

# Lived Experience Across the Life Course

A Story in Patient Self Advocacy



# Financial Disclosures

- 1. We have no financial relationships to disclose.**
- 2. We will not discuss off label use and/or investigational use in this presentation.**

# Who Are We

## Anna Cyr

- Mother
- Wife
- Parent Advocate
- Maternal Child Health Professional
- Dog Mom
- Nature Lover

## Maisy Cyr

- Daughter
- Sister
- Patient Advocate
- Social Worker
- Educator
- Podcast Co-Host



# Anna's Story

- Navigating all the challenges of being a new mom plus learning how to manage Mal's care
- Developing the advocacy skills necessary to protect her baby
- We don't know what we don't know

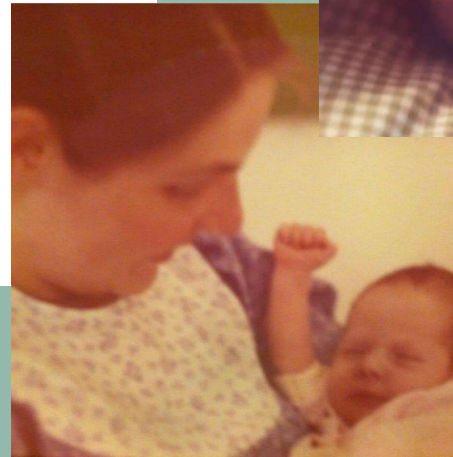
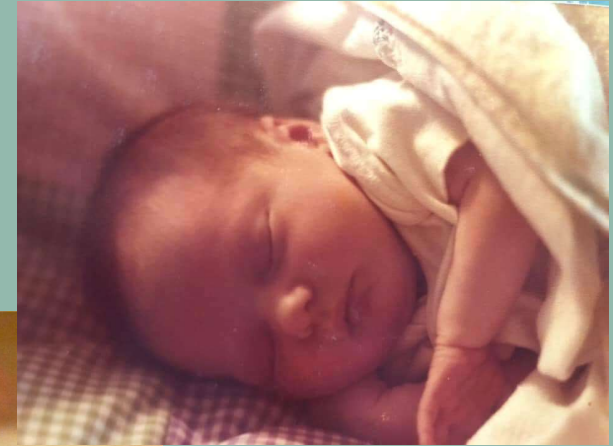


# Finding Her Voice

Realizing she had to be her daughter's voice

Working with doctors who listened...

...and those who didn't



# Raising Advocates

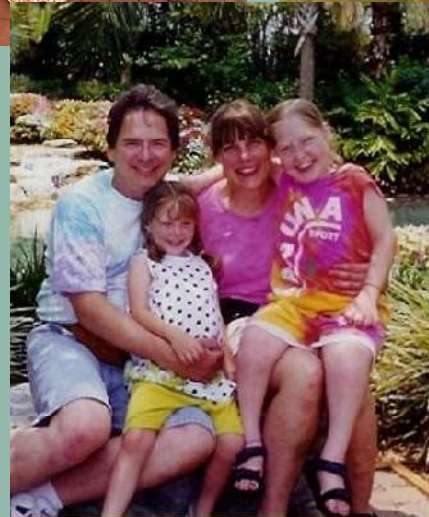
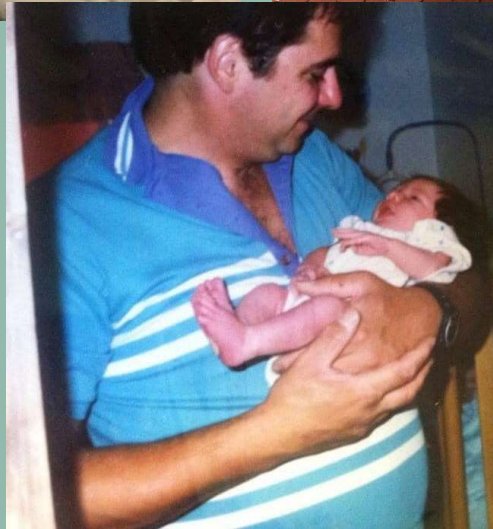
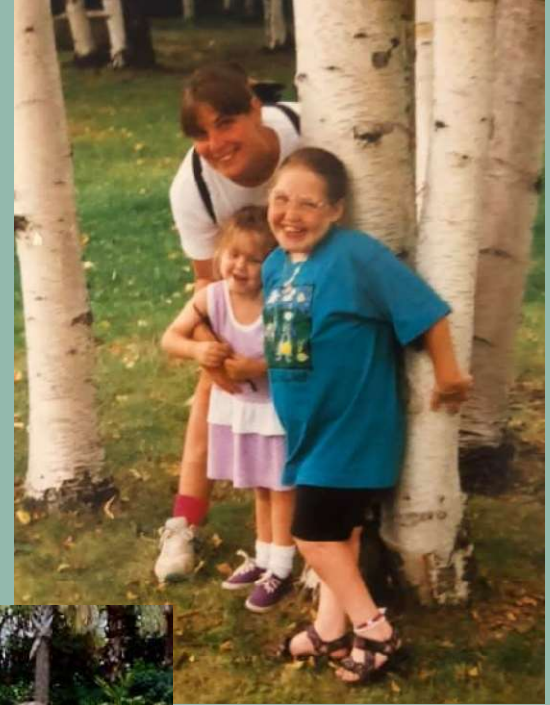
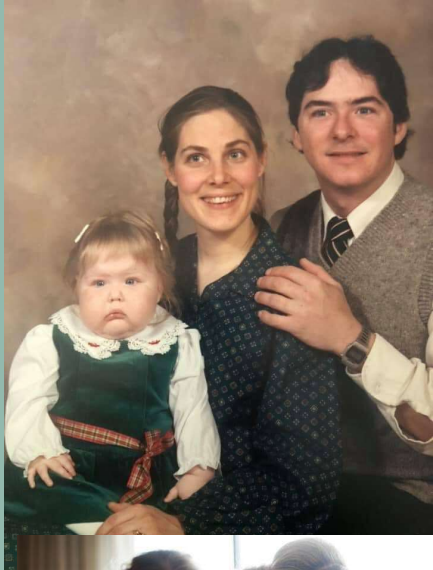
Understanding the importance of communication and clarity

Exploring all possible options

Not being afraid to ask







# Maisy's Story

- Watched her mom and her sister growing up
- Learned how to set up tubing before going to camp
- Independent by 16





# Adventure is Out There

- Rare disease = Uncharted Territory
- Scuba diving, camping, horseback riding, traveling, modeling
- Not *if*, but *how*



# Quality of Life

- Maintaining quality of life
- Dignity of risk
- Autonomy
- Life outside the hospital
- Providing options



# Learning Objectives

- **Validate importance of patient's lived experience**
- **Emphasize open communication with patient and patient's family**
- **Ensure clarity of understanding when presenting possible options for patient's care**
- **Consider longevity and quality of life outside of hospital when presenting options for patient's care**

# Thank you.

Listen to our podcast and follow us on Instagram to hear more about our experiences as people navigating life with a rare disease!



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