

# Community

The newsletter of the  
Les Turner ALS Foundation  
Issue 1, 2010

## The Strength of a Family

Jen and Dave Cassin

Until recently, Jennifer and David Cassin lived a fairly typical life in the northern suburbs of Chicago with their twins, Reiley and Jeremy. "We got married a little later in life," Dave explained. "We had our twins at 35. Jen had waited her whole life to have children." The couple was thrilled and happily enjoying life with their new family.

Unfortunately, things changed drastically in early 2009. They noticed that Jennifer had been slurring her speech. Her doctor confirmed it wasn't a stroke, as the family had feared. But that relief turned to anxiety when Jennifer was diagnosed with ALS.

In December of that same year, Jennifer was rushed to the hospital for respiratory issues. She had already been through a surgery for a feeding tube replacement, and had endured other complications caused by the disease. A life-saving tracheotomy was performed, which meant that round-the-clock care would now be required.

This turned out to be one of the most difficult moments for Dave. "I would advise people with ALS and their families to talk about these things early and often," he said. Prior to Jennifer's illness, they hadn't discussed long-term care and end-of-life decisions. Like most young couples, they believed they would have several years—hopefully decades—

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Many people  
one story



# Executive Letter



Dear Friends,

*Too long has gone by since our last newsletter!*

2009 was a difficult year for us, as we know it was for many of you. Tough financial times forced us to make the difficult decision to reduce funding to two of our programs; however, all of our programs remain active and productive. As you will read, we have particularly exciting news to share from our research team.

These challenging times have motivated us to be more resourceful than ever. Dr. Teepu Siddique, Les Turner ALS Foundation/Herbert C. Wenske Foundation Professor and Director of the Neuromuscular Disorders Program at Northwestern University Feinberg School of Medicine, received a federal stimulus grant from the National Institute of Environmental Health. Likewise, our families continue to come up with creative ways to raise funds through Family and Community Events. Our 2010 "Hope Through Caring" Award dinner raised an unprecedented \$520,000.

We believe 2010 is looking brighter every day. This year's appropriations include over \$300,000 toward research at both Les Turner ALS Research Laboratories, nearly \$350,000 to support the Les Turner/Lois Insolia ALS Patient Center, and over \$440,000 to support Les Turner ALS Foundation Program Services. We invite you to visit our website to read our 2009 Annual Report and learn more about the projects and programs we are funding in 2010.

As we come to the end of May, ALS Awareness Month, we think of the many stories we have heard over the years, the stories that drive us forward. While each is unique, many of us have been encouraged as we learn all that we have in common with other individuals and families—and how together we form the story of the fight against ALS.

Our theme for this newsletter is "Many People, One Story." We hope you will be inspired as you read, and as you consider the ways you can become more involved in this important story we are telling as a community.

Sincerely,

Wendy Abrams

## Advancing Research

### Breakthroughs Offer New Hope



Researchers from one of the Les Turner ALS Foundation's research labs at Northwestern University have discovered a link between inherited cases of ALS known as "familial ALS" and non-inherited cases known as "sporadic ALS." Dr. Siddique's team, led by Dr. Han-Xiang Deng, released a paper in the *Annals of Neurology* reporting that a protein called FUS forms inclusions in spinal motor neurons in most cases of ALS. Mutations in this gene have been previously linked to a small subset of familial ALS cases. Researchers thus linked a rare genetic cause to most cases of ALS, clearing the way for investigation into new forms of therapy.

This caps an exciting month in which an FDA-approved Phase I stem cell trial was featured on CNN. In addition, the Blazeman Foundation—also working with Northwestern University—has begun collecting skin cells to use in another stem cell investigation. Thanks to our researchers, Northwestern University, our friends at the Blazeman Foundation, our partners in ALS research around the country, and all our generous donors who have made these advances possible.



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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.

*On the cover: Jen Cassin with  
daughter Reiley and son Jeremy.*

# A Shared Journey

## Lisa Maire and Nancy Warp

Nancy Warp feared the unknown when her husband Richard was diagnosed with ALS in 2008. Lisa Maire remembered that feeling all too well. Her husband, David, had also been diagnosed a few years earlier. "It's odd when you hear the words. When Dave walked in the door and said, 'The doctors think I might have ALS,' all I could think was, *I've heard of it but I don't even know what it is.*"

Slowly at first, both women began to feel their way down an uncertain path. And despite many unknowns, they found a friendship in their shared journey. "I knew about some of the stuff they were going through," Lisa said of their first conversation. "And I think they kind of knew what I was going through, as much as you're able to anticipate that kind of thing."

"Everything clicked when we talked," Nancy agreed. "We needed a wheelchair for Rich, and they passed David's chair on to us. It was the first of many pieces of equipment they shared with us."

This almost immediate sense of connection was strengthened by one additional experience they had in common: both Rich and Dave were Marines. Lisa described how they had decorated Dave's chair with Marine stickers—and how that small coincidence further developed their bond.

Nancy found other coincidences that became sources of hope and support. "My son had been an undergraduate at Northwestern," she added, where the Les Turner/Lois Insolia Center for ALS treatment is located. And a visit to an ALS support group put her in touch with Ileana Mindel, a nurse consultant, who was able to refer her to that same center.

Rich's ALS progressed fairly rapidly. But even as their situation changed—sometimes daily—Nancy and Lisa continued to talk over email, sharing ideas and questions and difficulties. "Anything I wrote to her, she said she just read over and over," Lisa explained. "I learned so much by having to do it on my own, that I feel like I should help others with what I learned."



Rich Warp celebrates Fathers' Day 2009 with his wife, Nancy, and children.



Lisa and Dave Maire enjoy family time with their two children.

Dave passed away in early 2009, but Lisa continued to chat with Nancy over email whenever possible.

The Warps also remain committed to sharing the

knowledge they gathered along their journey. The memorial folder they created after Rich passed away in April 2010 shared some of the unique yet familiar details of Rich's life and his courageous battle with ALS. It was a quality Lisa always admired in Nancy, "She was always down-to-earth and real about everything."

"In a strange way," Lisa said, "ALS is like a red car. Once you get a red car, you suddenly notice all the red cars on the road. It's almost like everyone's got one."

She likens that to her progression from someone unfamiliar with ALS to a knowledgeable voice able to share her accumulated wisdom. "Once it happens to you, once you learn about it, you realize how many people are in this situation. And it made me feel great that someone could count on me and would trust me with that."

**Interested in connecting with other families affected by ALS?** The Les Turner ALS Foundation hosts monthly support groups in locations throughout the Chicago area. Visit [www.lesturnerals.org/supportgroups.htm](http://www.lesturnerals.org/supportgroups.htm), call 847-679-3311 or email [meetings@lesturnerals.org](mailto:meetings@lesturnerals.org) for times, locations, and more information.

## Celebrating 30 Years of Partnership with Northwestern

On May 25, Northwestern University honored the Les Turner ALS Foundation for 30 years of partnership and dedication to ALS research, education and patient care. The event consisted of a symposium, featuring presentations by leaders from both Northwestern and the Les Turner ALS Foundation, and a reception to celebrate the many accomplishments. We at the Foundation would like to thank Northwestern for putting on a wonderful evening, and for all their work over the past 30 years. We are honored to be your partners in ALS.



# The Strength of a Family *Jen and Dave Cassin, Continued*

before those issues became urgent. Dave insisted these discussions do not mean giving up. "It's so you know what to do if they're unable to give their input. I sometimes felt like I was making Jennifer's life decisions without her."

Left with few options when Medicare wouldn't cover in-home nursing care, the Cassins moved in with Jennifer's sister and her family. "That just confounds me on some level," Dave admitted of Medicare's refusal to support those costs. "They'll cover anything if you institutionalize the person, if you separate them from family. ALS is a terminal diagnosis. People with it have limited time left, and they want to spend that time with family and people they love."

For both Dave and Jennifer, it is family that keeps them going—both the support of their extended family, and the desire to give their children as much time as they can with their mother. "The support of our family has been invaluable. Because of their help, I can continue working to support our children. They take the daily load, including caring for the twins," Dave said.

"Even though the disease progressed quickly, I'm grateful for what we did have that first year," Dave said. "It wasn't like a car

accident, where mom is here one day and completely incapacitated the next."

Still, it is hard. Barely two years after her children were born, Jennifer could no longer care for them. "I see the heartache that Jen goes through on a daily basis," Dave said, "having to watch us raise the kids that she waited her whole life for. That's the heartbreaking part. That bothers me more than any of the rest of it."

When an ALS patient requires a ventilator, a visit from a nurse is an invaluable form of support for the whole family. Consider participating in the Les Turner ALS Walk4Life on September 12, 2010, and setting a fundraising goal of \$500. That money will cover an eight-hour RN shift for a family like the Cassins. Visit [www.alswalk4life.org](http://www.alswalk4life.org), call 847-679-3311 or email [events@lesturnerals.org](mailto:events@lesturnerals.org) to find out more about the Walk4Life and how you can help.

## A Heart for Home Care

**Shari Diamond, RN**  
ALS Nurse Consultant



*Shari Diamond celebrates the 2010 Hope Through Caring Award Dinner with Mike Fietterer and Steve Heronemus.*

As the first clinic nurse at the Les Turner/Lois Insolia ALS Center, Shari Diamond participated in the expansion of new programs, helped push research forward, and started support groups for patients and their families.

"Intrigued" by the chance to work with patients throughout the full extent of their illness, she quickly found that this was work her heart was "totally connected to."

"I remember meeting one patient in clinic. He lived alone and seemed to be managing fairly well at home by himself—or so I thought, until he told me that he slept in his kitchen with his head resting on the table every night because he could no longer get out of bed by himself. He said it was easier for him to rise from a chair. Hearing this moved me to tears."

As a skilled nurse, Shari knew that many solutions existed to make his situation more manageable. "I helped him get a hospital bed and a lift and recline chair. We were able to get a part-time care giver in from the state of Illinois to help him. These small things made such a big difference in his quality of life."

This experience changed the way Shari approached her job as a clinic nurse. "I could not imagine why this wonderful man had not reached out for help and then I realized that many patients living with this disease don't know what is available nor what to ask for. I learned to ask more questions about how people were really managing at home, because our focus during the clinic visit was more symptom and treatment oriented."

But Shari was not content to stop there. Well over a decade later, she took on an opportunity that allowed her new ways to implement this vision. After taking several years to be a "full-time mommy," Shari returned to the Les Turner ALS Foundation, this time as a nurse consultant making in-home visits to ALS patients and their families.

"I loved working in the clinic setting but if I am to be honest, I would have to say that I prefer working with PALS (people with ALS) and their families at home for a number of reasons. I find that PALS are more relaxed and have more energy not having traveled to get to an appointment. We are free to spend the time that is needed to address any and all concerns and answer questions in the privacy and comfort of their homes. I can walk

# It's a new day...

*with renewed hope and the same spirit and community of the Les Turner ALS Walk4Life*

**Sunday, September 12, 2010**

**Montrose Harbor**

LES TURNER

ALS  
walk



life  
CHICAGO

"I feel that the capacity to care for others is the one thing that can give life its deepest meaning and significance. This is why our family will always continue to fight to end this disease. Hopefully one day these efforts will get us closer to a cure and closer to the end of suffering for so many individuals with this disease. I remember one conversation with my mother, Susan Smith, when she was still able to talk. I asked her in regular passing if she needed anything and all she said was, 'I need a miracle.' Although our mother didn't get her miracle, hopefully with our efforts one day there will be that miracle for others suffering from this horrific disease." *—Kristen Smith, representing the 2010 ALS Walk4Life Family Chair, Team Wuja*



*PALS Bill Schmitt and Marty Woywod take in the gorgeous weather at the 2009 Walk4Life.*

**This year's Walk4Life will be one for the books!** We have a huge goal of raising \$1,000,000. It may seem very daunting, but with your help and dedication, it is completely attainable. In 2009, we had approximately 5,000 walkers. If each of our 5,000 walkers can raise \$200, we will hit the one million dollar goal!

This year's walk is focused on change and excitement. What better way to celebrate all of that than by raising \$1,000,000 in support of the Les Turner ALS Foundation!

This year, we are proud to offer each walker and each team their own fundraising web page. Your unique story and creativity is what draws donors in! Visit [alswalk4life.org](http://alswalk4life.org) to get started.

through a patient's home and see what might make life easier and safer for them and provide suggestions and resources to them. I have found that patients and their loved ones enjoy this additional personal connection outside of the clinic setting."

No two days are exactly alike for Shari. Her job on the home care team takes her from family to family, meeting with them to offer support, resources and solutions. "No two people have the same symptom set or rate of progression," Shari remarked, an uncertainty that requires adaptability for Shari, and for the patients and families. Nonetheless, Shari keeps in mind a single mission that guides her through each of these individual situations. "This is all about working together to provide whatever is needed to assure that PALS are getting the treatments, support services, resources and information they need."

A home visit from a nurse or social worker can cost \$250—and that does not include the cost of any equipment or home modifications that may be required. Use your imagination to create a Family and Community Event that will raise money to cover these and other patient care expenses. Visit our website, call our offices, or email [events@lesturnerals.org](mailto:events@lesturnerals.org) for ideas or for more information on how to get started.

## Welcome to Our New Team Members

Please join us in welcoming our newest staff to the Les Turner ALS Foundation family:

**Liz Liwazer**, Development Officer

**Megan Lenz**, Communications Manager

**Kim Oakley**, Special Events Manager

*We are excited to have them and are confident they will serve the Foundation well.*

## Get involved!

You'd be surprised how quickly you can gather friends and family to raise funds to support the Foundation's programs. YOUR dedication is the difference.

**We're here to help!** If you'd like to learn more about organizing your own fundraising event, please contact the Foundation at 847.679.3311 or [events@lesturnerals.org](mailto:events@lesturnerals.org).



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**It's easier than ever to stay involved with all our latest news and exciting events!**

- Visit our website to sign up for our monthly e-newsletter
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- Follow us on Twitter



## Upcoming Events

**Unitarian Church of Evanston Benefit Music Concert – Featuring Edgar Gabriel & String Fusion**  
 Saturday, June 12

**Lou Gehrig Day at Wrigley Field**  
 Saturday, June 19

**The Mingus Awareness Project**  
 Wednesday, June 23

**Masters of the Grill**  
 Sunday, June 27

**Diamond Dare with the Schaumburg Flyers**  
 Thursday, July 15

**Schaumburg Flyers Les Turner ALS Jersey Night**  
 Tuesday, August 10

**ROAR 4th Annual Ralph Russo Charity Golf Classic**  
 Monday, August 16



**Michael McDermott Benefit Concert**  
 Saturday, August 21

**Lou Gehrig Day at U.S. Cellular Field**  
 Sunday, August 29

**9th Annual Walk4Life**  
 Sunday, September 12

**Manicures and Merlot**  
 Monday, October 4