February 2013
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

Support Group February Meeting Notes:

February Support Group was attended by eight people. Two of these people were new to the group. As with any first time visitors we all introduced ourselves & shared why we attend the meetings. We discussed the process of being diagnosed with ALS, different rates of progression, resources available & the difficulty of respecting the choices of the person with ALS even if those choices are painful for you.

Upcoming events:

Next support group meeting: March 14th 2013 at Chippewa Valley Bible Church

Rockin' For A Cure

A Live Music Event Supporting ALS Patients in Wisconsin

April 20th, 2013

Holiday Inn Madison West
1109 Fourier Drive
Madison, WI 53717

- Live Music -

- Appetizers -

- Silent Auction -

- Raffle Prizes -

- Cash Bar -

$20 Ticket Donation

discounted rooms, too, at the Holiday Inn - $89/night.

13th Annual Benefit for ALS

All Proceeds Go to The ALS Association Wisconsin Chapter

Rockin For A Cure – ALS Benefit – We are excited to announce our Guest Speaker – Mr. Jim Eutizzi who has embraced a mission to bring the battle to cure ALS directly to the people, through presentations throughout Southeastern Wisconsin, You Tube Videos, and personal blogging. Jim is a DRUMMER, so it is also fitting that he would have a PASSION for helping Rockin' For A Cure. The founder of Rockin' For A Cure, Steve Weekes, was also a DRUMMER with ALS, who made it his mission to raise awareness and funding to cure this disease. Steve Weekes was a member of the Madison Scouts Drum & Bugle Corps. For more info, go to www.rockinforacure.org or call 414.704.0209.

EST. 1958
MADISON SCOUTS
CORPS

Brought to you by Alumni and Friends of the
MADISON SCOUTS DRUM & BUGLE CORPS
www.rockinforacure.org

Ask the Doc: by Edward Kasarskis, M.D., Ph.D

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.

Survival and ALS

Q: I've read that many people with ALS are now living longer. Is that true?

A: Yes, I am very pleased to say that people with ALS are, on average, experiencing a less rapid decline in their muscle function and living longer than we previously thought possible.

But science is still asking: why do some people survive longer than others? If you can figure out an answer to this question, then you might be able to develop a drug that would have the same protective effect for all ALS patients.

To this point just last year, two teams of researchers discovered some clues about genetics that appear to influence survival time in people with ALS. One study published in the journal Nature Medicine showed how a low level of the receptor, called EphA4, is associated with people who live longer with ALS than others. Another recently-published study, this time in the journal Nature, identified a new ALS gene (profilin-1) that appears to work "collaboratively" with EphA4.

These two studies suggest there may be a molecular pathway in neurons (nerve cells) that helps explain not only which people are susceptible to ALS, but also how rapidly their conditions might evolve. My colleague, Dr. Robert Brown, Chair of neurology at the University of Massachusetts Medical School, was a study co-author. He says these findings are particularly exciting because they suggest that suppression of EphA4 may be a new way to treat ALS.

But while exciting studies like these continue, other research has shown that supportive care as provided by a multi-disciplinary team at an ALS Clinic -- measurably extends function and life for people with ALS. In fact, the American Academy of Neurology ALS Practice Parameters has found that multidisciplinary clinics optimize healthcare delivery and quality of life, and prolong survival. Research shows that the clinics provide an extra 1 ? years of additional survival. Enthusiasm for these clinics is appropriate; they really are that good.

So how do these clinics do this? In the specialized multidisciplinary ALS clinics, people with ALS get comprehensive care from a coordinated team that includes the ALS neurologist, a physical therapist, an occupational therapist, a speech pathologist, a dietician, a social worker, a respiratory therapist and a nurse case manager. By seeing all these disciplines during a single visit, people with ALS and their families get their concerns identified early and thoroughly addressed by the team.

This is about much more than simple convenience, although that is a real benefit to the patient and family. The team works collaboratively, pooling the individual expertise, to solve problems. At the risk of overstating the case, there is no problem the team at an ALS Clinic hasn't seen. And the team members believe all problems have solutions. The multi-disciplinary team approach also helps people with ALS and their families know what to next expect what is around the corner in six months or so -- so they can be fully educated and prepared. It is my belief that the pooled expertise in the clinic can identify the next potential problem, suggest a solution, and prevent catastrophic problems from developing.

RESEARCH

In ALS, Neurons and Support Cells Change Each Other, for the Worse

February 4, 2013

New research funded in part by The Greater New York Chapter of The ALS Association and the Alabama Chapter of The ALS Association revealed that the disease process in amyotrophic lateral sclerosis (ALS) involves a complex genetic interplay between motor neurons and astrocytes. Motor neurons are the cells that die during the disease, leading to paralysis. Astrocytes normally support motor neurons but switch to the opposite role during disease progression.

“These results strengthen the case that astrocytes are central to the ALS disease process,” said Lucie Bruijn, Ph.D., Chief Scientist for The ALS Association. “Furthermore, the results are based on an exciting new disease model system, one that will allow us to test important hypotheses and search for new therapeutic targets.”

The study, published in *The Proceedings of the National Academy of Sciences USA*, was performed by Hemali Phatnani, Ph.D., and colleagues and led by Tom Maniatis, Ph.D., from Columbia University Medical Center in New York in partnership with colleagues at the HudsonAlpha Institute for Biotechnology in Huntsville, Alabama. The study was conducted in a cell culture model of ALS derived from embryonic stem cells and in mouse models of ALS. Normal and diseased motor neurons and astrocytes were cultured together in various combinations and then separately analyzed. The authors tracked changes in the two types of cells by carefully identifying the RNA each cell type produced. RNA is a genetic messenger molecule that indicates which genes the cell is using at any moment. It was not previously possible to simultaneously examine gene changes over time in motor neurons and astrocytes in the same experimental system. Tracking the two cell types at the same time allowed the investigators to observe how changes in each cell type influence changes in the other. The communication between neurons and astrocytes “is profoundly disrupted” by the disease process, they concluded. Cells communicate with each other by releasing molecules that bind to specific receptors on the surface of other cells. The authors found this normal communication system was disrupted in the disease, which resulted in a network of gene changes that reduced protective behaviors for both types of cells and increased harmful activity by the astrocytes.

“This study points out several potential points for treatment intervention,” Dr. Bruijn said, in order to prevent the loss of protective behavior or mitigate the harmful activity. An important next step is to determine whether the harmful pathways identified in this model of ALS are also seen in other models and in the human disease. Finding the commonalities between the models and human ALS should provide the most robust targets for therapies. This goal was furthered by establishing a massive public gene expression database that can continue to be built and interrogated for “ALS disease signatures” in the future.

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Take good care.
Julie Chamberlain, LPN
ALSNWWI Patient Services Outreach
715.271.7257
alsnwwi@gmailcom