

How to Share Your Story with Congress



During your virtual meetings with your Representative and Senators, you will talk about what it is like to live with a rare disease and how they can help kids and teens with rare diseases. Start by answering the following questions to outline your story. You can use your story to make an “elevator pitch,” which is about 2 minutes, to share with your legislators.”

What is the problem?

How should Congress solve the problem? How will it help?

What can your legislator do to help? Be specific

Advocating for Rare Disease & Sharing Your Story:

Drafting Your Pitch

Hi _____ ,
NAME OF REPRESENTATIVE OR SENATOR

My name is _____ and I am a resident of _____ .
YOUR NAME COUNTY/STATE

I'd like to use our time today to discuss _____ .
INSERT TOPIC/DISEASE/LAW/FUNDING

The reason why I am advocating for this is because _____ .
INSERT PERSONAL STORY (2-3 SENTENCES)

I know you _____ .
INSERT RELEVANT CONNECTION/STANCE RELATED TO LAWMAKER (IF APPLICABLE)

What you may not know is that _____ .
INSERT TWO POINTS/STATISTICS THAT MAY ENCOURAGE ACTION

I hope you will consider _____ .
INSERT ACTION
because it could mean _____ .
INSERT BENEFIT

Do you have any questions for me?

Thank you again for your time and everything
you do to help kids and teens with rare
diseases.

