

ALS Support Bulletin

Advising, Learning & Sharing

A PUBLICATION FOR ALS PATIENTS,
FAMILIES AND CAREGIVERS

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Information and Treatment links

www.alsa.org
www.alsaga.org
www.alscenter.org
www.als.emory.edu
www.als.mda.org
<http://alsgru.com/>
www.clinicaltrials.gov

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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

May 24th, 2015

ALS Awareness Day at Turner Field
Click [here](#) for more information

June 27th 2015

Issue: # 13

April 2015

Welcome to the April 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.

May is National ALS Awareness Month ... Advocacy is Key By Ted Harada

As many of you are aware, May is National ALS Awareness month. Obviously over the last year ALS has garnered a lot of awareness between the Ice Bucket challenge and the movie "The Theory of Everything" ALS has been in the public limelight. The attention is important for many reasons, not the least of which is that no one donates to a disease they never heard of. However there are many other reasons awareness is crucial. When it comes to public policy and influencing Congress as well as the Georgia General Assembly, the more that the legislators know about the disease, less work needs to be done to

educate them on ALS and why certain pieces of legislation are critical for ALS patients as well as the community at large. Every May, in conjunction with ALS Awareness month, The ALS Association holds an advocacy conference in D.C. This year the National ALS Advocacy Day and Public Policy Conference is May 10th - 12th. Patients, family members and

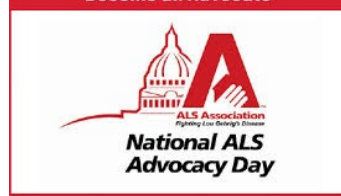
advocates from around the country fly in to participate in this important event. During those three days The Association explains to the attendees what legislation that they need the communities help with. The meeting culminates on the third day with all attendees going to Capitol Hill and educating their Senators and Representatives on ALS and the pieces of legislation that impact the community.

This year we will be asking Congress for four things:

1) 10 million dollars to continue funding the National ALS Registry hosted by the CDC

This registry is a crucial research project aimed at collecting many points of data about ALS patients with the ultimate goal of using the information to help researchers develop a treatment.

Become an Advocate



ALS Association
Educational Symposium
Cobb Energy Performing
Arts Centre
Click [here](#) for more
information.

September 14th, 2015
3rd Annual Terance
Mathis Celebrity Golf
Classic
Alpharetta, GA
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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

Dalton - Ross Woods
Adult Day Services. 1402
Walston Avenue, Dalton,
GA 30720

Fayetteville - Senior
Services Center. 4 Center

2) 10 million dollars for the ALS Research Program that is run through the Department of Defense

This program helps fund grants for scientists doing research on potential treatments for ALS that are in the beginning phases of laboratory research.

3) Support the Dormant Therapies Act

This act would help extend patent protection for drugs that may help treat diseases with unmet needs, such as ALS. This would provide incentive to drug companies to invest in research for complicated diseases such as ALS.

4) Support H.R. 628, The Steve Gleason Act

This act would ensure that patients who are using an audio communication device do not have their use of that device interrupted if they need to enter a hospital, nursing home or hospice facility.

As you can see, all four of these initiatives are crucial and would have a huge positive impact for ALS community. Rest assured that The Association is working on your behalf on issues like this year-round. Look for more information in May on how you can help raise awareness on these issues. Spreading the message is crucial. Whether it is through social media, educating your friends and family or emailing and / or calling your Congressional members, you as patients, family members and care givers are the most important advocates. Thank you in advance for all of your help. If you have any questions or want to know how you can become more involved in ALS advocacy, please visit www.alsaga.org.

Ted Harada is an ALS Patient and Advocate.

**The ALS Educational Symposium
By Liza Nordmark**

The upcoming ALS Educational Symposium will offer an unprecedented line-up of presentations and a lot of great resources. This is a great opportunity for people with ALS - including those who have just been diagnosed - to hear the latest on maximizing benefits, medical updates and more.

Living for Today, Learning for Tomorrow, a statewide educational symposium by The ALS Association of Georgia will be on Saturday, June 27 at the Cobb Energy Performing Arts Centre from 9:00 a.m. to 4:00 p.m. Registration starts at 8:30. am

The event brings together people with ALS, caregivers, medical professionals and exhibitors to discuss the latest treatment of Amyotrophic Lateral Sclerosis (ALS) - also known as Lou Gehrig's disease - including current symptomatic treatment options, supportive care, current research and alternative treatment. ALS is a progressive neurodegenerative disease that attacks nerve cells in the brain and spinal cord.

This year's keynote speaker is Dr. Lucie Bruijn, Ph.D, Chief Scientist,

Drive, Fayetteville, GA
30214

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

New Patient - The ALS
Association of GA. 5881
Glenridge Drive, Suite
200, Atlanta, GA 30328

Tucker (NEW) -
AMSVans
Meeting Room. 6275
Lawrenceville Hwy.
Tucker, GA 30084

**Traveling Saturday
Support Group** - Click
[here](#) for more information

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
click [here](#).



**Most types of life
insurance policies
have living benefits**

- Term
- Whole life
- Universal life
- Group policies

**Case studies of people
with ALS provide a
glimpse of living
benefits:**

The ALS Association. At The ALS Association, Dr. Bruijn leads a global ALS research effort, Translational Research Advancing Therapy for ALS (TREAT ALS™) with the goal to move treatment options from "bench to bedside." She has made it a priority to collaborate with other funding agencies, in particular The National Institute of Health, The Department of Defense and many other not-for-profit ALS organizations, as well as other foundations focusing on neurodegenerative research. These collaborations ensure that increased dollars are spent on ALS research. She is involved in project development, encouraging partnerships with academia and biotech, and has played a key role in forging collaborations amongst investigators. It is her strong belief that only through collaboration among a wide range of disciplines will we be successful in changing the course of ALS and finding a cure.

For further information about the symposium or to request a symposium registration form, contact The ALS Association of Georgia 404-636-9909 or info@alsaga.org. Individuals with ALS and one caregiver may attend the symposium at no charge; additional caregivers and other attendees are \$35 each, including lunch. After May 15, the registration fee is \$45. Register today at www.alsaga.org.

Liza Nordmark is the Corporate Partnership Manager for The ALS Association of Georgia. She has been with the organization for almost 5 years and is dedicated to helping ALS patient and families throughout the state of Georgia. You can reach her at liza@alsaga.org.

Sometimes information is activism...
***Learn about...and share...because benefits may not be
apparent***
By M.Bryan Freeman

You have to look for silver linings where you can. Having worked with seriously ill people for most of my career, I've found that they are often the best at seeing gifts where others of us might only see challenges. One of the things these friends have taught me is the power of community.

That was never more evident than during the last Georgia legislative session. Together we were championing the Life Insurance Consumer Disclosure Act. More about that later. Ultimately, our legislation was not approved but we did come away with a great "B" option - the establishment of a House Study Committee on Life Insurance Consumer Disclosure.

Our voices were heard - and, again, the impressive coming together of folks from so many walks of life to champion consumer disclosure on behalf of seriously ill people was heartening. And why is this disclosure issue so important?

Well, as you probably know, with serious illness often come financial challenges - even for those who have the best of health insurance. And still far too many folks don't know that their life insurance includes many "living benefits." That's what our work at the State Capitol was about: helping ensure consumers are better informed about their rights, privileges and benefits under life policies.

73-year-old female who was able to get 66% of the face value for her term policy in a life settlement in 2014.

64-year-old female diagnosed in 2012 was able to get 71% in 2013 in a life settlement.

52-year-old male was diagnosed in 2012 received 48% in a life settlement for his term policy in 2013.

43-year-old male, symptomatic in 2009, diagnosed in 2010. His \$1.3 million policy was on Waiver of Premium. He was able to receive 62% in a life settlement. 56-year-old male had two policies. A \$150,000 individual policy and a \$650,000 group policy; the latter was "ported" to an individual policy. Both were placed on Waiver of Premium. Diagnosed in July 2012. In October of that year he received 48% and 49% respectively on those policies.

The majority of all life insurance coverage is abandoned by the policy holder with no death benefit ever paid out. Consumers - and particularly those who are living with serious illnesses - do not consistently have sufficient information to make a decision about the current living benefits of their life insurance that best suits their individual circumstances. Living benefit options may include a loan against a policy, surrendering it for cash surrender value, receiving an accelerated death benefit, premium waiver, or a life settlement (in which a portion of the face value is paid out to the insured in cash to be used for any purpose) as well as other options.

So even though the Act was not passed this session, the powerful community of voices that came together made many more legislators and citizens aware of living benefits that may be able to be harvested to pay for health care or quality-of-life solutions. And with the help of many good folks like you, we'll be back at the Capitol next year. In the meantime we are working with the aforementioned study committee and perhaps using other channels to ensure that people know about and have an opportunity to make use of their benefits.

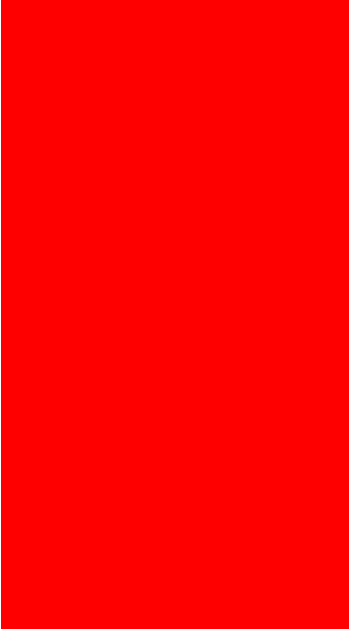
"Living with a universally fatal illness, I know how important understanding your financial options are when you are ill," says Ted Harada, who is an ALS patient and advocate. "People diagnosed with ALS and other terminal illnesses are overwhelmed with so many life-changing issues, and at the top of that list is how they are going to take care of their family as well as pay their medical bills."

He continues, "When you are sick and can't work, money is critical. Life insurance is hard to understand and confusing to people. This legislation would require disclosure of all the 'living benefits' available in life insurance, so those who have paid for coverage may understand it, rather than losing the coverage and finding out after the fact that a policy may have offered them substantial benefits. Knowledge is power and I believe that it is imperative that dying people who are already in a desperate and vulnerable position are empowered with the knowledge of their rights and benefits of what they have been paying for."

Ted's words ring true with me. Even though I have been a licensed life insurance agent for 36 years and helping folks with serious illnesses for more than 25 years, I am still learning every day about these benefits. I've asked here before and will ask again: Help me spread the word. Before someone lets a benefit policy of any type lapse or when they are making any life change like leaving a job or going on disability, tell them to ask questions and get good information about what their options might be."

Sometimes even the people advising you don't have a clear understanding of how you might best leverage your benefits and you often have a limited time in which to act. That sounds like a bad commercial, but it is true, For instance, you usually only have 31 days from your date of separation or termination from an employer to exercise the right to convert a group policy so that it continues to be yours.

As a community, we can ensure that as many people as possible know



the intricacies of their benefits so that they may best leverage those based on their individual circumstances. Financial planning for seriously ill folks is a different ballgame, and I am glad we are playing it together. It will take every one of us to win.

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. He has long partnered with numerous non-profits-locally, statewide and nationally-to present programs on the best use of existing assets, and employer and government benefits. Visit www.YouCanSellYourLifeInsurance.com or, for specific information about your individual circumstances, policies and potential living benefits, call 404-233-8275.

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