You, yes, YOU!

You have heard it before, but it’s true: many voices are louder than one single voice. This is the power of advocacy.

Using your voice, sharing your rare disease story and joining with others to amplify the message, brings the needs of the rare disease community to the attention of local, state, and federal government officials.

If you do not participate in advocacy, then your unique voice and rare disease story will not be heard.

The rare disease community needs advocates like YOU to ensure that policymakers and legislators are aware of the challenges facing rare disease patients and caregivers from getting a diagnosis to accessing treatments and cures. Without your story, legislators can’t effectively support policies that help you, your families, or others with rare diseases.

For more information, contact: Shannon von Felden (RDLA Program Director) at svonfelden@everylifefoundation.org
rareadvocates.org
HOW
To Get Started

- Sign up to receive communications from RDLA at www.rareadvocates.org.
- Participate in Rare Across America meetings with legislators in August 2020. Register at www.RareAcrossAmerica.org.
- Come to Washington, DC for Rare Disease Week on Capitol Hill 2021. Find out more, including how to apply for a travel stipend, at www.rareadvocates.org/rdw.
- Schedule a meeting with your Member in their district office or on Capitol Hill.
- Invite your Member of Congress or their staff to events held in your community.
- Attend events like townhalls that your Member of Congress holds in the district and state.
- Participate in meetings about research and therapy development for your disease area at NIH or the FDA. Learn more, including how to apply for travel stipends at raregiving.org.
- Engage with legislators on social media.
- Write letters or emails to your legislators.
- Write op-eds for your local newspapers.

As a rare disease patient, it's important to make our voices heard so we are considered in this climate of healthcare reform, especially considering our preexisting conditions may not be protected in future regimes.

- Rebecca Strong. (Rare Disease Advocate)