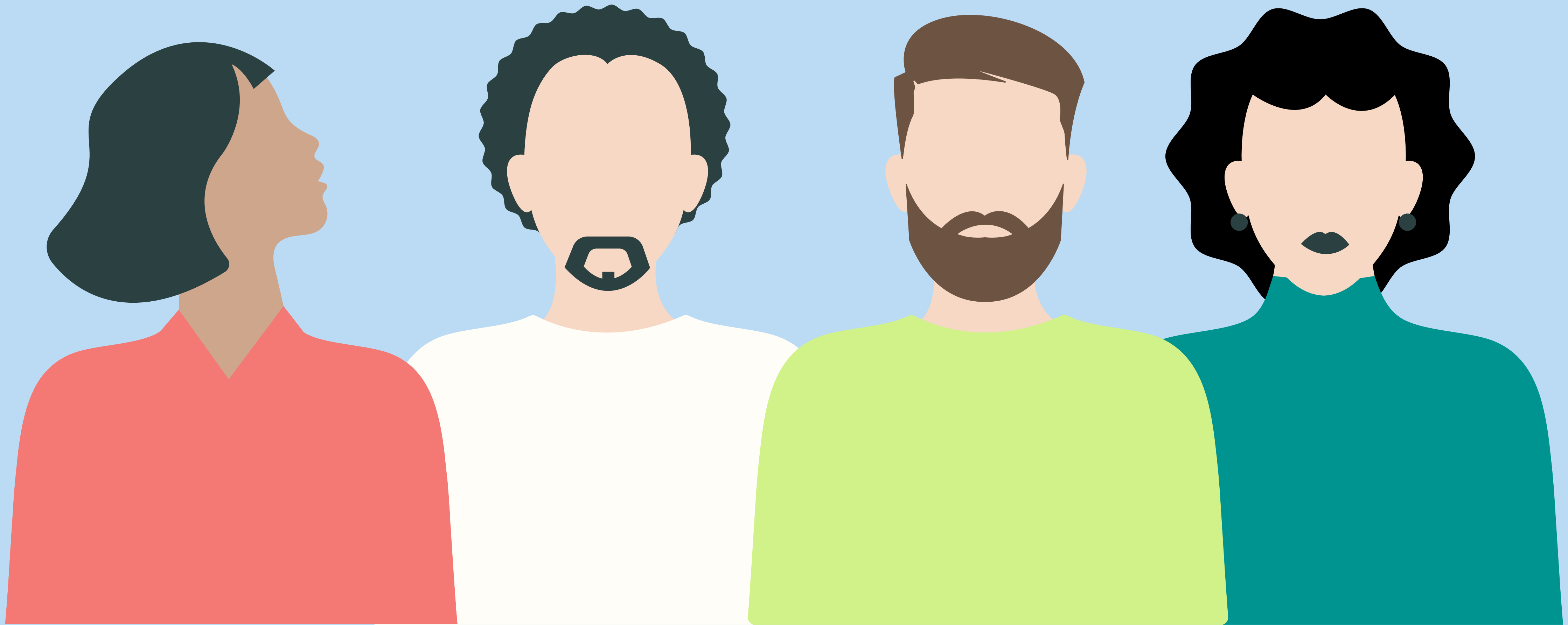
Preparing for Legislative Advocacy

A video series providing strategies for success



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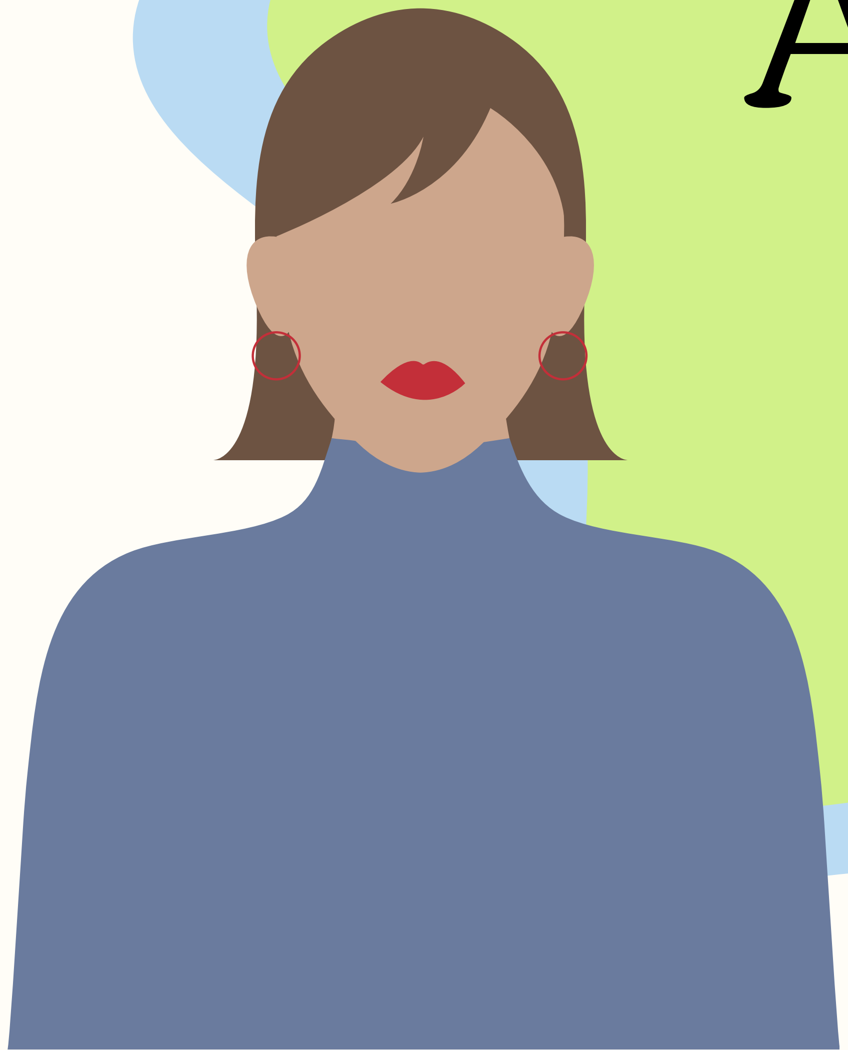
Learning Agenda

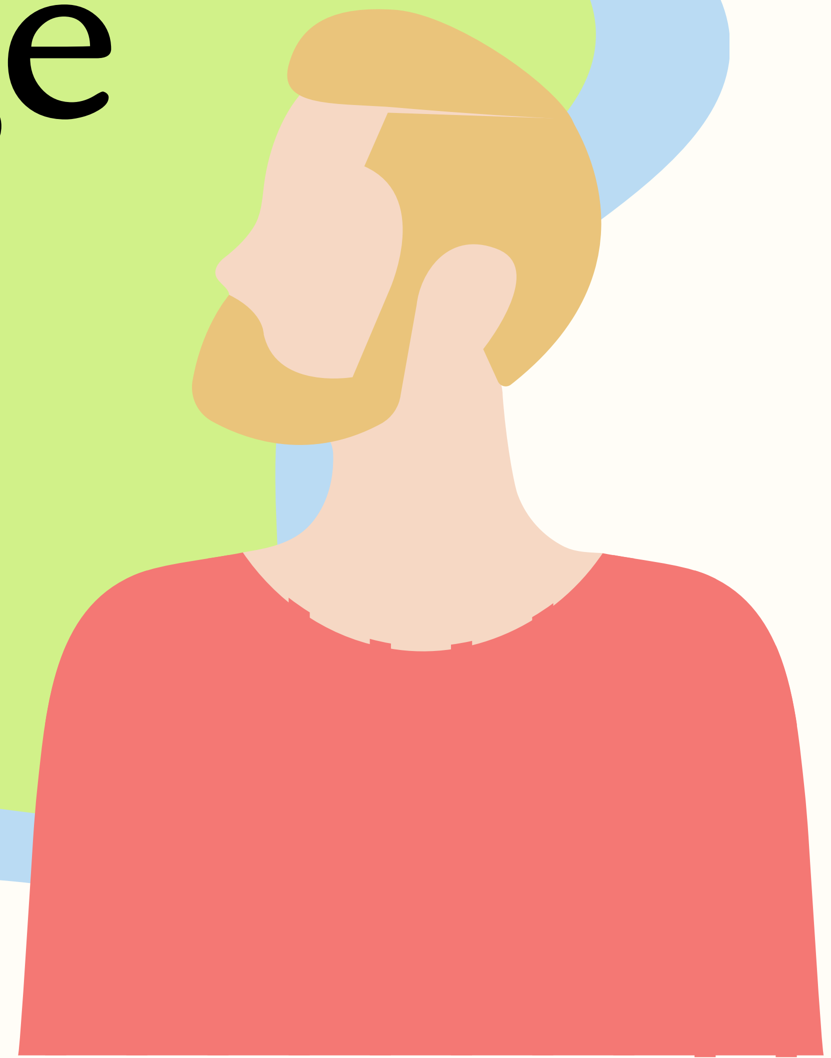
This module will include:

- Parts of an advocacy message
- Crafting an effective personal story
- Developing and delivering an ‘Ask’
- Effectively communicating an elevator pitch

Crafting Your Advocacy Message

Module 3





Parts of An Advocacy Message

Problem
Briefly describe the problem

Impact
How it affects many people or communities

Personal Story
How it personally affects you or your family

Solution
Propose a clear and actionable solution

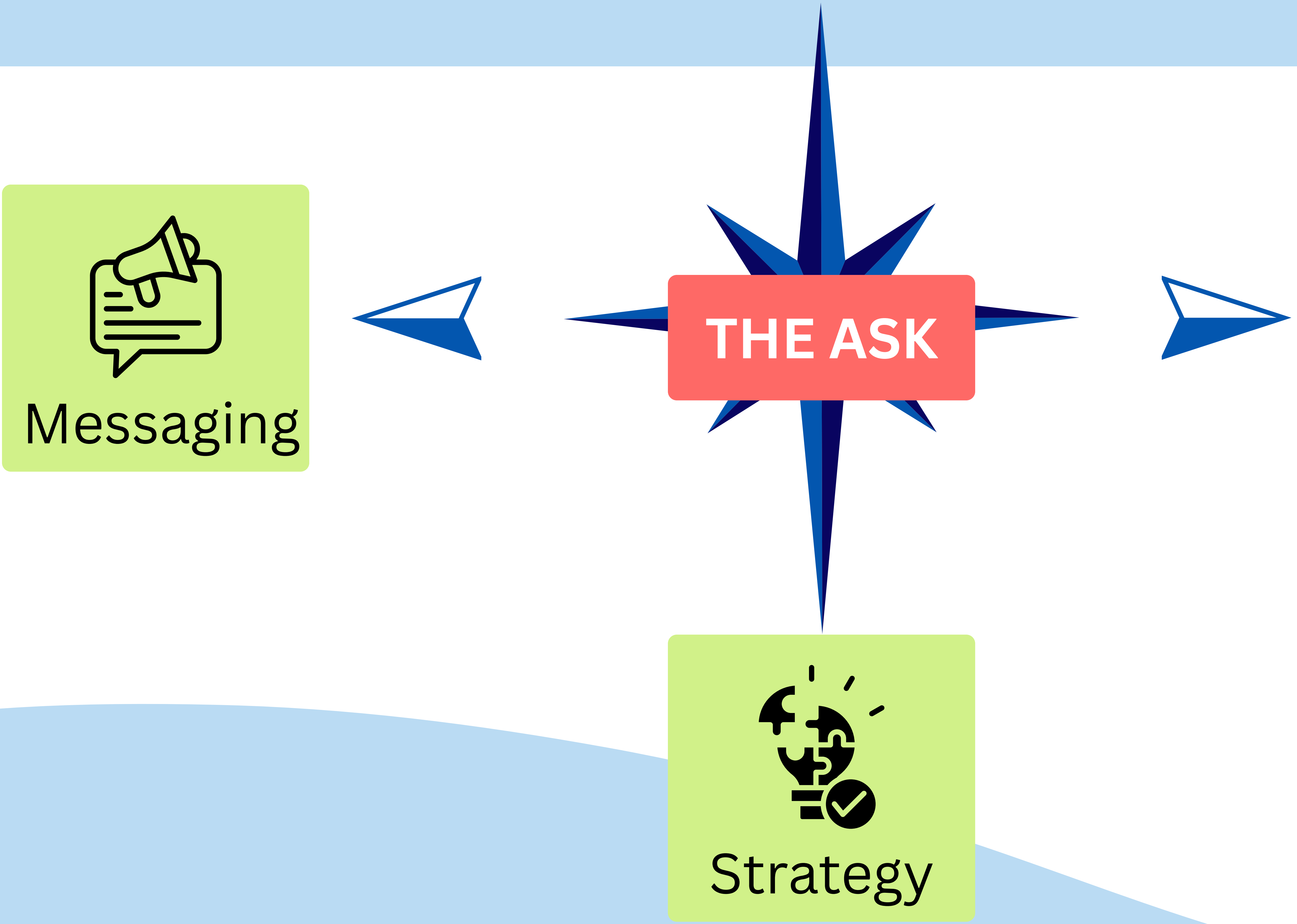
Ask
Make a specific, measurable request

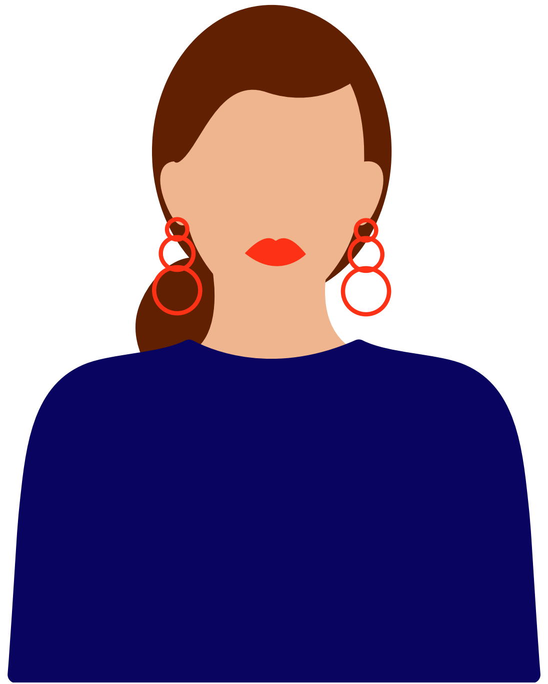
What Is An “Ask”

Knowing What You Want
From Your Legislator

The Ask

THE FOCUS OF YOUR MEETING



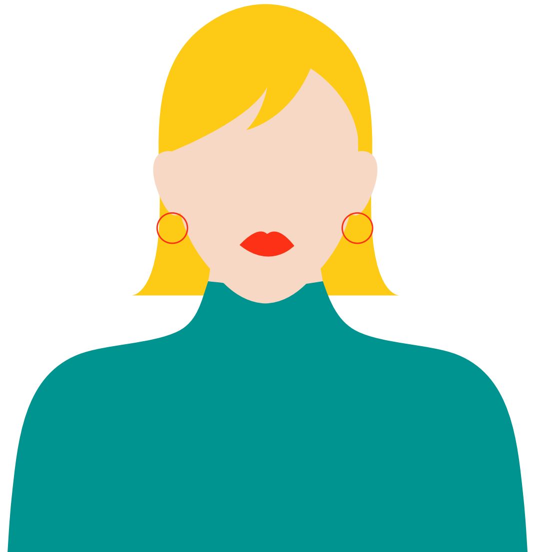


The Ask

The "ask" is the heart of any advocacy campaign, outlining what advocates are hoping to achieve.

IT SHOULD BE:

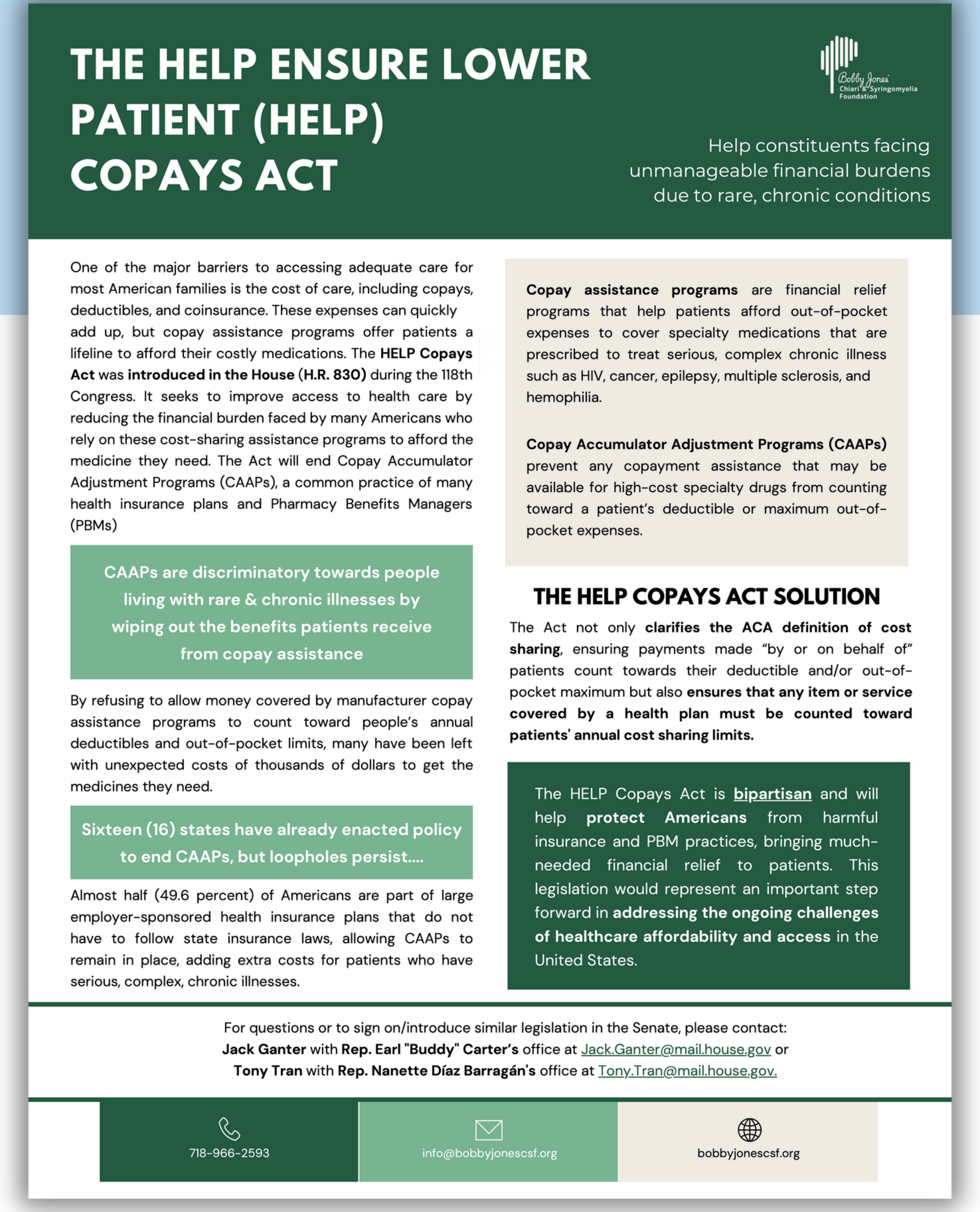
- Clear
- Concise
- Achievable
- Measurable



The One- Pager

It Should Include:

- The organization you represent *(if applicable)*
- Organization or personal contact information
- Bill number and name
- Summary of the problem
- Summary of the solution
- How your representative can help
- List of other supporter



THE HELP ENSURE LOWER PATIENT (HELP) COPAYS ACT

Help constituents facing unmanageable financial burdens due to rare, chronic conditions

One of the major barriers to accessing adequate care for most American families is the cost of care, including copays, deductibles, and coinsurance. These expenses can quickly add up, but copay assistance programs offer patients a lifeline to afford their costly medications. The **HELP Copays Act** was **introduced in the House** (**H.R. 830**) during the 118th Congress. It seeks to improve access to health care by reducing the financial burden faced by many Americans who rely on these cost-sharing assistance programs to afford the medicine they need. The Act will end Copay Accumulator Adjustment Programs (CAAPs), a common practice of many health insurance plans and Pharmacy Benefits Managers (PBMs)

CAAPs are discriminatory towards people living with rare & chronic illnesses by wiping out the benefits patients receive from copay assistance

By refusing to allow money covered by manufacturer copay assistance programs to count toward people's annual deductibles and out-of-pocket limits, many have been left with unexpected costs of thousands of dollars to get the medicines they need.

Sixteen (16) states have already enacted policy to end CAAPs, but loopholes persist....

Almost half (49.6 percent) of Americans are part of large employer-sponsored health insurance plans that do not have to follow state insurance laws, allowing CAAPs to remain in place, adding extra costs for patients who have serious, complex, chronic illnesses.

Copay assistance programs are financial relief programs that help patients afford out-of-pocket expenses to cover specialty medications that are prescribed to treat serious, complex chronic illness such as HIV, cancer, epilepsy, multiple sclerosis, and hemophilia.

Copay Accumulator Adjustment Programs (CAAPs) prevent any copayment assistance that may be available for high-cost specialty drugs from counting toward a patient's deductible or maximum out-of-pocket expenses.

THE HELP COPAYS ACT SOLUTION

The Act not only **clarifies the ACA definition of cost sharing**, ensuring payments made "by or on behalf of" patients count towards their deductible and/or out-of-pocket maximum but also **ensures that any item or service covered by a health plan must be counted toward patients' annual cost sharing limits.**

The HELP Copays Act is **bipartisan** and will help **protect Americans** from harmful insurance and PBM practices, bringing much-needed financial relief to patients. This legislation would represent an important step forward in **addressing the ongoing challenges of healthcare affordability and access** in the United States.

For questions or to sign on/introduce similar legislation in the Senate, please contact:
Jack Ganter with **Rep. Earl "Buddy" Carter's** office at Jack.Ganter@mail.house.gov or
Tony Tran with **Rep. Nanette Díaz Barragán's** office at Tony.Tran@mail.house.gov.

718-966-2593 | info@bobbyjonescsf.org | bobbyjonescsf.org

The One- Pager

It Should Include:

- The organization you represent *(if applicable)*
- Organization or personal contact information
- Bill number and name
- Summary of the problem
- Summary of the solution
- Call to action
- List of other supporter

THE HELP ENSURE LOWER PATIENT (HELP) COPAYS ACT

Bobby Jones Chiari & Syringomyelia Foundation

Help constituents facing unmanageable financial burdens due to rare, chronic conditions

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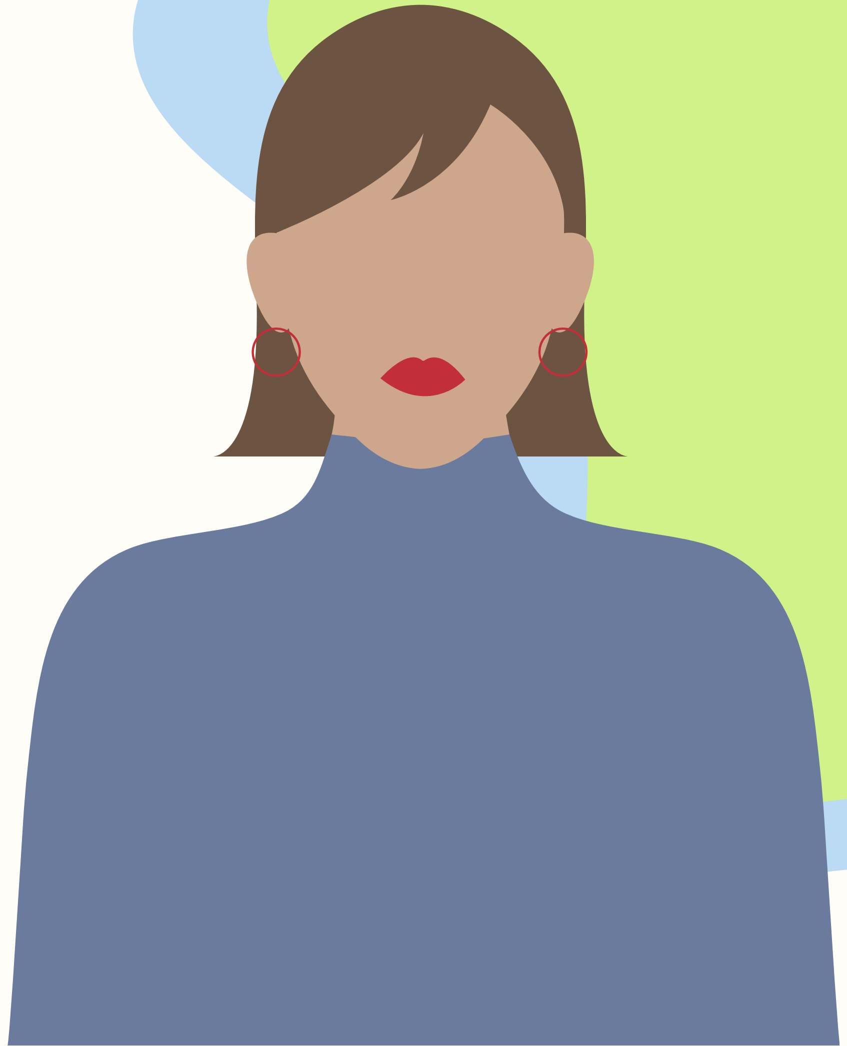
Crafting Your Personal Story



Crafting Your Personal Story

Developing A Strategy

1. Grab Their Attention
2. Focus On a Defining Moment
3. Connect Emotion to Policy
4. Make It Relatable
5. Support the Ask

Personal Story Basics

- Think of it as a 2-3 minute movie trailer
- Details are important to us but might overwhelm the listener
- Share with passion and conviction
- Avoid using medical jargon
- Relate your story to others

Brainstorming Your Personal Story

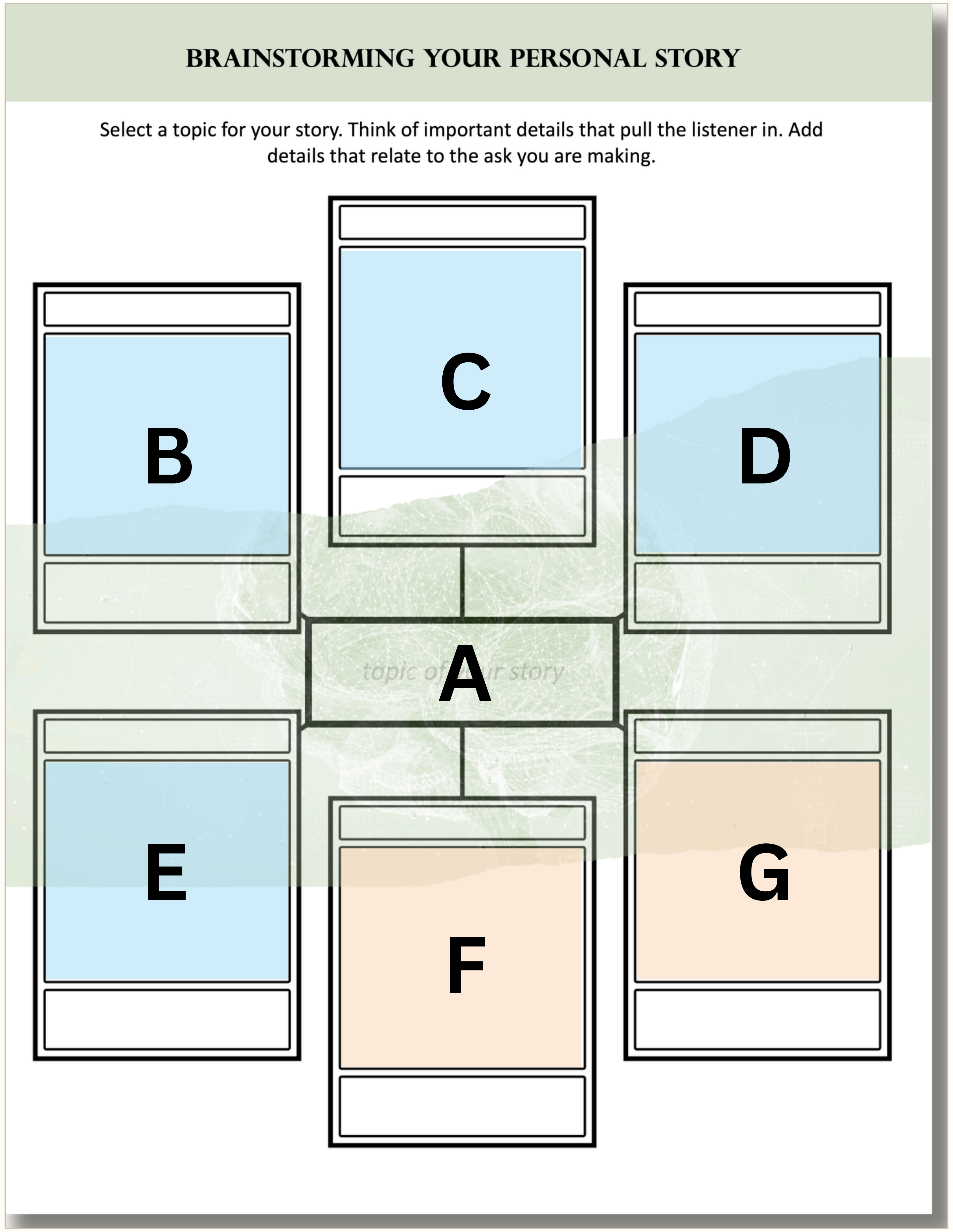
What do people find powerful and moving about the challenges you have faced?

What do you feel passionate about sharing?

What aspect of your life or your family's situation drove you to advocate?

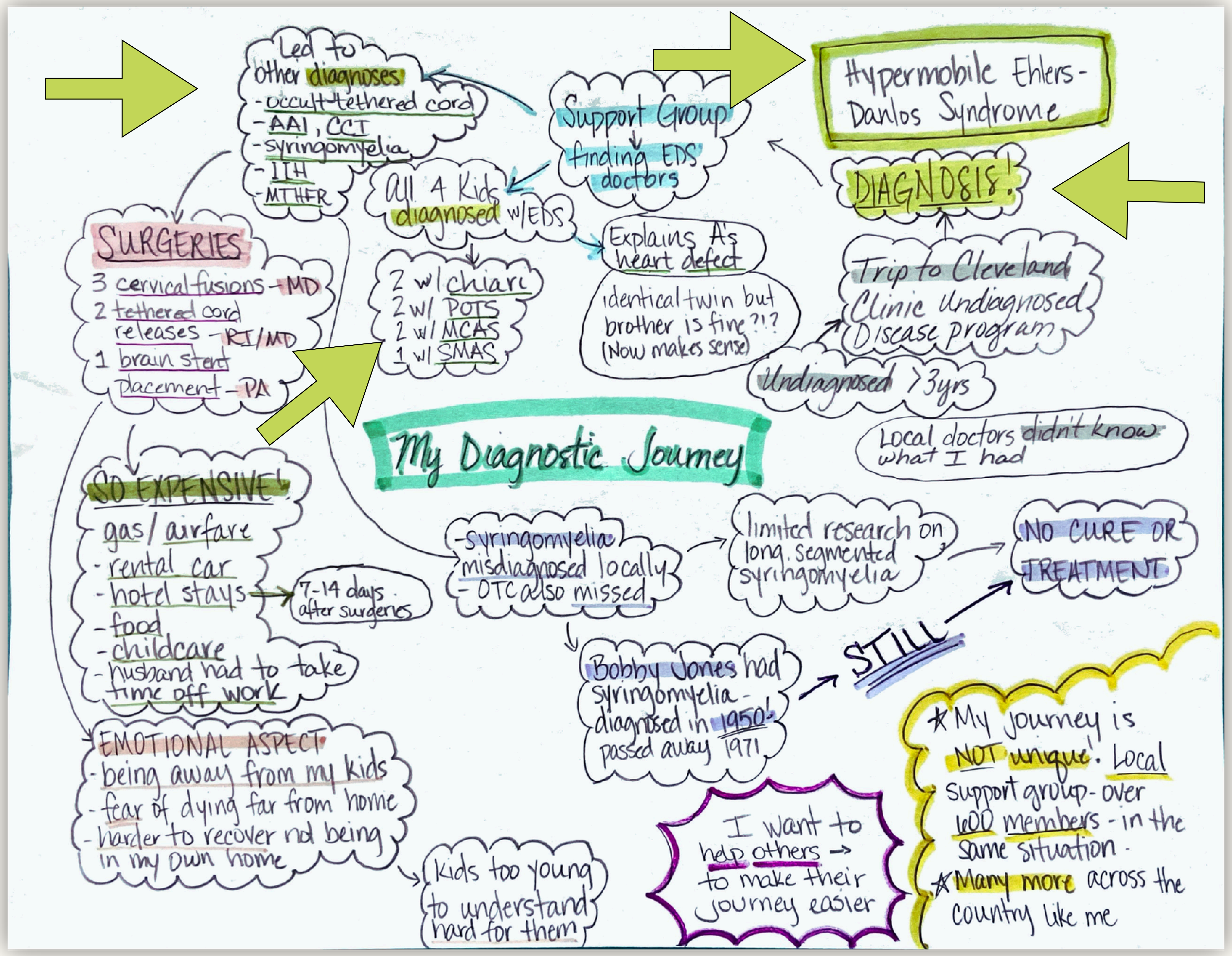
Brainstorming Your Personal Story

A	**TOPIC**- My Diagnostic Journey
B	Diagnosed in Cleveland due to lack of knowledgeable providers in my area
C	Surgeries performed in MD, PA, & RI because of lack of local surgeons
D	The costs associated with travel to see specialists were in the thousands
E	All 4 kids have EDS, 2 with Chiari, 2 with POTS/MCAS, 1 with a CHD
F	Average time for hEDS Dx is over 10 years
G	Bobby Jones died over 50 years ago, with syringomyelia, and there is still no effective treatment or cure



Bubble Map Brain Storming

- Space to let ideas flow
- Highlight to make connections
- Decide on most important aspects
- Don't forget to tie your story into the bigger picture



Putting It Together

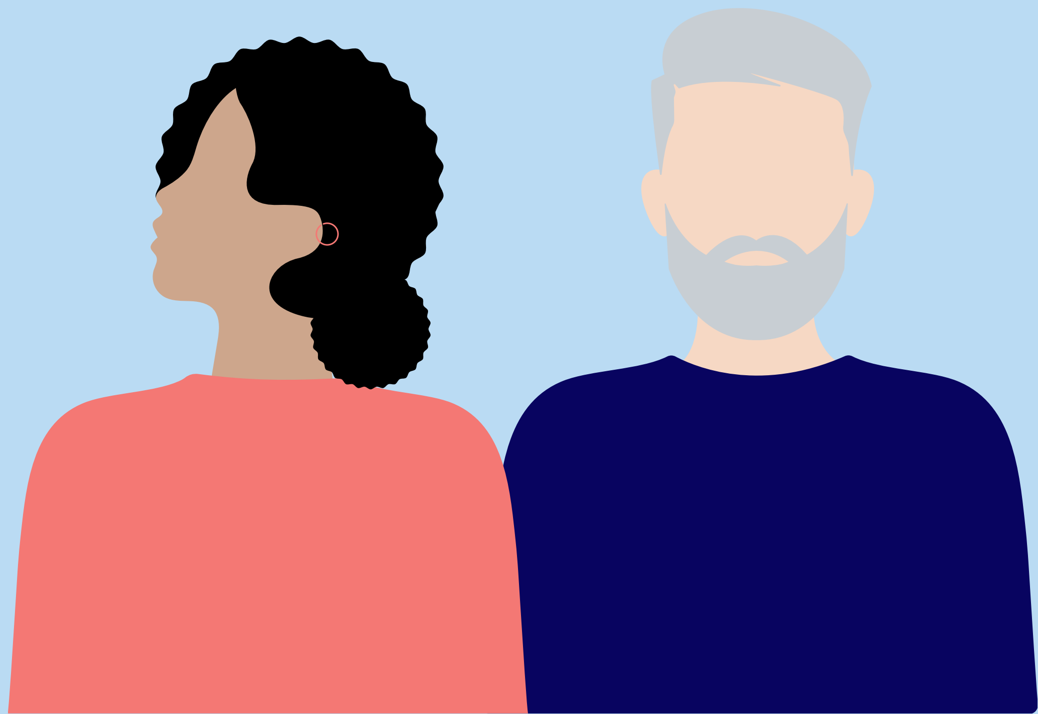
Key Points:

- Does it leave you wanting to know more about my family and our struggles?
- Does it evoke emotions in you? What are they?
- Could you sense the passion and conviction in my voice?
- Was it relatable or did you feel a connection?

Bridge To The Ask

Introduction For Others Making the Ask

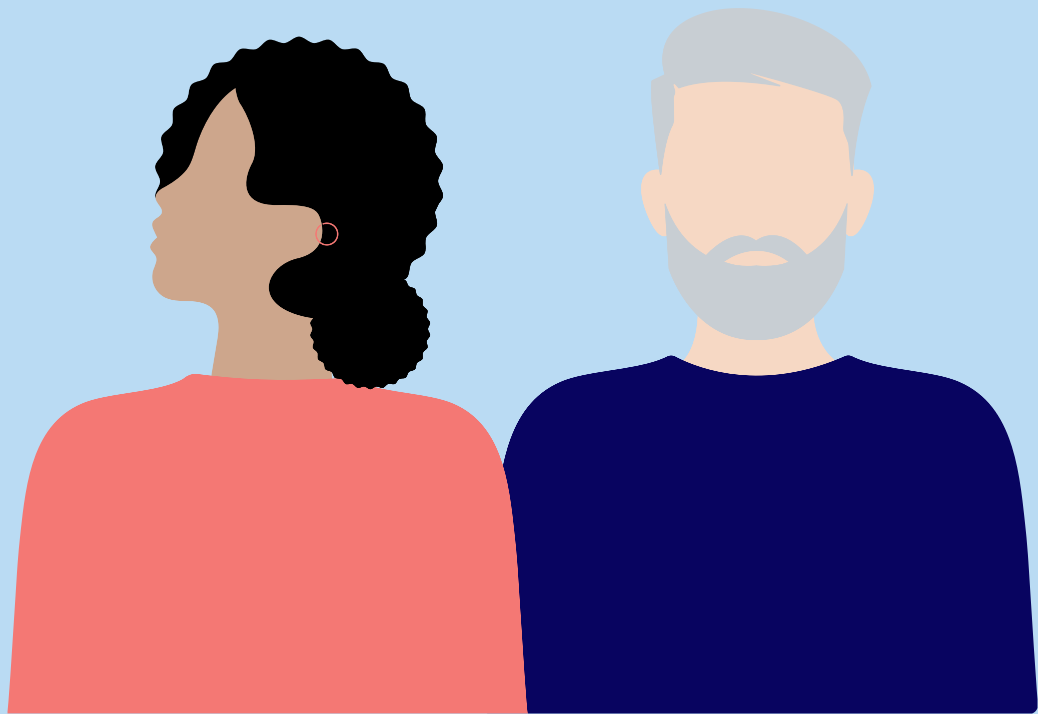
The challenges my family faces aren't just my story; It's the story of thousands of families living with complex, rare, or under-recognized conditions. We need better access to specialty care regardless of ZIP code and more funding for rare disease research. Because for people like me, getting a diagnosis is just the first step. Accessing the care and treatments we need to survive becomes a full-time job. And right now, even after decades of research, conditions like syringomyelia still have no effective treatments or a cure.



Bridge To The Ask

Expand Access To Interstate Telehealth

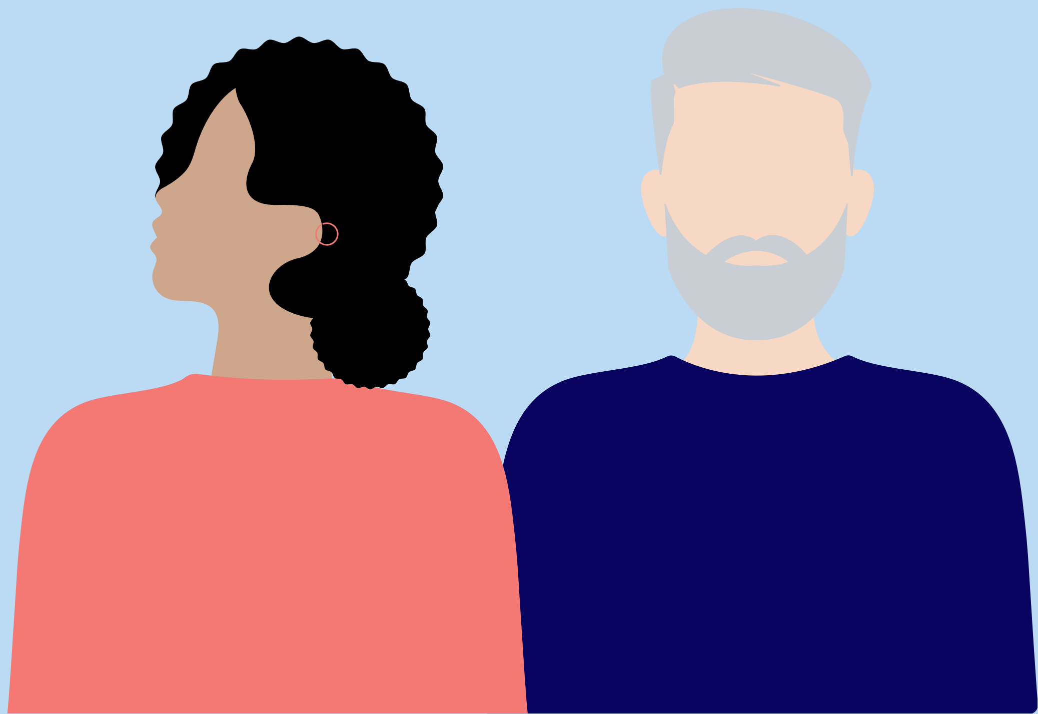
Many of the nation's experts in these rare conditions are concentrated in a few states. Telehealth allows patients like me and my children to receive expert care without facing the financial and logistical burden of constant travel. We must **expand access to cross-state telehealth** to ensure families can get the care they need. So many of us rely on out-of-state specialists because local providers simply aren't trained to treat these conditions. Telehealth is a lifeline—it's more than convenience, it's access to survival. I hope you'll stand with us.



Bridge To The Ask

Increase Federal Funding For Research Into Rare and Connective Tissue Disorders

That is why I am asking for an **increase in federal funding for research into rare diseases and connective tissue disorders** like syringomyelia and Ehlers-Danlos Syndrome. These are serious, life-altering conditions, yet they remain under-researched. People like me are often left with no effective treatment options even decades after diagnosis. Research funding can change that.



Fine Tuning Your Story

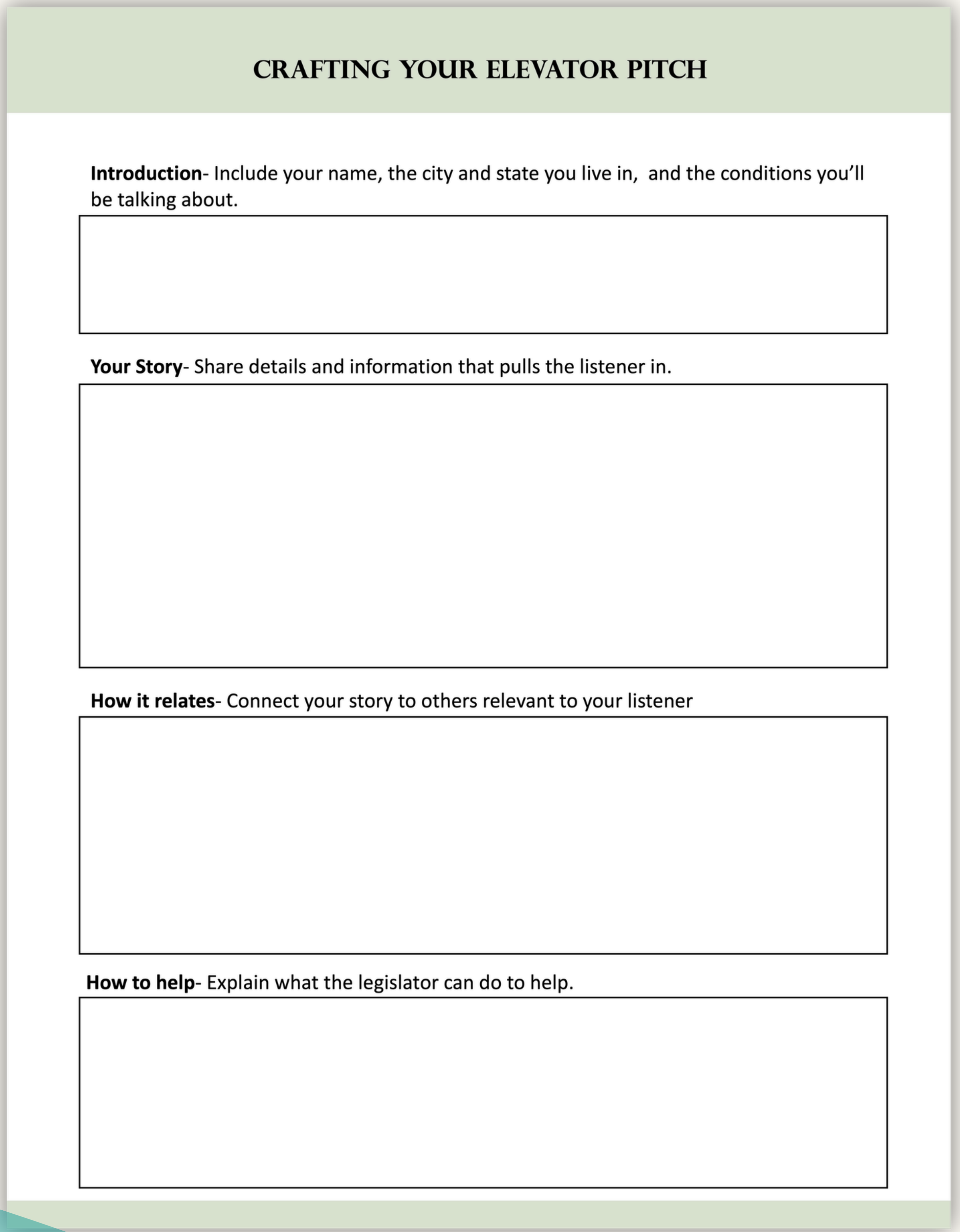
Making a BIG Impact in a SMALL Amount of Time

1. Time yourself sharing your story to make sure it fits into 2-3 minutes.
2. Don’t “memorize” your story. It should flow naturally.
3. Practice sharing your story with others who can give you feedback.

Tip: Your story is like a movie trailer-
short, compelling, and connected to your ask. Save the full story for follow-up!

Elevator Pitch Building Worksheet

- Introduction- Basic information; Introduce the problem; Affect on your community
- Your Story- The heart of your message; Emphasizes the problem's effects
- The Solution- Explain what is needed to solve the issue
- How To Help- How your legislator can support your cause; Present the Ask



CRAFTING YOUR ELEVATOR PITCH

Introduction- Include your name, the city and state you live in, and the conditions you'll be talking about.

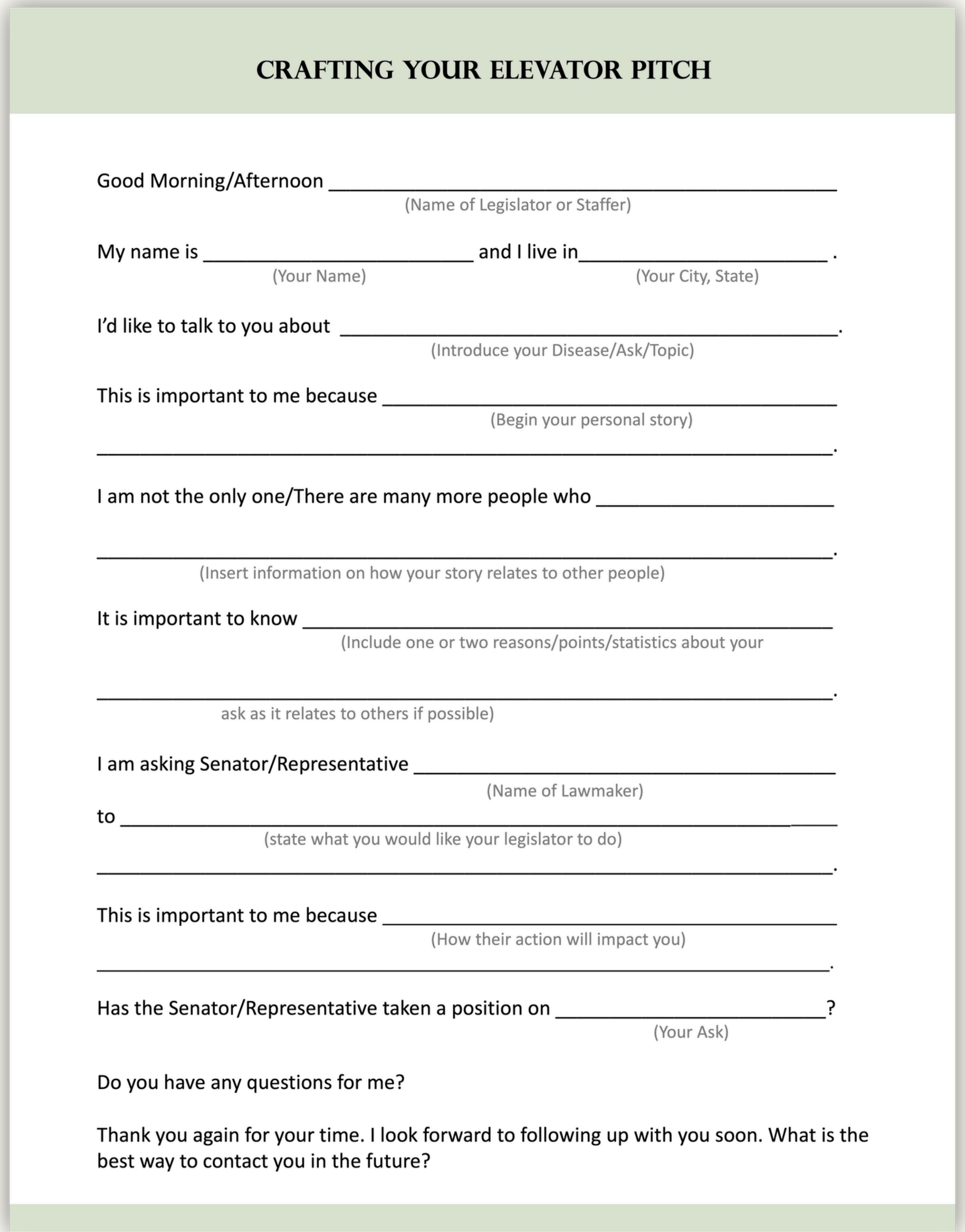
Your Story- Share details and information that pulls the listener in.

How it relates- Connect your story to others relevant to your listener

How to help- Explain what the legislator can do to help.

Elevator Pitch Building Worksheet

- Mad Lib Style- Most amount of prompts to help you craft your message
- Key Components- Maintains the structure of the previous worksheet with less details
- Versatile- Allows you to deliver your message via email, written letter, or in conversation



CRAFTING YOUR ELEVATOR PITCH

Good Morning/Afternoon ______________________
(Name of Legislator or Staffer)

My name is ______________ and I live in______________ .
(Your Name) (Your City, State)

I'd like to talk to you about ______________________.
(Introduce your Disease/Ask/Topic)

This is important to me because ______________________
(Begin your personal story)
______________________.

I am not the only one/There are many more people who ______________
______________________.
(Insert information on how your story relates to other people)

It is important to know ______________________
(Include one or two reasons/points/statistics about your
______________________.
ask as it relates to others if possible)

I am asking Senator/Representative ______________________
(Name of Lawmaker)
to ______________________
(state what you would like your legislator to do)
______________________.

This is important to me because ______________________
(How their action will impact you)
______________________.

Has the Senator/Representative taken a position on ______________?
(Your Ask)

Do you have any questions for me?

Thank you again for your time. I look forward to following up with you soon. What is the best way to contact you in the future?

The Elevator Pitch

Create interest, not information overload

Don't try to tell the whole story. Make them want to learn the rest.

Pulling It All Together

Problem

Impact

Personal Story

Solution

Ask

Key Points

01 A strong message includes the Problem, Impact, Personal Story, Solution, and Ask

02 Personal stories make your message powerful and memorable

03 Tailor your message based on who you're speaking to (e.g., legislator, staffer, public)

04 Practicing your message and pitch builds confidence

BRAINSTORMING YOUR PERSONAL STORY

Select a topic for your story. Think of important details that pull the listener in. Add details that relate to the ask you are making.

topic of your story

Crafting Your Elevator Pitch

Introduction- Include your name, the city and state you live in, and the problems or issues you'll be talking about.

Your Story- Share details and information that pulls the listener in.

Present the solution & Ask- What would alleviate the burdens or hurdles created by the problem.

How to help- Explain what the legislator can do to help.

CRAFTING YOUR ELEVATOR PITCH

Good Morning/Afternoon ____
(Name of Legislator or Staffer)

My name is ________________________ and I live in______________________ .
(Your Name) (Your City, State)

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This is important to me because ____
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I am not the only one/There are many more people who _____________________

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(Insert information on how your story relates to other people)

It is important to know ____
(Include one or two reasons/points/statistics about your

____.
ask as it relates to others if possible)

I am asking you to ____
(state what you would like your legislator to do)
____.

This is important to because ____
(How their action will impact you)
____.

Can I count on you to support ____?
(Your Ask)

Are there any questions I can answer for you?

Thank you again for your time. I look forward to following up with you soon. What is the best way to contact you in the future?