



## **Remembering Our Beloved Friend and Leader, Stephen Winthrop, Chair, The ALS Association Board of Trustees**

It is with heavy hearts that we share that Stephen Winthrop, Chair of The ALS Association Board of Trustees and person with ALS, died peacefully early Monday morning. Our hearts are with his wife, Jane, and their two daughters.

Stephen was diagnosed with ALS on November 6, 2013. Stephen and Jane immediately began working to help raise awareness and support for the fight against ALS. They set up a Facebook page – [WillWinAgainstALS](#) – to “advocate, raise awareness, and fundraise to wipe out ALS!”

Stephen and Jane’s Walk to Defeat ALS team was regularly the highest-raising team for The ALS Association’s Massachusetts Chapter. He often told his own story- you can view Stephen’s address at the 2015 Walk event in Boston [here](#).

In August of 2014, Stephen took the ALS Ice Bucket Challenge. You can view his very funny and cute video [here](#).

In 2015, Stephen was elected to the The ALS Association Board of Trustees. He wanted to serve because, as a slow progressor, he wanted to make an impact and move us closer to a world without ALS.

In February of 2017, Stephen received The ALS Association’s Hero Award, given annually at our Leadership Conference. You can read a nice write-up of that ceremony in Stephen’s local paper, [the Wayland Town Crier](#).

In April of 2017, Stephen was elected as Chair of the Board of Trustees. At that time, we sat down with him to ask about his thoughts on ALS and leading the Board. You can read that interview [here](#).

During his five years of living with ALS, Stephen participated in as many clinical trials as he was able and served as an ALS research ambassador. He also helped lead the first patient-centered, community-led ALS guidance for drug development.

Below is a statement from CEO Calaneet Balas, as well as tributes from some members of our Board and others who knew him. If you'd like to make a donation to help support ALS research in Stephen's honor, you can do so at [alsa.org/StephenWinthrop](https://alsa.org/StephenWinthrop).

Calaneet Balas, President and CEO, The ALS Association:

*"Stephen Winthrop was loved by everyone who knew him. He was a man of uncommon wisdom and grace, which he brought with him to everything he did, including his own journey with ALS. There is no doubt that he helped make a significant impact in the fight against ALS through his leadership of the Board and his efforts to raise awareness and support for our mission. We all loved working with him, and he will be truly and deeply missed."*

Mark Calmes, Vice Chair, The ALS Association Board of Trustees:

*"Stephen was a tremendous person in so many different ways, who did not let ALS define him. He has left an indelible mark on the Association and the entire ALS community. I am missing him dearly."*

Cam Ward, Secretary, The ALS Association Board of Trustees:

*"We are all grateful to have had Stephen and his family in our lives. People living with ALS live better today because of him."*

Bill Soffel, Board Member, The ALS Association Board of Trustees:

*"Stephen possessed a very unique combination of gifts – a brilliant mind, and the ability to relate to, and put at ease, everyone he came in contact with. I think that's what made him such a great leader, and why we, as fellow ALS Association board members, were so honored to serve alongside him."*

Stuart Obermann, Board Member, The ALS Association Board of Trustees

*"Stephen was a selfless leader who gave his all to the fight against the disease. God Bless him and his family."*

Mark Stancil, Board Member, The ALS Association Board of Trustees

*"Stephen was such a genuine and truly selfless individual that gave everything he had to fight ALS. We are all better people for having known him. Our thoughts and prayers are with Jane and his family – blessings to you all."*

Connie Houston, Board Member, The ALS Association Board of Trustees

*"Stephen was a beautiful person and his love of his family and his inner strength inspired me. I am blessed to have served with him and am committed to continue to serve in memory of him and fight to find a cause, treatment and cure."*

Lance Christian, Executive Director, The ALS Association Oregon and SW Washington Chapter

*"Stephen was man of great integrity and intellect. He brought both those traits plus a big heart to his leadership of The ALS Association. Big shoes to fill. Deepest sympathies to his family."*

Brian Frederick, Executive Vice President, The ALS Association:

*"Stephen was a man of tremendous integrity and compassion who inspired all those around him. Both before and after his diagnosis with ALS, he lived a life that truly mattered."*