

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.

### Courage

People living with ALS guide us in how to live with courage every day.

### 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.

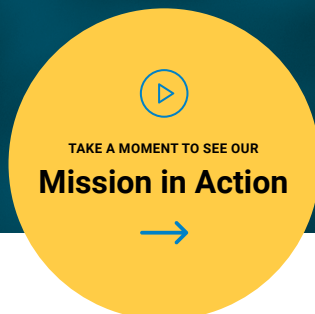
### Individuality

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







Evangelos Kiskinis  
Left

“

*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



## ALS Research and Clinical Care

**M Northwestern Medicine**  
Feinberg School of Medicine

Les Turner ALS Center

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.

**\$5.13M**

*Amount we have raised to date toward our endowment goal*

**\$1.02M**

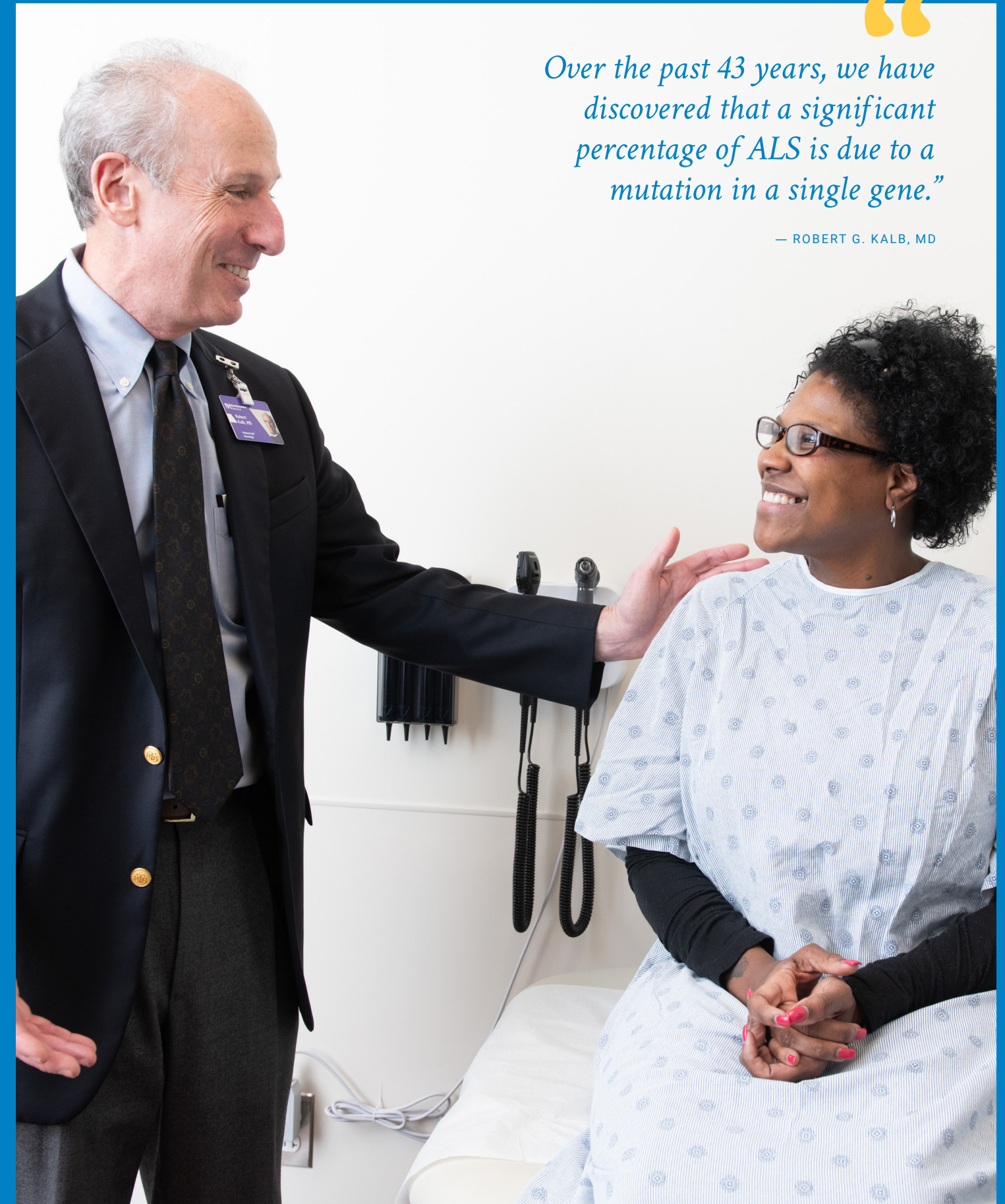
*Amount we funded to the Center for current research and clinical care in 2019*

### 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.



<u>Grant Title</u>	<u>Primary Investigator</u>
Translating Research and Implementation for ALS (TRIALS)	Senda Ajroud-Driss, MD
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 GTPases and genetic forms of ALS	Robert G. Kalb, MD
Mechanistic Insight into Proteasome impairments evoked by DPR's	Robert G. Kalb, MD



“  
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



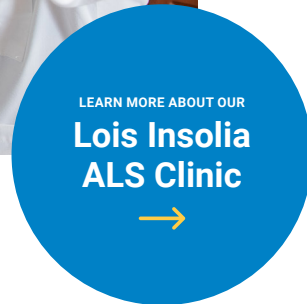
## Clinic and Clinical Trials

### 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.



Senda Ajroud-Driss, MD, Right



### 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 nurse resource coordinator



one research coordinator

#### Total Clinic Team Now Includes



six neurologists



two pulmonologists



two advance practice nurses



one nurse resource coordinator



one genetic counselor



nurses



dietitians



medical assistants



respiratory therapists



occupational therapists



speech-language pathologists





## CLINICAL TRIALS AT THE LOIS INSOLIA ALS CLINIC



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 Ozdinler, 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.*



## Our Les Turner ALS Family

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.



10,026

Event Attendees



10,710

Donors



8,317

Social Media Followers



505

Volunteers



324

People Living with ALS



16

Staff Members



21

Board of Directors Members



75

Les Turner ALS Center at Northwestern Medicine Staff Members

## 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

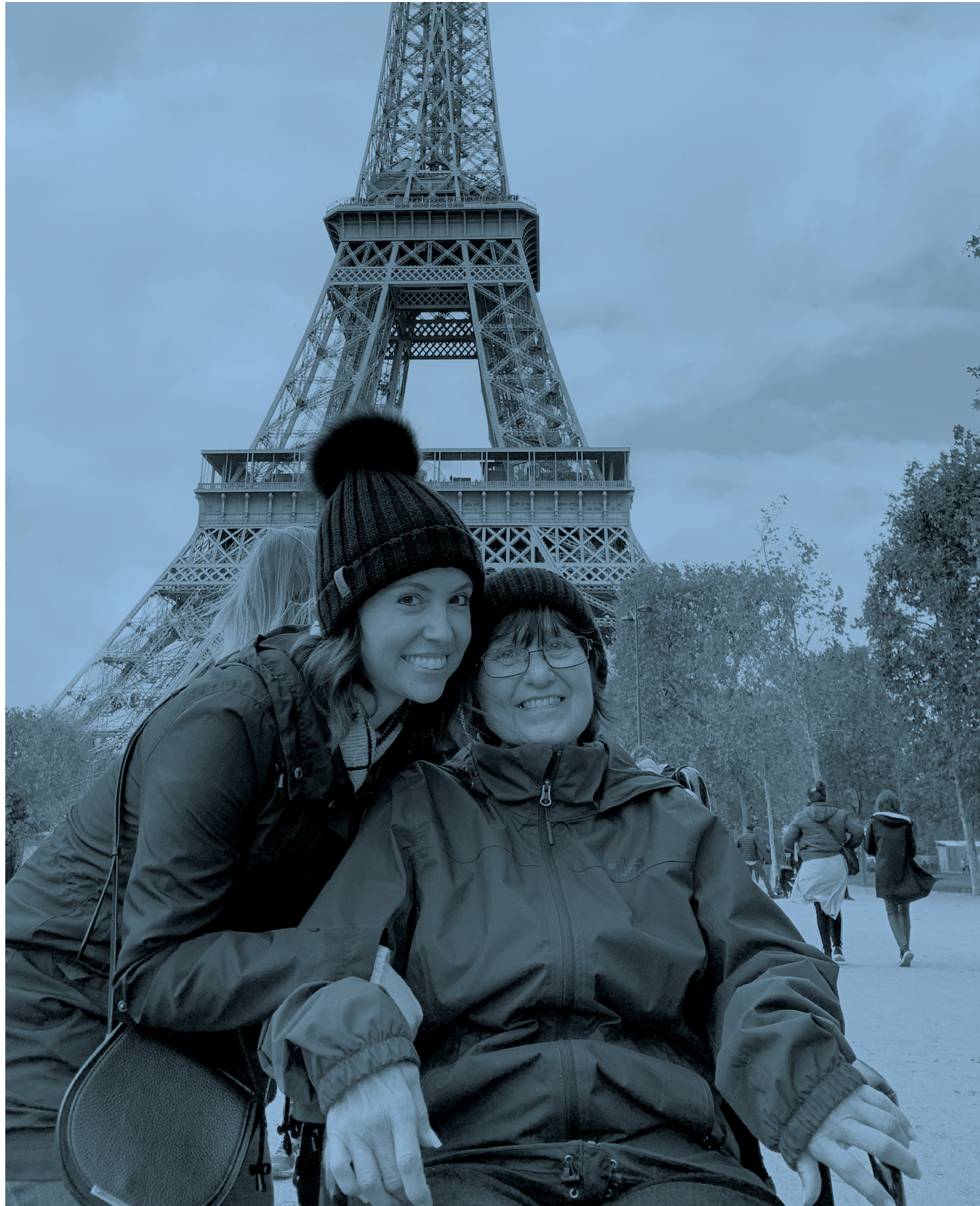
\$96,989

grant dollars to people living with ALS and their families through our four grant programs: Walter Boughton Foundation Support Services Grant, Dan Nelson ALS Respite Grant Program, Stuart Rosen ALS Transportation Program and the Assistive Communication Program



Support Services team member **Ileana Mindel, RN**, retired after nearly 25 years of working for the Foundation. Ileana 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 **Ileana Mindel Support Group Fund** was established to ensure people living with ALS can continue to receive the support they need.





## Searching for Guidance and Finding a Family

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.



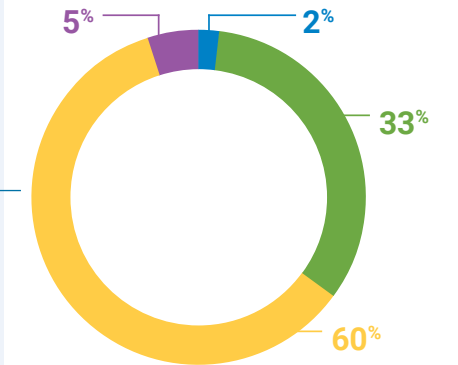


## Financial Highlights

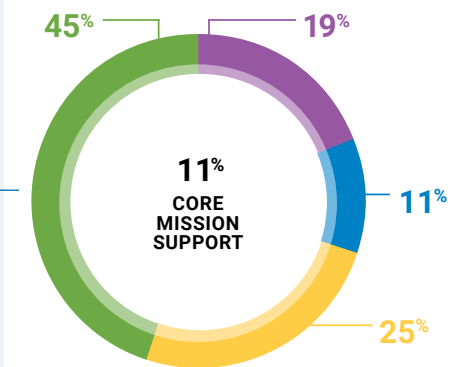
In 2019, the Les Turner ALS Foundation invested 89% of its expenditures, or nearly \$3.4 million, in ALS support services, research, clinical care and education. Core mission support includes critical functions such as strategic planning, infrastructure and development efforts to ensure that our programs 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.

REVENUE	2019	2018
Fundraising Events (net)	\$1,219,833	\$1,099,281
Individuals, Corporations, Foundations	2,213,162	1,792,287
Grants and Contracts	178,166	189,501
Investments	61,872	33,383
<b>Total Revenue</b>	<b>\$3,673,033</b>	<b>\$3,114,452</b>



EXPENSES*	2019	2018
<b>Core Mission Support</b>		
Management	\$188,825	\$203,770
Development	\$236,258	\$216,051
<b>Total Core Mission Support</b>	<b>\$425,083</b>	<b>\$419,821</b>
<b>Direct Program Expenses</b>		
Research/Endowment	\$ 650,696	\$800,000
Lois Insolia ALS Clinic	370,000	270,000
Support Services	831,600	780,988
Education	1,518,987	327,673
<b>Total Direct Program Expenses</b>	<b>\$3,371,283</b>	<b>\$2,178,661</b>
<b>Total Expenses</b>	<b>\$3,796,366</b>	<b>\$2,598,482</b>
Change in Net Assets	\$(123,333)	\$515,970
Net Assets - Beginning of Year	\$1,750,484	\$1,234,514
Net Assets - End of Year	\$1,627,151	\$1,750,484



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](http://lesturnerals.org), or at the offices of the Les Turner ALS Foundation.



## Leadership and Staff

### BOARD OF DIRECTORS



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**Sarvesh Soi**



**Melissa Wilder**

\*Executive Committee

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Support Services Coordinator

**Lauren Webb, LCSW**  
Director of Support Services  
and Education

### Support Group Facilitators

**Elsa Cherwak, PT**

**Anne Lidsky, PhD**

**Ileane Mindel, RN**

### Independent Auditors

**WIPFLI**  
Palatine, Illinois

### Affiliations

**Northwestern Medicine**  
Feinberg School of Medicine  
Les Turner ALS Center

**COMMUNITY**  
HEALTH CHARITIES  
OmniCare Health

**INTERNATIONAL ALLIANCE**  
OF ALS/MND ASSOCIATIONS



Information is current as of the printing of this report.

**Steve Schapiro**  
**Hallie Kobylski**  
Editorial

**Brit Allen Design**  
Design



## 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. Unfortunately, we are unable to recognize all donors in this report.

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\$100,000 AND ABOVE

Foglia Family Foundation  
Mr. and Mrs. Robert P. Ives  
Paul & Joan Rubschlager Foundation  
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Director of Development

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sschapiro@lesturnerals.org

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Mr. and Mrs. Mark Saas  
Mr. and Mrs. Christopher Samaras  
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Mr. Kevin Sanders  
Mr. Paul Santacaterina  
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### MATCHING/WORKPLACE GIVING

Abbott Laboratories Employee Giving Campaign  
AbbVie Inc.  
Accenture LLP  
Adobe  
ADP  
Aetna Foundation, Inc.  
AIG Matching Grants Program  
Allianz  
Allstate - Employee Giving  
The Amgen Foundation  
AON Foundation  
Apple Matching Gifts Program  
ArcelorMittal  
Argo Group, Inc.  
The Arthur J. Gallagher Foundation  
AT&T Employee Giving Campaign  
The Bank of America Charitable Foundation  
Barilla America, Inc.  
Bauer Built Inc.  
Baxalta Community Giving Programs  
Baxter Employee Giving Campaign  
The Baxter International Foundation  
Best Buy  
BKD Foundation  
BlackRock Matching Gift Program  
BNSF Railway Foundation  
The Boeing Company  
BP Foundation, Inc.  
Bright Funds  
CAF America - Charities Aid Foundation of America  
Cardinal Health Foundation  
The CarMax Foundation  
CDK Global  
Chevron  
Chicago Title Insurance Company  
Chicago Tribune Foundation  
Employee Matching Gifts  
The Children's Place  
Circle of Service Foundation  
The Clorox Company Foundation  
Community Health Charities  
Crum & Forster Insurance  
CSG Systems, Inc.  
Dell Employee Matching Gifts  
Deutsche Bank Americas Foundation  
Discover Financial Services  
Exelon Corporation  
Fidelity Charitable  
Follett  
Frontstream  
Gap, Inc.  
Gartner  
GE Foundation  
Genentech Employee Giving Program  
gettyimages  
Give with Liberty  
Goldman Sachs & Co. Matching Gift Program  
Google  
Grainger Matching Charitable Gifts Program  
Guggenheim Capital, LLC  
Henry Crown and Company  
Home Depot  
Honeywell International Charity Matching

Illinois Tool Works Foundation  
Industrial Developments International, LLC  
James Hardie Building Products, Inc.  
JCPenney - Employee Giving  
The John D. and Catherine T. MacArthur Foundation  
John Hancock Financial Services, Inc.  
Keller Foundation  
KeyBank Foundation  
Kirkland & Ellis Foundation  
KPMG Gives  
LinkedIn  
Loomis, Sayles & Company, L.P.  
Los Alamos National Security, LLC  
Macquarie Capital Funds, Inc.  
Macy's/Bloomingtondale's Foundation  
Marcum Foundation, Inc.  
Markel Corporation  
McDonald's Corporation  
Medtronics Foundation  
Meeting Tomorrow, Inc.  
Merchant Services  
The Merck Foundation  
Microsoft Corporation  
Mondelez International Foundation  
Monsanto Fund  
Morgan Stanley Global Impact Funding Trust, Inc.  
Motorola Solutions Foundation  
Network for Good  
New York Life  
Oracle Corporation Matching Gifts Program  
Pacific Gas and Electric Company  
Pepsico Foundation  
Pfizer Foundation Matching Gifts Program  
Prudential Financial Inc  
RSC Foundation, Inc.  
S&P Global  
Salesforce Foundation  
SAP Software Solutions  
Silicon Valley Community Foundation - Dell  
Silicon Valley Community Foundation - Pepsico  
Solix Inc.  
State Farm Companies Foundation  
Takeda Matching Gift Program  
Tennant Foundation  
Thrivent Financial  
TransUnion  
Travelers  
Truist  
Uline, Inc.  
Union Tank Car Company (UTLX)  
United Way  
United Way of Greater Philadelphia and Southern New Jersey  
United Way of Metropolitan Chicago  
United Way of The Greater Triangle  
USG Foundation  
Valdes Engineering Company  
Verizon Foundation  
Viacom  
Visa U.S.A. Inc.  
Visual Marketing, Inc  
The Walt Disney Company Foundation  
Wells Fargo  
William Blair and Company  
Wintrust Financial Corp.  
Wolters Kluwer

### GIFTS IN KIND

101.9FM THE MIX WTMX/Chicago  
670 The Score  
ABC7 Chicago  
The Actors Gymnasium  
American Blues Theater  
American Writers Museum  
Barb Haines  
Bea Ferreira  
Beggars Pizza  
Boka Restaurant Group  
Bunches  
Cabot  
Carlucci Rosemont  
Chicago Shakespeare Theater  
Chicago Wolves

Chicago Zoological Society/Brookfield Zoo  
Clara Williams Company  
The Clayton  
Comcast  
The Comedy Shrine  
Court Theatre  
Dana Hotel and Spa  
Dawn Sanderson  
Destination Fitness in Home Training, LLC  
Donna Pontiatowski  
Drury Lane Theatre  
East Bank Club  
Entertainment Cruises  
Executive Service Corps of Chicago  
Fogo de Chao  
Freeborn & Peters LLP  
Frick Services, Inc.  
Gene Siskel Film Center  
The Godfrey Hotel Chicago  
Graziano's Brick Oven Pizza  
Hotel Goodwin  
House of Blues  
Howl at the Moon  
Illinois Sports Facilities Authority  
iO Theatre  
Iron Works Hotel  
Joffrey Ballet  
Johnny's Kitchen & Tap  
Jonathan Lewis  
Jonathan Lewis  
Ken Hoffman  
Lettuce Entertain You Enterprises, Inc.  
Lisa Hanley  
London House Chicago  
Loyola University Chicago - Intercollegiate Athletics Dept  
M&B Delivery  
Margie Gipson  
Maxine, Ltd.  
Melinda Evans-Williams  
Michael & Michael Salon  
Mireille's Studio  
The Morton Arboretum  
Nancy Shoemaker  
Northlight Theatre  
Northwestern University Athletics  
Norton's  
Oceanique Restaurant  
On Stage Salon & Spa  
Organization Name  
Pam Lynch  
Panera, LLC  
Porchlight Music Theatre  
Ravinia Festival  
Relax the Back  
Robert Campbell Fine Portraiture  
Rockford IceHogs Hockey Team  
Rosebud Restaurants  
Sean Fallon  
The Second City  
Shedd Aquarium  
SixtyFour - A Wine Bar  
Sky High Sports  
Skydeck Chicago  
Sparkling Ice  
Terry O'Brien  
Thomas Boleky  
William Dwyer  
Tracy Jalsoszynski  
Univision  
Urban Oasis  
Viaggio Restaurant Chicago  
Wendy Shea  
Whirly Ball  
White Eagle Golf Club  
Wines for Humanity  
Zanies Comedy Club

Every effort has been made to include all donors of \$1,000 or more. We apologize for any errors or omissions. Please contact us so we may correctly acknowledge your support in the future.

Thank you!



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

## 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 ok?

**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

[Visit our COVID-19 Resources page on our website to learn more about how we're supporting people living with ALS through this crisis.](#)

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  
[Register Now](#) →



**ALS Walk for Life**

Saturday, September 26, 2020  
[More details to come](#)



The best way to stay up to date on all of the exciting things happening at the Les Turner ALS Foundation is to follow us on social media and [sign up for our e-newsletter](#).

f t i @LESTURNERALS

To learn more visit  
[LESTURNER.ORG](http://LESTURNER.ORG)

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**Thank you** for joining  
us to create a world  
free of ALS.