

Hope and help
for people
with ALS

lesturnerals.org

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From Generation to Generation: Embodying the True Spirit of "Paying it Forward"

Ride for 3 Reasons

In 2001, Barrington community member Bob Lee began one of the most important journeys of his life. After reading Mitch Albom's *Tuesdays with Morrie* and feeling so inspired by the words of the main character, Morrie Schwartz, Bob passed the book on tape to a neighbor who had retired and was moving to California.

"He [the neighbor] loved the book so much he listened to it twice. Five months after moving, he called to tell me he had been diagnosed with ALS," said Bob. This pushed Bob to begin thinking about his own life and what he wanted to do with the time he had left.

One day, while out on a bike ride, a plan formed and the Ride for 3 Reasons was born. Over the course of the next 11 years, Bob embarked on three separate bike rides across the continent, raising tremendous amounts of both money and awareness for three reasons: hospice, cancer and ALS. In all, Bob biked close to 12,000 miles and raised over \$1.3 million, split evenly among the three causes. While each ride brought in more donors and raised more money, the rides also gave Bob more opportunities to educate people about all three causes.



Jan and Bob on a ride together

"Hearing him speak, even back then, I knew I wanted to ride across the USA the way he had."

In 2007, as Bob spoke at local elementary schools, he unknowingly planted a seed in the mind of a third grader who never forgot Bob's remarkable achievements.

"I remember sitting 'criss-cross-apple-sauce' on the gym floor of my elementary school," said Jan Gierlach. "Hearing him speak, even back then, I knew I wanted to ride across the USA the way he had."

Nine years later, at age 17, the "If you can dream it, you can do it" seed from Bob's presentation had grown in Jan's mind. With the support of his parents, Jan began to develop a plan to make his own cross-country trek on a bicycle.

Remembering his inspiration, Jan reached out to Bob to introduce himself and learn more about the logistics of planning such a ride. While Jan's initial goal for his ride was to gain a sense of independence before starting college, Bob urged Jan that biking for a cause beyond himself would make it a much richer experience.

"I'd love for you to do this for a Ride for 3 Reasons," Bob said. And to Bob's delight, Jan agreed. Now, Jan has picked up the torch as the next generation to Ride for 3 Reasons, riding for the same three causes Bob had.

"It's very rewarding to see Jan take on this challenge. I'm honored to know him and be involved with this. The real lesson for me is, you never know who's listening or observing what we're doing. To me, it's neat there was that connection for Jan and that he was really listening and not pinching the little girl next to him on that gym floor," said Bob.

Story continued on back panel.



Jan and his family

A Touchdown for ALS

Northwestern University Football Supports the Foundation



Members of the NU football team at the Strike Out ALS 5k

While most are enjoying the perks of a Chicago summer, a few miles north of the city, the Northwestern University Football team is busy preparing for its upcoming season. Motivated by those fighting a battle every day, these student-athletes are set to tackle ALS. Like those living with ALS, the team is optimistic for the future – one where a cure exists.

It's this common ground that sparked a unique partnership between the Northwestern University Football team and the Les Turner ALS Foundation through Uplifting Athletes; a national nonprofit run by current student-athletes using college football as a platform to provide inspiration to the rare disease community through the power of sport.

“It is an incredible privilege to play football at the highest level and to continue our education at an institution like Northwestern,” NU offensive lineman and chapter President of Uplifting Athletes, Tommy Doles, said. “In return, we want to take every opportunity we can to give back, especially when we can use our platform as football players to stand for something we believe in and have a positive impact on the Chicagoland community we have grown to love.”

Tommy, along with other members of the Northwestern chapter, chose the Les Turner ALS Foundation as their cause to support after reading the university newsletter and discovering the transformational work being done by the Foundation. Having witnessed his grandfather battle ALS, it was an easy decision for Tommy and the group to make.

“While my grandpa was fighting the disease, it meant the world to have someone say they cared about what we were going through,” Tommy said. “I want to give that encouragement to every patient in the Chicagoland area, letting them know we have their backs.”

To learn more about Uplifting Athletes, visit upliftingathletes.org and look for team members at upcoming Foundation events. ■

Providing Hope in Your Community

Family and Community Events

Much like those living with ALS, no two Family and Community (FamCom) events organized on behalf of the Les Turner ALS Foundation are the same. In addition to five signature events the Foundation hosts throughout the year, approximately 30 additional events are hosted at a community level by event organizers just like you with proceeds benefiting the Foundation. For some organizers, planning a FamCom event is a way to remember a loved one while others plan events to honor someone who is courageously living with ALS, allowing families and friends the opportunity to give back to the Foundation for services it provides families.

“We are looking to spread awareness, so we soon can find a cure for ALS.”

One such event is the Sanderson Golf Outing, planned in honor of Cory Sanderson, who is currently living with ALS. “It has provided an outlet to raise awareness about this horrible disease Cory is battling,” said Dawn Sanderson, Cory’s wife. “It has given us something else to focus on and look forward to.”

FamCom events range from various sport outings to bake sales, but it is the personal stories from the people living with ALS and their family and friends hosting the event that makes each one unique.

For Cory Singer, planning a casino night for coworkers is an uplifting, supportive way for a company to rally around a colleague whose mom was diagnosed with ALS. “One of our own at FCL (Builders) has experienced the tragedy ALS brings to a family and we want do our part to help prevent others from experiencing the same,” Cory said.

FamCom event organizers help bring the overall mission of the Foundation to local communities across the country by raising not only awareness, but also vital funds for support services and research. “Not only are we looking to raise money to benefit families and patients affected by this disease, we are looking to spread awareness, so we soon can find a cure for ALS,” Cory said.

FamCom events, whether big or small, have a lasting impact on those the Foundation serves. To learn more about how you can create your own FamCom event, visit lesturnerals.org. ■



Attendees at the Matt Creen Golf Outing

Walk for Hope. Walk for Help. Walk for Life.

ALS Walk for Life

Chicagoland's largest gathering of ALS patients, families, friends and supporters will gather on Sunday, September 18 for the 2016 ALS Walk for Life at Soldier Field in Chicago. The Walk is a day of community, remembrance and celebration and, best of all, anyone can join! It's free and open to the public. Join us as we Walk for Hope, Walk for Help and Walk for Life. Read below on why Team Chair, Matt's Minions, feels the Walk is an essential way to support the Foundation:

"Many people like to support a cause that makes a difference. In our case, that cause is the Les Turner ALS Foundation. Without the Foundation we would be facing this journey in the dark. Through their efforts we feel anything is possible. With amazing dedicated people that offer hope and help via the support groups, home team visits, awareness, the Clinic, research and everything else that makes the organization great, the Les Turner ALS Foundation fights for us and makes a huge difference in many people's lives. ALS does not just impact an individual, it impacts the entire family. People that are not familiar with the disease may not realize this. People that know us know the impact ALS has and how the Foundation supports us. We are blessed to have such kind, supportive and generous family, friends, community and the Foundation to support us in our fight against ALS." ■



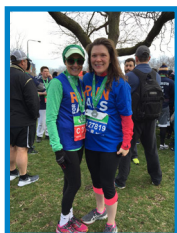
Matt's Minions at the 2015 ALS Walk for Life

[Visit ALSWalkforLife.org to learn more](http://ALSWalkforLife.org)

Running for Those Who Can't

Team Race for ALS in the Chicago Marathon

Each fall, thousands of runners set their sights on participating in the Bank of America Chicago Marathon on behalf of charity race teams like the Les Turner ALS Foundation's Team Race for ALS. As a member of the Team, runners fundraise to provide hope and help for those living with ALS. Meet a few of the amazing members of Team Race for ALS who will be racing towards a cure on Sunday, October 9. To join the team, visit lesturnerals.org.



Sherlyn Brubeck, *Certified Financial Planner and wife of PALS, Ryan*

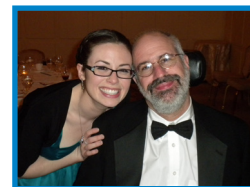
From: Oak Brook, Illinois

"I chose the Chicago Marathon because it is our home town. I can't tell you how many years I have cheered on the runners and secretly wished I could run this race. Also, the only way I am ever going to finish a marathon is if I know Ryan is there at the finish line waiting for me!"

Michelle Jacobson, *Actor and daughter of PALS, Dick*

From: Los Angeles, California

"My dad was diagnosed with ALS in 2011. Before that, he ran marathons himself. Because I have been a runner since high school, participating on Team Race for ALS seemed like a perfect way to honor him. Many of my friends in my running group run marathons, and they inspired me to finally do a full marathon."



Carissa Hidder, *Tax Accountant and niece of PALS, Judy*

From: Dallas, Texas

"I've been running and racing for a few years and I would often hear the phrase, 'Run for those who can't'. I never fully understood what that phrase meant until recently, and now it carries a lot of weight with me. When the miles get tough or I don't want to run that day, all I have to think about is my Aunt Judy, and all the others who no longer have the opportunity to walk or run."

Brandi K. Lee, *Active Duty Air Force and friend of PALS, Teresa*

From: Kansas City, Missouri

"I hope to continue to raise awareness about ALS and the difficulties faced by those living with the disease. I hope with money and awareness we continue making progress for a cure. Also, I want Teresa, and others, to know they are not alone. I will run for her, and others, when they cannot. I will continue to run and fight on their behalf."



Highlights from the Annual National ALS Registry Meeting

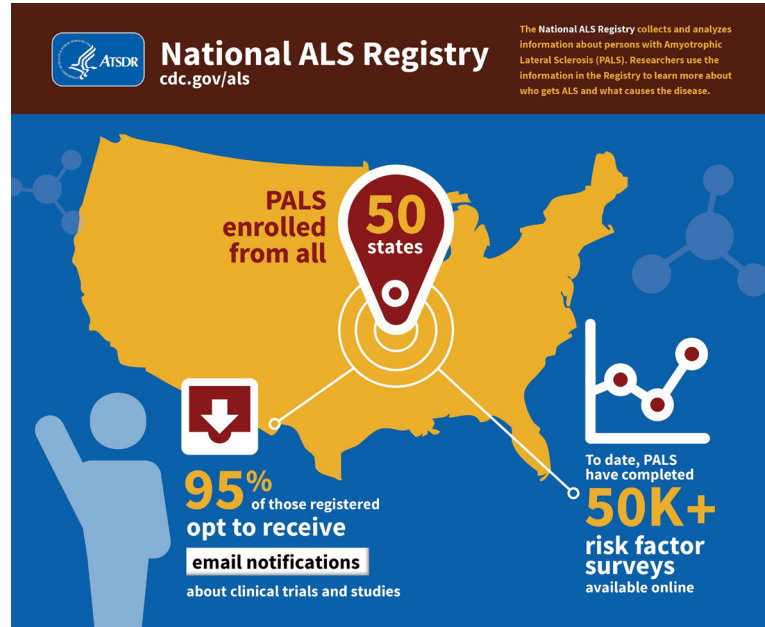
ATSDR Annual ALS Surveillance Meeting 2015

Each year the National ALS Registry holds a meeting to update stakeholders on the progress of the Registry. They also discuss data from the Registry and strategies to further enhance the Registry for all stakeholders. The 2015 meeting was attended by 45 people including PALS, researchers, neurologists and representatives from support groups.

By now, most PALS have heard of the Registry and why it is important to join and be counted. But, not everyone knows about the other aspects of the Registry.

Those who join can provide information about themselves.

- The Registry has collected demographic and risk factor data on PALS in all 50 states, and more PALS are enrolling every day.
- Almost 50,000 surveys have been completed, across the 17 risk factor survey modules.
- As new risk factors are identified, new risk factor modules can be created.



PALS who join the Registry can choose to receive emails about research studies and clinical trials.

PALS can then contact the investigator if they are interested in taking part in the study.

- The Registry began notifying PALS in 2013.
- More than 95% of PALS who join the Registry choose to receive email notifications.
- Emails have been sent about 21 different research studies.
- Each year there have been increases in the numbers of emails sent over prior years.
- In 2014, approximately 27,000 emails were sent. Midway through 2015, 30,000 emails had been sent.
- More than 70,000 emails have been sent to PALS regarding research opportunities.

National ALS Biorepository to be added to the National ALS Registry.

The Registry conducted a pilot project to see if it was feasible to have a biorepository as part of the Registry.

- The goals of the pilot project were to:
 - Maximize the scientific use of specimens.
 - Maximize cost-efficiency.
 - Make recommendations for maintaining the biorepository long-term.
 - Recommend a process for providing access to the specimens to researchers.
 - The project received biological specimens from 330 participants.
 - All specimens have been processed into smaller amounts. ATSDR anticipates making these pilot specimens available to researchers later in 2016.

Results from the pilot indicated that a permanent biorepository connected to the Registry is feasible and warranted. Therefore, the new National ALS Biorepository will become fully operational in the fall of 2016. It will have the largest bank of blood and tissue samples from persons with ALS in the US. Samples from the biorepository can be paired with data already being collected from the risk-factor surveys.

Registry Funded Research

In addition, participants heard updates on studies the Registry has funded to learn more about ALS and possible causes of the disease. They also heard about activities to evaluate the completeness of the Registry and ways to increase the number of PALS joining the Registry.

Conclusion

The National ALS Registry is making tremendous progress not only through quantifying the incidence and prevalence of ALS in the US, but also by connecting PALS to clinical trials, providing funding for ALS research and collecting biospecimens to help researchers. But the Registry can't exist without PALS. Consider joining the Registry if you haven't already and don't forget the surveys where you can provide information important to researchers as they look for the causes of ALS. ■

To learn more about the Registry, visit cdc.gov/als
Note: The Foundation is proud to be an active partner of the National ALS Registry.

Letter from the Executive Director

Andrea Pauls Backman



Dear Friends,

The story of the Foundation begins with one man, Les Turner, diagnosed with a hard to pronounce and little-known disease who, along with his family and friends, started the Foundation at a meeting in a living room. As a result of this core group organizing small events for ALS research, the Foundation grew and has

continued to flourish for the past 39 years.

Today, the Les Turner ALS Foundation is proud to be one of the nation's first ALS organizations and remains one of our country's largest, independent ALS dedicated groups. We started with a grassroots model of individuals working together to make an impact, and the stories you will read in this issue show how that model is still essential to the work we do today.

You will meet a handful of the incredibly committed individuals who, like Les Turner's friends and family in 1977, make a difference in the lives of people living with ALS in creative and innovative ways. People like those highlighted in this issue, and people like you, are how we continue to be Chicagoland's number one provider of hope and help for people living with ALS.

You will be introduced to marathon runners, cross-country bikers, football players, walkers and event organizers – all of whom have found unique and purposeful ways to support the Foundation. But, what's really impressive when reading through these stories is these people represent only a small sliver of the ways in which you, too, can get involved with the Foundation.

While reading this issue, I encourage you to think about how you can find your own way to help support the nearly 90% of people living with ALS in Chicagoland served by the Foundation. Whether it is as simple as a jeans day at your office or as complex as a cross-country adventure, we are here to help you find a meaningful way to make an impact in the fight against ALS.

Together toward a cure,

Andrea Pauls Backman

HELP FREEZE ALS

FreezeALS.org

Every 90 minutes,
someone in the US
is diagnosed with ALS.

Every 90 minutes,
someone in the US
dies from ALS.



Thank you to those who became ALS advocates for the ALS Awareness Month campaign this past May! Advocates across the country spread awareness about the Foundation and ALS. Between social media views and sticker cards, **we reached over 360,000 impressions to raise awareness to Freeze ALS!**

In addition to ALS Awareness Month, the annual Tag Days drives were also a huge success! Since 1997, Tag Days drives have raised over \$1 million to support the Les Turner ALS Foundation. This year, 13 drives scattered across Chicagoland brought in \$40,000.

It's Easy to Get Involved:

- Sign up for our e-newsletter
- Volunteer
- Join a Special Event
- Donate

Visit lesturnerals.org to make a difference and stay informed!

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Disclaimer
All care has been taken in preparing this newsletter. This information is of a general nature and should be used as a guide only. Always consult your physician before starting any treatments.

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Ride for 3 Reasons, continued from front page

Jan will graduate from high school a semester early in December and take off on his solo bike ride in February of 2017, riding 3,300 miles from San Diego, California to St. Augustine, Florida, raising money and awareness for the Ride for 3 Reasons. While a fundraising goal has yet to be set, Jan and Bob have no doubt this ride will build upon the success and the lessons of the three prior trips Bob completed.

For Bob, Jan's ride is about inspiration. "You think of Jan, at the age of 17 taking on this huge challenge and of people hearing his story and asking, 'What can I do to make a difference and how big can I make it?' It's pretty special."

Note: Bob Lee recently retired from the Board of Directors of the Les Turner ALS Foundation after 14 years of dedicated service. Inspired by his friendship with and support of many PALS, Bob helped raise hundreds of thousands of dollars for ALS research and patient care, which he continues to do. We are tremendously grateful to Bob for his passion and concern for all PALS and his devoted service to the Foundation, as both a board member and active supporter.

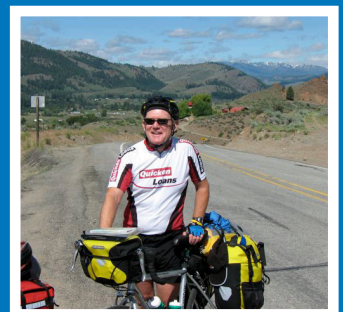


Photo Caption: Bob Lee on his second Ride for 3 Reasons