

**LES  
TURNER  
ALS  
FOUNDATION**



**2018  
ANNUAL  
REPORT**

# LETTER FROM BOARD CHAIR & CEO

Dear friends,

If you are receiving this annual report, you helped change the life of someone impacted by ALS. Thank you hardly seems like enough for what you did in 2018. Let's take a look at your impact:

## YOU PROVIDED HOPE THROUGH SCIENTIFIC RESEARCH

You helped fund nearly \$1.1 million to our Les Turner ALS Center at Northwestern Medicine. Our Center is the only one in Chicagoland, and one of a few in the country, to effectively join transformative ALS research with unparalleled clinical care. By integrating the work done in our four ALS-dedicated laboratories to uncover the causes of ALS, discover effective therapies and find potential drug targets with the multidisciplinary clinical care, research studies and clinical trials happening in our Lois Insolia ALS Clinic, we are paving the way towards a cure.

## YOU PROVIDED A LOCAL COMMUNITY OF SUPPORT

You empowered our Les Turner ALS family; a community of people that includes those living with ALS, those caring for people with ALS and those who love or have loved someone with ALS. Last year, we nurtured that family through support groups, local and national professional in-services, our ALS News You Can Use Educational Meeting and the Les Turner Symposium on ALS and NeuroRepair at Northwestern Medicine. We're a resource for best practices, referrals, equipment – anything and everything people affected by ALS may need. Our wealth of knowledge is unmatched, and we are always one phone call away.

## YOU PROVIDED INDIVIDUALIZED CARE FOR PEOPLE AND FAMILIES AFFECTED BY ALS

You facilitated nearly 1,700 personal visits to people living with ALS in the comfort of their homes, ensuring, from day one, no one goes through this journey alone. We know from our own families' experiences with ALS, no two cases of ALS are the same. That's why we care for each person living with ALS – one person at a time. We answer their questions, provide encouragement and give them the confidence needed to live with this terrible disease.

All of this is possible because of you. Thank you for being a part of our Les Turner ALS family. While we have made great strides, we haven't yet solved the full mystery of ALS. But because of your continued support, we won't give up until we turn our shared vision of a world free of ALS into a reality.

Together towards a cure,



**Ken Hoffman**  
Board Chair



**Andrea Pauls Backman**  
Chief Executive Officer

# MISSION & VALUES

What do  
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.**

How do  
we do  
it?

## HOPE THROUGH SCIENTIFIC RESEARCH

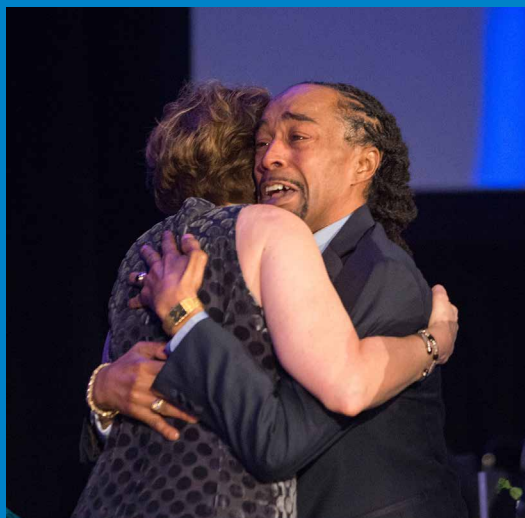
Our Les Turner ALS Center at Northwestern Medicine effectively connects the worlds of research and patient support to ensure the best care is provided and the brightest minds are working to find a cure.

## A LOCAL COMMUNITY OF SUPPORT

Over the last forty plus 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.



# YOUR IMPACT

## Hope Through Scientific Research

In 2018, we awarded nearly **\$1.1 million in grant dollars** to the Les Turner ALS Center at Northwestern Medicine, including a grant to fund much-needed multidisciplinary clinical care at the Lois Insolia ALS Clinic.

From this gift, the Center awarded **six unique research grants** in the areas of drug development, genetics, cellular mechanisms and novel ALS models. We're committed to creating a world free of ALS. By understanding how ALS operates, scientists can develop more effective treatments while working toward the discovery of a cure.

**M Northwestern Medicine**  
Feinberg School of Medicine

Les Turner ALS Center



## 2018 Research Grant Summary

### GRANT TITLE

### PRIMARY INVESTIGATOR & COLLABORATOR(S)

Answer ALS

Senda Ajroud-Driss, MD; Answer ALS;  
Northeast ALS Consortium (NEALS)

Characterizing the Role of DNA Methylation  
Dynamics in ALS Pathophysiology

Evangelos Kiskinis, PhD

Discovering Novel Genetic Causes of  
Sporadic ALS

Teepu Siddique, MD

Drug Discovery using Upper Motor Neuron  
Survival as Readout

Hande Ozdinler, PhD;  
Richard Silverman, PhD

Investigating How Mislocalized Proteins  
Contribute Towards Neurotoxicity in C90RF72-  
Based Models of ALS/FTD

Evangelos Kiskinis, PhD

Novel Drugs for ALS/FTD

Teepu Siddique, MD

*"These awards will allow us to expand our efforts to decipher the pathological mechanisms that give rise to this devastating disease. The Les Turner ALS Center at Northwestern Medicine provides us with an unparalleled community of researchers and clinicians with the common goal of defeating ALS."*

– Evangelos Kiskinis, PhD  
Assistant Professor in Neurology and  
Physiology, Northwestern Medicine  
Feinberg School of Medicine



In 2018, you helped us raise over **\$3.1 million** for research, comprehensive ALS care and core mission support.  
**THANK YOU!**



## A Local Community of Support

In 2018, our Les Turner ALS 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 the work we do. Each one of you is a unique, irreplaceable member of our family, supporting and inspiring us every step of the way as we make our way closer to a world free of ALS.



**9,025**  
Event Attendees



**8,584**  
Donors



**7,470**  
Social Media Followers



**1,115**  
Education Participants



**577**  
Volunteers



**233**  
People Living with ALS



**17**  
Staff Members



**19**  
Board of Director Members



**31**  
Clinicians



**42**  
Researchers

## Individualized Care

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

### IN 2018 WE PROVIDED:



**1,670**  
visits from our nurses & social workers to the homes of people living with ALS



**908**  
appointments at our Lois Insolia ALS Clinic to people living with ALS



**525**  
Support Group Participants received vital help through five monthly groups

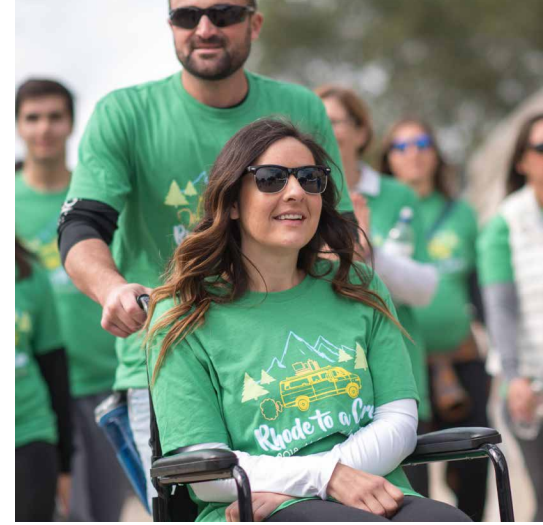


**\$103K**  
in grant dollars to 80 families living with ALS to help ease the cost of basic necessities



# OUR VALUES

Our values are the essence of who we are and what we believe in. Guided by these values, we are growing our programs, expanding our reach and working hand-in-hand with other groups in the ALS community to move us closer to our vision of seeing a world free of ALS.



## We Value Collaboration



### ANSWER ALS

We are determined to create a world free of ALS, but we can't do it alone. In 2018 our Les Turner ALS Center at Northwestern Medicine began sample collection and enrollment in the largest coordinated collaborative ALS research effort in history. Comprised of nearly two dozen research entities at leading institutions across the country, 1,000 patients and 8 clinic sites, Answer ALS' mission is to build a database of the most comprehensive clinical, genetic, molecular and biochemical assessment of ALS. As these huge amounts of data are collected, Answer ALS is sharing it freely, enabling researchers around the world to make a more immediate impact in the fight against ALS. We are proud to lend our expertise to this monumental research effort and grateful for those living with ALS who have agreed to be enrolled in the program.

## We Value Tenacity



### I AM ALS

In 2018, a new patient-led, patient centric organization called I AM ALS burst onto the scene determined to reshape public understanding of this disease. As the nation's oldest independent ALS organization, we were honored to be asked by I AM ALS to offer our expertise in the ALS community and act as its fiscal sponsor. Our fiscal sponsorship of I AM ALS has allowed this bold, groundbreaking movement to launch quickly in early 2019, making an immediate impact in our community.

## We Value Family



### CAMP HOPE LOVES COMPANY

ALS doesn't just affect the person diagnosed. It affects the entire family. That's why our care for each member of the family is customized and personal. In 2018, we formalized a partnership with an organization called Hope Loves Company to bring a summer camp program to the Chicagoland area in 2019 for the children and grandchildren of our families affected by ALS. This incredible program is offered free of charge and will foster a safe space for young people affected by this disease to connect and do what all good camps do - allow kids to just be kids.

# We Value Individuality

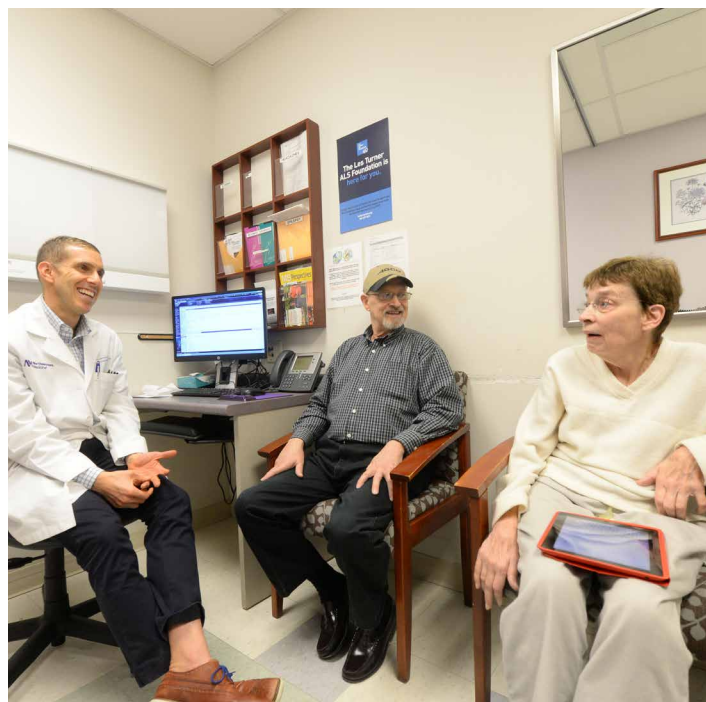
## VIRTUAL SUPPORT GROUPS

Each person affected by ALS, family members included, need individualized support to help them through their journey with ALS. Last year, we launched a new support service program specifically designed for young adults. Many young adults whose parents or grandparents are living with ALS live away from home and require specific support for their unique needs. Since traveling to a meeting may not always be possible, we've created an online community of support led by our licensed social workers to accommodate the individual needs, busy schedules and geographic locations of young adults.

# We Value Expertise

## ALS CLINICAL CONFERENCE

Our Les Turner ALS Center at Northwestern Medicine ensures the brightest minds are working to help improve the lives of people living with ALS. Last September, that expertise was on full display when clinicians from our Center hosted the *First Annual Updates in the Diagnosis and Management of ALS* at Northwestern Medicine, designed to be an annual conference. As the first local conference of its kind, 75 providers outside of Northwestern's network were introduced to the benefits of multidisciplinary ALS care offered by our leading experts at the Center, its coordination of care with the Support Services Team at the Foundation and the ways in which all our health professionals are extending and improving the quality of life for people living with ALS.



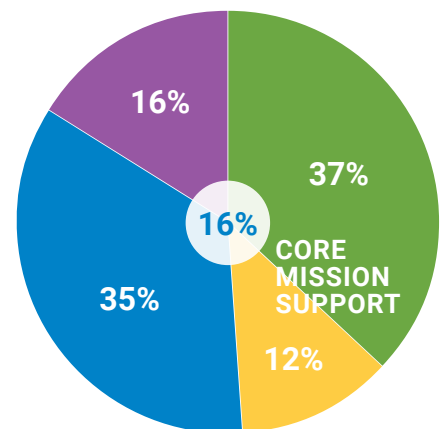
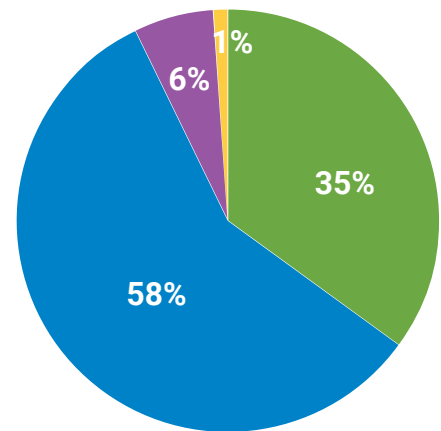
# FINANCIAL HIGHLIGHTS

In 2018, the Les Turner ALS Foundation invested nearly \$2.2 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 is absolutely necessary to ensure this 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                                  | 2018               | 2017               |
|--|--------------------|--------------------|
| ● Special Events (net)                   | \$1,099,281        | \$1,293,532        |
| ● Individuals, Corporations, Foundations | 1,792,287          | 939,023            |
| ● Grants and Contracts                   | 189,501            | 139,328            |
| ● Investments                            | 33,383             | 20,061             |
| <b>Total Revenue</b>                     | <b>\$3,114,452</b> | <b>\$2,391,944</b> |

| EXPENSES                             | 2018               | 2017               |
|--------------------------------------|--------------------|--------------------|
| <b>Core Mission Support</b>          |                    |                    |
| Management                           | \$206,756          | \$216,882          |
| Development                          | \$210,593          | \$203,379          |
| <b>Direct Program Expenses</b>       |                    |                    |
| ● Research/Endowment                 | \$800,000          | \$660,000          |
| ● Lois Insolia ALS Clinic            | 270,000            | 470,000            |
| ● Support Services                   | 773,569            | 790,584            |
| ● Education                          | 337,564            | 128,300            |
| <b>Total Direct Program Services</b> | <b>\$2,181,133</b> | <b>\$2,048,884</b> |
| <b>Total Expenses</b>                | <b>\$2,598,482</b> | <b>\$2,469,145</b> |
| Change in Net Assets                 | \$515,970          | \$ (77,201)        |
| Net Assets - Beginning of Year       | \$1,234,514        | \$1,311,715        |
| Net Assets - End of Year             | \$1,750,484        | \$1,234,514        |



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.





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Vice Chair



**Matthew Brown**



**John M. Coleman, III, MD**



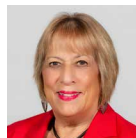
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\*Executive Committee

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

## Affiliations

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Feinberg School of Medicine

Les Turner ALS Center



## Independent Auditors

**Wipfli**  
Palatine, Illinois

Information is current as of the printing of this report.

**Jordyn Landberg**  
Editorial

**Bri Allen Design**  
Design

# OUR GENEROUS SUPPORTERS

The Les Turner ALS Foundation appreciates 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.

*To make a donation, please contact Steve Schapiro, Director of Development at 847.679.3311 or [sschapiro@lesturnerals.org](mailto:sschapiro@lesturnerals.org).*

## HONORED FRIENDS

\$100,000 AND ABOVE

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AmazonSmile Foundation - Amazon.Com  
Ameritrade  
Anthem  
ACON Foundation  
ArcelorMittal  
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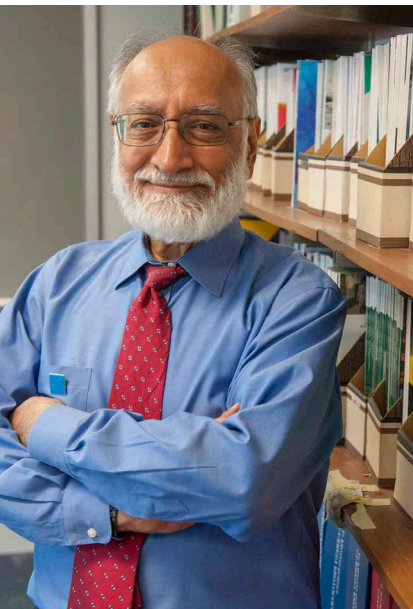
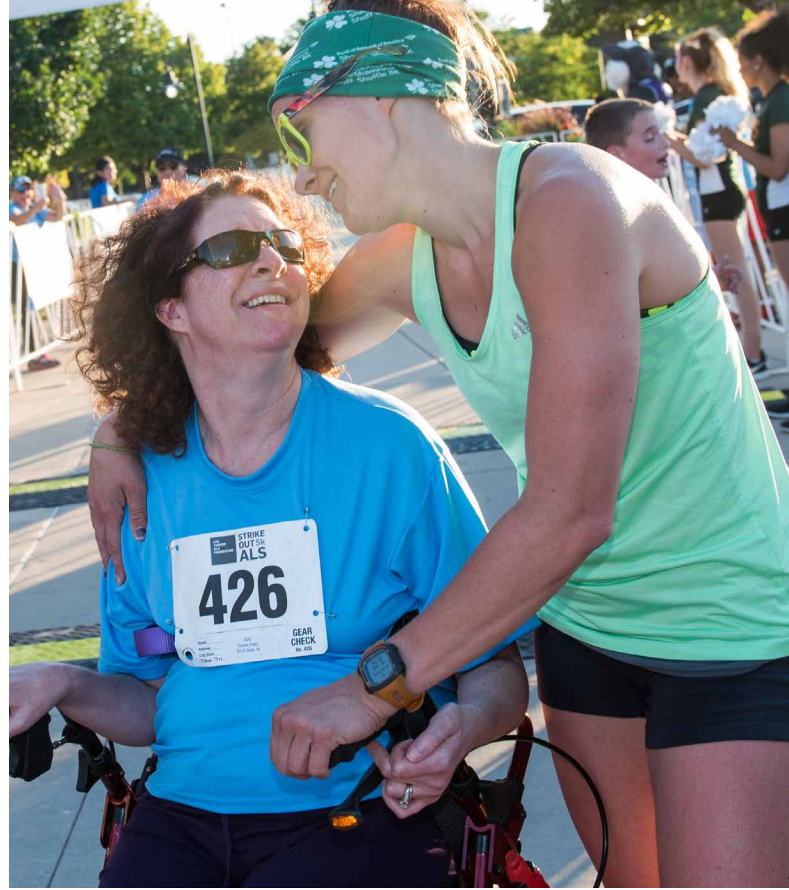
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**Thank you!**

# LOOKING FORWARD

2019 is sure to be another year of incredible growth and opportunity to make real change in the ALS community and for people living with ALS, thanks to continued support from donors like you. We are excited to share updates with you from new initiatives like Camp Hope Loves Company for the youngest members of our community, the release of the first dataset from Answer ALS and a brand new clinical trials program at our Les Turner ALS Center at Northwestern Medicine.

THANK YOU FOR JOINING US AS WE CONTINUE TO MAKE GREAT STRIDES TOWARDS 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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