

Having trouble viewing this email? [Click here](#)



Cure for ALS

May 23, 2011

Dear ALS Advocates and Friends,

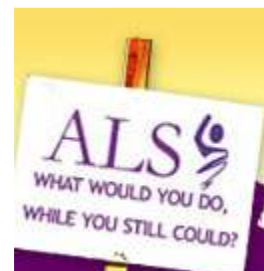
*ALS Awareness Month is drawing to a close, but there are still events occurring this week and into the weekend supporting ALS Advocacy and fundraising. I've had the pleasure of working on or attending several events this month. I'll first brag a little on my family and our successful 5th Annual ALS Run for Life 5K, which was on May 7. We had the best weather we've ever had, the largest crowd of over 1500 in attendance, and raised the most money! Donations are still trickling in, but the total to date in proceeds benefiting ALS research is **\$36,364**. We are grateful for the many fundraising teams, sponsors, volunteers, and of course amazing participants. If you'd like to see photos from the morning, [click here](#) and scroll down to "ALS Run for Life." A few days after the race, a group of us from the Georgia ALS Advocacy Team were present at the Cumming City Council Meeting, where **Mayor Ford Gravitt** read and signed a proclamation to make May, **ALS Awareness Month in Cumming, GA**. It was an honor to be there and very meaningful to hear as he read why advocacy is so important to this, often overlooked, disease.*



5K Fun Run and Volleyball Tournament Honoring Dr. Patrick Mulholland

May 25, 2011
Providence, RI
 4:00pm - 6:00pm
 Benefiting the ALS Association

To make a donation [click here](#).





Below you will find a recap on the **ALS Public Policy Conference and Advocacy Day** from ALS Nurse and Clinician, **Nicole Yarab** who was there. I'll also introduce you to **Tim LaFollette**, whose life with ALS is being documented in the web series, [Often Awesome](#).

Speaking of documenting, last Friday I attended a special screening of the documentary, [Season of a Lifetime](#), which tells the story of ALS patient and Greenville High School football coach, **Jeremy Williams**. You may remember Jeremy from the May 2010 Extreme Makeover Home Edition program. When [Season of a Lifetime](#) comes to a theater near you, you must go see it. The Williams family's model of faith, family, love, and living each day to the fullest will inspire you.

I hope that you've noticed, participated, or volunteered for something that involved ALS Advocacy and Awareness this month. The month isn't over yet, so if you haven't, check out the events listed on the right to find one you can support.

Best regards,
Karen Duffy (kd)

[Cure for ALS](#)

Find us on Facebook 

ALS Public Policy Conference and Advocacy Day Recap

By Nicole Yarab, RN

The **ALS Public Policy Conference and Advocacy Day** went very well again this year. On Tuesday May 10th, PALS, family members and all ALS advocates swarmed Capitol Hill armed

June 19, 2011
Guelph Lake Sports Fields
Guelph Ontario
TIME: 8:00am - 4:00pm

[Click here](#) for more information.

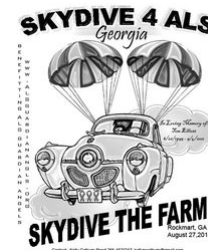
Tri State Trek
July 22-24, 2011
270 mile bike ride for ALS from Boston to New York



[Need More Cowbell](#)

Skydive For ALS in GA

August 27, 2011
Rockmart, GA



[Click here](#) for more information.

STOP ALS

That's the message of the ALS car magnet. Buy one (or more!) for your vehicle and help spread awareness.



Magnets are 4 1/2 inches.
\$5.00 each
5 for \$20.00
10 for \$35.00. Price includes shipping.

with their personal stories and specific asks for their representatives. This year we asked Congress to sign onto the "Dear Colleague" letter supporting appropriation of \$10 million continue funding the [ALS Registry](#) thru the Centers for Disease Control and Prevention (CDC). This ALS Registry was officially up and running as of November 2010. This funding is vital to continue the CDC's efforts to reach out to underserved populations in our urban and rural communities. In order to obtain accurate information, we need to get everyone with ALS to register.

The second "ask" was for Congress to continue it's support of the **ALSRP (ALS Research Program) through the Department of Defense (DOD)**. We asked our congressmen to sign onto another "Dear Colleague" letter to appropriate \$15 million to support translational research. There is some funding thru the National Institutes of Health (NIH) and non-profits (ALS Association/MDA) for bench(Lab) research and funding from private industry and the NIH for clinical trials. However, many projects that look promising in the lab never make it to the next step. This translational research, the middle part of the pipeline, has been supported thru this program (over \$25 million to date).

Finally, we were looking for support for the **MODDERN (Modern our Drug and Diagnostics Evaluation and Regulatory Network) Cures Act** and an original sponsor of the bill. Many potential new diagnostic tests and potential treatments never make it or are delayed in getting to the marketplace due to very strict patent rules and due to the lack of diagnostic codes for a new test. While regulations are important to keep us safe, we are hoping that the process can be reevaluated and streamlined. This is supported by the National Health Council (NHC) and isn't specific to ALS. Many different disease organizations are a part of the NHC.

Visit [Cure for ALS](#) to download an order form. Proceeds from magnet sales will be donated to the [Emory ALS Center](#).

Dash For A Cure



[Track CarolAnn and/or make a donation.](#)



Often Awesome, The Series

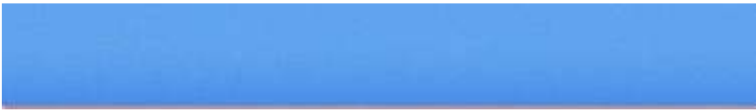
I've been meaning for several months to include **Tim LaFollette's** *Often Awesome* series in the newsletter. Tim is a rock musician, from Greensboro, NC whose grandmother and mother both died from ALS. When weakness began in his body, Tim most likely knew what was happening to him, and in April 2009, at the age of 29 years old, Tim was diagnosed with the same disease that had already taken two members of his family.

I don't know Tim personally, but like so many ALS patients I've known, he refused to go home and wait for the disease to direct his days. Instead, Tim wanted to leave behind a legacy, while creating an avenue for ALS Awareness along the way. Along with the love of his life, **Kaylan**, Tim has opened his life to **Andy Coon** and **Blake Faucette**, who film the episodes of the online series, *Often Awesome*. There are 31 episodes so far,

and I expect that Episode #32 will be posted very soon. You will want to take time to visit the Often Awesome website to catch up on the series. You'll laugh and cry, however, you will also share in the love being poured out to Tim and Kaylan, and the support that the ALS community draws from them, and from those who continue to host events and draw strength from this amazing couple.

I tried to write a summary of Tim, but found that a feature from the [Buckley Report](#) on FOX8 in Greensboro, NC handled the assignment much better than I could have.

You can view *Often Awesome* episodes [here](#). **The latest episode is from a recent concert at the Greene St. Club. It contains some strong language - but hey, they are rockers right? **



[Forward email](#)



This email was sent to teamduffy@gmail.com by teamduffy@gmail.com | [Update Profile/Email Address](#) | Instant removal with [SafeUnsubscribe™](#) | [Privacy Policy](#).

Cure for ALS | 42 Lakecrest Circle | Suwanee | GA | 30024