

ALS Association's 2020 National Advocacy Conference Goes Virtual

Not to be deterred by the COVID-19 pandemic, ALS Association advocates from across the country held more than 350 virtual meetings with members of Congress Tuesday, adapting the Association's longstanding annual Advocacy Conference to ensure the safety of participants.

Historically, upwards of 600 ALS advocates gather in the nation's capital for days of face-to-face meetings with their elected representatives in the Congress and the Senate.

"COVID-19 makes our policy priorities all the more relevant," said Kathleen Sheehan, vice president of public policy at The ALS Association. "The pandemic exacerbates the financial, emotional and clinical needs of the ALS community and it was imperative to let legislators know that, even if it meant modifying our conference to a new platform."

This year's virtual conference kicked off with a series of webinars where participants were updated on the Association's public policy priorities for 2020, including a message from Senator Tom Cotton (R-AR) and live appearances by Senator Mike Braun (R-IN) and Representatives Jason Crow (D-CO) and Peter Welch (D-VT). The three-part webinar series also included sessions updating participants on developments in ALS research and the changing environment of care due to the COVID-19 pandemic. More than 340 participants including people living with ALS and their families then participated virtually in meetings with congressional representatives to share their powerful stories. "We are so grateful to the many people across the nation who advocated with us. Our 'Behind the Scenes: Advocacy in Action' on each call was a success," said JoCarolyn Chambers, Care Services Manager from the Oklahoma service area.

"Everyone on our video calls could hear the phone conversations with our legislators perfectly, as if we were all in their offices with them. It was a great alternative."



Oklahoma and Florida constituents participate during the 2020 National Advocacy Conference

The conference wrapped up Wednesday with a final push, The ALS Association's Call Congress Day, where advocates called their senators and representative and urged them to pass the ALS Disability Insurance Access

Act (S. 578 / H.R. 1407). Supported by 62 senators and 238 representatives – more than half of each chamber – the ALS Disability Insurance Access Act would waive the five-month waiting period before people living with ALS can receive their SSDI benefits.

“Last year my family and I were able to travel to DC for the conference and visit the Hill in person. This year the calls were virtual, but the issues are just as urgent,” said Troy Fields, person living with ALS and ALS advocate. “Increased research funding, the elimination of the five-month waiting period for SSDI, and getting Medicare to include home infusions in their reimbursement schedule are critical changes needed to support people with ALS.”

Our federal advocacy work focuses on educating and mobilizing all members of Congress in a nonpartisan fashion to achieve the mission of The ALS Association: To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

Visit our website to learn more about the Association’s public policy priorities and our advocacy guiding principles.

To learn more about how The ALS Association incorporates virtual advocacy into our fight for better public policies listen to this recent episode of *Connecting ALS*.

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