

Tips to Effectively Advocate

By sharing your story with policymakers, you can make a difference in available federal funding for research, raise awareness, and shape legislation.



GETTING STARTED

It's important that elected officials hear from you about how policies & funding will affect YOU. Engagement with elected officials is all about building relationships with the goal of becoming a valuable resource on Rett syndrome. Tips for achieving this:

- 1 Be confident. Present yourself as the expert you are.
- 2 Plan and practice your message.
- 3 Be clear and concise. Less is more.
- 4 Have a goal — raise awareness, ask for funding, or share legislative concerns.
- 5 Tell your personal story. Stories are more compelling & impactful than statistics.

TAKE ACTION



Letters & Emails

Writing to your elected officials is an effective way to make your voice heard & to share your experience with Rett syndrome. Send letters to the elected official's office, addresses can be found on the Congress Member's website. Emails can be easily sent through the IRSF Advocacy tool on the website. On the tool you will be given an email template to plug your story into.

www.rettsyndrome.org/advocacy



Phone Calls

Congress Members record how many calls they track how many calls they receive on a particular issue. It's noted when the phone rings off the hook from constituents who want to be heard. Be sure to do these things when calling: Use the Educational Guide on the website for talking points, leave a message if no one answers & follow up at a later date, identify yourself & state that you are a voter, be courteous & polite, and ask for the staffer to update you with any action taken.



Meetings

Most of the time Congress Members travel to their states & hold meetings during congressional recesses. If you are comfortable with meeting your elected official, IRSF is happy to assist you with preparing for your meeting. It's always a good idea to plan ahead, remain flexible, and have handouts. The same applies to virtual meetings!

FOLLOW UP

Advocacy doesn't stop at one call, letter or email. Follow up to continue to build a relationship with the staffer & elected official. The need for advocacy never ends. Share your efforts on social media & encourage others to join you in advocating.