

ALS Support Bulletin

Advising, Learning & Sharing

A PUBLICATION FOR ALS PATIENTS,
FAMILIES AND CAREGIVERS

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www.alsa.org

www.alscenter.org

www.als.emory.edu

www.als.mda.org

www.clinicaltrials.gov

[www.georgiahealth.edu/
neurology/specialties/
neuromusc](http://www.georgiahealth.edu/neurology/specialties/neuromusc)

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ALS Upcoming Events

March 23 to Aug 28

A Hike of Hope on the
Appalachian Trail
Georgia to Maine

www.donsbrother.com

September 9

Terance Mathis Celebrity
Golf Outing for ALS.
Alpharetta Athletic Club

www.cureforals.com

September 21

Walk to Defeat ALS
GA World Congress

Issue: # 9

August 2013

Dear Kola,

Welcome to the August 2013 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 with patients and caregivers of the disease.

Commanding the ALS Battlefield

By Karen Duffy

Colonel (Retired) Scott Johnson is a pALS who has been instrumental in bringing changes to how the State of Georgia, the Army, and the VA support and care for Wounded Warriors and Veterans with ALS. He believes that his twenty-two plus years of service to God and country was preparing him to serve as a leader for Veteran pALS.

One might say Colonel (Retired) Scott Johnson's entire life was grooming him to be the advocate and leader he is today. Growing up in a military family with his father in the Air Force, Scott learned early on to assess changing situations and quickly adapt - military relocations with his family meant Scott attended nine different public schools before high school graduation in 1981. He earned his Bachelor of Science in Geology/Geophysics from Midwestern State University in 1985, a Master of Science in Administration from Central Michigan University, and tried three different career paths before enlisting in Officer Candidate School (OCS). In June 1988 Scott was commissioned as a Second Lieutenant in the U.S. Army Corps of Engineers.

Colonel (Retired) Scott Johnson's lists of achievements in education, military assignments, and leadership are a result of his foundation of faith and attitude of hard work. He holds the following Military Awards:

Legion of Merit; Bronze Star (2); Meritorious Service Medal (5); Army Commendation Medal (3); Joint Service Achievement Medal (2); Army Achievement Medal (3); Humanitarian Service Medal (2); Parachutist Badge; and Sapper Tab. Other Decorations include the Joint Meritorious Unit Achievement Medal, Kosovo Campaign Medal, Iraq Campaign Medal, Global War on Terror Expeditionary Medal, and Global War on Terror Service Medal.

In 2008, Scott began experiencing weakness in his body. By 2009 he also noticed foot drop and knew it was time to see a neurologist. In June 2009 Scott received the diagnosis of ALS. Military veterans are twice as

Centre
www.alsaga.org

October 5, 2013
4th Annual ALS Run for
Jeremy 5k, Hamilton GA
www.runforjeremy.com

October 26
3rd Annual Skydive for
ALS Guardian Angels
Thomaston GA
Click [here](#) for more
information



Did you find the information
in this newsletter helpful?

Are there any 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

likely to develop ALS as those who have not served.
<http://walk.alsgru.com/>)

Scott's full time caregiver is his wife, Kim Ann Burdeshaw, Lieutenant Colonel (Retired), U. S. Army. Kim retired from military service in 2012 to take care of Scott. They have two sons, Connor and David and live in Evans, GA. You can stay up to date on current issues and news concerning veterans with ALS from Scott's blog, The ALS Battlefield. (<http://scjohnson63.tumblr.com/>)

Scott's faith has not wavered since his diagnosis; once again he is using his faith and leadership talents to s



Scott and his dog, Joy enjoying a sunny day

Feet for ALS Committee.

erve others. Colonel (Retired) Scott C. Johnson has both collaborated with and worked to adjust the policies of the ALS Association and Paralyzed Veterans of America to impact VA policy and US legislation. He also served on the ALS Treat Us Now Steering Committee. Scott continues to identify and develop care, research and support issues that impact ALS patients in addition to serving on the Augusta ALS Board and Beat

It's a Team Effort By Nicole Yarab

ALS is a progressive, neurodegenerative disease that causes severe muscle weakness and the loss of the ability to speak, eat, cough, move and breathe. When ALS strikes an individual, simple, everyday tasks become more time-consuming and challenging. While researchers work to find better treatments and ultimately a cure, it remains essential for people living with ALS and their caregivers to have support and guidance throughout the arduous journey.

Why attend a multidisciplinary ALS clinic?

Research shows that individuals living with ALS treated in a multidisciplinary ALS clinic live an average of 12 months longer. In the 2009 American Academy of Neurology Practice Parameter Update, an Italian study was cited that showed that those people with ALS who attended specialty ALS clinics vs. a general neurology clinic were more apt to utilize Rilutek (riluzole), PEG (feeding tube) and NIPPV (Noninvasive Positive Pressure Ventilation, i.e.-BiPAP) and had fewer hospitalizations. These people had a longer survival. People with ALS can maintain independence longer and enjoy improved quality of life when provided with options for symptom management, assistive and adaptive equipment, education, care services and emotional support.

The "one-stop-shop" model of a multidisciplinary clinic provides an opportunity for people with ALS to access comprehensive, best-practice treatment, education and support throughout the ALS journey. At ALS

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 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.

clinic, a team of health care professionals with specialized training, expertise and dedication to those living with ALS are available in one place at one time. People with ALS can benefit from the combined experience and expertise of the various team members. These specialists can often anticipate an individual's needs before they become a problem. This "one-step-ahead" approach allows people with ALS to proactively collaborate with the team to devise individualized care plans that best meet their needs. Due to the progressive nature of ALS and the constant need to adapt to change, regular 3-4 month follow-ups are recommended. While ALS clinic day can sometimes be intense, it does allow a person the opportunity to see all necessary specialists the same day a few times a year.

There are several multidisciplinary ALS clinics across the country that are sponsored, supported and/or certified by one or more of the following: The ALS Association, the Muscular Dystrophy Association, private foundations or institutions.

The core multidisciplinary team most often consists of the following health care professionals:

- Neuromuscular-trained neurologist
- Nurse
- Social Worker
- Respiratory Therapist (RT) or Pulmonologist
- Speech-Language Pathologist (SLP)
- Dietician
- Occupational Therapist (OT)
- Physical Therapist (PT)

Additionally, other professionals and community partners may be actively involved in an ALS clinic setting. The team may also include one or more of the following:

- The ALS Association Chapter liaison
- MDA representative
- Mental Health Professional
- Chaplain
- Durable Medical Equipment Specialist
- Assistive Technology Professional (ATP)
- Home Care Professional
- Palliative Care Professional

Multidisciplinary team members strive to help individuals maintain muscle function and the ability to perform activities of daily living. Here are some examples of how these specialized allied health professionals partner with the neurologist in the ALS clinic to provide ongoing assessments, education and treatment options throughout the journey:

- RT: Assess breathing/educate on non-invasive options like NIPPV/"BiPAP"/"Cough Assist" and trach/vent
- SLP: Assess speech and swallowing; educate on changes associated with ALS; offer compensatory strategies to conserve

energy and maintain safety when eating; discuss options for communication and eating

- Dietician: Assess hydration and nutrition needs; provide counseling on various issues including weight maintenance, bowel irregularity, dehydration, etc.
- OT: Assess upper body strength and function/provide options for head/shoulder support, hand/arm support and range of motion; safety; compensatory strategies, adaptive clothing and items to assist in maintaining independence with activities of daily living
- PT: Assess lower body strength, gait; provide range of motion and flexibility exercises; safety; assess/measure for appropriate mobility options that may include ankle-foot orthosis (AFO), cane, rolling walker, custom motorized wheelchair

The multidisciplinary clinic model aims to assist people with ALS in maximizing their independence and quality of life in a safe, caring and supportive environment. While the journey is not an easy one, each step can be a bit easier when it's a team effort.

Nicole Yarab, RN, is Manager, 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.

2013 Walk to Defeat ALS By Liza Nordmark

The ALS Association proudly introduces the 11th annual Walk to Defeat ALS on September 21st, 2013 at the Georgia World Congress Center! The Walk to Defeat ALS is more than just a few mile trek, it's an opportunity to bring hope to people with ALS while raising money for a cure.

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 the 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.

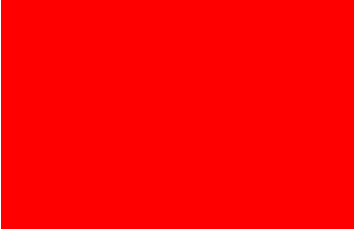
Each year, there is more to celebrate. Research is making great strides and encourages us all to believe that we will see better treatments and an eventual cure for ALS. In the meantime, we do all we can to support ALS people living with ALS and their families here in Georgia.

Join us in celebrating a day of hope!
For more information or to sign up for the Atlanta Walk, go to

<http://web.alsa.org/2013atlantawalk>.

If you have any questions, please contact Liza Nordmark at 404-636-9909 or Liza@alsaga.org.





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