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Cure for ALS

2011

August 25,

Dear ALS Advocates and Friends,

It has been a very exciting week in the world of ALS! In case you haven't heard, scientists at Northwestern University's Feinberg School of Medicine have identified a common cause of ALS. The study brings significant hope for ALS patients to open doors of new drug therapies and treatment, and brings the cure another step closer. Make sure to read the article below, one of many published this week.



In April, I told you about Doug McConnell who was preparing to swim the English Channel in memory of his father who died from ALS. Besides the daunting training regimen, Doug had to overcome tremendous adversity to accomplish the swim, which he completed on Sunday, August 22. He raised over \$130,000, which benefited the Les Turner Foundation. What a week for the organization - the Les Turner Foundation is also a major supporter of the Northwestern University's Feinberg School of Medicine. You'll want to read the recap of Doug's English Channel swim.

Art Sale Fundraiser for ALS
September 9, 2011
 5pm-8pm
 Rehoboth Beach, DE

On the right, you'll find upcoming fundraisers and opportunities to participate or make a donation. I like that there are a wide variety of fundraisers popping up to benefit ALS. I've seen art shows and school plays, running and cycling events, book sales, skydives, and this weekend there is a community [garage sale and concert](#) in Pennsylvania to support ALS. This means that advocates are being creative and using resources familiar to them. I'm convinced that together we can make ALS as recognizable as AIDS, Autism, MS, and Parkinson's Disease.



[Click here](#) for information.

Keep sharing your knowledge of the disease and your stories

TaylorMade Fore Craig

of loved ones with others. We need to be the voice for those who no longer have one.

Best Regards,
Karen Duffy (kd)

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Breakthrough could lead to effective treatment for ALS

By William Mullen / Chicago Tribune

CHICAGO - Researchers say they found a common cause behind the mysterious and deadly affliction of amyotrophic lateral sclerosis, better known as Lou Gehrig's disease, which could lead to an effective treatment.

Dr. Teepu Siddique, a neuroscientist with **Northwestern University's Feinberg School of Medicine** whose pioneering work on ALS over more than a quarter century fueled the research team's work, said the key to the breakthrough is the discovery of an underlying disease process for all types of ALS.

The discovery could also help in developing treatments for other, more common neurodegenerative diseases such as Alzheimer's, dementia and Parkinson's, Siddique said.

The Northwestern team identified the breakdown of cellular recycling systems in the neurons of the spinal cord and brain of ALS patients that results in the nervous system slowly losing its ability to carry brain signals to the body's muscular system.

Without those signals, patients gradually are deprived of the ability to move, talk, swallow and breathe.

"This is the first time we could connect (ALS) to a clear-cut biomedical mechanism," Siddique said. "It has really made the direction we have to take very clear and sharp. We can now test for drugs that would regulate this protein pathway or optimize it, so it functions as it should in a normal state."

The announcement of the breakthrough is in Monday's issue of the research journal *Nature*. The paper lists 23 contributing scientists, including the lead authors, Northwestern neurological researchers Han-Xiang Deng and Wenjie Chen.

ALS afflicts about 30,000 Americans. With no known treatment for the paralysis, 50 percent of all ALS patients die within three years.

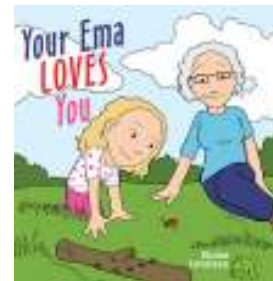
In 1941, New York Yankee baseball star Lou Gehrig died at 37 of the disease that now carries his name.

October 6, 2011
Cross Creek Country Club
Mt. Airy, NC



[Click here](#) for more information.

Children's Book Authored by ALS Patient



[Click here](#) to order

ALS Run for Jeremy 5K
October 8, 2011
Hamilton, GA



[Click here](#) to register or donate.

100 Innings of Baseball

Amelie Gubitz, a research program director at the **National Institute of Neurological Disorders and Stroke**, said the Northwestern research is a big step forward in efforts worldwide to conquer ALS. [Read the full article](#)

Spectacular
October 8, 2011
Quincy, MA

[Click here](#) for information.



Despite Neck Surgery, Doug McConnell Raises Money for ALS

Article by: JANET MOORE , Star Tribune

Doug McConnell had just polished off a big greasy plate of fish and chips while in Dover, England, when the call came.

"Can you swim the English Channel tomorrow?" he was asked. Of course, he could swim it, McConnell thought. He knew he was ready. The 53-year-old Chicago-area investment banker had been training for the notoriously difficult trek from Dover to the French port of Calais for more than two years. Part of that training was disrupted by a severely herniated disc in his neck that required a cervical disc replacement, made by Fridley-based Medtronic Inc.

On Sunday, **McConnell swam across the 30-mile channel in 14 hours, 18 minutes** -- the 48th person over the age of 50 to swim the Channel. "I'm a little sore, a little beaten down, but pretty good overall," he said the next day.

McConnell decided to try the Channel swim as a way of raising money for ALS, or Lou Gehrig's disease, a neurodegenerative disease that claimed his father, David, in 2006. Ultimately, he hooked up with the **Les Turner ALS Foundation's** research program at **Northwestern University's Feinberg School of Medicine** and raised more than \$130,000 to benefit the Skokie, Ill.-based foundation.

"It's just fabulous," **Wendy Abrams**, executive director of the ALS foundation, said of McConnell's accomplishment. "Doug is amazing."

But McConnell's feat almost didn't happen after he was diagnosed two years ago with the herniated disc that was rendering his left arm nearly useless. [Read more](#)



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