



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*

April 11, 2013 Support Group Meeting Notes:

April meeting was canceled due to inclement weather.

Upcoming events:

Caring for the Caregiver

Featuring Janie Jasin, Speaker, Humorist, Author

Friday May 3, 2013 11:30 am – 3:30 pm

Sacred Heart Hospital Community Auditorium

Any Professional or Family Caregiver is invited to attend.

Limited seating, call Center for Healthy Living 715.717.1600

**ALS Fundraiser - Sunset Tavern – Black River Falls Poker
Run - registration from 10:00 am – noon – back at 5:00
pm Horseshoe & Bean Bag challenge starts at 11:00 am
Prizes 50-50 Raffle Music Fun !!!! Saturday June 8
2013. For more information, please call (608) 633-2193**

I attended the

9th Annual ALS Care & Research Symposium April 20, 2013 at the Sheraton Milwaukee Brookfield Hotel in Brookfield, WI. Please allow me to share some highlights of the day.

After a good breakfast I took my time & visited with approximately twenty exhibitors. They ranged from providing accessible home modifications, customizable communication tools, mobility modifications, home medical equipment, home care service options, stabilizing respiratory health, Hospice & Palliative Care, nutrition support, massage therapy & Paralyzed Veterans of America. Besides helpful resource information I came away with freebies – candy, ink pens, note pads, tote bags, measuring tape, medication organizer, etc. It was fun.

The Keynote Speaker was Richard Bedlack, MD, PhD.

His talk was excellent. I'd like to share his background because it is impressive! Rick Bedlack grew up in a small town in central Connecticut. He went to college at William and Mary in Virginia, then back to Connecticut for an MD & PhD in Neuroscience at UConn. Finally, he came to Duke where he completed his Medicine internship, Neurology Residency, Neuromuscular Fellowship, and Doctor, and the American Academy of Neurology Patient Advocate of the Year. He has received ALS research grants, participated in ALS clinical trials, published more than 60 ALS articles & recently edited a new book called Masters in Clinical Research Science. He is currently a tenured Associate Professor of Medicine/Neurology at Duke, Director of Duke ALS Clinic, & Chief of Neurology at the Durham Veterans Affairs Medical Center. He has won awards for teaching & patient care, including best Neurology teacher at Duke, Health Care Hero, Strength Hope & Caring Award, America's Best ALS: A Patient Care Guide for Clinicians. He is the outgoing Chairman of the North American ALS Research Group (ALSARG) & leader of the international ALSUntangled program which utilizes social networking to investigate alternative & off label treatment options for patients with ALS.

After lunch two men & two women told their personal stories of living with ALS. Bless their hearts for their willingness to share with about 200 people. Each family was inspiring & encouraging. I left – just like last year – so grateful I was fortunate enough to attend.

If you are interested in attending next year the Chapter website is www.alsawi.org

Take good care.

Julie Chamberlain, LPN

ALSNWWI Patient Services Outreach

715.271.7257

alsnwwi@gmail.com

