



ALS Support Group of NW WI

**A Gathering of Individuals Touched by ALS
Share Joy, Sorrow, Laughter, Tears, and Hope.**

Receiving a diagnosis of ALS is challenging and can be very overwhelming. The ALS support group provides a safe place where patients, families, friends, and caregivers Gather to share information, support, and resources with others who understand.

Second Thursday of each month, 1:00pm – 3:00pm At Chippewa Valley Bible Church in Chippewa Falls

May 9, 2013 Support Group Meeting Notes:

Meghan Lee Donahue a Rehabilitation Engineer at SVRI at UW Stout spoke about her job helping people with disabilities use technology to increase their quality of life. Sometimes people are able to return to work, other times just to get through the day. The bottom line was pretty much if you have a body part that works Meghan would be able to hook you up with a communication device.

John Jaeckel & his wife Deanna from Hayward, WI represented our State for National Advocacy Day in Washington DC. John has provided us with the following article written by his daughter.

Heros in Red

You are likely familiar with the pink ribbon signifying the tremendous battle against breast cancer. This symbol gained its popularity from the efforts of many individuals who created this awareness. It is our knowledge of the disease, personal connection, and/or recall of heartbreaking stories that creates the lump in our throat at hearing the “C” word. Cancer

research, funding, and advancement have been made possible by millions of people making it a priority to rid future generations of this painful and exhausting journey. Here comes the unthinkable; after being tested repeatedly with no leads, your doctor enters the room, avoids eye contact, and eventually mutters the words, “I’ve got bad news, it’s not cancer.”

Have you ever seen a red “A”? You may be picturing the symbol from the American classic, The Scarlet Letter; a story of shame, isolation, and a lack of forgiveness. Unfortunately, this is much like the feeling the “A” presents upon diagnosis. Your life is completely turned upside down after hearing those horrifying 3 letter, *ALS*. Up until about 3 years ago, I will attest to having minimal knowledge of ALS; only knowing it brought about a quiet, painful connotation. I became uncomfortably familiar with those 3 letters quicker than I could imagine. These letters, I was told, provided little to no knowledge or hope. They threatened to take away everything I knew, cherished, and loved. The diagnosis was simply unfair. How could one ever explain why a great man who is such a highly respected teacher, coach, mentor, husband, and father (to many) receive such a fate? ALS, more commonly known as Lou Gehrig's disease (after the famous baseball player), is a neuromuscular disease that causes atrophy, loss of ability to communicate and swallow, and eventually traps you inside of a body that is unable to function independently. ALS has a 2-5 year life expectancy (representing quantity, while the quality is unique to each patient). Currently, there are about 30,000 Americans with ALS because of its rapid turnaround of patients. There is no known cause, treatment, or cure. You are left with few options to proceed with the life you once had planned. But that is only if you are willing to accept that.

My family has received endless love, support, and opportunities in the last 3 years. Our friends and family have wrapped their arms around us, making sure we know they are always available and willing to help in anyway they can. I rarely come home without hearing, “How’s your dad? You let him know we pray for him everyday!” My parents have a strong foundation in their faith and pursue every opportunity to be thankful for each and every blessing in our life. We were also referred to one of the most knowledgeable and confident women I’ve ever met. Karen Hurd presented the fact that there *is always* something you can do and opened our eyes to power of nutrition when our hope was scarce. Because of these resources, we are blessed with 3 solid years of life under our belt after being diagnosed. (Yes, we are proudly breaking the traditional outcome.) Recently, we were presented with the opportunity to move from *affected to advocate*. The Wisconsin ALS Chapter invited my family to ALS Advocacy Day in Washington, DC to connect other PALS (people with ALS), learn about new medical advances, and most importantly, advocate on Capitol Hill. While this was our agenda, it does not display an accurate account of our trip. Instead, I left Washington, DC a far different person than arrived 4 days prior.

Our journey started with hearing from OJ Brigance and Steve Gleason, two former NFL football players known for their tremendous speed and strength, who at a very young age have become victims of ALS. The term victim doesn't really fit, however. Both men used eye-gaze software, using tremendous precision and patience to deliver messages that left our eyes overflowing with compassion. Their progression, quick and relentless, has taken every personal independence and made them nearly unrecognizable to the men who once took the

field every Sunday. Yet, every day they get up ready to fight, advance knowledge of ALS, and help others. The irony in the “football themed” event gave me chills as I sat next to the former player who still can’t seem to shake his love of the game. Steve Gleason coined the phrase, “No white flags.” It soon became very evident that I was not in a room full of victims as I once thought, but rather amongst some of the most courageous, resilient individuals of our country.

We picture heroes as strapping, strong individuals who fly, lift trucks, and save lives. The heroes I met had been robbed of their voice, ability to walk, eat, or breath, as well as their independence; yet, refuse to relinquish the opportunity to save lives. Many of them know that they will likely not see the impact of their actions in their lifetime but continue their pursuit to ensure this not be the fate of others in the future. Their relentless effort to pay it forward instilled a desire in me to do the same. In the woods of Northwest Wisconsin, it is easy to feel alone in this battle but I am now a part of a greater family. One that spans from coast to coast, each member in their own unique phase of progression who refuse surrender.

Other speakers included some of the world’s most brilliant doctors and scientists who have dedicated their lives to progressing the advancement of research in the ‘disease without hope.’ Their tireless efforts continue to bring new data, understanding, and answers to the endless questions surrounding ALS. They stressed the importance of being a part of medical research studies. Clarifying that without people willing to advance medicine, it will stay at a stationary state. There are two necessary elements in progressing medicine; knowledge, which comes from research and application, both requiring a financial foundation. This was the focus of our journey to Capitol Hill. Every state was represented by at least one family affected by ALS. As the only Wisconsin representative at the conference, we had lots of responsibility that could bring great possibilities. Our purpose was to share our story and promote continued funding for research as well as the National ALS Registry, that tracks all patients affected by ALS with the intention of targeting its cause. Ideally, with a cause, you can find treatment and ultimately change the fate of these 3 letters. I’m proud to inform you that every Wisconsin representative came forward feeling strongly about the advancement of finding answers to ALS. We were fortunate to meet with our district representative and local Haywardite, Congressman Sean Duffy, who offered his support in anyway he could. His efforts, combined with the rest of our representatives will hopefully continue to keep Wisconsin as one of the strongest ALS advocacy states in the nation. Our advocacy at the Nation’s Capital brought an army of heroes proudly displaying their red “A” and making it clear that there are “no white flags.”

Ultimately, it does not matter who you are or what cards you have been dealt. It is your resilience to pain and hardships. It is your ability to wake up everyday knowing that you can *always do something* to make an impact. Understanding that changing the world isn’t merely a matter of speaking eloquently or “standing” up to your enemy. Most importantly, that heroes are not in the size of their arms, but rather the size of their *choice* to make a difference, against all odds.

Sara Jaeckel

**5th Grade Teacher
Gebhardt Elementary**

John Jaeckel will be our speaker for the 7-11-13 support group meeting and will be featured in the next issue of The Hope Line.

Hope to see you at our Annual ALS Walk & Wheel-a-thon Sunday June 9, 2013!!

**Take good care.
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