

New Initiative Advocates for and Raises Awareness of Women under 35 Living With ALS

Her ALS Story launched with more than 20 founding members, all young women living with ALS around the world

New York, NY (**August 25, 2021**)- [Her ALS Story](#) is a growing group of women who were diagnosed with amyotrophic lateral sclerosis (ALS) in their 20's and 30's. The group is dedicated to finding treatments and cures that end ALS and its' typical prognosis of two to five years to live, while raising awareness and advocating for those with ALS along the way.

All of the inaugural members of Her ALS Story were diagnosed before the age 35 and are joining skills, talents and expertise to:

- Engage the media to raise awareness of this ALS Community
- Encourage every female representative and senator into the existing ALS Caucus
- Partner with researchers to study females with ALS and improve access to expanded access programs

Among the early programs that this group has initiated in the five months since its inception are the “In Her ALS Shoes” movement and partnership with Steven Madden as well as collaborations with international designers to raise awareness of the disease and its ability to strike any one, of any gender and any age. This month, Her ALS Story premiered Ady Barkan’s documentary, “[Not Going Quietly](#)” at the Asbury Film Festival to raise awareness and funding for the cause.

“We have our futures ahead of us, and we won’t accept the status quo of two to five years,” says founder Leah Stavenhagen. “As young women who have to face the harsh realities of ALS head on, I believe that our voices are especially powerful.” She adds, “Despite being brought together by the worst of circumstances, it is inspiring and empowering to work alongside other Her ALS Story members. Never before have I felt such a clear purpose in life.”

Member Kate Nycz says, “These women are pistols, they are fired up. We are working with I Am ALS to work through the government side of it, advocating for access to different drugs, different trials, trying to get any therapy that may be promising to come to fruition and give us a chance.”

About Her ALS Story

We are a group of women diagnosed with ALS before our 35th birthdays. To challenge the stereotype that ALS is an older white man’s disease, we foster an open dialogue about our declining health in female-centric media outlets. We cultivate relationships with female

lawmakers to improve current insurance and Medicare standards, and introduce legislation to speed up the drug pipeline. We raise money for the pursuit of unbiased, supercharged ALS research to ultimately end this devastating disease.

About ALS

Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, is a progressive and fatal disease, attacking neurons that control voluntary movement. These neurons die over time. The result is the gradual loss of muscle movement, speech, swallowing, and eventually, breathing. Unfortunately, people with ALS usually have a shortened lifespan and may die within a few years of diagnosis. (Source: Centers for Disease Control)

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