National ALS Community Holds 3-Day Demonstration at Washington Monument

Nonprofit I AM ALS plants 6K flags for ALS Awareness Month following FDA approval of tofersen, an example of how a community-led movement impacts new treatments

I AM ALS plants 6,000 flags at Washington Monument representing each person who will be diagnosed with ALS this year.

WASHINGTON, D.C., UNITED STATES, May 11, 2023 /EINPresswire.com/ -- As May marks ALS Awareness Month, the nonprofit, patient-led movement I AM ALS is raising awareness about the disease in the nation's capital by planting 6,000 blue flags in front of the Washington Monument, on display from May 11-13.

The demonstration comes just two weeks after the U.S. Food and Drug Administration (FDA) granted accelerated approval to tofersen to treat a rare genetic subtype of amyotrophic lateral sclerosis (ALS).

The 6,000 flags represent the number of Americans diagnosed with ALS annually. Many of these flags will display the names of people currently living with ALS and those who have passed away, as well as age at diagnosis and age when they passed.

The event is intended to bring all individuals and families—with a direct connection to ALS or not—into the solution.

This moment is imperative to showcase our collective power to make change in a disease that has been 100% fatal for over 150 years. In addition to the urgent need for curative treatment for the 6,000 people diagnosed with ALS each year, research and cures for ALS can help unlock critical breakthroughs for other neurodegenerative diseases.

"The message is clear: everyone needs to pay attention, because ALS can affect anyone, at any age," said Andrea Goodman, CEO of I AM ALS. "We aim to show the world that we are committed

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>
> *Andrea Goodman, CEO of I AM ALS*

to accelerating treatments and cures and all of you can be part of ending it. We invite the world to see us, hear us, act with us, and- ultimately- end ALS with us."

I AM ALS was founded by Brian Wallach and Sandra Abrevaya after Wallach was diagnosed with ALS in late 2017 and given six months to live. The couple decided that the only path forward was to fight for their two young daughters and so many other families impacted by this disease.

They began to imagine a world where ALS is chronic. Their first step was connecting the insights of researchers with deep experience in the field utilizing the organizing tactics from successful political campaigns. As part of their vision, Wallach and Abrevaya began reaching out to friends, many of whom were political campaign veterans from both sides of the aisle, to design a movement using community organizing approaches in the fight against ALS.

"Over the last few years, we have been truly fortunate to see more and more people who do not have a connection to ALS jumping into the fight. Together with people living with ALS, caregivers, and other advocates they are helping to transform ALS from a fatal disease to a chronic one. With your help, we can make this a reality and change the future for so many people impacted by ALS and other neurodegenerative diseases. I hope you will join us in this fight," Wallach says.

Since its launch in 2019, I AM ALS has grown an active community made up of over 200 incredible advocates, worked with key members of Congress to launch the House and Senate ALS Caucuses (now with over 150 members), engaged more than 45,000 email subscribers, driven 295,000+ actions through their digital advocacy platform, and engaged industry partners to change the clinical trial and legislative landscape.

Additionally, I AM ALS led the passing of two historic bills—ACT for ALS and a bill to eliminate the five-month waiting period for social security disability benefits—and worked with congressional champions to secure $40 million in fiscal year 2023 for the ALS research program through the Department of Defense, as well as $75 million for the ACT for ALS's Expanded Access Program (EAP).

To learn more about I AM ALS or to join the cause, visit https://iamals.org.

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