How To Make Connections with your Members of Congress

Connecting with your Members of Congress is an important first step in making your rare disease story heard!

When members of Congress hear from kids in their district (the area they represent) like you, they are more likely to support rare disease bills.

*A **legislator** is someone who makes laws.*

To make a connection with your Senator or Representative you can:

- **Meet with your legislator:** Have a family member or loved one help you set up a virtual or in person meeting with your member of Congress. You can do this by contacting your members' staff for further instructions.
- **Research:** Look at your legislator's website or social media to learn more about them and what issues are important to them.
- **Invite** your Member of Congress or their staff to an event held in your community. If you are planning an event, they or their staff might attend to meet you and others.
- **Write a letter** or email to your legislators.
- **Call** your legislators' offices to share your story. A staff person will answer the phone, and you can leave a message with them to share with the legislator.
- **Send** "thank you" messages (call, email, letter, social media post) when your legislators support rare disease issues.

When should I engage with my Representative and Senators?

Anytime and all the time! Start out slowly and bring up the issues you care about most.

As a bill moves through Congress, let your legislators know how you feel about it. Don't wait until it's too late to voice your support or concerns about a bill you care about.

***Congress** is the legislative branch of the government. There are 535 members of the U.S. Congress: 435 in the House of Representatives and 100 in the Senate.*

TIP!

You can find your legislators' contact information on their personal website, Congress.gov, or your state legislature's website.

TIP!

Staffers are an amazing resource and Members of Congress depend on them to tell them what issues affect the people who live in their district.

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I'm nervous about meeting with my legislator. What can I do to prepare?

As a young advocate, you are the voice of the future, and your members of Congress want to hear from you. It can be scary to meet with legislators and their staffers. Sometimes knowing what to expect can help you feel more confident. The legislator will want to hear how rare diseases affect you and why it's important for them to know about it. You can practice sharing your story and what you will ask the legislator to do before you meet with them. Here is a worksheet and tips to help you get started.

Hear from kids and teens like you!

"Every time I meet with my legislators, I always think about how just a few years ago in the hospital, I never would've considered that my health battles would one day be my fuel to advocate for positive changes. Stories are what moves bills into action, and getting involved with advocacy is an amazing opportunity to turn your struggles into a powerful asset!"

– Nell Choi
17 years-old,
Neuromyelitis Optica

TIP!

After meeting with your legislators, ask if they would be willing to take a picture with you. You can share this photo in follow up communications!

"There are no age barriers in advocating for our basic civil rights as rare patient children. I have been in 15 Congressional meetings over the last three years, and it gets easier every time. Why is that? Because you can share your legislative 'asks' with sincerity by being brave, fierce, and rehearsed. We are not only using our voices for ourselves, but also for other rare patient children that cannot use their voices. We just need to remember that when meeting with Congressional Members, they are humans just like us, and chances are they know someone that has a rare condition, because we are 30 million strong nationwide! Together, WE ARE RESILIENT!"

– Sati Cooper-McCann
10 years-old, Stickler Syndrome (COL2A1) with Hypermobility

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