

FOR IMMEDIATE RELEASE

**ATAXIA PATIENT ADVOCACY ORGANIZATIONS APPLAUD THE U.S. SENATE FOR PASSING THE
BIPARTISAN “NATIONAL ATAXIA AWARENESS DAY OF 2020” RESOLUTION**

Washington, D.C., (November 20, 2020) – The National Ataxia Foundation (NAF) and the Friedrich’s Ataxia Research Alliance (FARA) applaud the United States Senate on behalf of Ataxia patients and their families for passing the National Ataxia Awareness Resolution of 2020 (S.Res. 717). Led by U.S Senator Elizabeth Warren (D-MA) and U.S. Senator Cindy Hyde-Smith (R-MS), this resolution designated September 25th 2020, as National Ataxia Awareness Day in the United States. We thank Senator Warren and Senator Hyde-Smith for their commitment to raise awareness of Ataxia. We are grateful for the time and attention both Senate offices gave to this mission. We would also like to thank MA State Senator Moore and Senator Lamar Alexander, for their assistance in getting the resolution passed.

"Ataxia is a rare neurodegenerative disease that has affected Americans of all ages, and it is important that we bring awareness to the disorder and support those impacted," said Senator Warren. "That’s why I’ve introduced -- and the Senate has passed -- a bipartisan resolution with Senator Hyde-Smith to raise awareness about the need for further research, improved treatment, and a cure."

"There is great need to increase awareness of Ataxia, its characteristics, and the devastating effects these incurable neurodegenerative diseases have on victims and their families. With greater awareness, we can push for better treatments and, with time, a cure," said Senator Cindy Hyde-Smith.

"This resolution gives visibility and voice to those living with Ataxia and demonstrates the power in advocacy. We are grateful for the partnership between FARA and NAF, and we share urgency in advancing diagnosis and treatments for Ataxia." said Jennifer Farmer, CEO of FARA, and Andrew Rosen, Executive Director of NAF.

The resolution not only defines this extremely complex group of diseases, it underscores the need for greater awareness not only in the general public, but among health care professionals as well. This will hopefully improve the diagnostic journey and access to care for so many that spend years in search of a diagnosis and access to the specialists in this field. This is a historic accomplishment in bringing greater awareness of Ataxia nationally.

This resolution would not have been possible without the NAF/FARA Advocacy Committee who worked tirelessly over the last two years to get this resolution passed. The Joint Advocacy Committee includes Brigid Brennan, John Mauro, Andrew Rosen, Lori Shogren, and Lauren Sormani. This powerful legislative statement is a direct result of advocacy by the ataxia community. NAF and FARA thank them for sharing their stories and experiences with Ataxia. Their voices were heard!

Full text of the resolution can be found [here](#).

About NAF: NAF is a nonprofit organization established in 1957 to help persons with Ataxia and their families. The Foundation’s primary purpose is to support Ataxia research, provide vital programs and services for Ataxia families, and help in the search for a cure. NAF is the only organization in the United States dedicated to the disease that serves all types of Ataxia. NAF works closely with the world’s leading Ataxia researchers, promoting exchanges of ideas and innovation in Ataxia discovery.

About FARA: FARA is a non-profit, tax-exempt organization dedicated to the pursuit of scientific research leading to treatments and a cure for Friedreich’s ataxia. FARA's Mission is to marshal and focus the resources and relationships needed to cure FA by raising funds for research, promoting public awareness, and aligning scientists, patients, clinicians, government agencies, pharmaceutical companies and other organizations dedicated to curing FA and related diseases.

NAF Executive
Director:

Andrew Rosen
andrew@ataxia.org
763-553-0020

FARA Chief
Executive
Officer:

Jennifer Farmer
Jen.farmer@curefa.org
484-897-6160

Media Contact:

Stephanie Lucas
Communications Manager
stephanie@ataxia.org
763-231-2744

To learn more, contact us or visit ataxia.org