

# 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
- Committees they participate on
- What bills they have introduced
- 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 treatments
- Access to essential care

### 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?

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What can you improve for next time?

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



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