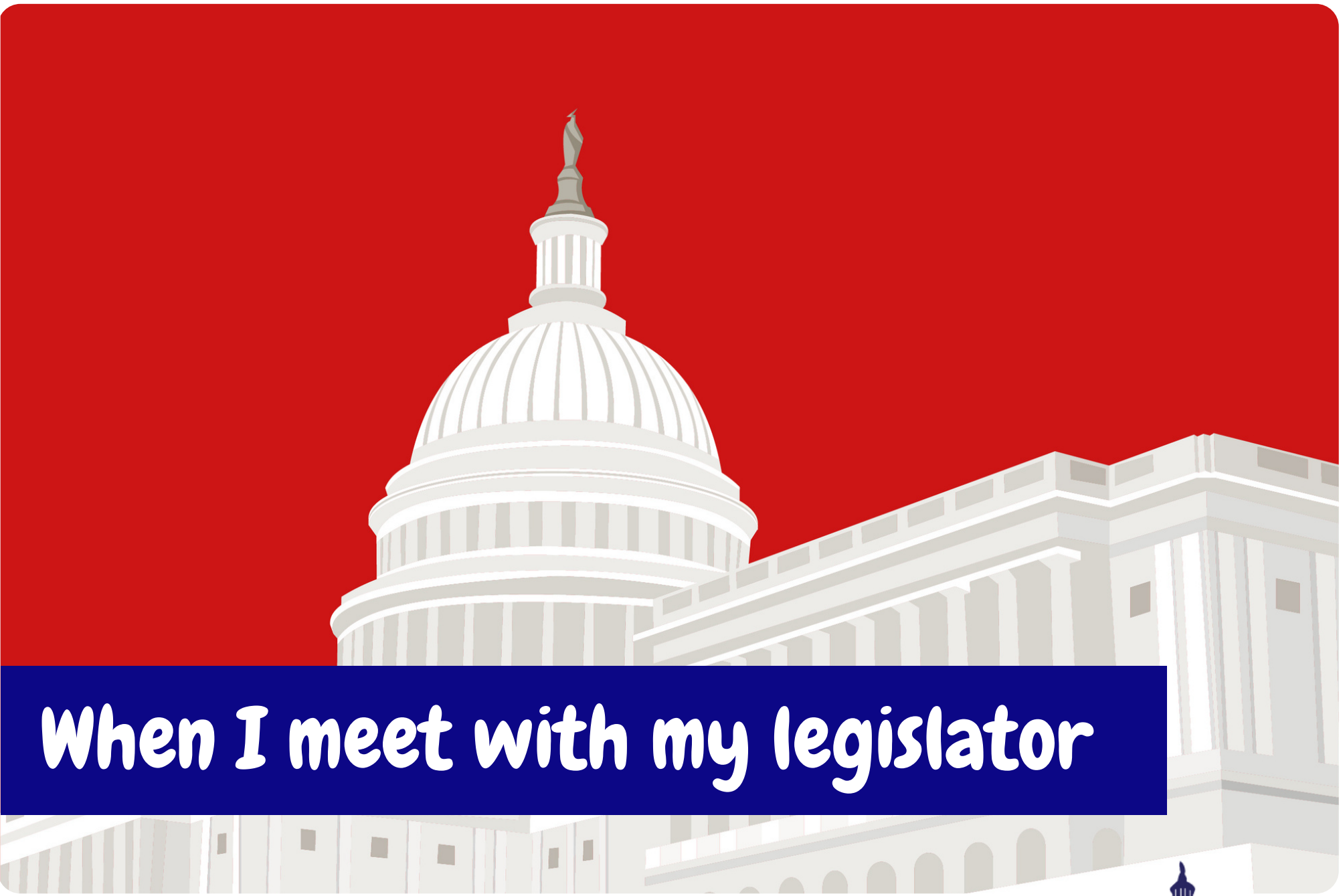


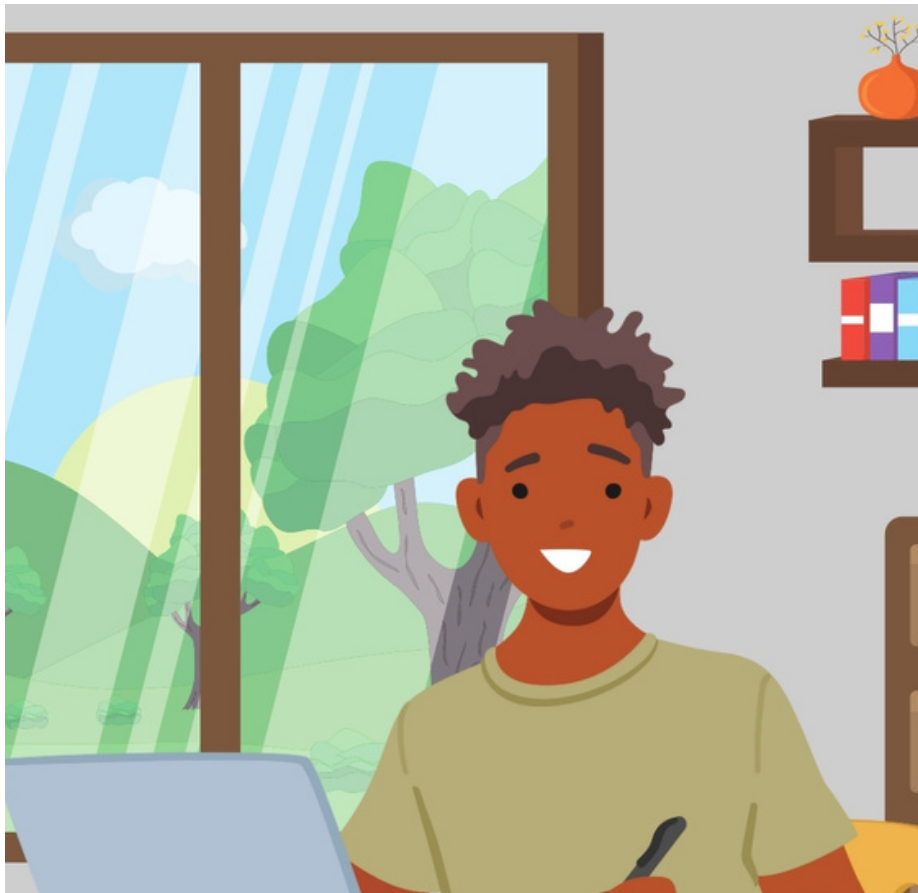


When I meet with my legislator

www.everylifefoundation.org

    @EveryLifeOrg @RareAdvocates





I'm going to meet with a legislator. Legislators make important decisions that can help me and others with rare diseases.

I can prepare for this meeting by writing down what I want to say, and I can practice in the mirror or with a trusted adult.

Sometimes the legislator can't make the meeting, and so I might meet with their staffer. That is great too! A staffer is someone who works closely with the legislator.



This meeting will last for 15 to 30 minutes. It will happen over a video call, where I can see them, and they can see me.

There will be other people on the call with me. It might be my grown-up, other kids like me, or someone from the EveryLife Foundation. It's ok if there are only 1 or 2 people with me, I won't be alone!

If my grown-up is not on the call, they can be nearby to help me.



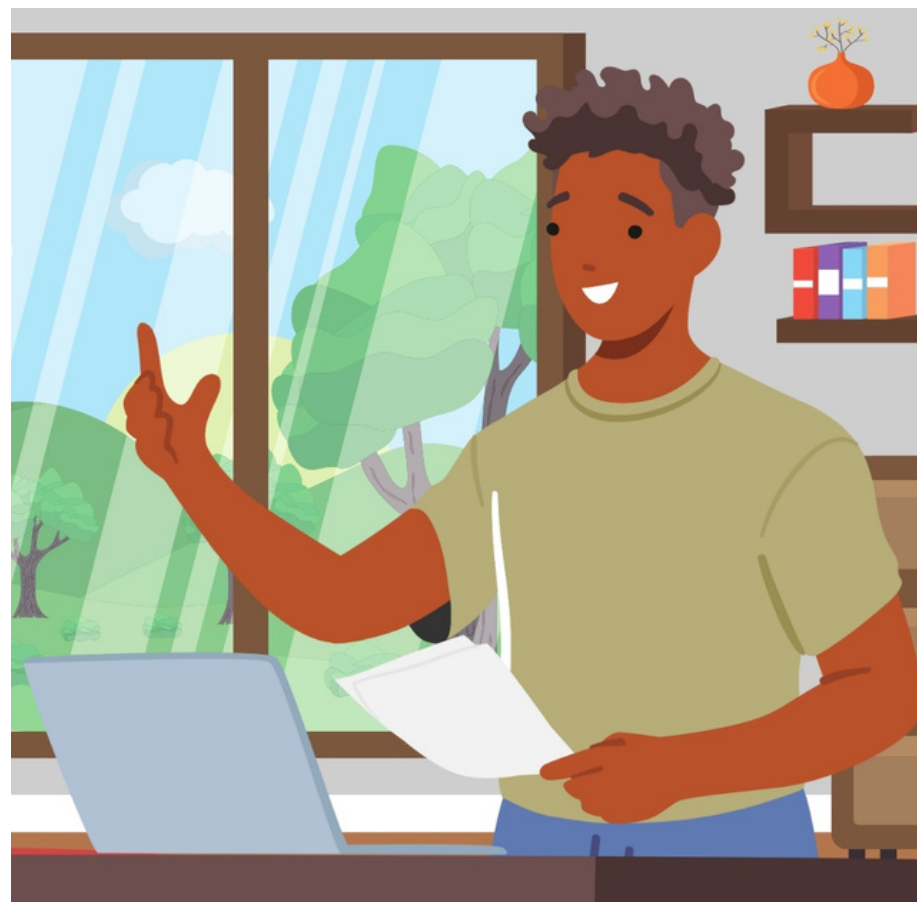
When the call starts, I can say hello, wave, or smile! I can tell them:

- My name
- How old I am
- Where I'm from
- The name of my rare disease

Then I will tell them my story. I can talk about how I was diagnosed or how my disease affects my life. I will have my notes on How to Share Your Story with Congress to help me.

If there are other kids in my meeting, I will share for 2-3 minutes. This will give others time to tell their stories. If I'm the only kid in my meeting, I will have more time to share my story.

I will do my best to speak clearly and use simple words.



I will also tell them about a bill, the bill number, and how it could help me. I can use the 1-pager with the information about the bill to help me with this.

I may not know many details about the bill, but that's ok! Sharing my story is the important part!

Then I can ask them to cosponsor the bill. Cosponsor means that the legislator supports the bill and thinks it's a good idea. This can help it become a law.



When I am finished speaking, I can ask if they have any questions.

If I don't know the answer to a question they ask – that's ok! I can say "I'm not sure, but I will have my grown-up or the EveryLife Foundation get you an answer." I can write down the question to help me remember it.

I can also ask them my own questions.



I am brave, and I can do this!

I am an expert on my own story and that matters most of all.

At the end of the call, they will thank me and say goodbye. I can say thank you, goodbye, or wave.

Sharing my story helps make a difference for people like me!