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# Advocacy 101

**Amy Basken, MS**

Co-Founder, Executive Director  
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# Disclosures

- I have no relevant financial relationships with any of the products or services discussed, today
- I do not intend to discuss unapproved or investigative use of commercial products



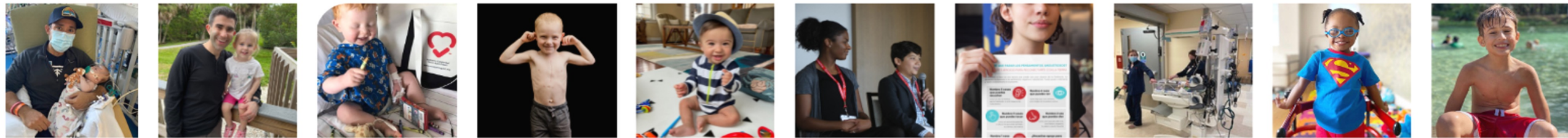
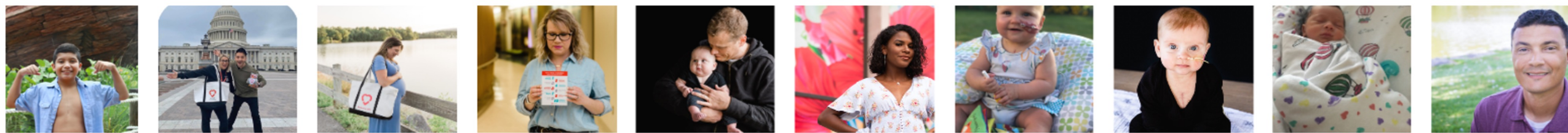
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# REMEMBER YOUR WHY

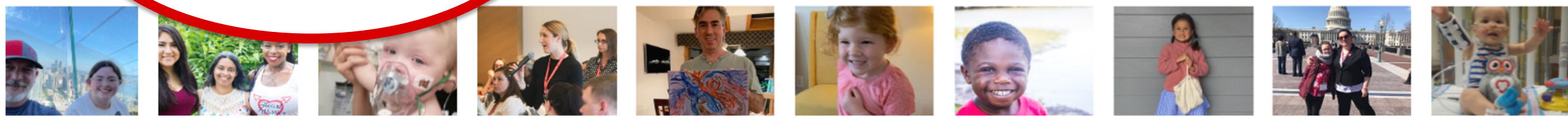


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# OUR WHY





# Advocacy

to change "what is"  
into "what should be"



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# Advocacy is Everywhere!



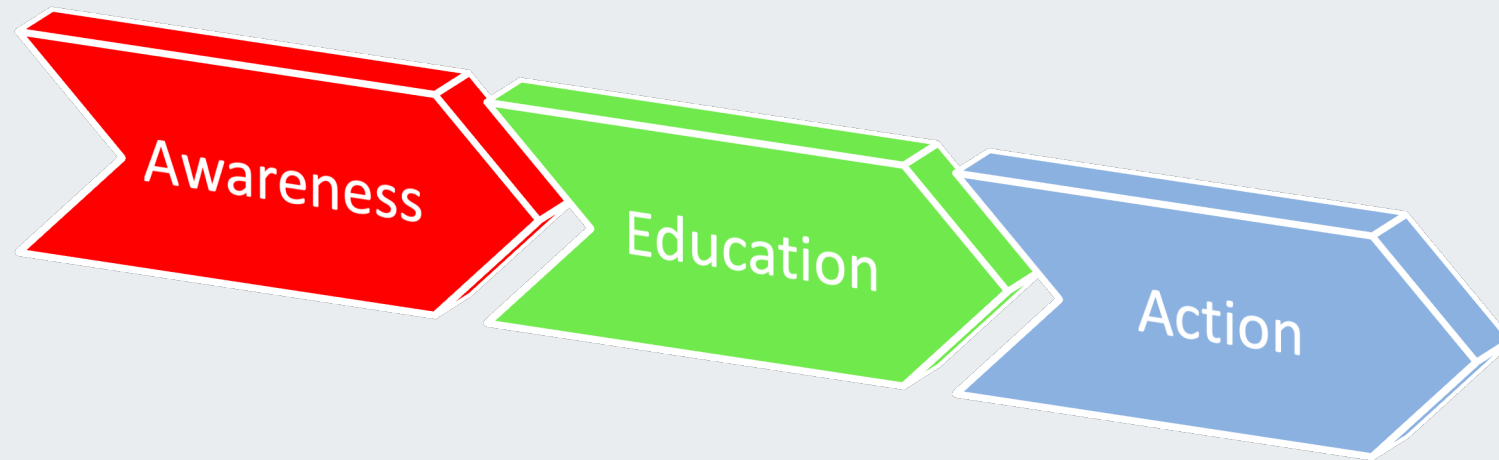
Children are  
very good at it!



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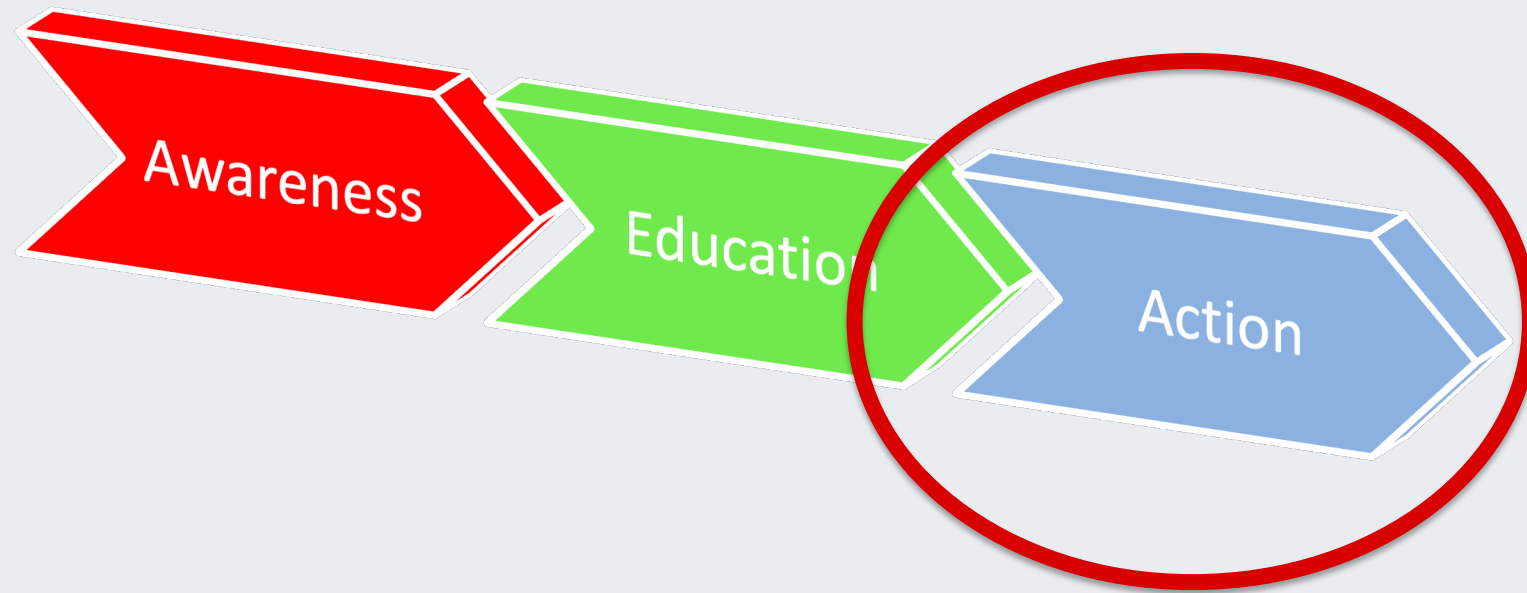


**Move decision makers to action and make changes that help the entire community**



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**Move decision makers to action and make changes that help the entire community**



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# Successful Health Advocacy



- Relevant and Contextual
- Collaborative
- Planned
- Targeted
- Has Specific Goals



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# Two Key Components

1.

You need to know  
what you want

-and-

2.

You need to know  
how to get it



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# Identifying the Problem

- What are priorities for patients and families?
- What are priorities for the field as a whole?



*8th World Congress of  
Pediatric Cardiology  
and Cardiac Surgery*  
AUGUST 27 – SEPTEMBER 1, 2023  
WASHINGTON D.C.

**CALL TO ACTION ON ADDRESSING  
THE GLOBAL BURDEN OF PEDIATRIC  
AND CONGENITAL HEART DISEASES**



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# Commonalities

- Early Detection
- Patient Education
  - About the disease
  - About the need for lifelong care
- Need for Data
  - Registry
  - Research
- Socio-Economic Burden
  - Cost of care
  - Travel issues
- Stigma
- Resources / Devices
- Human Capacity / Workforce

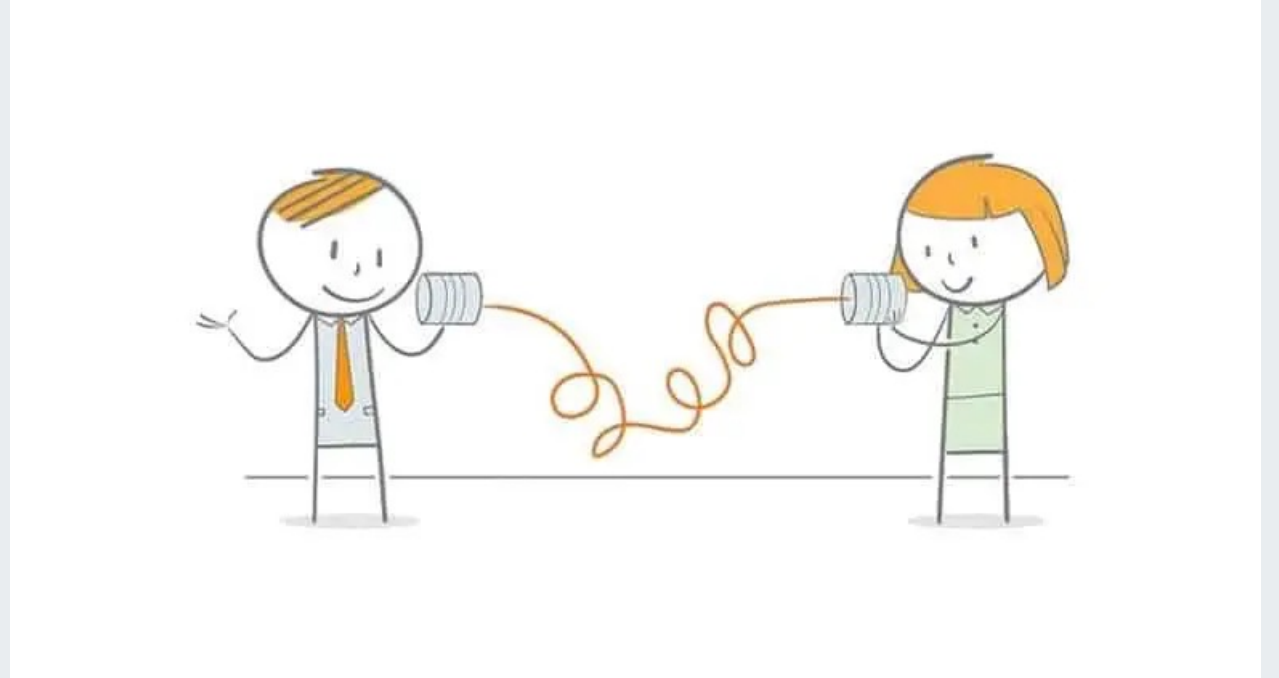


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# Communicating the Problem

- Policy Statements
- **Brief and Compelling Lay Statements**
- **Supporting Stories / Anecdotes**



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# The Path to Change

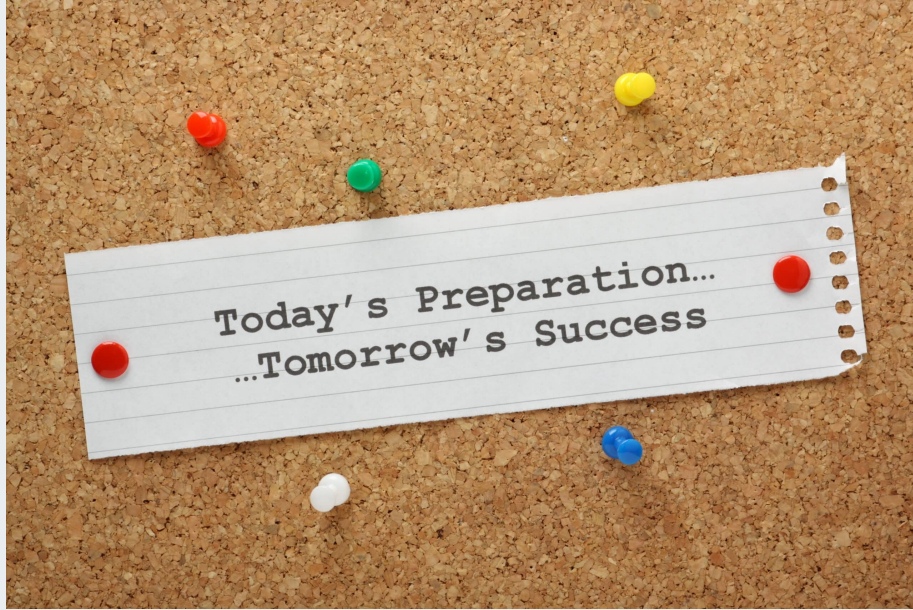
**“On-going process of building partnerships so that others will act for and with you, turning passive support into educated action.”**

**- American Association of School Librarians**



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# Develop a Plan



- Prioritize Priorities
- Identify Policy Levers
- Build Your Case
- Identify and build relationships with Key Partners
- Plan for Longevity
- GO!!



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# It takes time!



And perseverance.



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# Identify the Policy Levers



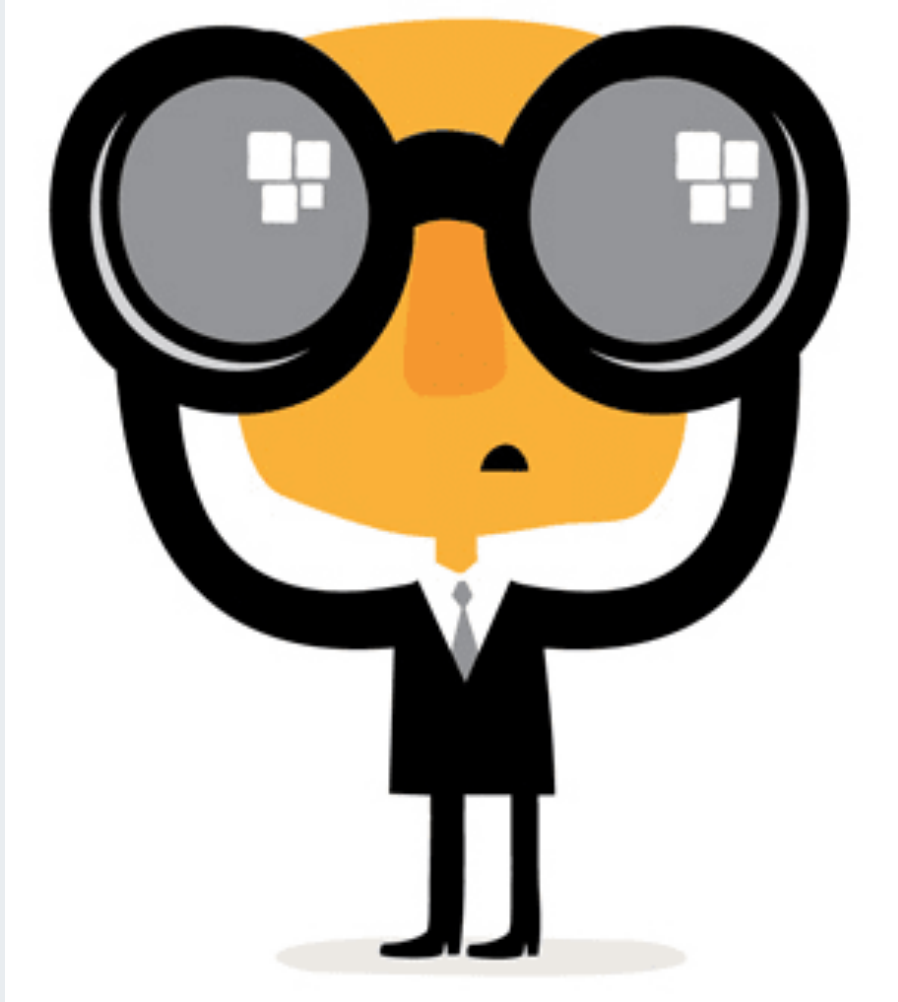
- Government / Agency
- System / Practice Change
- Behavior Change



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# Build Your Case

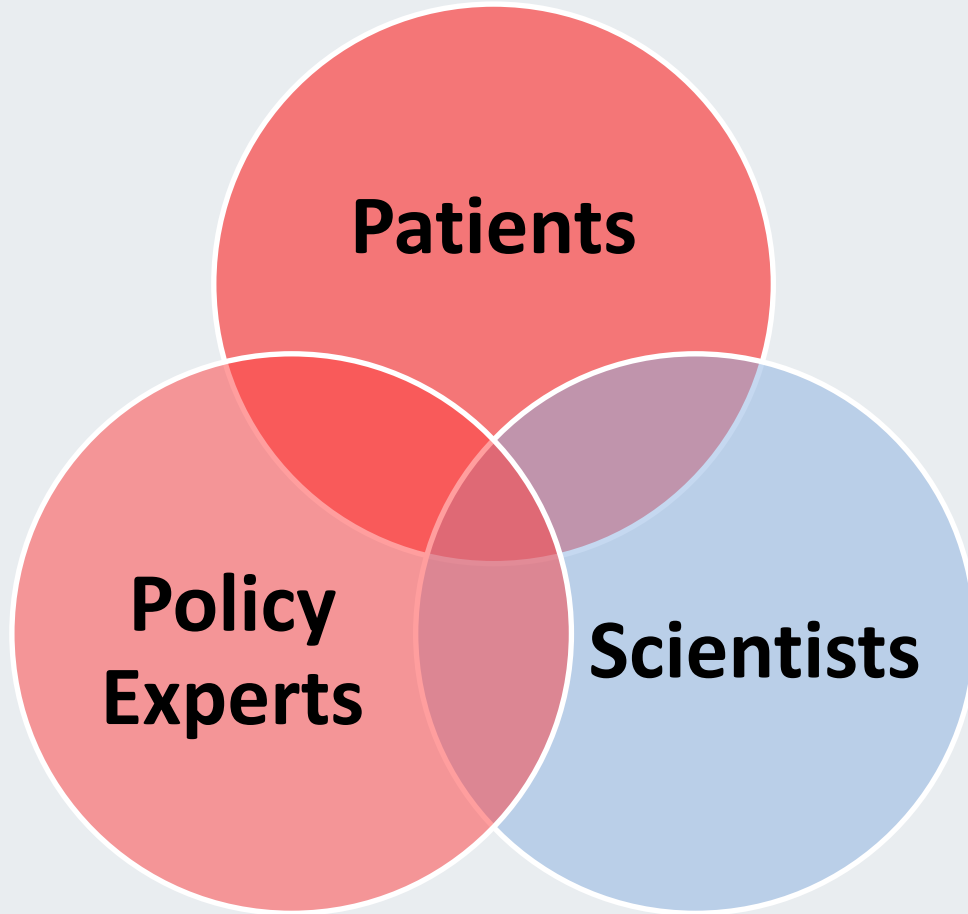


- Know all sides of the issue
- Pros / Cons
- What matters to those who make policy?



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# BUILD YOUR CORE TEAM



# THINK BIGGER!

- Health Care Providers / Health Systems
- Industry / Device Partners
- NGO's
- Champions in other diseases
- Champions with-in Government



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# Advocacy Can be a LONG HAUL

- Sustain your passion
  - Remember your why
  - Fill your own cup
- Grow more champions
- Share the load
- Celebrate wins / learn from speed bumps

**TRUE LEADERS  
DON'T CREATE  
FOLLOWERS.  
THEY CREATE  
MORE LEADERS.**



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# ELEVATING THE PATIENT VOICE

Your  
*Story*  
Matters



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FACTS TELL.  
STORIES SELL.  
-UNKNOWN



THIS is why  
patient advocacy  
matters.



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**If you think you're  
too small to have an  
impact, try going to  
bed with a mosquito.**



Anita Roddick



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# Empowering Patients and Families to tell their story

Providing the **opportunity**  
and **information**  
necessary to succeed



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# Opportunity: Support patient participation



- Intentional
- Accessable
- Purposeful for the patient

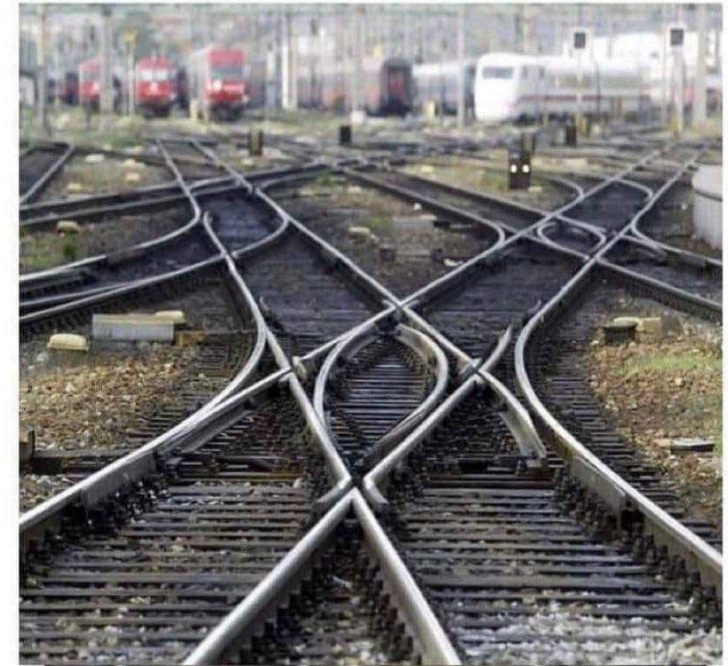


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# Information: Becoming a Storyteller

- It takes practice
- Keep it simple – and short
- Be clear – use plain words and avoid medical jargon
- Speak from the heart and talk about your experience
- Be accurate, honest and persuasive
- It's ok to use emotion
- Avoid relying on statistics
- Stay on topic
- Be relatable – why are you telling your story?

me telling a story



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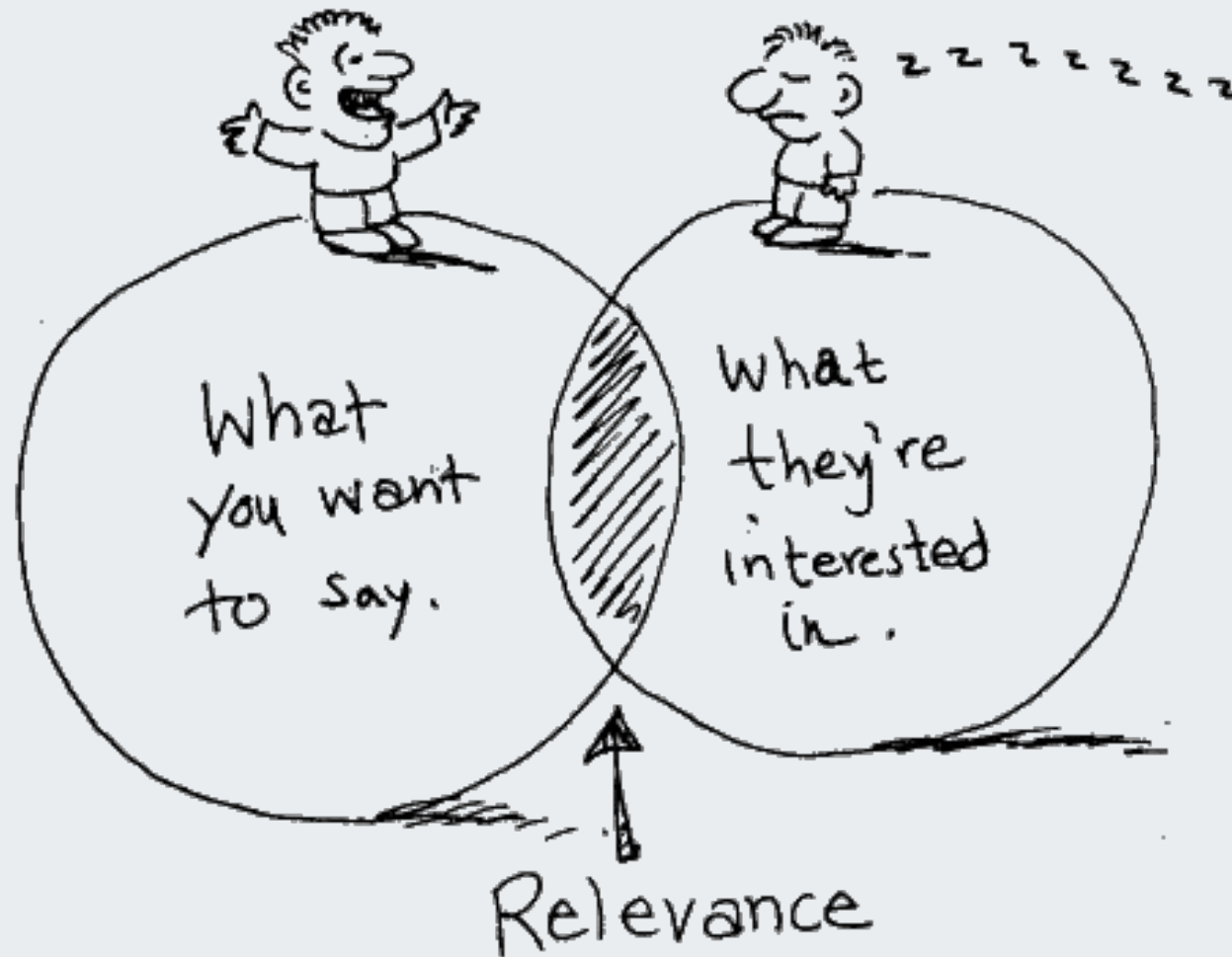
# Building Your Story

- Where does your story begin?
- What do we need to know about you?
- What challenges have you faced?
- What choices did you make? And why?
- What can we do together?



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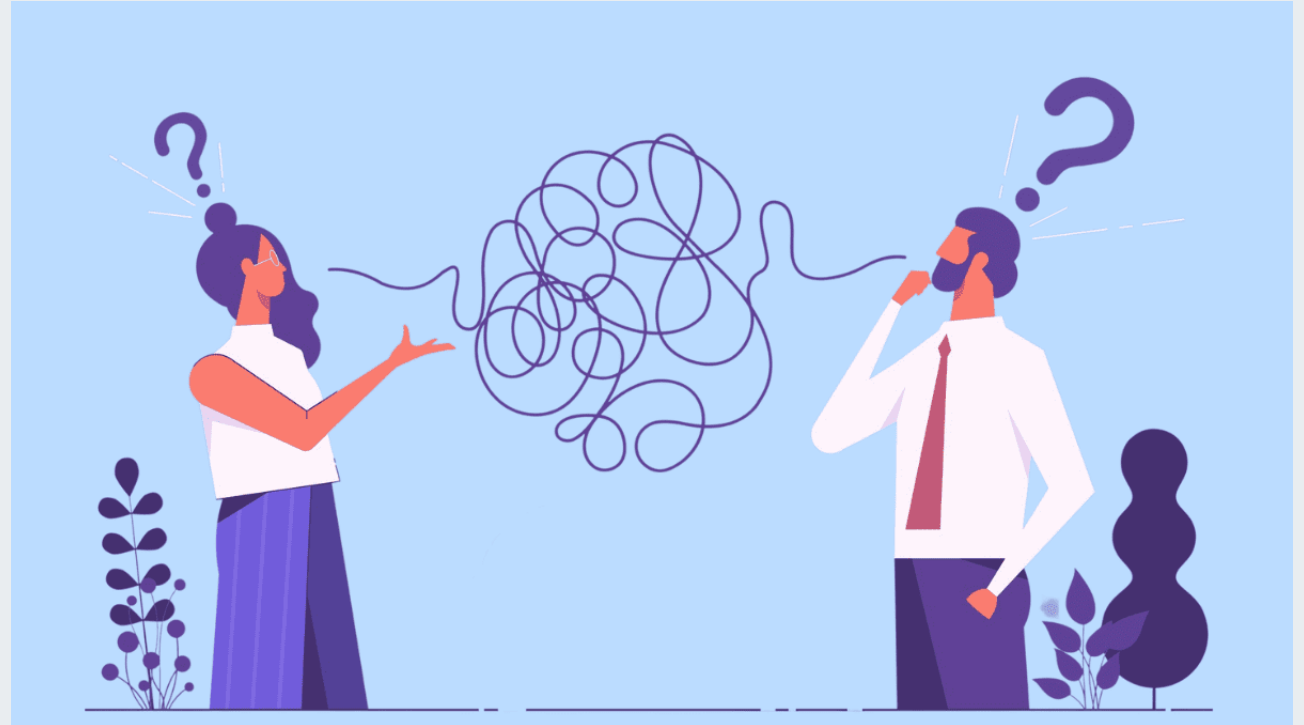
# Know Your Audience



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# Effective Communication

- 3 P's:
  - Be Personal
  - Be Positive
  - Be Polite
- 3 Parts:
  - Introduction
  - Story
  - “Ask”



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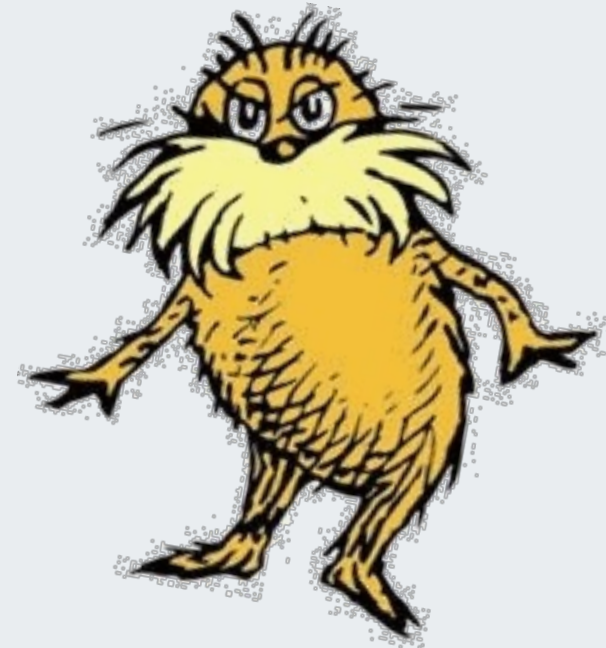
**Advocacy is a  
team sport centered on  
building relationships**



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Unless someone like you  
Cares a whole awful lot,  
Nothing is going to get better.  
It's not."

Dr. Seuss – *The Lorax*



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# Thank You!

“No matter how insignificant what you do may seem, it is important that you do it.” - Ghandi

**Amy Basken**  
abasken@conqueringchd.org



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