

# 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.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)

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#### ALS Upcoming Events

##### **March 12th 2014**

ALS Awareness Day at  
GA State Capitol  
Atlanta, GA  
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##### **March 15th 2014**

Denim & Diamonds  
Dahlonega, GA  
[More Information](#)

##### **May 3, 2014**

Fiesta 5K/15K  
Cumming GA  
[More Information](#)

Issue: # 11

February 2014

Welcome to the February 2014 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.

#### **Tie-Dye Love**

**By Karen Duffy**

*I was asked to write an article about Mickey Johnston (AKA "Shy Tuna"). If you don't know who he is, keep reading and get ready to be uplifted. After reaching out to him with some questions, I knew that you would rather hear from the Shy Tuna in his own words, rather than mine...*

My name is Mickey Johnston, my wife Debbie and I have been married 33 years. We have 2 daughters, Amanda (32) and Allison (21), and a lovely granddaughter Bella (11). We live in Dallas, Ga.

In February of 2011 I was diagnosed with Bulbar ALS. I was 49 years old at the time, and had been having symptoms for about 3 years. We had never heard of ALS, and began researching it. No good news there. I was pretty sure I was living my final days.

We soon learned that I am a "Slow Progressor". Currently, my speech is at about half-rate of the norm, my tongue is weak, swallowing is fair, breathing is good, arms are weak and fine motor skills are difficult. Under the advisement of my team of doctors at the VA, I had a feeding tube put in last month. I don't need it yet but am being pro-active, because I will. I have seen no effect on my legs. Through adapting, I can still do most things including driving.

We have a strong faith in God, (not sure how one could deal with ALS without it), and I feel God has healed me to where He wants me for today. He also wants to know what I am going to do with that healing. One of the Ministries I have is visiting with pALS and sharing what I have learned about ALS, and just being an ear as someone who understands what they and their families are dealing with. I also give them a Tie-Dye shirt. Who doesn't love a tie-dye shirt? I call it "Tie-Dye Love". I love my, (unfortunately), growing ALS Family and pray for them every day.

**May 7-10, 2014**  
ALS Public Policy &  
Advocacy  
[More Information](#)

**June 21st, 2014**  
ALS Symposium  
[More Information](#)

**Got Feedback?**

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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 about the support groups including dates and time of meetings, please contact the ALS Association of GA at 404-

I also love my life, which has improved since my diagnosis. Therefore, I am thankful for ALS. I know that this is hard for most to understand, but that is just where I am at. I can't change it, so I'm going with it and enjoying each day that God gives me.

In the words of Morrie Schwartz, "Once you learn how to die, you will know how to live".

I believe in that. I live that.

***How you can help spread Tie-Dye Love***

My Daughter, Allison, attends Jacksonville State in Alabama. A friend of hers is in the Kappa Alpha Order Fraternity and their philanthropy work is with the MDA. Allison and I pitched an idea to them for a "Tie Dye-athon" fundraiser in the Spring to raise awareness and funds for ALS. They loved the idea and we are currently working with them to hammer out how to go about it. We will get the information out about it as it is available. Our idea was for people to make two tie-dye shirts. One for themselves and one to donate to a pALS. I want to see all pALS clothed in tie-dye. Wouldn't that be cool?

I think so.

Humbled,  
Mickey Johnston



Mickey with Steve and Hope  
Dezember

**Hidden Money in your Group Life Insurance Policy  
You might find hidden money in other life policies too**

**By M. Bryan Freeman**

I recently logged onto a forum for people with ALS and heard yet another story of someone with ALS desperately in need of funds to pay for treatment and for adapting to a rapidly changing life. Such stories are all too common and always especially break my heart because, from the work I do professionally, I know that people routinely walk away from big money that they could have easily accessed. I have been preaching about this for more than two decades, but still too few people know about it, so I have recently recommitted to getting the word out, and I hope you will help me.

The first thing you can help me spread the word about: It's important to know that most people leave or retire from their job long before death. Thus, most group life policies are never subject to claims. (That is why group life is such an inexpensive product.) Worse still, people who are sick walk away from their group life policies, even after being diagnosed

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

with a life-threatening illness. The sad truth is they just don't know such a policy can be converted into an individual policy and kept for the benefit of their beneficiaries, or can be the source of cash while they are living by applying for any living benefits in the policy, or can be converted and sold for cash as I describe below.

You see, you usually only have 31 days from your date of separation or termination from an employer to exercise the right to convert the group policy. In fact, multiple (other) benefits must be addressed and may be contained inside your group policy itself. For instance, there may be a waiver-of-premium clause that you may or may not want to apply for; it could mean not having to pay premiums if you are ill and qualify. Or your group life policy may be the key to a "lump-sum cash" benefit that a person diagnosed with late-stage cancer or ALS can receive.

There is a right way to prioritize accessing the benefits in such a policy in order to maximize the money. Any misstep could limit your ability to access cash now from the policy. Group policies are custom-designed and are not all standard so it takes a professional who has experience analyzing group policies for just this exact situation to find all the possible benefits. Unfortunately, the typical HR professional or financial advisor does not specialize in working with people with life-threatening illnesses and therefore has little experience in looking at your group life coverage this way and for these reasons.

It is imperative to understand your employee (work-related) benefits. In addition to group life insurance, do you have group health, short- or long-term disability insurance, long-term-care benefits, 401(k) or other benefits at work? We have limited space here, so I will stick with our conversation on group life and at least two options to receive cash. One option is to get an advance on the amount of the death benefit. This is typically called either a "living benefit" or an "accelerated death benefit." The second option is called a life settlement. In short, a life settlement means you can sell your life insurance to a licensed specialty finance company for a portion of the face value of the policy and no longer pay premiums.

Many folks have individual policies, and those can work for this too, but most younger folks have a group life policy through a job. These ways to harvest the dollars from your life policies also apply to veterans, service members and federal employee policies.

Good to know: Most types of individual life insurance policies and many group policies qualify (once converted or continued - each policy is different and options must be assessed). Proceeds of these life insurance monetization techniques can be used for anything. You can use it for direct health care expenses, paying bills, buying a van, paying rent or your mortgage, gift-giving, travel or anything else.

But please, more than anything do not walk away from your group policy (you only have 31 days from employee termination to convert it) because when you do, you may be walking away from the money that could make your days brighter.

*M. Bryan Freeman, Founder and President of Habersham Funding, LLC,*

is recognized for his longstanding efforts in providing insurance and financial solutions for people with serious illness. In 2012 he helped spearhead the ALS Association, Georgia Chapter's Educational Symposium. In 2013 he spoke to the ALS Association Advocacy Day & Public Policy Conference in Washington, D.C. He has partnered with numerous non-profits-locally, statewide and nationally-to present programs on the best use of existing assets, and employer and government benefits [www.YouCanSellYourLifeInsurance.com](http://www.YouCanSellYourLifeInsurance.com)

## **Neurological Disease Residence Becoming a Reality in Georgia**

It is hard for people with ALS to plan ahead because the progression of disease is different in every person. One constant however is that there will come a time when the ability to be able to accomplish daily tasks and be independent will be lost. Many pALS have family members and caregivers who are able to come to their aid, but there are those who live alone and do not have family or assistance nearby. Under construction now in Dahlenega, GA is a skilled nursing center that will fill the void for those without daily care, and also give back independence lost to pALS and others with neuromuscular disease.

Chelsey Park Health & Rehabilitation (Chelsey Park) will be the first of its kind center in the state of Georgia and when complete, the fourth in the U.S.A. with this state-of-the-art technology installed. The center will serve neurological patients with multiple sclerosis, ALS (Lou Gehrig's), muscular dystrophy, Huntington's and those who have experienced a cerebrovascular accident (CVA or stroke) along with patients needing short-term rehabilitation. Serving patients across Georgia.

Community Health Foundation has announced they will match all corporate donations by 100% in support of Chelsey Park Health & Rehabilitation (Chelsey Park). CHF is a 501c(3) organization and has developed the Chelsey Park CAUSE to support in the purchase of state of the art technology, room furnishings and ongoing support serving patients with neurological diseases while at Chelsey Park.

A fundraiser is being held on March 15, 2014, hosted by Community Health Foundation. The Denim & Diamonds event at the Cottrell Ranch in Dahlenega will raise money for Chelsey Park, and here is the agenda for the evening:

- 5:00 p.m. Cocktail hour and silent auction
- 6:30-10:30 p.m. Dinner and dancing
- Dress: classy denim, skirts, boots and sport coats
- Dinner prepared and served by Chef Kern
- Music by Radford Windham & Stepback Cadillac Band

One hundred percent of all proceeds from Denim & Diamonds and

donations made to CHF, designated for Chelsey Park, will go directly to the center to purchase the specially designed equipment and technology, along with the ongoing operational costs associated with neurological patient care.

Special thanks to our sponsors Points North magazine and Lynn & Mike Cottrell of the Cottrell Foundation.

More information about Chelsey Park and the Denim & Diamonds, as well as details and videos about the center and its technology can be found on their website: [www.chelseyparkhealth.org](http://www.chelseyparkhealth.org) and [events.chelseyparkhealth.org](http://events.chelseyparkhealth.org).



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