



# LES TURNER ALS FOUNDATION

TM



A YEAR OF  
*RESILIENCY*  
& *CHANGE*

2020 Annual Report

# LETTER FROM THE BOARD CHAIR & CEO

Dear friends,

It would be an understatement to say that 2020 was a year full of challenges and change. While our daily lives were upended by the COVID-19 pandemic, the Les Turner ALS Foundation's commitment to providing the best quality of care and support to those affected by ALS during these uncertain times never wavered. Spurred by the resiliency of people living with ALS, the pandemic pushed us to be nimble and resourceful and shift how we provide essential information and offer vital services.

*As an organization, the pandemic made us stronger and more forward-thinking.*

You are receiving this report because you have supported the Foundation as we faced these challenges together. Through your generous donations, sponsorships, volunteerism and overall involvement, you have helped change the life of someone living with ALS today or someone who will be diagnosed tomorrow.

2020 started off with a record-breaking in-person Hope Through Caring Gala on February 22 at Chicago's Radisson Blu Aqua with over 560 people. Who could have predicted that it would be our last in-person event of 2020? In March, we shifted to all virtual programming for the remainder of the year. Support Group meetings were moved to Zoom, and we implemented a robust telehealth platform for

ALS Support Services Coordinator visits and clinic appointments at our Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine.

Thanks to our loyal donors, overall donations and fundraising events remained strong throughout 2020, including our Strikeout ALS 5K and 1 Mile Run, Walk and Roll and the ALS Walk for Life, and end of year giving broke recent records.

Our ALS research program at the Les Turner ALS Center at Northwestern Medicine did not miss a beat, with six groundbreaking basic science and clinical research projects fully funded in 2020. In addition, there has been tremendous headway in new ALS treatments and clinical trials, including rapid enrollment of patients in the breakthrough HEALEY ALS Platform Trial.

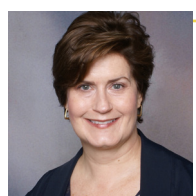
As we write this, there is much hope that the impact of vaccinations will help us return to a more normal way of life. Our primary concern, as always, is the health and safety of our extended Les Turner ALS family, of which you are an essential part. In 2021, we expect that our major fundraising events and services will be delivered in a hybrid model for the future, with a mix of in-person and virtual components to ensure the safety of all involved.

Because of you, we are a leader in comprehensive ALS care, allowing thousands of people affected by ALS to count on us. Thank you!

Together toward a cure,



*Ken Hoffman*  
Board Chair



*Andrea Pauls Backman*  
Chief Executive Officer

2020

# ACCOMPLISHMENTS

## 2020 Highlights



**\$1.5M**

funded to our Les Turner ALS Center at Northwestern Medicine, which continues to be at the forefront of ALS research and clinical care at the national and international levels.



**40%**

percent increase of our one-on-one personalized visits with people and families living with ALS in 2020 over 2019, using a virtual platform.



**981**

patient appointments in 2020. Thanks to telemedicine, people with ALS were able to have easier access to their doctors and providers at our Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine.



**120**

need-based grants were awarded to people living with ALS for equipment, respite care, assistive technology, clinic transportation and COVID-19 emergency aid.



**2,213**

visitors to our dedicated COVID-19 webpage, which provided those impacted by ALS with the latest news, information and resources.



**2,000**

people benefited from the Foundation's community education programs.

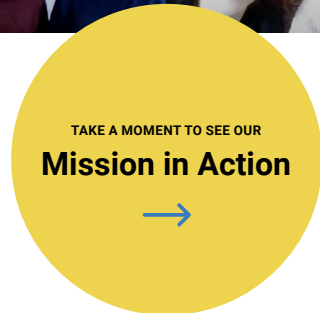


# LIVING OUR VALUES

*The Les Turner ALS Foundation is a Leader in Comprehensive ALS Care*

## OUR MISSION

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.



## WHAT WE DO

### Individualized Care

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 into the future.

### Local Community Support

Over the last 44 years, we've built a local community that feels like family, empowering and encouraging individuals living with ALS and their loved ones to connect with others and develop a network of support, information and resources.

### Hope through Scientific Research

Our Les Turner ALS Center at Northwestern Medicine effectively unites the worlds of research and patient support to ensure the best care is provided and the brightest minds are working to find a cure.

# OUR VALUES

COLLABORATION



COURAGE



EXPERTISE



INDIVIDUALITY



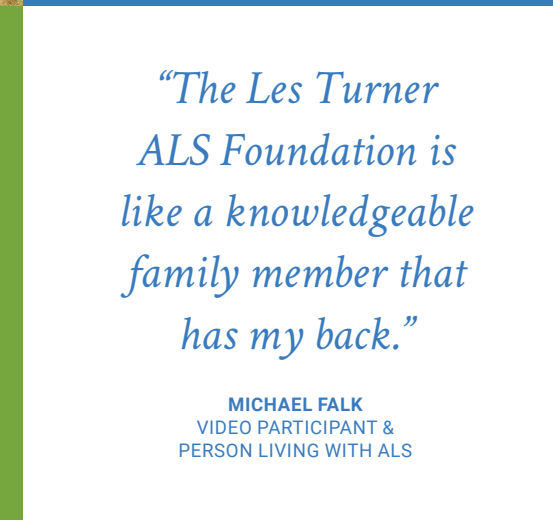
KINDNESS



*“The Les Turner ALS Foundation is like a knowledgeable family member that has my back.”*

MICHAEL FALK  
VIDEO PARTICIPANT &  
PERSON LIVING WITH ALS

TENACITY



# YOUR IMPACT

THANKS TO YOUR GENEROSITY, OUR SIGNATURE FUNDRAISING EVENTS WENT OFF WITHOUT A HITCH IN 2020 DESPITE THE CHALLENGING ECONOMIC CLIMATE. TOGETHER, WE LEARNED THAT WHETHER WE CONGREGATE IN PERSON AT A LARGE HOTEL BALLROOM, AT A LOCAL PARK FOR A SMALL COMMUNITY GATHERING OF FRIENDS AND FAMILY, OR FROM THE CONFINES OF HOME ON OUR COMPUTERS AND PHONES, **CREATING A WORLD FREE OF ALS COLLECTIVELY REMAINS OUR DRIVING FORCE.**

## FUNDRAISING EVENTS

### HOPE THROUGH CARING GALA 2021

In what would be our last in-person fundraiser of the year on February 22, 2020, the Hope Through Caring Gala **raised a record-breaking \$940,000.**

### STRIKE OUT 5k ALS

In July, the first-ever virtual Strike Out ALS 5k & 1 Mile Run, Walk and Roll **raised nearly \$60,000.**

### ALS WALK FOR LIFE

Our virtual ALS Walk for Life in September **raised over \$560,000** and allowed our supporters to form teams and walk safely and conveniently in their own community. By going virtual, we were joined by Walk participants from 32 states and three countries.

### YPG FOR ALS

Other virtual events in 2020 included our All in for ALS Casino Night hosted by our Young ProfessionALS Group and our annual Tag Days fundraising drive during ALS Awareness Month.

## NEW

### SPONSORSHIP PROGRAM

In 2020, the Foundation launched a new sponsorship program to **deepen our engagement with industry partners**, focused on building year-round holistic sponsorship support. People and families living with ALS benefit from the awareness of the work of our industry partners, who, in turn, enrich the Foundation's programs and events.

## WHAT OUR SPONSORS ARE SAYING

*"We thoroughly enjoyed being a part of the ALS Walk for Life!*

*It is such a motivating event for us to see ALL the support there is for this population. We at Numotion are very excited for the partnership we have with the Les Turner ALS Foundation and look forward to building upon it."*

*"Cytokinetics is proud to partner with the Les Turner ALS Foundation to help patients and families facing ALS. We are inspired by the strength of the community and the foundation's important role in research, patient care and education. Through our collaboration we believe that we can truly make a difference."*

**YOU ARE THE SPECIAL SAUCE THAT MAKES ALL THE WORK OF THE LES TURNER ALS FOUNDATION POSSIBLE.**

FROM NOVEL ALS SCIENTIFIC RESEARCH AND EXPERT CLINICAL CARE AT OUR LOIS INSOLIA ALS CLINIC AT THE **LES TURNER ALS CENTER AT NORTHWESTERN**

**MEDICINE** TO COORDINATED EXPERTISE FROM OUR ALS SUPPORT SERVICES COORDINATORS, YOU ARE MAKING A TREMENDOUS IMPACT IN THE ALS COMMUNITY.

# PATIENT FOCUS



## A NATIONAL LEADER IN MULTIDISCIPLINARY CARE

Our Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine, one of the first multidisciplinary ALS clinics in the country, continues to be a nationwide leader and is at the forefront of clinical care and ALS research. In addition to the multidisciplinary care that patients

receive at the Clinic, they work with the Foundation's support services team to receive individualized support for themselves and their loved ones.

Studies show that patients living 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, *something we've known since 1986.*

## 2020 DIGITAL MARKETING SNAPSHOT



As stewards of our communications and marketing outreach, your willingness to take action and share the latest information on ALS treatments, fundraising events, advocacy issues and volunteer opportunities with your network of friends, family and colleagues made a huge impact.

### 500,000 Impressions

on our Facebook, Twitter and Instagram pages and an increase of almost 10 percent in social media followers in 2020.

### 10,000 Views

of our ALS Walk for Life Facebook Live event.

### 100,000 Visits

to our website, leturnerals.org.

### 3 Launches

of new online resources: ALS Learning Series webinar program, Foundation blog and a revamped Clinical Trials webpage.

## SUPPORT SERVICES HIGHLIGHTS



Despite the pandemic and shift to telehealth, patient appointments at our Lois Insolia ALS Clinic **increased by 13 percent for new ALS visits** and **5 percent for return ALS visits** in 2020, reflecting the great need in the community.



**Enrollment in the breakthrough HEALEY ALS Platform Trial**, an innovative study designed to accelerate the path to effective treatments for ALS, **commenced at our Lois Insolia ALS Clinic in Fall 2020.**

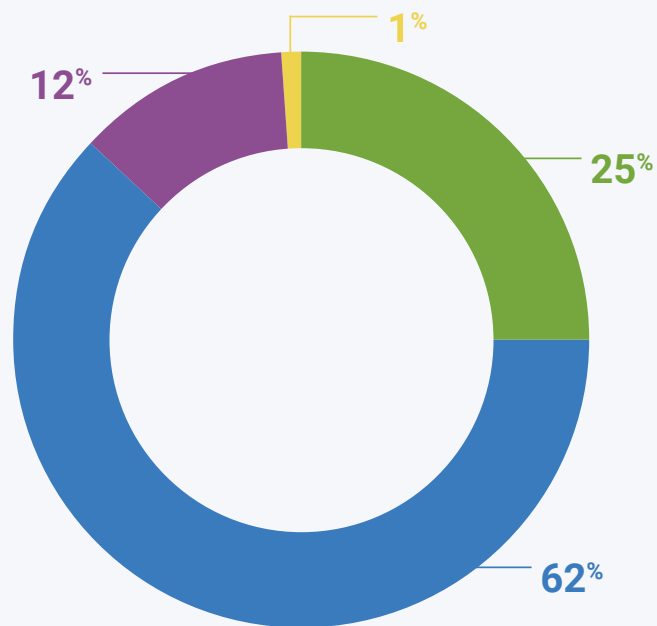


**More than 400 people attended our annual Les Turner Symposium on ALS in November.** The virtual day-long event was highlighted by a keynote address from Sabrina Paganoni, MD, PhD, Assistant Professor of PM&R at Harvard Medical School and co-principal investigator of the HEALEY ALS Platform Trial.



**More than 1,400 people benefited from community education programs**, including our new bereavement support groups and online ALS Learning Series, where we hosted webinars on topics such as ALS clinical trials and genetics and ALS.

# 2020 FINANCIAL IMPACT

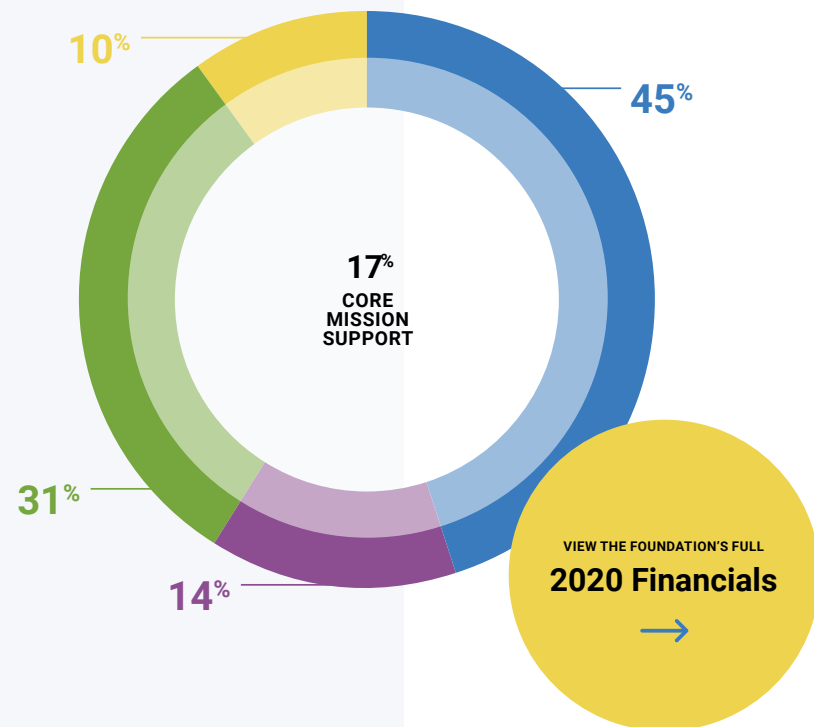


## REVENUE

- Individuals, Corporations, Foundations
- Fundraising Events (net)
- Grants and Contracts
- Investments

## EXPENSES




- Research/Endowment
- Support Services
- Lois Insolia ALS Clinic
- Education



VIEW THE FOUNDATION'S FULL 2020 Financials

# LEADERSHIP & STAFF

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*\*Executive Committee*

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|--|---|
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| <b>Cara Gallagher, MA, LCPC</b><br><i>Support Services Coordinator National ALS Registry Associate</i> | <b>Easton Stevenson, LCSW</b><br><i>Support Services Coordinator</i>          |
| <b>Karen Gianni</b><br><i>Office and Database Assistant</i>  | <b>Julie Stowell, RN, CHPN</b><br><i>Support Services Coordinator</i>         |
| <b>Hallie Kobylski</b><br><i>Communications and Marketing Manager</i>                                  | <b>Cara Tighe</b><br><i>Foundation Intern</i>                                 |
| <b>Deb Marron</b><br><i>Office and Human Resources Manager</i>   | <b>Lauren Webb, LCSW</b><br><i>Director of Support Services and Education</i> |

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- Steve Schapiro**
- Bri Allen Design**

## Support Group Facilitators

- Elsa Cherwak, MPT**
- Anne Lidsky, PhD**
- Ileane Mindel, RN**

## Independent Auditors

- Wipfli**  
*Palatine, Illinois*

## Affiliations

-  **Northwestern Medicine\***  
*Fairberg School of Medicine*
-  **Les Turner ALS Center**
-  **COMMUNITY HEALTH CHARITIES**  
*Give. Connect. Help.™*
-  **INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS**
-  **CHARITY NAVIGATOR**  
*Four Star Charity*
-  **UNITED WAY SEAL OF TRANSPARENCY**  
*2020*

# 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**

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**Steve Schapiro**

*Director of Development*

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May 2021  
ALS Awareness Month

**STRIKE  
OUT 5k  
ALS**

July 2021  
STRIKEOUTALS5K.ORG

**ALS  
WALK  
FOR LIFE**

September 18, 2021  
Soldier Field  
ALSWALKFORLIFE.ORG

## LOOKING FORWARD

There is no sugarcoating it, 2020 was a rough year. But 2021 brings a bright light of hope that better days are ahead. With May being ALS Awareness Month, we have a full plate of fun, informational and engaging programs planned throughout the month. Don't miss our Strike Out ALS 5K and 1 Mile Run, Walk & Roll in July, and our ALS Walk for Life in September.

*Thank you again for your continued support of the Foundation as we continue to make great strides together toward a world free of ALS.*



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](#).

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