

# ALS Support Bulletin

## Advising, Learning & Sharing

A PUBLICATION FOR ALS PATIENTS,  
FAMILIES AND CAREGIVERS

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[www.alsa.org](http://www.alsa.org)  
[www.alsaga.org](http://www.alsaga.org)  
[www.alscenter.org](http://www.alscenter.org)  
[www.als.emory.edu](http://www.als.emory.edu)  
[www.als.mda.org](http://www.als.mda.org)  
[www.clinicaltrials.gov](http://www.clinicaltrials.gov)  
[www.georgiahealth.edu/neurology/specialties/neuromusc](http://www.georgiahealth.edu/neurology/specialties/neuromusc)

### Join Our List

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### ALS Upcoming Events

#### May 2nd, 2015

9th annual FIESTA  
5k/15k Challenge -  
Forsyth Conference  
Center, Cumming, GA  
Click [here](#) for more  
information

#### June 27th 2015

ALS Association  
Educational Symposium  
Cobb Energy Performing

Issue: # 12

February 2015

Welcome to the February 2015 issue of the ALS Support Bulletin. This is a publication from HisGrip Home Care in close collaboration with professionals, patients and caregivers of Amyotrophic Lateral Sclerosis(ALS - Lou Gehrig's) disease. The goal is to Advise, Learn and Share information with patients and caregivers of the disease.

### Sometimes Laughter is the best medicine By Karen Duffy

On January 30, 2015, James Rodatus, an Atlanta pALS, entertained the crowd who gathered at the Famous Pub to Raise a Glass to Kick ALS's A\$\$\$. The event, hosted by Becky Kidd, was a thank you to the Emory ALS Center's clinic team. James, a stand-up comic, was a terrific act to begin the evening. We wanted to give you a more formal introduction to James in this issue's Living Life With ALS. I had the pleasure of interviewing James and here is his story.

KD: How about sharing some of your personal background - where you grew up, career, etc.?

JR: I grew up in metro Atlanta and went to college and law school at Mercer University. That's where I met my wife. She was in her first year of medical school and I was in my last year of law school. When she finished med school, we left Georgia for Virginia in 2008 when my wife started residency with the US Navy.

KD: When did you notice symptoms/something was wrong? How long to get diagnosed?

JR: I noticed something was wrong when I started having trouble hanging up my clothes. At first both my wife and I thought I had simply torn a rotator cuff. I was a bit confused when my primary care doctor referred me to a neurologist, but I still didn't think it was anything serious. Of course it came as a shock when my neurologist told me it was either ALS/Motor Neuron Disease, Muscular Dystrophy, or Spinal Stenosis. Like so many other people diagnosed with ALS, I was healthy and active. I was a regular, albeit fairly slow runner, I didn't smoke, and my cholesterol was enviously low. All that said, I was fortunate for several reasons. My primary care physician made the right call by referring me to a neurologist right away. A lot of people aren't that lucky. My neurologist at Navy Medical Center Portsmouth was very quick to get me into all the necessary testing (EMG, MRI). Since my wife was in the military, my out of pocket expense for all of this was \$0. I was diagnosed in September 2013, and my neurologist recommended that I go to a center that specializes in ALS research and that's how I found out about

Arts Centre  
Click [here](#) for more  
information.

**September 14th, 2015**  
3rd Annual Terance  
Mathis Celebrity Golf  
Classic  
Alpharetta, GA  
[Click here](#) for  
information.

### Got Feedback?

Did you find the information in this newsletter helpful? Are there specific topics that you are interested in? Would you like to contribute to an upcoming issue? The Editorial Team wants to hear from you. Click [here](#) to contact us.

### Resource Group Meetings

**Athens** - Oconee  
Veterans Park. 3500A  
Hog Mountain Rd,  
Watkinsville, GA 30677

**Fayetteville** - Senior  
Services Center. 4  
Center Drive,  
Fayetteville, GA 30214

**Marietta** - First United  
Methodist Church.56  
Whitlock Avenue,  
Marietta, GA 30064

**New Patient** - ALS  
Association of GA. 1955  
Cliff Valley Way, #116,  
Atlanta, GA 30329

For additional information

Dr. Glass and the Emory ALS Center.

KD: How has your sense of humor and comedy helped you throughout your ALS journey?

JR: I started doing comedy because, around 2011, I had a series of rather boring jobs. I was an Assistant DA in Georgia, and that job scratched the performer's itch that I've always had. I got a bit stir crazy once I had a job that kept me chained to a desk and required little in the way of mental energy. Thankfully, I got a boring job that let me work at home and that gave me enough time to pursue stand up. I had been performing for about two years when I was diagnosed. At that point, stand up had become a regular part of my life and it never crossed my mind to stop performing. I couldn't not talk about ALS on stage since it's obviously a major part of my life. It's helped tremendously. At first it was awkward to talk with people about my condition, but now it's pretty easy for me to tell people I've just met about ALS. After all, I've talked about it several times with a room full of strangers. Humor helps us deal with tragedy-not by insulating us from it, but by helping us confront it head on. When I started writing about ALS, it was easier for me to handle it in a rational and relaxed way. It still seemed horrible, because it is, but through comedy, I can confront the horror of ALS head on. I have little control over the disease, but I can regain some control over my life and emotions through comedy.

KD: Do you have any advice for those who have recently been diagnosed?

JR: This is a tough one. ALS hits everyone differently. With me it started fairly slowly in my arms, and it hasn't moved on much from there. With some people it starts with their ability to speak and swallow. Others, it starts in their diaphragm and they have to make the decision as to whether or not to get on a ventilator rather quickly. I can't really speak to those situations. By comparison, I'm relatively lucky. I've got drastically reduced arm strength, but I can still race cars, walk, and talk, do stand up, and drink beer.



That said, there are a few things that I think apply to all of us.

1. **Don't give up hope.** That's hard to do when you have a disease with no known cause or cure. My hope lies in the fact that the research going on right now is truly ground breaking, and we're closer to a cure, or at least a viable treatment more than we ever

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](http://www.alsaga.org).

- have been.
2. **At the same time, prepare for the worst.** I've never had to worry about wheelchair accessibility in my home. I do now. At the time of my diagnosis, I was living in a three story townhouse, now my wife and I are looking for a house with a master on the main floor and a big bathroom.
  3. **If there's anything you've always wanted to do, go do it.** While you still can. Don't be afraid to ask people for help either. My best friend and I went out to Las Vegas to race Ferraris. It was absolutely amazing, and I would have regretted it if I had passed up the chance to do it.
  4. **There are a lot of people out there who are incredibly dedicated to finding a cure for ALS and helping people with the disease.**

*James has been with the group, Geek's Night of Comedy for several years in the Tidewater area of Virginia. They had previously raised money for charities including the Juvenile Diabetes Foundation. On February 12, 2014, James announced his ALS diagnosis during his performance, and Geek's Night of Comedy began raising money for ALS. Since that show they have raised \$3,000 for ALS research.*

## **Challenge Congress to Make a Difference in the Fight Against ALS**

**By Nicole Yarab**

The ALS Association invites you to join the ALS community in Washington, D.C. for the National ALS Advocacy Day and Public Policy Conference 2015, May 10th-12th. A Mother's Day BBQ is planned for all advocates, their families and new friends in the ALS community. On Sunday evening, the Candlelight Tribute at Freedom Plaza returns and provides time to reflect on those who've fought the ALS battle before us and who continue to inspire us every day.

The conference will commence with an exciting "convention-style" session to recognize and energize advocates from across the US. The Public Policy team will host a "Prep for the Hill" session where tools and key information about public policy priorities will be provided. This will empower ALS advocates to clearly deliver their message on Capitol Hill. According to The ALS Association's Public Policy Department, "The US government remains the single largest source of funding for ALS research and health care in the world. We need to make sure Members of Congress know that the fight against ALS is not over because of the success of the Ice Bucket Challenge." Advocacy Day is an empowering experience and a wonderful opportunity to tell your ALS story and let Members of Congress know more about ALS and why more must be done now. Click [here](#) to learn about current legislative priorities.

This annual conference also provides an opportunity for ALS advocates to network with one another and learn the latest news about promising developments in ALS research. Additionally, people living with ALS will have an opportunity during the conference to participate in a NIH research project that aims to learn more about the causes of ALS.

The halls of Congress are bustling every day with visitors and lobbyists

from every possible interest group vying for time, attention and funding for their cause. Seeing the faces and hearing the stories from constituents in the ALS community leaves an indelible mark. Being an active part of this special day and a year-round advocate is an honor and a privilege.

You may ask, "What difference can one person make?" When the ALS community comes together with one voice, we accomplish so much. Click [here](#) to see some of the amazing results of ALS Advocacy efforts to date.

If you are interested in participating with The ALS Association Georgia Chapter delegation, please contact 404-636-9909 or visit [www.alsaga.org](http://www.alsaga.org).

To learn more about this year's National ALS Advocacy Day and Public Policy Conference agenda, registration and hotel accommodations for this year's event, click [here](#).



*Nicole Yarab, RN, is Director, Certified Center Programs, The ALS Association National Office. She previously served in several nursing capacities at Emory University, including Nurse Director of the Emory ALS Clinic.*

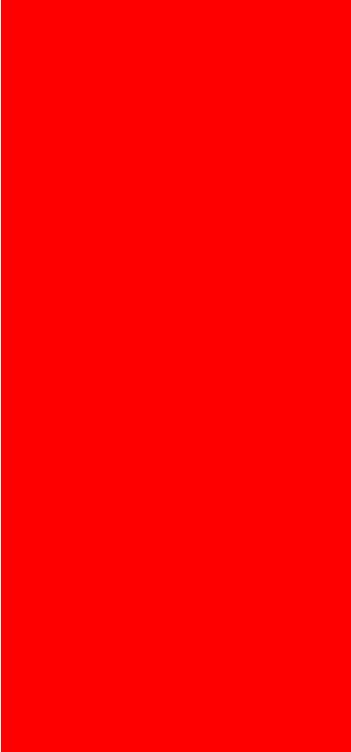
## **Respiration - How to deal with the cold months. By Rob Kelley**

With the winter months and cold and flu season ahead of us, here are some very important tips to help prevent some of the issues that could make us sick.

This sounds simple but hand washing is definitely one of the most valuable tools during this upcoming season. Care-givers must always wash their hands and keep them clean and free of germs before assisting loved ones and patients.

Wear your BiPap regularly to help rest the crucial organs in your bodies. This will certainly make you stronger and able to resist those nasty bugs going around.

How about the favorite machine in our arsenal of machines? Everyone's friend (I hope) - the Cough Assist! If used correctly, this could be one of the best tools to help PREVENT the ever dreaded pneumonia. Perform the full treatment at least two if not three times per day. By doing these



treatments, you are moving the mucous that is down in your lungs around. This is key to avoiding infection. Even if you do not feel like performing the cough cycle, you may use the Cough Assist machine to exercise your lungs. Keep your lungs good and open by taking in big deep breaths.

Keeping your equipment clean is crucial during this season. Clean it regularly to keep it free of bacteria.

Please practice these simple tips to avoid catching infections during the cold months. Remember, if you are having difficulty with your BiPap or Cough Assist, do not hesitate to call your Health Care company and ask for help. Have your respiratory therapist go over the process again.

Practice certainly makes perfect. Do not leave your equipment unused and collecting dust.

*Rob is with Home Medical Professionals, a company that specializes in providing the very best of patient care and medical equipment for the home.*

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