Grant Program, Stuart Rosen ALS Transportation Program and the Assistive Communication Program

Support Services team member Ilana Mindel, RN, retired after nearly 25 years of working for the Foundation. Ilana led over 1,000 support groups for the Foundation in her years of service and helped hundreds of families fighting the disease. In her honor, the Ilana Mindel Support Group Fund was established to ensure people living with ALS can continue to receive the support they need.
It started with Mom’s sudden slurred speech. After seeing multiple specialists, a diagnosis of ALS was made in January of 2019. Within a month we had packed up the family home in St. Louis and moved Mom and her two dogs to our home in Glen Ellyn.

“We were shocked and devastated to hear the letters ALS. We felt lost and alone. But then we discovered the Les Turner ALS Center at Northwestern Medicine and we found reasons for hope and much needed answers. Words cannot express how much the Les Turner ALS Foundation means to my family.”

Recently, Mom’s walking really started to deteriorate. She had a couple of scary falls. Our nurse, Julie from the Les Turner ALS Foundation, set us up with a wheelchair specialist. My mom was hesitant about ordering the chair, but Julie pointed out it would give her some of her independence back, and this helped put things into perspective for Mom.

We truly don’t know where we would be without the guidance of our Les Turner family. They have been there for us each step of the way, helping us navigate through difficult decisions and appropriate medical equipment. We are truly so grateful to our Les Turner family!

— TERRI GAVRONSKI AND HER MOTHER, ELOISE NILGES
A Vibrant Legacy Lives On

Vibha Dave was a leader in Chicagoland’s expansive Indian community, ran her own real estate agency and was a 2018 Women’s Empowerment Power Business Award recipient for Best Real Estate Professional.

After her diagnosis with ALS, Vibha, her husband, Prafull, and her family turned to the Les Turner ALS Foundation.

When Vibha passed away earlier this year, her family and friends created a fundraiser in her honor to further support our Chicagoland ALS community.

“Things would have been so much harder had it not been for the support and infrastructure the Les Turner ALS Foundation provides”
— AALOK, SON OF VIBHA

Over $50,000 was raised by Vibha’s family and friends to help us create a world free of ALS in Vibha’s memory. The funds raised by family’s like Vibha’s ensure the Les Turner ALS Foundation can continue to support people living with ALS today and in the future.
Financial Highlights

In 2019, the Les Turner ALS Foundation invested 89% of its expenditures, or nearly $3.4 million, in ALS support services, research, clinical care and education. Core mission support includes critical functions such as strategic planning, infrastructure and development efforts to ensure that our programs continue to grow and are sustainable for the future. The growth and effectiveness of our work depend on a solid core at the center of our organization. Investing in our infrastructure ensures efficiency and ensures the Foundation is available to serve the ALS community for years to come.

We are committed to operating at the highest level of financial integrity and caring for the ALS community in Chicagoland in the most effective and compassionate way possible.

The foregoing condensed financial statements have been derived from the audited financial statements, which are available for public inspection on the Foundation website, lesturnerals.org, or at the offices of the Les Turner ALS Foundation.
Leadership and Staff

**BOARD OF DIRECTORS**

- Ken Hoffman*  
  *Board Chair

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  *Vice Chair

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  *Chair

- Deborah Cooker

- Randi Forn*  
  *Vice Chair

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- Gentry J. Doffen

- Jarron Jones  
  *Secretary

- Daniel Bati

- Doreen Hope

- Jenna Jones  
  *Treasurer

- Diana Ponzo

- Mary Lou Pitre

- Joshua P. Newcombe

- Eric Bannister Cole

- Philip Schwartz

- Sriwath Soi

- Melissa Wilder

*Executive Committee

**FOUNDATION STAFF**

- Andrea Pauls Backman, MBA  
  *Chief Executive Officer

- Laura Embrey, MA  
  Support Services Coordinator

- Dania Caza  
  Events Manager

- Mark Gallagher, MA, LPC  
  *National ALS Registry Coordinator

- Karen Gacek  
  Office and Development Assistant

- Maria Katzoff  
  Communications and Marketing Manager

- Deb Marone  
  Office and Human Resources Manager

- Jena Warrick, MS  
  Events Manager

- Steve Schapiro, MS  
  Director of Development

- Karen Streiff, RN, CHIPN, CCM  
  Support Services Coordinator

- Karen Stephenson, LCSM  
  Support Services Coordinator

- Julie Stawell, RN, CHFN  
  Support Services Coordinator

- Lauren Webb, LCSM  
  Director of Support Services and Education

**Support Group Facilitators**

- Elsa Cherneck  
  PT

- Anne Linky, PhD

- Inara Mindel, RN

**Independent Auditors**

- WIPFLI  
  Hoboken, NJ

**Affiliations**

- Michigan Medicine
  - Detroit ALS Center

- UnitedCerebral Palsy

- Caregiver Connect

- ALS Association

- Community Options

- Senior Services of Southeastern PA

- The ALS Association Central PA Chapter

- Eternity Care Services

- Galloway Design

- Image in Color

- CoreCo

- Avalon Creative

- Mid America Commercial Group

- Whole Foods Market

- Marquise Catering

- The John P. Stoeckel Group

- The John P. Stoeckel Group
Our Generous Supporters

The Lest TurnerALS.org Foundation is grateful for every donation, regardless of the amount. The following list of donors represents gifts of $1,000 and above. Unfortunately, we are unable to recognize all donors.

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Ms. Martha Campbell Mr. and Mrs. Miguel F. Caceres Mrs. Janet Byrnes Mr. Douglas Burton Mr. Keith W. Bruch Mr. and Mrs. Matthew S. Brown Mr. Franklin Brehmer Boyle Family Foundation Mr. and Mrs. Richard Beuke Mr. Steve Berliant Ms. Jennifer Awe Mr. and Mrs. Brian Andre

ADVOCATES $1,000 - $4,999

Mr. and Mrs. Kenneth A. Hoffman Mr. and Mrs. Jonathan Harris Gofen and Glossberg, L.L.C. Mr. and Mrs. Mark Eisenberg Ms. Laverne Dillon

SUPPORTERS $500 - $999

Mr. and Mrs. Ramiro Donnell The Dolins Group, Ltd. Mr. Oscar Diaz Mrs. Katherine Felton Extended Home Living Services Mr. and Mrs. David A. Hoffman Mr. and Mrs. Jonathan Harris Mrs. Dorothy Hardy Hanig’s Footwear Inc.

ADVOCATES $1,000 - $4,999

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CONTACT US TO MAKE A CASH OR STOCK DONATION

Steve Shapiro Director of Development 687.673.3311 steveshapiro@broadstreet.com

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Dell Foundation
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Baxter
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Campaign

GIVE WITH LOVE
COVID-19: Our Response

Since early March, our country has been effectively locked down in response to the COVID-19 pandemic. This has created challenges for all of us. How do we work from home with a spouse and our children present? How do we safely get groceries and medicine? How do we make sure our elderly relatives are okay? How do we keep our families living with ALS healthy and safe?

These are strange and scary times. Surreal, even.

Living with ALS feels much the same way to many people. In these difficult times, we look to our families who are living with ALS to show us what the resiliency needed to get through this crisis looks like. And we have taken swift and assured action to make sure people living with ALS in our community receive the important support we’ve always provided. We’ve also made the following changes to accommodate the pandemic.

**TELEHEALTH**

Being a phone call away never rang truer. We are continuing to coordinate care between in-home visits and patient visits to the Les Turner ALS Center at Northwestern Medicine while our Clinic and Support Services teams conduct telehealth visits.

All of our support services are fully available, despite the pandemic. As always, one of our Support Services Coordinators is never more than a phone call away.

**COVID-19 EMERGENCY RELIEF FUND**

We are helping people living with ALS with basic needs through the pandemic. As of May 1, 2020, we have awarded 20 grants to people living with ALS and their families to help fund essential needs like groceries, face masks, cleaning supplies and access to technology.

**UPCOMING EVENTS**

- **Strike Out ALS 5k and 1 Mile Run, Walk & Roll**
  - Thursday, July 16, 2020
  - More details to come

- **ALS Walk for Life**
  - Saturday, September 26, 2020
  - More details to come

Thank you for being an essential part of the Les Turner ALS Family. We can’t create a world free of ALS without you!
Thank you for joining us to create a world free of ALS.