

Crafting Your Story

Below are some things to think about when crafting and sharing your story across audiences. The first three are always important, and the rest you will refine as you practice and gain experience. It's okay if you feel nervous or uncomfortable. The most important step is the first – getting started! Telling your story will become easier over time.

Join the conversation.

Many people are helping to advance medicine and science. In order for the rare disease puzzle to be complete, it needs to include all voices – including yours!

Outline your goals.

Decide why you're telling your story – is it to help someone understand your needs, raise money, or change laws or the direction of research? Pinpoint what you want to accomplish so that you can effectively inspire and motivate your listeners.

Understand your audience.

Before preparing your story, it helps to know your audience. Think about their perspective, what questions they might have, and what is most important for them to know.

Remember your key messages.

Before you start, it's helpful to write down key points to deliver. Aim for 3 to 5 specific messages, with no more than 1 to 3 sentences each.

Nail down your elevator speech.

An elevator speech should be as short as the time it takes to ride in an elevator (about 60 to 90 seconds). Introduce yourself, describe your condition and its impact, and preview what you want your audience to do.

Elevate your confidence.

Practice your elevator speech with a friend or family member, or use your phone to record yourself.

Ask the following questions:

- How did it sound? Interesting? Boring?
- Did you keep it short and clear, without extra words (you know, um, like)? Did you include a call to action?

Note what to change and go for it again! Think about how you'll answer easy and hard questions.

YOU are the expert!

Your story belongs to YOU. While opinions and priorities may differ for each audience, no one can question your experience. You get to decide what to share and when.



Do these things for an impactful story

1. Offer background information, external resources
2. Get your key messages in early
3. Show your audience how your story applies to them
4. Be concise – less is more!
5. Be authentic – don't memorize your answer
6. Balance fact and emotion