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Cure for ALS

October 4, 2011

Dear ALS Advocates and Friends,

I've literally started this newsletter four times within the last month. Every time I think I'm ready with "hot of the press" ALS news, another milestone is announced in research, or a new trial is launched. The frustration I have had in attempting to keep up is actually great news in the world of ALS. I'm thrilled that each time I log into my email, Facebook, or Twitter I see multiple postings regarding ALS.

In this newsletter you'll read a new campaign to unify ALS awareness, an exciting update regarding the ALS Registry, and learn about the touching tribute to a former NFL player who has ALS.

Added to the list of upcoming fundraisers and events is the Walk to Defeat ALS. This is a major fundraiser for the ALS Association, and walks occur all year long across the country. The Atlanta Walk to Defeat ALS is October 22. Click on the link to find the date of the walk closest to you.

Share the sunflower (you'll have to read on to find out what that means), host or participate in a fundraiser, and continue to spread awareness everywhere you go. pALS are counting on you!

Best Regards,
Karen Duffy (kd)

[Cure for ALS](#)



Adopt the Sunflower



**ALS Run for Jeremy 5K
October 8, 2011
Hamilton, GA**



[Click here](#) to register or donate.

**100 Innings of Baseball
Spectacular
October 8, 2011
Quincy, MA**

One common frustration among ALS patients and advocates is that there isn't one symbol or color that signifies the disease. Everyone knows that a pink ribbon represents breast cancer. A purple puzzle piece signifies autism.



In an effort to unify public awareness, ALS patient, **Shirley (Hoffman) Schmelzle** launched a campaign to adopt the sunflower as the official symbol of hope for those battling with ALS. The disease may be silencing Shirley's voice, but she is generating noise in her goal to use the sunflower symbol to provide a simplified and consistent external public image representing ALS Awareness that is easy to recognize and visually unifying.

[Read more details here](#), and encourage other ALS organizations to make the sunflower a common symbol of ALS awareness.

ALS Registry Update

Great news received from the ALS Association this week...

The Senate Appropriations Committee has voted to provide an additional **\$6 million for the ALS Registry in 2012!!** The funding will allow the Registry to continue to identify cases of ALS across the country, collect additional information about the disease and expand exciting projects such as adding a biorepository and tools to help people with ALS learn about and enroll in clinical trials.

This is a tremendous victory for every person with ALS. It is a clear sign that Congress recognizes the critical role the Registry can play in the fight to find the cause, treatment and cure for ALS. It also is clear that ALS is a priority for the Senate. The Committee reduced funding, or eliminated it entirely, for most other health care programs. In fact, funding for the entire Department of Health and Human Services was reduced. Yet, the Senate maintained strong support for the Registry by keeping funding at the current level.

The full Senate still must vote on the Department of Health and Human Services Appropriations bill that includes the Registry funding, and the House Appropriations Committee also must vote on their version of the bill. Therefore, there are a number of steps remaining in the legislative process before we can declare victory this year.

You can learn the latest news in ALS Public Policy by following

[Click here](#) for information.



Walk to Defeat ALS

The Walk to Defeat ALS® is The ALS Association's biggest annual event, which raises funds to sustain patient care and support cutting-edge research by the world's best and brightest scientists. Choose a walk near you, then rally together your friends, family, and co-workers to form a walk team and make a difference!



[Click here](#) for information.

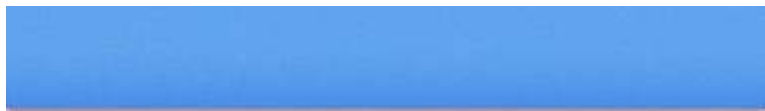
Former NFL Player Surprised By Tribute



In case you missed it, the **New Orleans Saints** paid tribute to former defensive back, **Steve Gleason** last week. Now battling ALS, Steve was surprised with a touching tribute at the September 25th game against the Houston Texans.

it on [Twitter](#) or on [Facebook](#).

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