



## **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*

### **August 8, 2013 Support Group Meeting Notes:**

**We had one of our best meetings this month which I attribute to our special speaker Mr. John Jaeckel from Hayward, WI. He shared about his trip with his wife & daughter to Washington D.C. for ALS National Advocacy Day. He shared photos from the trip & stated that because of this experience he feels more compelled to be an advocate himself.**

**For the second month in a row we have had very good attendance with new people each time. We had a young woman who has lost her Father to ALS & also had made this same trip to D.C. read an article that she had written about her experience. It was heartfelt & touching. Mr. Jaeckel's daughter has also written an excellent article. We hope to have both printed on our web site soon. [www.alsnwwi.org](http://www.alsnwwi.org)**

**We heard about Mr. Jaeckel's personal story with ALS. Everyone shared reasons why they came & questions they had. We spent some time discussing not only medical approaches available but also a number of alternative treatments that may provide hope. ALSUntangled by Dr. Richard Bedlack, MD, PhD is a helpful website that will shine a light on scams & let us know what deserves a second look.**

### ***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.*

## Restless Nights, No Clear Reason

**Q:** My mother was diagnosed with ALS about five months ago. She had been very healthy, and then the first sign that she developed was slurred speech. Now she is unable to speak or walk, and while she is still able to feed herself, she's starting to have a hard time with that. But she's also having a lot of trouble sleeping, and she moans or cries about every hour throughout the night and needs my dad to put her into her wheelchair and take her to the bathroom. Most of the time it turns out she didn't need to go. The doctor has put her on sleeping medication, but it's not working all that well. What should we do?



*Dr. Kasarskis*

**A:** I'm very sorry to hear about your mother. Without hearing more, it's hard for me to know for certain what to recommend, but I think it may helpful to you and hopefully for other readers if I give it a try.

There are a few things to consider. First, it's possible that something other than ALS is causing your mother's night time discomfort and making her want to go to the bathroom so often. She may have a urinary tract infection, which typically causes someone to want to urinate frequently, often with a sense of urgency. One option would be to ask your physician to test her urine to see if she has an infection.

You mother also might have what is called an "overactive bladder," something that can be caused by muscle spasms. If this is what she is dealing with, her physician could prescribe a medication, called an "anti-cholinergic," which could reduce bladder spasms and might incidentally also help her deal with any excess saliva, a common problem among people with ALS. That's because a side effect of anticholinergic drugs is that they decrease saliva production. Excess saliva is often hard for people with ALS to deal with, especially when they have trouble swallowing. She also may be agitated or upset for other reasons. She could be having muscle cramps or restless legs syndrome, something that seniors frequently encounter, with or without ALS. There are drugs and treatments available for that.

Your mother may also be experiencing respiratory problems. People with ALS often develop difficulty breathing, which is related to weakness in the muscles that are involved in respiration. It's possible that sleeping medication could make the situation worse. That's because as she sleeps more soundly, she may find it harder to breathe deeply, and she awakens when the amount of oxygen in her blood dips below the necessary level for good oxygen circulation in the body. That might cause her to feel agitated or uncomfortable, and let's face it: going to the bathroom is a natural thing to want to do when you're uncomfortable in the middle of the night. Again, I am speaking in generalities since I have not evaluated your mother personally.

Your mom might benefit from pulmonary function studies or possibly an "overnight sleep study" to assess the situation. Her physician may decide to make it easier for her to get the oxygen she needs during the night by giving her what is called non-invasive ventilation ("Bi-Pap"), a pressurized breathing system that involves putting a plastic mask over her nose and mouth at night, with a machine doing some of the breathing work for her.

Complicating all of this is the fact that your mother is having trouble speaking. That means that her specific needs are hard for her to express, making it harder for your dad to make her comfortable. A variety of communication aids and devices are available to help with that.

All of these possibilities point to the fact that treating ALS is multi-faceted and involves a broad understanding of the unique challenges of the disease. That's why I would strongly recommend that your mother regularly visit an ALS clinic in addition to continuing her care with her primary care physician. In the clinic, she will be seen by a neurologist who specializes in ALS and a team of people, including respiratory and physical therapists, a nutritionist, an occupational therapist and a nurse, who would provide her with practical, multi-disciplinary care and support.

## New Study Shows Complex Role of Immune System in ALS

In a study supported by The ALS Association, researchers have identified the molecular signature of immune cells involved in the ALS disease process and used it to better understand the disease-related role of these cells, which surround dying motor neurons.

In the study, which was published in the journal [Cell Reports](#), researchers studied microglia, a type of immune cell found in the central nervous system (CNS). They identified 29 genes that distinguish microglia from other cells in the CNS. Using these as cell-specific markers, they were able to study the proliferation and movements of microglia during the ALS disease process in ALS mice in unprecedented detail.

The researchers found that the microglia may have both neurotoxic and neuroprotective effects. This result may suggest that treatments that broadly suppress the immune system may not be the most effective strategy against the disease, but further work will be needed to explore that possibility.

“This study provides an important new tool to study the role of these cells in ALS,” said Lucie Bruijn, Ph.D., Chief Scientist for The Association. “We can now use this tool to answer questions about the disease process, which we have not been able to ask before. That should help us determine the best way to manipulate the immune system to aid in fighting the disease.”

The research was performed by Isaac Chiu, Ph.D., of Harvard Medical School, and colleagues, under the supervision of Tom Maniatis, Ph.D., of Columbia University Medical Center with the assistance of Richard Myers, Ph.D., of the Hudson Alpha Institute for Biotechnology in Huntsville, Alabama. Dr. Maniatis’s work is supported by the Greater New York Chapter of The ALS Association, and Dr. Myers’s work is supported by the Alabama Chapter of The ALS Association.

**Take Good Care**  
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