



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

July 2013 Support Group Meeting Notes:

17 people attended our July Support Group Meeting. This was the first meeting for six of these people, with two having been recently diagnosed with ALS. We were happy to have such a large group .It was a good meeting with many topics brought up & many questions answered.

One member who lost his wife to ALS in May of this year stopped in to donate equipment, supplies & money in his wife's memory. It was important to him to let the group know that they were very helpful during their time dealing with ALS. This is exactly why we exist.

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

Are There Limitations on Joining Clinical Trials?

Q: I recently learned that people with ALS who were diagnosed a year ago or longer are not eligible for clinical trials. Why would that be?

A: All clinical trials have a set of specific selection criteria for participants. Sometimes they are related to the individual's disease and often the criteria are related to age, gender, and distance to the study site. It all depends on the particular study and what features have to be "ruled out" to be sure they won't affect the outcome of the study.



Dr. Kasarskis

One of the challenges in enrolling people with ALS in a clinical trial is that just getting diagnosed typically takes about a year on the average. It usually takes about 9 to 12 months to diagnose someone with certainty, and the minimum time it takes to be diagnosed is usually 6 months.

With ALS, there is a fairly narrow window for recruiting clinical trial participants depending on the study. You have to know for sure that the potential trial participant has ALS, so practically speaking, it is almost impossible to enroll an ALS patient who has the disease for only 3 months. At the other extreme if researchers are studying a drug that involves measuring the progression of ALS, they may not accept volunteers who have had the disease for 9 to 12 years. That's because this person with a slowly-progressing form of the disease probably won't have measurable changes during the normal course of a clinical trial.

Sometimes people are not accepted into clinical trials for other reasons. For example, we've had studies that involved measuring a patient's changes in breathing status. But if someone with ALS has their breathing at 100% of normal, they might not be able to join the trial. We've also been involved in a study that was measuring muscle fatigue; some people could not participate because they didn't have enough strength to hold the "grip dynamometer" which was used to monitor changes in muscle power.

So the bottom line is that each clinical trial is different and each has their own set of rules (entry criteria).

RESEARCH

ALS Association-Supported Study Shows Combining Two Growth Factors May Have Advantage in ALS Treatment

A study published in the scientific journal *Molecular Therapy*, which was supported by the [Wisconsin Chapter of The ALS Association](#) and led by University of Wisconsin at Madison researchers, shows in ALS that two growth factors may be better than one.

Growth factors are proteins produced by one set of cells in the body that help promote the health of other cells. Previous work has shown that both VEGF (vascular endothelial-derived growth factor) and GDNF (glial-derived neurotrophic factor) can promote the survival of motor neurons in models of ALS. Motor neurons are the cells that die in ALS and lead to paralysis.

"This study provides support for the idea that delivering growth factors to muscle may be beneficial in ALS," said Lucie Bruijn, Ph.D., Chief Scientist for The ALS Association. "Further work will be needed to

explore this option, but it has the advantage of being less invasive than delivering the same growth factors to the spinal cord.”

Masatoshi Suzuki, Ph.D., and colleagues tested whether the two growth factors together could provide more benefit than either alone. These researchers engineered stem cells to produce both growth factors and then injected these cells into the muscles in a rat model of ALS. The combined treatment increased lifespan and improved features of the motor neurons at the point where they contact muscle.

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Take good care.
Julie Chamberlain, LPN
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