Practice Your Pitch Webinar
Rare Across America 2020
July 21, 2020
Welcome

During this webinar, you will:

- **Receive tips and coaching** from communications experts that will help you tell your story with impact, and inspire action
- **Refine your elevator pitch** and develop a clear and concise “ask”
- Breakout into smaller-groups for an opportunity to **practice and receive feedback** from our team with personalized coaching
Meet Your Coaches

Katie Burns  
Vice President  
SmithSolve

Britta Dornan  
Senior Director of PR and Patient Engagement  
EveryLife Foundation for Rare Diseases

Chris Smith  
President and CEO  
SmithSolve

Shannon Von Felden  
RDLA Program Director  
EveryLife Foundation for Rare Diseases

Mary Morlino  
Patient Engagement Consultant  
EveryLife Foundation for Rare Diseases

Katelyn Laws  
RDLA Program Coordinator  
EveryLife Foundation for Rare Diseases

Jessie Barrett  
Account Manager  
SmithSolve
Your Voice Matters.
• Today is not your only chance to share! Apply what you learn today to share your story on camera and inspire action.

• We’re using an app called **Cinebody** that allows you to create video from anywhere, on any device, in just a few simple steps.

• Everything you film in the app will automatically upload to the cloud, allowing Fast Forward for RARE to easily share your story!
Why Do It?

• It’s easy! In less than 30 seconds, you can download Cinebody and start filming your 90-second elevator pitch.

• Following this webinar, the first 15 advocates who submit their pitch on video through the Cinebody app will receive:
  • Personalized feedback from a Fast Forward for RARE coach
  • An edited copy of your video to share on social media or with your representatives
  • The opportunity to have your video featured on the FastForwardforRARE.org website
Embed Heather's video
Meet Heather

• Heather visited the Fast Forward for RARE booth during Rare Disease Week
• She told her story on camera and received immediate feedback
• She shared her experience and video to raise awareness

Fast Forward for RARE – Every voice matters! fastforwardforrare.org
Are you interested in sharing you rare disease story with Smith Solve and #FastForwardForRare? Use this link to learn more about the initiative and how to share your story.
Where are you from?
How many times have you met with legislators?

Never - this is my first time!

1-3

3-5

5-10

10+
Why Tell Your Story?
Rare Disease Ecosystem

Join the Conversation

Legislators & Regulators
Patient Organizations
Traditional & Social Media
Professional Societies
Industry
Patients, Families & Caregivers
Physicians & Investigators
YOU!

The Story Belongs to the Community
What is Your Ask?

| Rare Across America 2020  
Suggested Legislative Asks |
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<tbody>
<tr>
<td>Join the Rare Disease Congressional Caucus</td>
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<tr>
<td>Cosponsor the Creating Hope Reauthorization Act, S. 4010/H.R. 4439</td>
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<td>Extend Flexibilities for Community Home Health and Telehealth to Enable Critical Access Beyond the Public Health Emergency</td>
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Choose what is most important to you and be prepared
Message Delivery
Identify Legislators

- Understand legislator role in target legislation
- Understand what committees they participate in or lead, what bills they’ve introduced
- Understand their platforms and views on the issue you’re targeting (or similar issues)
- Read/review their social media channels, website, or any other relevant materials
Prepare Materials

- Key messages (bullet points)
- Elevator speech (90 seconds)
- Supporting materials
  - Concise issue background
  - Implications for their community
Rules of the Road

You are in the driver’s seat

Balance fact and emotion

Less is more
Craft Your Message

Problem
Solution
Call to action
Key Dos

- Get your messages in early
- Show how the problem applies to them and their constituents
- Be concise – avoid long or complex thoughts
- Remember you are the expert
- Be authentic – no need to memorize
- Keep it brief, less is more
- Be prepared with your one-pagers and congressional score cards
- Send a thank you letter
Self Practice

• Use your phone to record your elevator speech
• Play it back and think about the following questions:
  • How did it feel? Compelling? Boring?
  • Did you keep it brief? Did you speak clearly?
  • Did you repeat yourself?
  • Are you using words that don’t add value? (you know, um, like)
  • Did you include a call to action?
  • What did you do well?
• Note what to change and go for it again!
Breakout Sessions

- Materials to have on hand:
  - Tips and Advice Flyer
  - Prepare Your Pitch Worksheet
  - One-Pagers of Legislative Asks

- You will automatically be placed in a breakout session, be sure to click “join” to enter the breakout room.

- If you are interested in participating in live role play, please let your coaches know by including your name, location, rare disease affiliation, and ask in the chat window; we’ll repeat these instructions in the breakout.

- Following the breakout session, you will automatically be placed back into the main session for closing remarks.
Closing Remarks
Share Your Story to Inspire Action

- Visit [FastForwardforRARE.org](http://FastForwardforRARE.org)
- Hear directly from rare disease advocates about the issues important to the rare disease community
- Help bring attention to the causes that matter most to you by sharing your story on social media
- Don’t Forget! If you’re one of the first 15 advocates to submit your video via Cinebody, you’ll receive personalized coaching and an edited copy of your video to share
- Together we will:
  - Advance important legislation
  - Improve understanding of rare diseases
  - Support development of new treatments
Thank you.