

Tips to Inspire Action



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READY

Do Your Research

Get to know your legislators by visiting their websites and social media channels to learn:

- Their general views
- What bills they have introduced
- Committees they participate on
- Their position on your issue

Identify a Key Challenge

As a parent, caregiver, or advocate, you may face many challenges. Pick one to highlight:

- Access to diagnosis
- Access to essential care
- Access to treatments

Know Your Ask

Be clear about what you want your legislators to do.

- Introduce the specific legislation and bill number that will drive change

SET

Craft Your Pitch

Break your message into three parts that are easy to share and remember.



Problem



Solution



Ask

GO

Key Dos

- Get your key messages in early
- Be concise - less is more
- Balance fact and emotion
- Be authentic - no need to memorize

Meeting Virtually?

Remember These Tips!

1. Test Your Tech

Check your internet connectivity, and confirm that your camera and microphone are working

2. Set the Scene

Find a room with optimal lighting and eliminate all distractions

3. Have an Agenda

Organize your thinking and stay on message



Your voice matters! By sharing your story, you will:



Make an impact on
federal policy



Improve understanding
of rare diseases



Support development
of new treatments

Practice, Practice, Practice!

- Review your key messages
- Use your phone to record and review your 90-second elevator speech
- prepare answers to anticipated questions, including difficult or unexpected ones

Your Personal Assessment

What did you do well?

What can you improve for next time?

Be Yourself. Remember, you are the expert.
No one knows your story better than **YOU!**



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