



Mapping Out Your Experience

A Guide for Telling Your Rare Story No Matter the Audience



Step 1: Who are you and who are they?

My name is _____ and I am _____. Thank you _____
YOUR NAME YOUR ROLE AND DISEASE THEIR NAME
 for taking the time to meet with me. _____
DESCRIPTIVE SENTENCE REFERENCING THEIR ROLE



Step 2: What is the one, main thing you want?

I would like you to _____ because _____
OBJECTIVE

ACHIEVEABLE OUTCOME / MAIN POINT

DESCRIPTIVE SENTENCE TO FURTHER EXPLAIN YOUR OBJECTIVE



Step 3: Where are you in the rare disease space?

I'd like to focus on _____ . What you may not know, is that _____
WHERE THE DISEASE / ISSUE LIES

SUPPORTIVE DATA / FACTS

DESCRIPTIVE SENTENCE TO FURTHER SUPPORT YOUR FOCUS



Step 4: Why does this matter?

The impact of having _____ affects (me / my child / my family / society) by _____
NAME OF THE DISEASE SELECT A GROUP

PHYSICAL, MENTAL, AND/OR FINANCIAL IMPACTS

DESCRIPTIVE SENTENCE FOR HOW THEY CAN MAKE AN IMPACT



Step 5: How can they help?

I hope you'll consider _____ , because it could mean _____
YOUR ASK A POSITIVE OUTCOME
 _____ . Do you have any questions?

Thank you for your time.