



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

October 10 , 2013 Support Group Meeting Notes:

October meeting saw a good turnout on a beautiful Fall day. We decided that since our group is growing it would be helpful to use name tags for future meetings. We talked some on if we should write up some ground rule guidelines that could be read at the start of meetings. Also the idea of a loan library was mentioned with the offer to the group that if they had a specific Title of a book or just a subject in general I would be happy to supply books. One man suggested golfing & another requested novels. Now I can be flexible but somehow the book needs to relate in some way to ALS.

One attendee who lives on Round Lake has offered to host a support group meeting if people would be willing to drive. The place is BEAUTIFUL and feels like therapy just to look at the lake. Handicapped assessable. She was thinking Spring or Fall.

The announcement was made of the upcoming MDA Symposium in MN that was free to the public.

Two attendees had just lost a family member to ALS. This would be the 8th family member in three generations. They gave the group money that family members had donated to our group specifically for supplies for the monthly meeting. Thank You & God Bless You & our heartfelt sympathy.

We also discussed Accupuncture & Chiropractic as possible speakers for upcoming meetings.

Ask the Doc: Q & A with Edward Kasarskis, MD, PhD

- *Edward Kasarskis, M.D., Ph.D. is Director of the multidisciplinary ALS Center at the University of Kentucky Neuroscience Center in Lexington, Kentucky, professor in the Department of Neurology at the University of Kentucky, and Chief of Neurology at the VA Medical Center in Lexington KY.*

- **Q:** My neurologist has told me that he has had very little experience with people with ALS. I live four hours from the nearest big city. What am I missing by not having a physician with specific expertise in my disease?

- **A:** There are, in a sense, two separate phases of ALS: the diagnostic period of determining whether you do indeed have the disease and the time after diagnosis that involves managing issues and challenges that will be coming in the future. Working with an ALS expert is critical in both phases.



Dr. Kasarskis

- We have no definitive way of making the diagnosis of ALS; there is no blood test, spinal fluid test or imaging test that can make the determination. (People are working hard to develop such a test, but there is nothing available yet.)
- So in order to make the diagnosis, a physician needs to see a solid history of progressive weakness, but also has to rule out other causes for your symptoms, including metabolic issues, various nerve or muscle diseases, or structural problems within the spinal column (such as spinal stenosis). This may explain the extensive testing that likely was your experience. Getting a second opinion is an important part of that process.
- A second opinion is also a good investment in your peace of mind. It puts you on the right path for appropriate treatment and support. Before the diagnosis is determined, there is a certain amount of uncertainty that is really nerve wracking. Yet I've found that people, once they know their diagnosis is accurate, can usually roll up their sleeves and get to work learning about ALS and the challenges that lie ahead. They are able to adapt to a pro-active approach to managing their illness.
- Once you are certain you have ALS, it's important to find a team of people who can help you manage the disease and anticipate potential problems before they arise. The best bet is to go to a dedicated ALS clinic for your care. Your local neurologist is undoubtedly a good physician, but it will be very difficult for him or her to assemble the full team that will be needed for your care in a timely fashion.
- At an ALS clinic, you'll get evaluated by a neurologist who is an expert in ALS, and you will work with a multi-disciplinary staff that includes a physical therapist, respiratory therapist, occupational therapist, registered nurse, nutritionist, and others all experts in managing ALS. The team is also trained to help family caregivers learn specific things they can do to best support the person with ALS. An expert team anticipates what the next challenges will be in the next three, six or nine months and can help problem-solve your particular situation.
- I would encourage others who, like you, live hours from an ALS clinic to find a way to visit such a resource regularly, say every three months. Many of our patients make the drive the day before their appointment, stay overnight in a hotel, go to the clinic the next day, and then drive home. Sometimes clinics can arrange alternate visits with your local neurologist, who can confer with the ALS clinic neurologist as needed.
- The way I figure it, every three months you would invest about 12 hours of travel and clinic time for the benefit of your health. Sure, the effort involves inconvenience and expense. Travel can be arduous as ALS progresses. But a commitment of 12 hours isn't that great for an investment in maintaining your ability to function. I would encourage you to literally "go the extra mile" to get the most informed, experienced care you possibly can, in concert with your local neurologist and primary care physician.

- **Upcoming Webinars**

► *Equipment Designed for Safe Transfers and Effective Mobility*



Monday, October 21, 2013 at 11:00 am, Pacific Daylight Time

Session number:

Session number: 824 394 547

Session password: Atcalloct2013

Call-in toll-free number (US/Canada): (877) 668-4490

[Click here](#) to register for the call and get call details.

Take Good Care

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