

# Community

The Newsletter of the Les Turner ALS Foundation

Hope and help for  
people with ALS.

lesturnerals.org

Paying It  
Forward  
page 1

A Walk to  
Remember  
page 3-4

With Collaboration,  
A Brighter Future Ahead  
pages 3-4

Camp  
HLC  
page 5

You Are Part  
of Our Family  
page 6

## Paying it Forward



**“When I was first diagnosed 26 years ago, I knew nothing at all about ALS. The Les Turner ALS Foundation, however, knew everything. They were there to share that knowledge and provide guidance and support and have been by my side ever since.”**  
—Mindy Evans-Williams, a person living with ALS

ALS is scary. Really scary. But the Les Turner ALS Foundation exists to care for those affected by the disease, answer their questions and support people living with ALS, just like Mindy. “The endless support, advice and guidance assures me that I am not making this journey alone. I feel that the Foundation is always by my side like a guardian angel.”

Mindy knows firsthand just how essential the Les Turner ALS Foundation is in providing the best care and support for those affected by ALS and their families. “With their financial support over the years, I was able to hire a caregiver, purchase motorized wheelchairs, 2 wheelchair accessible vans, a computer and several communication devices as well as a Hoyer lift,” says Mindy.

Now Mindy is taking the opportunity to pay it forward

and support the Foundation and others currently living with ALS. “I know the stress and frustration of trying to carry on with very limited finances. I currently find myself in a position to be able to assist others who are now sorting through the difficulties and uncertainty that I once faced.”

On March 9, 2019 at our annual gala, Mindy Evans-Williams will receive the Hope Through Caring award, which honors those whose extraordinary commitment to the fight against ALS has helped raise funds for research and clinical care, provide services for people with ALS and their families, and increase public awareness.

“Simply said, ‘It is better to give than to receive.’ If I can help someone else through their tough times, if I can make their lives easier, I am more than happy to do so. I can honestly say that it brings me as much joy to help, as it does to those that receive it.”

The Les Turner ALS Foundation has meant the world to me. It is like having a second family.

They are always there at your side to provide assistance and share information. They truly know their stuff, and you will never have to go through it alone.”

People like you and Mindy make our work possible and ensure that no person living with ALS must make this journey alone. Pay it forward like Mindy and head to [lesturnerals.org/get-involved](http://lesturnerals.org/get-involved) to see how you, too, can help create a world free of ALS and support people living with ALS and their families.





## Letter from the CEO

Andrea Pauls Backman

Dear Friends,

**Care. Community. Cure.** I can't think of three words that better describe the work of the Les Turner ALS Foundation and our approach to the complexities of ALS—the support we give to counteract the disease's overwhelming impact on individuals and their families, the tremendous caregiver burden that we help to lessen, the multiple medical disciplines we provide to coordinate care and the scientific secrets we are uncovering in our pursuit of a cure.

Toward that end, over the last few months, the Foundation participated in the ALS community's patient-focused drug workshop with the FDA, where over 100 experts in the field, including people living with ALS, discussed best practices in designing clinical trials to speed drugs to market. We presented at the Center for Disease Control's National ALS Registry Meeting, where over a dozen research studies are being funded to help uncover environmental links to ALS. Several of the ALS researchers at our Les Turner ALS Center at Northwestern Medicine presented their work at NEALS, the Northeast ALS Consortium and, just recently, we announced our partnership with Hope Loves Company Inc., to bring a weekend camp program for children and teens to Chicagoland next September.

In this newsletter, you will see a common theme emerge in our work—the theme of family. From families coming together at our ALS Walk for Life, to our family of Chicagoland researchers and clinicians collaborating with peers around the world to the addition of a camp program to serve our youngest members, we are here to **care** for your family, create a strong ALS **community** of support and find a **cure**.

And we know when we come together as a united family in the fight against ALS, we are not only stronger, but we are closer than ever to seeing an end to this terrible disease.

This issue shares the stories of different members of our family, joining together with one common goal—to see a world free of ALS. You are not alone. We are all in this together and we are with you every step of the way. To **care**, to create **community** and to uncover a **cure**.

Andrea Pauls Backman

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- Hallie Kobylski

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- Kirsten Goede

## National ALS Registry

Visit [cdc.gov/als](http://cdc.gov/als) for more information



# A Walk to Remember

After many months spent rallying teams, fundraising and preparing for the big day, you championed another successful ALS Walk for Life! This year was our 17th Walk and just when we think it can't get any better, you prove us wrong.

More than 7,000 of you joined us for a beautiful walk along the Museum Campus and through Soldier Field making this one of the biggest Walks yet, helping us raise close to \$850,000 for people living with ALS.

But the Walk is more than a fundraiser. While each of us has had our own unique journey with ALS, the Walk brings us together as one community, united in our vision to see a world free of ALS. It's a day of celebration and a reminder of how much stronger we are when we work together. The Walk, and each of you, inspires us and gives us the strength to take our next steps.

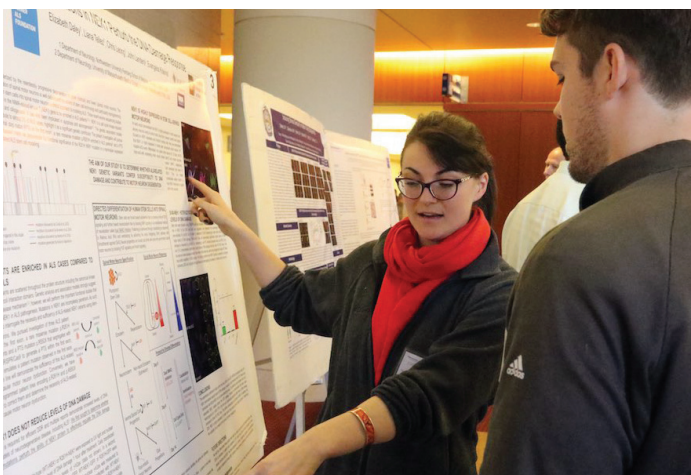
Thank you to everyone who joined us at the Walk including all of the people living with ALS, our generous sponsors and the donors who make our mission possible. We can't Walk for Life without YOU! See you next year!

**“To be there with that many people with ALS and to have the support of other people with ALS, it's very uplifting.”**

*—Theresa Meyer, wife of Wendell Meyer, a person living with ALS*



## WITH COLLABORATION, A BRIGHTER FUTURE AHEAD



Since our founding over 40 years ago, we have been committed to our vision of seeing a world free of ALS. This vision is one of the reasons we established the Les Turner ALS Center at Northwestern Medicine. Through the collaborative model of the Center, a future without ALS is not only possible, but within our reach.

The Center brings together leading experts in ALS research, treatment and support who are committed to our family and to finding a cure. Our Center 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. This comprehensive approach is a model for best practice in the ALS field and why clinicians, researchers and care providers are drawn to the Center and the educational events and conferences we host.

In September, the Center hosted its First Annual Updates in the Diagnosis and Management of ALS Conference at Northwestern Medicine. Conference organizer, clinician and Foundation Board Member John Coleman, III, MD said, “We had 75 medical profession-



“To see that we are not walking this path alone, to know that while this journey is far from over, no one is alone. The inspiration and hope from this amazing community have sustained us...”

—*The Rhode to a Cure*



als from across the Chicagoland area. Many staff members from our multidisciplinary clinic presented best practices in clinical management of ALS. There was great excitement about what we're doing at the Les Turner ALS Center at Northwestern Medicine and the benefits of working with the Les Turner ALS Foundation.”

Sharing our multidisciplinary approach in elongating and improving the quality of life for people living with ALS not only helps our Les Turner ALS families in the Chicagoland area, but also equips care providers with the tools to help people living with ALS outside our geographic area of care.

And this November, our Center hosted the 8th Annual Les Turner Symposium on ALS and NeuroRepair featuring keynote speaker Merit Cudkowicz, MD, MSc, Chief Neurology Service Director at Massachusetts General Hospital's ALS Center.

In her keynote, Merit shared, “There has never been as hopeful a time for ALS treatment development as now. There has been an

explosion of great science discoveries that point to targets for drug discovery. The ALS field is poised for a real change in treatment.”

The Symposium included an *Ask the Experts* clinical panel, research posters and presentations from leading members in the field of ALS research. We shared vital information and answered many questions regarding patient care while celebrating groundbreaking news in ALS research and clinical trials with people living with ALS, their families, scientists, researchers and clinicians.

We are immensely proud of the work being done at the Center. Our Center connects researchers, clinicians and support services enabling advancements achieved at our clinic to influence research conducted in our labs and vice versa. We believe it's imperative for scientists and patient care providers to work together to develop therapies, provide the best care possible and move us closer to finding a cure. And we know, through all these efforts, the Les Turner ALS Center at Northwestern Medicine is bringing that cure within reach.



# CAMP HLC

## A NEW PROGRAM FOR KIDS

We are excited to announce an expansion of our programming dedicated to children. In September of 2019, through a new partnership with Hope Loves Company, Inc., we will offer a weekend sleepover camp in the Chicagoland area specifically designed for children and young adults who have or had a loved one battling ALS, called Camp HLC.

Like all of our programming, Camp HLC will be offered free of charge and will give young people a safe space to receive emotional and educational support from experienced educators, social workers and specialists. Perhaps even more important is the opportunity it will provide to create lifelong friendships and connections with other young people in the Chicagoland area going through similar, painful situations.

"This camp will be a profound experience that will allow kids to feel 'normal,' and to connect with peers who truly understand what it's like to have or to have lost a loved one to ALS. It will be both powerful and magical and I am thrilled to be a part of it," said Laurie B. Fieldman, LCSW, Director of Social Services at the Les Turner ALS Foundation.

Camp HLC will include typical camp activities like hiking, water activities and crafting with the added benefit of counselors being available for campers who wish to seek support and therapeutic sessions where kids can talk about their feelings surrounding ALS.



**HOPE  
LOVES  
COMPANY™**

Hope Loves Company, Inc. has run eighteen camp programs across the country over the last six years. Founder Jodi O'Donnell-Ames was inspired to create Hope Loves Company when she realized the lack of resources available to her three children, all of whom lost a parent to ALS at a young age.

**Registration for Camp HLC will open in the spring of 2019. To learn more about how your child can reserve a spot, please contact Jodi O'Donnell-Ames at [jodi.odonnell-ames@hopelovescompany.org](mailto:jodi.odonnell-ames@hopelovescompany.org) or Hope Loves Company at [contact-us@hopelovescompany.org](mailto:contact-us@hopelovescompany.org).**

**You can also reach the HLC office at 609 730 1144.**

**Campers ages 6-21 years old are welcome, as well as parents and chaperones.**

LES  
TURNER  
ALS  
FOUNDATION

Les Turner ALS Foundation  
5550 W. Touhy Avenue, Suite 302  
Skokie, IL 60077-3254

847 679 3311 main  
847 679 9109 fax

[lesturnerals.org](http://lesturnerals.org)

## YOU ARE PART OF OUR FAMILY



Visit [HelpCureALS.org](http://HelpCureALS.org) to give today

My name is Matthew Scott Usher. My wife and I have three wonderful children ages 19, 10 and 9. But I don't know if I will be able to see them graduate from school, get married or have their own children...because ***I have ALS.***

The stress ALS has placed on my family is indescribable. My children fear losing their father. I don't know if I will be able to grow old with my wife. My disease is not only taking a physical and emotional toll on me, but on those I love most. And I didn't know how to help them.

***But the Les Turner ALS Foundation has been there for me and my family, when we needed them most, every step of the way.***

They come into my home and address my personal needs, even before I know what those needs are. They are there when I need them. And when my wife and kids need them. ***They have become part of our family.***

But they could not be here if it weren't for your generosity. Without the Les Turner ALS Foundation, I don't know where I would turn. And with your support, I have hope. ***Please give today.***