

ALS Support Bulletin

Advising, Learning & Sharing

Ah... there is just so much to see!

By Luanne Atkins and Bonnie Shaver

My brother Jim and his wife Bonnie were my biggest support team when I lost my job and was struggling with what to do. The job market was not profitable and retirement was not an option. They were both there for me, giving me the courage to start over again. Unfortunately, that same year, Jim passed away from pancreatic cancer and Bonnie was diagnosed with ALS, Amyotrophic Lateral Sclerosis, often referred to as Lou Gehrig's disease.

After my brother and Bonnie's husband, Jim, died we knew that we had to lean on each other for support. I decided to move to Marietta to become Bonnie's caregiver and we immediately made travel an obsession. Our first big trip was to a resort just outside of Honolulu, Hawaii. We stayed for a wonderful week along with two other friends. We did an enormous amount of sightseeing in those days. We have been on a ten-day cruise to the Inside Passage of Alaska. We have taken several other trips but the best one was a six-week road trip across the United States and Canada. We covered 32 states and 3 provinces in Canada starting in Boston, to Maine, Niagara Falls, Banff, Yellowstone, Olympic Peninsula, San Francisco, the Grand Canyon. Ah...there was just so much to see!

Here are some tips we learned during our travels that might help.

- Be flexible. Traveling can be exhausting, whether by car or plane. Allowing time to rest was high on our priority list. On a cruise, side trips aren't flexible and need to be planned for accordingly. When flying or cruising, be sure to tell your travel agent that you are traveling with a handicap person.
- Ask for handicap accessible rooms. On a visit to Mt. Rainier, we decided to spend one night at Paradise Inn. It was dark, cold and foggy as we drove the winding mountain road. When we got there, it was a beautiful old lodge but lacking in a few modern conveniences such as TV, Internet and elevators. We had requested a first floor room. We "assumed" wrong. Imagine our surprise when we entered on the third floor and found our room two

floors down in the basement! Needless to say, we learnt our lesson there and going forward, always called ahead to ask for "a room accessible by a wheelchair".

- Do your research. We are brochure hoarders! We gather our information and plan our time. Hotels, restaurants and visitor centers are great sources. We love the book "The Next Exit" by Mark Watson. Available, in bookstores and online, this is a great source for places to eat, stay and play. There are many free or low cost places to visit across the country. We prioritize our outings by things we most want to see then and then fill in other activities as time and energy allowed.
- Plan, Plan, Plan. Do not wait until the last moment to plan a trip, especially somewhere new. We always have an agenda of each day's activities before leaving home. We do not always follow it, but it helped us be more aware of our time and reminded us the things most important on our list.
- Know your limitations. On our Alaskan cruise, Bonnie decided a helicopter ride to the Mendenhall glacier was something she wanted to do. Can you imagine climbing into a helicopter without the use of your arms? It wasn't a pretty sight.

We have had several "miss-adventures" on our travels. In Northern California, we decided to



drive through the Redwood Tree and set the camera up on a tripod so Bonnie could record the event. Unfortunately, I couldn't hear her and thought she was motioning me on through the tree when she was actually telling me to move over. Needless to say, we brought a little "tree rub" home with us as a souvenir.

All in all, I wouldn't trade a minute of our travels for anything. We are headed out in a few weeks on a Caribbean cruise.

Snorkeling will be the new challenge, but we will find a way.

Happy and safe travels to you all.

Luanne Atkins is a caregiver and sister-in-law of ALS patient, Bonnie Shaver. They both reside in Marietta, GA and are determined to live life at it's fullest every single day.

SUPPORT GROUPS

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| Athens Oconee Veterans Park, 3500A Hog Mountain Rd, Watkinsville, GA 30677 | Alpharetta Mount Pisgah UMC, South Campus, 9820 Nesbit Ferry Rd, Room A006, Alpharetta, GA 30022 | Fayetteville Senior Services Senior Center, 4 Center Drive, Fayetteville, GA 30214 | New Patient ALS Association of GA, 1955 Cliff Valley Way, #116, Atlanta, GA 30329 |
| Macon Central Georgia Rehab, 3351 Northside Drive, Macon, GA 31210 | Marietta First United Methodist Church, 56 Whitlock Avenue, Marietta, GA 30064 | Norcross Norcross First United Methodist Church, 2500 Beaver Run Road, Norcross, GA 30071 | FOR ADDITIONAL INFORMATION ABOUT THE SUPPORT GROUPS INCLUDING DATES AND TIME OF MEETINGS, PLEASE CONTACT THE ALS ASSOCIATION OF GA at 404-636-9909 OR VISIT THE WEBSITE www.alsaga.org |
| Columbus My Party Place, 1019 Broadway, Columbus, GA 31901 | Cleveland The Bridge Church, 976 Kytile Street, Cleveland, GA 30528 | Rome Rome First Methodist Church, 202 East 3 rd Avenue, Rome, GA 30161 | |

Roadmap to a Cure 2012

By Nicole Yarab

Mother's Day weekend is a special time of year. A time to honor our moms and celebrate all they have done for us. In the ALS community, Mother's Day weekend is extra special. This year, the ALS Association's National ALS Advocacy Day and Public Policy Conference will be May 13-15, 2012 in Washington, D.C. The weekend will begin with a Roll Call of delegates, where a representative from each state/ALSA Chapter will stand to acknowledge their participation, and briefly introduce their advocacy team. Some states are represented by one person while others may have more than 30 people ready to meet their elected officials on Tuesday. Next up is a session entitled, Preparation for the Hill which will give you all the necessary tools to communicate a clear and unified message to our elected officials. On Sunday evening, the Mother's Day BBQ is a fun time to socialize with your family, advocacy team and new friends in the ALS Community. One of the most touching and memorable highlights of the weekend is the candlelight vigil/rally at Freedom Plaza.

Monday's Public conference will start with a plenary session on ALS research. We'll hear about how people, just like you and me, have helped to generate over \$650 million dollars in government-funded ALS research since 1998. We'll learn more about how the ALS Research Program at the Department of Defense and the National ALS Registry are working towards better treatments and a cure and helping us to better understand the disease. Several breakout sessions are offered and you can choose which to attend based on your interest. Sessions include Congressional meetings 101, Advocacy Throughout the Year and Veterans Benefits. Further information on the MODDERN Cures Solution and the Prescription Drug User Fee Act as well as the biology of ALS and Chromosome 9 will be presented.

What is this all about?

Go to www.alsa.org/advocacy and download the Road Map to a Cure brochure to learn more!

Tuesday, May 15th 2012 is the big day. ALS Advocates from all 50 states go to Capitol Hill to meet with their respective senators and congressmen. You might say, "What difference can I make?" Here are a few examples of the amazing results of our ALS Advocacy efforts:

- 2001- ALS becomes the only disease without a 24-month waiting period for Social Security and Medicare benefits
- 2009- Veterans Affairs makes ALS a presumptive service-connected disease, making thousands of military veterans eligible for much needed financial support, equipment and care
- 2010- People with ALS began self-enrolling in the first National ALS Registry

Every May, hundreds of ALS advocates swarm Capitol Hill and cannot be missed! I can tell you from personal experience, that many of the congressional staff have told us that the impact of this day is significant. People are in and out of their offices all day long throughout the year. Everyone wants something and there are many different worthy causes and special interest groups fighting for government funding. The faces and stories of ALS shared during these meetings are unforgettable. Meeting a real person who is living life everyday with ALS or listening to a family member talk about their loved one, who was taken by ALS, leaves an indelible mark on people's hearts and minds.

Being an active part of this special day and throughout the year is an honor. It is extremely powerful to see the results of our advocacy efforts.

This is a wonderful opportunity to meet other people with ALS and their families from across the USA, and to learn more about what is going on in ALS research and public policy. If we all come together with one voice, it's amazing the difference we can make. **WE NEED YOUR SUPPORT.** As the National ALS Association office says, **"Without it, the progress we have realized may not continue and the fight against ALS may fall victim to politics and budget cuts. You have made a difference through advocacy."**

Let's make 2012 Georgia's year to shine! Please join me and the ALS Advocacy Team of Georgia in Washington this Mother's Day weekend.

Nicole is the ALS Nurse Clinician at the Emory ALS Center. You can contact her at nlessar@emory.edu. Also please visit the ALS Advocacy Team of Georgia Facebook page.

Information and

Treatment Links

www.als-mds.org

www.als-link.org

www.neurology.emory.edu/ALS

www.clinicaltrials.gov

www.alscenter.org

Equipment Educator - Patient (Hoyer) Lifts

A patient lift can either be a sling lift (such as a Hoyer Lift, a brand name) or sit-to-stand lift. This is an assistive device that allows the transfer of patients between a bed and a chair or similar resting places using hydraulic power. Sling lifts are used for patients whose mobility is limited. They could be mobile (or floor) lifts or overhead lifts (suspended from ceiling-mounted or overhead tracks). The sit-to-stand lift is designed to help patients with some mobility but who lack the strength or muscle control to rise to a standing position from a bed, wheelchair, chair, or commode. They use straps, vests, or belts (as opposed to slings) to make the transition possible.

When a person with ALS is no longer able to help with transfers, the use of a patient lift is necessary. There are different kinds of patient lifts, but the Hoyer lift is the most popular.

The way a Hoyer lift works is that a sling is placed underneath the patient and the boom arm of the lift picks up the sling with the person in it. Once the patient is raised up, the whole setup - lift, sling, and patient is rolled to the location that the patient is being transferred to. The boom arm is then lowered, and the patient is carefully guided down to the transfer location.

There are many different slings available. The U sling will allow the sling to be easily taken on/off of the patient. If you receive a different kind of sling, it will be difficult or impossible to take

the sling on/off the patient when not in use. This is important because a patient should not sit on the sling for extended periods of time. Sitting on a sling for a long period of time can put the patient at risk for pressure sores.

Tip: Sometimes people with ALS are leery of lifts, feeling insecure and vulnerable swinging in this new contraption. Practice on other family members to get a feel for it and to allow the patient to see it in action. Once the mechanics have been mastered, this is a terrific piece of assistive equipment.

The **ALS Support Bulletin** is a quarterly publication from HisGrip Home Care in close collaboration with professionals, patients and caregivers of Amyotrophic lateral sclerosis (ALS Lou Gehrig's disease) to **Advise, Learn and Share** information to patients and caregivers of the disease. To request copies of this publication or to be added to the distribution list, please contact the **Editor, Nike Aremu at nike.aremum@hisgriphomecare.com**.