

## A special Valentine's Day story

## TRICKETT WENDLER'S STORY IS ONE OF EXTRAORDINARY LOVE, GENEROSITY AND COURAGE. SHE IS DEFINITELY AN INSPIRATION FOR ALL OF US ON THE ACTIVE AGAINST ALS TEAM, AND WE WANTED TO SHARE HER STORY WITH ALL OF YOU.

Trickett (Fewell) Wendler lives in Wisconsin with her husband and three children. In June 2013, at the age of 39, she was diagnosed with a rare familial form of ALS, the fast progressive SOD1 gene. Trickett was in a wheelchair by July. With the support of family and friends, Trickett shares about living with ALS and her family's journey with the disease on her Facebook page.

Trickett has faith that greater awareness will lead to a commitment for a cure. This past Valentine's Day, she was invited by her daughter Tealyn's 5th grade teacher, Mrs. Ward, to speak to the class.

Trickett expected hard questions from the curious students, but didn't anticipate their selfless generosity. Before she could catch her breath and put on her "no tears" face, a 10-year-old student asked, "How would you like \$253 for medical bills and research for a cure?"



Trickett Wendler (center) on her Valentine's Day visit to her daughter Tealyn's fifth grade class. The students surprised Trickett with a \$253 donation that they had raised on their own.

Mrs. Ward had prepared the class a few days before Trickett's visit by quoting Dr. Stan Appel's message to Congress: "ALS is not an incurable disease. It's an underfunded disease."

A little boy, Alex, asked the teacher, "What if we raised funds? Can we do that to help?"

To Mrs. Ward's surprise, Alex came back the next day with a pink donation box decorated with words of encouragement to fight ALS. Over the next two days, the fifth graders returned to school with contributions from families and piggy banks. The children made a seemingly small but profoundly moving gesture. It was just that simple to them: the students decided *we can do something about this*, and did.

Wearing her heart on her sleeve, Trickett responded to the children's sometimes difficult questions like: How do you stay strong and be there for your family? "I can be there for them," she said, "because they're here for me. My fifth grader has a lot of responsibility. She helps me get my socks and shoes on, and she stands next to me so I don't fall. My heroes are my family."

Trickett later reported that it was sometimes hard to know how to answer honestly. A child asked: Do you think you'll ever walk again? As Trickett reflected, "It's hard because we were having an honest conversation and my realistic side knows it isn't likely, but there is a part of me that has hope. So I told them the truth, that I don't know, but I really hope so."

As she wrote on her Facebook page, "These students teach me hope and how to keep my courage."

We encourage you to also be inspired by Trickett's zest for life and her commitment to building awareness about ALS and raising research funds for a cure. You can like her Facebook page here.





# Young People Making a Difference



YOUNG PEOPLE ARE PASSIONATE, and when they know about a problem, they want to help! Here at Active Against ALS, we continue to see again and again that the youth in our community are inspired to make a difference. We strive to foster this spirit and welcome youth of any age to participate in our activities, make up their own, or help us to organize, like U-M sophomore Eli Sugerman who joined our Events Committee, or U-M fraternity members Kevin Dickey and Dan Scott who attend our board meetings as Phi Delta Theta representatives.

#### SAM SUGERMAN'S ANNUAL RIVALRY RIDE

In October 2012 Sam Sugerman raised over \$8,000 by bike-riding from Spartan Stadium to The Big House on Michigan vs. Michigan State game day. Sam received outpourings of support from both sides of the field, and the experience energized him to make this an annual event, called the "Rivalry Ride." This past October, Sam and his buddy Ben Chosid (8th graders at Tappan Middle School) led their friends and family in the 65-mile ride from The Big House to Spartan Stadium. It was a cold, rainy morning as they rode off, but they were full of spirit, decked out in their bright Active Against ALS gear. Join the ride this fall on Oct. 25. Contact sugrosen@comcast.net for more information.

#### THANK YOU, PIONEER SENIOR STUDENT COUNCIL!

Pioneer High juniors and seniors hit the football field this fall in a Powder-puff Flag Football game. These amazing girls, hoping to bring back an old tradition, showed the boys cheering them on how flag football is really played. Senior Class President Tess Thompson suggested Active Against ALS as the recipient organization for the proceeds. She reported, "Everyone loved the idea. Many of our student council members, including myself, play field hockey with Maddie Schoeni and/or have volunteered for Active Against ALS before, so we were excited for the opportunity to raise money and awareness for ALS. We also know that Active Against ALS focuses on being active, so we thought that a flag football game would be a great way to support your cause."

#### **DID SOMEONE SAY SPRING CLEAN OUT?**

Vivian Ross, 10 years old and a long-time supporter of Active Against ALS, is organizing a Spring Garage Sale. As she wrote to the board, "I would like to propose the idea to have a garage sale to raise money to find a cure for ALS. I just thought it would be fun to have one, [and] we have like a literal ton of stuff to sell and we could raise thousands of dollars just by selling stuff we don't want anymore."

Stay tuned for details about Vivian's Garage Sale! And if your child wants to get active, we welcome his or her participation!



#### SCIENCE ADVISORY BOARD. Our

Distribution Committee, led by Caren Goldberg, a U-M pediatric cardiologist, has been working hard to put together a Scientific Advisory Board. The committee is identifying leaders in the field who will help us keep abreast of ALS research and ensure that our donations make the biggest possible difference. We hope to have the SAB set up in the next few months and we will post information on our website.

**TEAM GLEASON.** Steve Gleason, a retired defensive back for the New Orleans Saints, was diagnosed with ALS in 2011 at age 34. Through the non-profit Team Gleason, Steve advocates for the use of technology and makes it available for patients with ALS. Watch this inspiring video and check out Team Gleason's website.





TO THE MANY PEOPLE WHO ARE BEING ACTIVE AND FIGHTING LOU GEHRIG'S DISEASE!

#### FAMILY FIELD DAY SEPTEMBER 2013

Although the 6th Annual Family Field Day was our wettest yet, hundreds of folks came out, smiling and energized. Thank you to Burns Park Principal Chuck Hatt and 5th grade teacher Sandy Kreger for spending the whole afternoon with us! Thanks also to Olympic skater Emily Samuelson who helped out and inspired our kids with her Olympic training stories. We appreciate everyone who participated, and we thank our sponsors and volunteers. This is always a fun, spirited day and we are already planning for Sunday, September 28. We can't wait to see you there! Want to be on the planning committee? Contact Susan Miller at: info@a2a3.org.

#### PHI DELTA THETA'S "WHAT'S THE SCORE?" FUNDRAISER



The brothers at Phi Delta Theta set up a table on South University on home game Fridays and sold chances to win a prize for guessing the game's score. Nice way to help people learn about ALS and raise funds! Thanks, guys!

#### THE 2<sup>ND</sup> ANNUAL RIVALRY RIDE



Thank you to Sam Sugerman and all the riders who participated in the 2nd Annual Rivalry Ride.

#### PIONEER FLAG FOOTBALL EVENT



Thank you to Pioneer Senior President Tess Thompson and the Pioneer Senior Student Council for organizing a girls' flag football game to raise funds

for Active Against ALS. We appreciate the Council's efforts, which will hopefully set the stage for making this an annual event.

#### **END-OF-THE-YEAR APPEAL**

Thank you to all who responded to our first ever end-of-year appeal. Your dollars go directly to ALS research and are critical funding

sources for researchers working to find a cure.

#### Events at a Glance

BOX CAR DERBY Saturday, March 29

TWINKIE RUN Monday, April 1

#### ACTIVE AGAINST ALS AT THE BURNS PARK RUN

Sunday, May 4

#### ACTIVE AGAINST ALS AT A2-DEXTER RUN

Sunday, June 1

ELECTRIC BOLT Sunday, July 28

FAMILY FIELD DAY

Saturday, September 28



Volunteers Elaine Spreitzer and Shelly Webber man the bake sale table at last fall's Family Field Day.

## Thank you to all our generous volunteers!

Active Against ALS is a grass-roots organization run totally by volunteer efforts. The board wants to thank the dozens of individuals who give their time on our planning committees, our organizational commitees and our events. Whether running a board retreat, designing a poster, or tapping the root beer keg, we are deeply grateful for your participation and your support of Active Against ALS!



# Ann Arbor ACTIVE AGAINST AGAINST

#### RAISING FUNDS. RAISING HOPE.

2020 Shadford Road Ann Arbor, MI 48104 734.623.9877 info@activeagainstals.org

WWW.ACTIVEAGAINSTALS.ORG

## 6th Annual Box Car Derby

Saturday, March 29 on South University. Start time: 10:00 a.m. Come join this crazy, fun day! Race or cheer on racers. We guarantee lots of smiles. For more information or to register, click here.

### Summer Events to Remember

It's hard to think summer with all this snow, but it'll be here before we know it! In July, the Buhr Park Sharks will swim hundreds of laps for ALS research, plus we have the 4th annual Electric Bolt run through downtown Ann Arbor. Visit activeagainstals. org to stay updated.

Annual April Fool's Day Twinkie Run

The Twinkie is back and we have them! After being tied up in bankruptcy court last year, the Twinkie is ready to go. Come on out to this wacky April Fool's day 5K Monday, April 1 at 6:15 p.m. For more information or to register, click here.

## Create Your Own Fundraiser

Do you have an idea to raise funds for ALS research? We'd love to help you get your effort going. We have had bikers, runners, swimmers, virtual bakers and lemonade makers! Check out the great initiatives here.

> 2020 Shadford Road Ann Arbor, MI 48104

