

# ALS Support Bulletin

## Advising, Learning & Sharing

A PUBLICATION FOR ALS PATIENTS,  
FAMILIES AND CAREGIVERS

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### Information and Treatment Links

[www.als.mda.org](http://www.als.mda.org)

[www.alsa.org](http://www.alsa.org)

[www.als.emory.edu](http://www.als.emory.edu)

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

[www.alscenter.org](http://www.alscenter.org)

### Join Our List

[Join Our Mailing List!](#)

### ALS UPCOMING EVENTS

#### September 17th

Fundraising event sponsored by HisGrip Home Care

Jersey Mike's Subs.

4075 Old Milton Parkway,  
Alpharetta GA 30005

Benefiting ALS Assoc. of GA

#### October 6th

3rd Annual ALS Run for Jeremy, Hamilton GA.

Benefiting Emory ALS Center

[www.runforjeremy.com](http://www.runforjeremy.com)

September 2012

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Welcome to the September 2012 issue of the ALS Support Bulletin. This 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. The goal is to Advise, Learn and Share information to patients and caregivers of the disease.

### Caring for Persons with ALS (pALS) ... Then and Now

By Susan Blanton & Cynthia Douthat

To say that living with ALS is hard is an understatement. Challenges come sometimes daily, sometimes monthly, and it can be difficult for people with ALS (PALS) and caregivers to adapt to managing the progression of the disease. Advances in patient resources and initiatives over the years have evolved to bring help to caregiving today. Two Georgia women, both having been caregivers twice for loved ones with ALS, recently shared how life with ALS 20 or 30 years ago was the "dark ages of caregiving."

Susan Blanton's family was from Greenwood, MS, and in 1965 her mother was diagnosed with ALS. She was told she had perhaps 3 to 6 months to live. Susan shares, "There were no support groups and very little information on caring for an ALS patient except to make them comfortable. We did not have the wonderful speech assistive equipment or other adaptive devices available today." At the time there were no nursing homes or assisted living facilities. Susan's mother spent the last 17 months of her life at Greenwood Hospital, where she died in 1969 after a hard fought battle.

Susan's husband Tony was diagnosed in May 2005. "My mother living and dying with this devastating disease educated me and has made me so very appreciative of the doctors, their staff, the research being done today, and finally a greater awareness of ALS. I am in a better position to be an ALS caretaker because of our family's experience."

Cynthia Douthat never imagined that she would be an ALS

**October 19th**

7th Annual Night of Hope  
Gala

Benefiting MDA/ALS  
[www.mdanightofhope.org](http://www.mdanightofhope.org)

**October 20**

Walk to Defeat ALS  
Benefiting ALS Assoc. of GA  
[www.alsaga.org](http://www.alsaga.org)

**October 27**

Skydive ALS - GA  
Newnan, GA  
Benefiting ALS Guardian  
Angels  
[alsspidermonkey@gmail.com](mailto:alsspidermonkey@gmail.com)

**SUPPORT GROUPS**

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

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

**Macon** - Central Georgia  
Rehab. 3351 Northside  
Drive, Macon, GA 31210

**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  
about the support groups  
including dates and time of  
meetings, please contact the  
ALS Association of GA at

caregiver to two loved ones. Cynthia's father was diagnosed in 1984. Her life was in transition at the time so Cynthia moved to Kansas City, where her parents lived, to be able to help. Cynthia found Sue Worthington from a phonebook search (pre-internet era), who was the main caregiver for her husband who had ALS. "Sue was the heart of the ALS Association (ALSA) in the area. She came over to the house and spent a lot of time with all of us, helping us to not feel alone in the journey." Cynthia immediately got involved. The ALSA chapter had monthly support group meetings in a church basement, and there were also small group meetings (one for pALS, one for caregivers, and one for kids).

Fast forward to 1993 when Cynthia was married, living in Atlanta, and was on the Board of Directors for the local ALSA chapter. In 2005, she noticed fasciculations on her husband and a visit to Dr. Glass confirmed what she already knew. Her husband had ALS.

Marsh, Cynthia's husband, was not interested in support groups, but he had a group of friends from church who came to visit every Thursday for more than a year. It was great fellowship for all. Marsh attended the ALS clinic at Emory quarterly. Reflects Cynthia, "The team was so helpful every time. We always had questions and new issues."

The differences in the resources Cynthia's dad had and those available to Marsh were many. While her dad had just a scooter, a La-Z-Boy chair, and a slide board, Marsh had a lightweight transport wheelchair and then a power wheelchair. He also had a Cough Assist machine, a Bi-PAP machine, a computer to be his voice, and other advanced equipment. Marsh declined more quickly than her dad and died just two years later in 2007, which reminds Cynthia firsthand how ALS progresses differently in individuals.

Advice from Susan and Cynthia for pALS and caregivers:

- Don't go it alone - The worse possible scenario is to be isolated dealing with this disease.
- Take advantage of every resource out there - The ALS Association, Emory ALS Center & Clinic, MDA, the Veteran's Administration, Paralyzed Veterans, Social Security, neighbors, church friends, kind strangers...it's all good!
- Look at each day as your new "normal" - Continue routines, normal conversations, normal gatherings, normal food/beverages (however possible).

[404-636-9909](tel:404-636-9909) or visit the website [www.alsaga.org](http://www.alsaga.org)



Diet supplements are made more palatable if made into milk shakes with your favorite fruit or other flavor added, instant breakfast added will give it an extra boost of energy!

- "Cue" friends and family on what to do - Encourage loved ones that it's ok to be funny, to ask questions, to talk about stupid things, etc. It's an important gift to let others know what you want and need...they want to be there for you but most don't know how to do that.

*Susan Blanton lives in Lawrenceville and is caregiver for Tony, her pALS husband. She is an active member of MDA's Night of Hope Gala planning committee.*

*Cynthia Douthat lives in Atlanta. She was caregiver to her father and husband, both pALS. She has served on the Board of Directors for the ALS Association in Kansas City and Atlanta, and currently serves as a National Trustee of the ALS Association.*

## **2012 Atlanta Walk to Defeat ALS - Ten Years of Triumph By Liza Nordmark**

2012 marks the 10th anniversary of the Atlanta Walk to Defeat ALS. In recognition of this landmark, the theme for this year's walk is Ten Years of Triumph. We are encouraging both new and former teams to sign up early so we can ensure recognition of everyone's contribution to improving the lives of ALS patients and families in Georgia. The 2012 Walk has been scheduled this year for October 20th at the same location as 2011 - the Georgia World Congress Center International Plaza. Since beginning in Decatur, Georgia, the Atlanta Walk has raised over \$4 million in the fight against ALS. The funds raised help support the ALS clinics at Emory and in Augusta in addition to helping support the Augusta satellite clinic in Macon. A portion of the proceeds also goes to research through our national affiliation.

The Atlanta Walk to Defeat ALS is not just about fundraising but provides an annual opportunity for ALS patients, families, caregivers and friends to come together to raise awareness about ALS, celebrate the lives of the brave people who struggle with ALS, and join together as a visible force with a common message of hope for the future. Each year, there is more to celebrate. Research is making great strides and encourages us all to believe that we will see better treatments and an eventual cure for ALS. In the meantime, we do all we can to support ALS patients and families here in Georgia.



*Liza is the Events and Community Relations Coordinator at the ALS Association of Georgia. Please contact her at [\(404\) 636-9909](tel:404-636-9909) or at*

[liza@alsaga.org](mailto:liza@alsaga.org) for additional information about forming a team or signing up to participate.

## **Managing Excessive Saliva**

**By Nicole Yarab, RN, BA**

Some people living with ALS experience difficulty with excessive saliva. When swallowing muscles weaken, saliva pools in the mouth and drooling may occur. You might think that saliva production has increased, but in fact you are likely swallowing less frequently. This can be one of the most aggravating symptoms people with ALS can experience and can interfere with quality of life. The good news is that there are several options available to manage oral secretions.

Your physician or healthcare professional may ask you specific questions to determine the appropriate treatment option for you. This article will briefly review some common complaints and some of the treatments available for managing saliva. If you're having excess saliva and the consistency is thin, your physician may recommend a medication to dry up the secretions. If the amount of pooling or drooling is minimal, you may choose to defer medication and deal with issue on your own. An oral suction machine with Yankauer catheter is a good option for people who are not interested in taking a medication but would like assistance in removing excess secretions from their mouth. It can also be an important supplement to medications.

If you find that the symptoms are embarrassing or interfering with your social life, your physician may offer to prescribe a medication to dry up the excess saliva. There are several options to help "dry up" saliva and reduce drooling. Common first line medications include hyoscyamine (Levsin) and glycopyrrolate (Robinul). Hyoscyamine sublingual tablets are placed under the tongue, dissolve and will cause a drying effect that lasting for a few hours. Glycopyrrolate is another option which may be swallowed or taken through a feeding tube. Saliva production increases with eating, so it may be beneficial to take these medications 30 minutes to an hour prior to a meal. A more long-acting option is a Scopolamine patch, which is placed on the skin every 72 hours. If the desired effect isn't achieved, your healthcare provider may adjust the dosage or change your medication. If drooling is severe, sometimes a physician may prescribe atropine ophthalmic drops to be used orally. If all medications have failed, Botox injections or radiation of the salivary glands may be options to consider. These treatment options can cause remaining secretion to be quite thick and the effects may last months to years, so they

are not typically first line options.

Whenever a medication is used to cut back on the amount of saliva, another problem may occur- thick, glue-like secretions. Saliva management is often a balancing act between "drying it up"



and "thinning it out." If you are not drinking enough fluids, you may become dehydrated, which makes saliva thicker. Over-the-counter medications containing the ingredient guaifenesin are often used to thin out the consistency of the saliva and make it more manageable. In order for the guaifenesin to do its job, it must be taken with plenty of water. Some brand name medications containing this ingredient are Robitussin and Mucinex. Many

healthcare providers will recommend combination of treatments, taking both a medication to reduce the amount of saliva, increased fluids and guaifenesin to keep the consistency more manageable and having an oral suction machine on hand. It is important to realize that treatments are not one size fits all. Please discuss your symptoms with your physician who will know best how to customize a treatment plan for you.

*Nicole Yarab, RN, BA is the Manager for the ALS Association Certified Center Programs. She has published multiple articles, is a well-recognized speaker, and has continuously participated in public events in support of the ALS community. Nicole may be reached by email at [nyarab@alsa-national.org](mailto:nyarab@alsa-national.org).*

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