



Impactful Advocacy: Mastering the Art of Your Bleeding Disorder Story

*Presented by
Anne Henningfeld, MA, CTRS &
Michael Jay Gardner
Beyond Recreation*



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What is the Hemophilia Council of California?

Our Beginning

HCC is a 501(c)3 nonprofit organization formed in 1989 to meet coordinate the shared advocacy agenda of the four California hemophilia organizations

Our Focus

HCC coordinates statewide access, education and advocacy efforts on behalf of individuals living with bleeding disorders and rare or chronic conditions

Our Advocacy

HCC advocates to protect access to care, promote progressive treatment options and advance the quality of life for these individuals, families and caregivers



Mission & Vision

Our Mission

To improve access to care and treatment options in order to advance the quality of life for people with bleeding disorders through advocacy, education, and outreach in collaboration with our founding member organizations

Our Vision

Open access to quality innovative care and choice of treatment for all people with bleeding disorders



Telling Your Advocacy Story

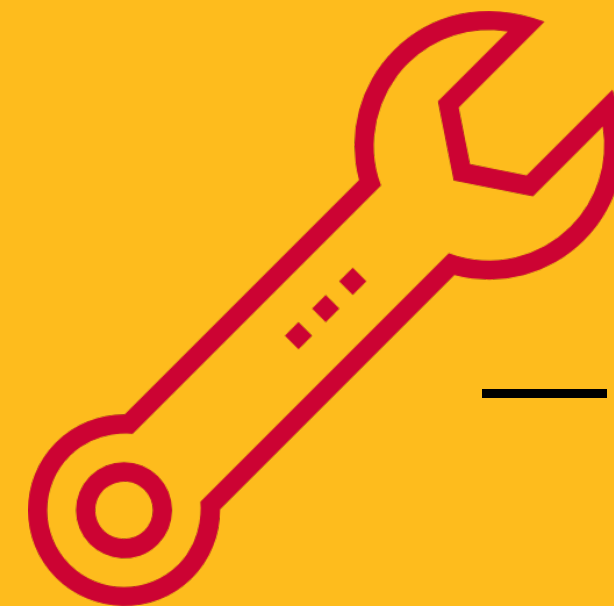
with Beyond Recreation



**While our
stories are
complex, our
time (and their
attention) is
limited.**

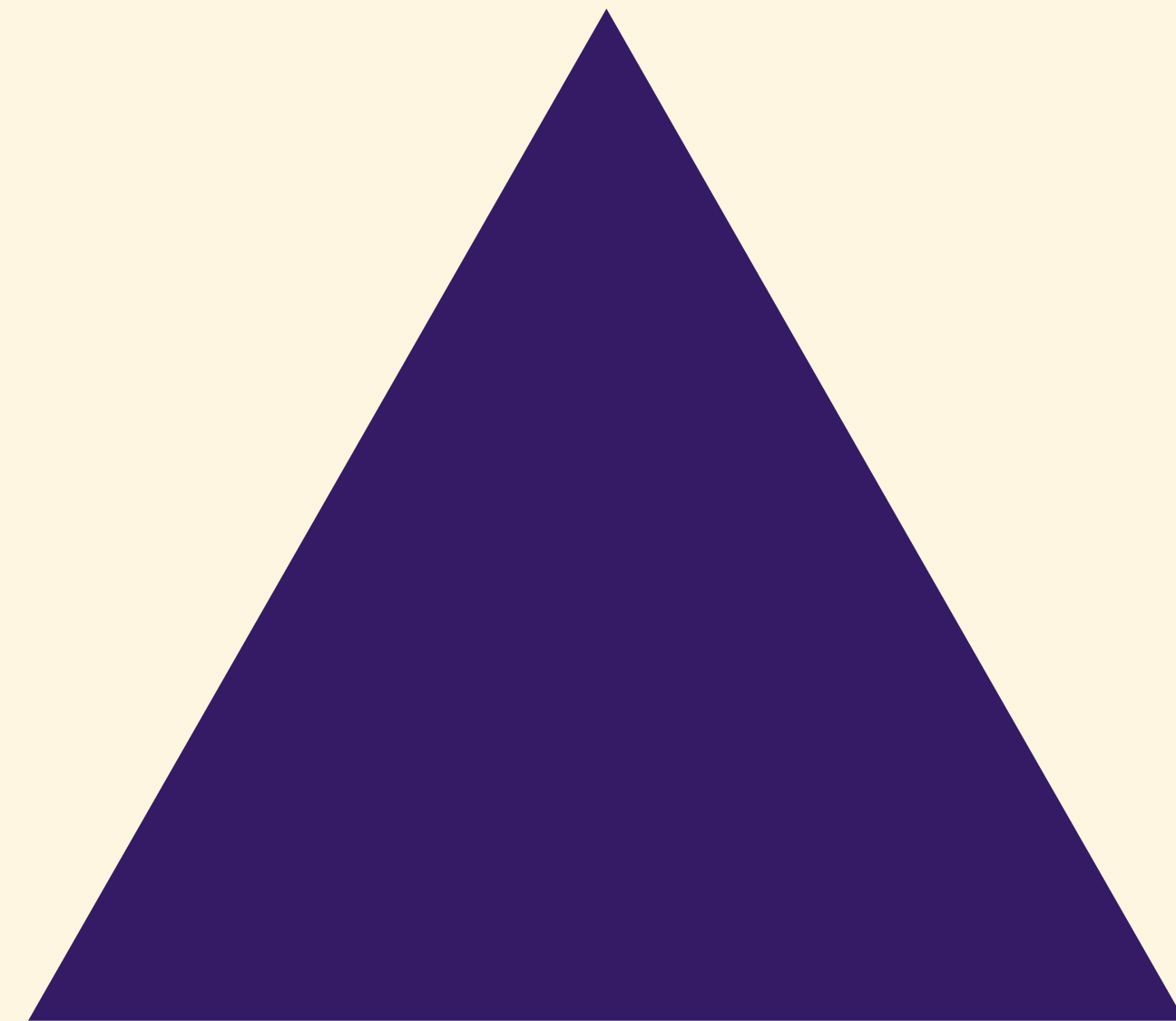
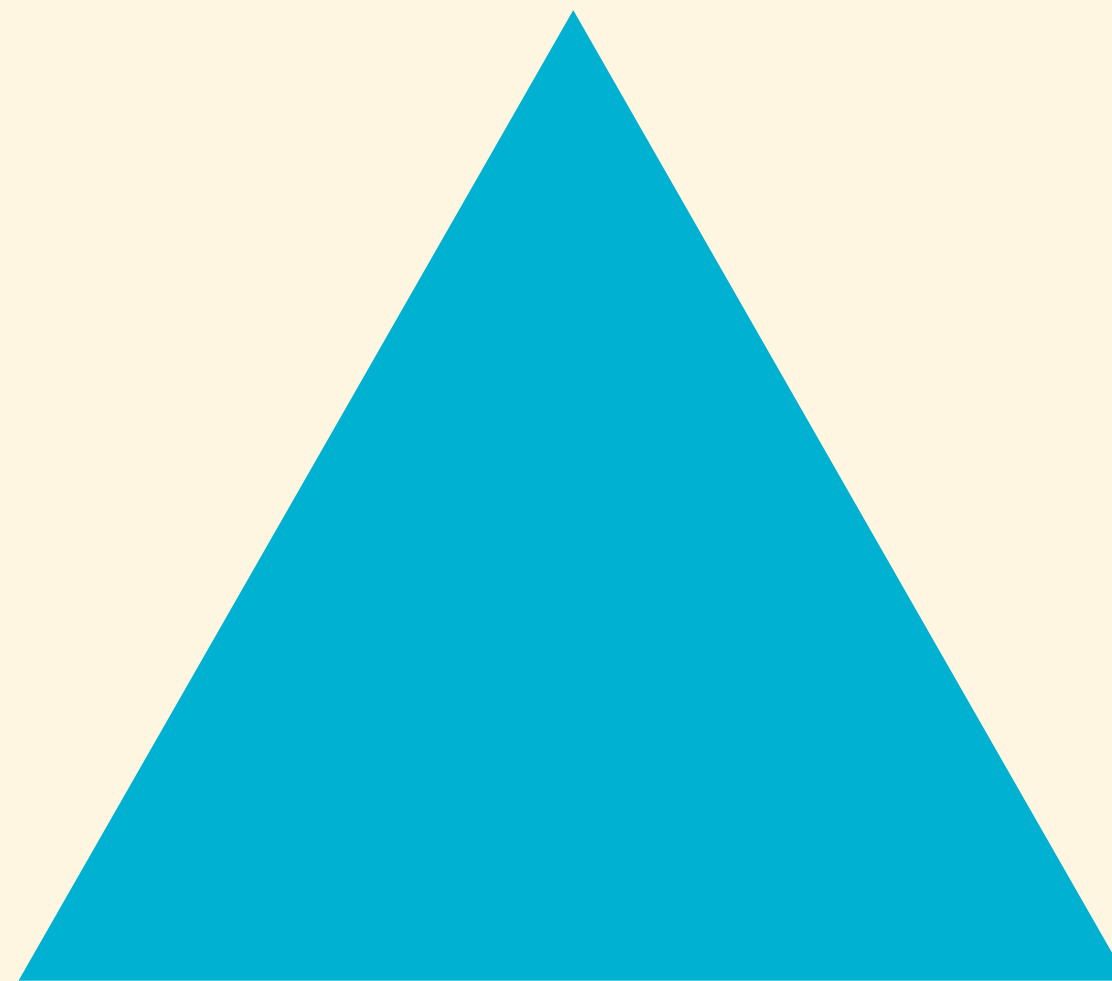
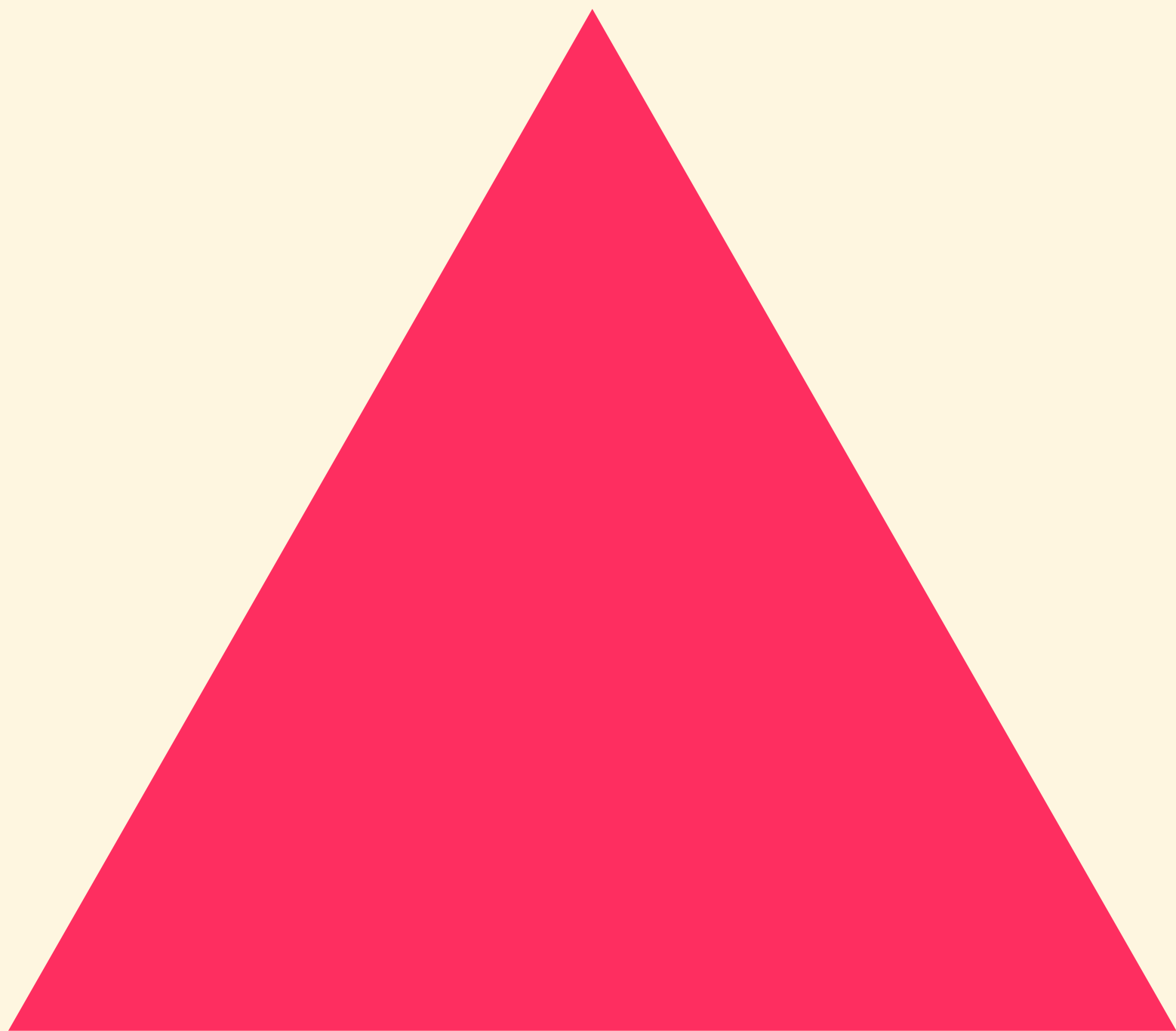


Fix it!

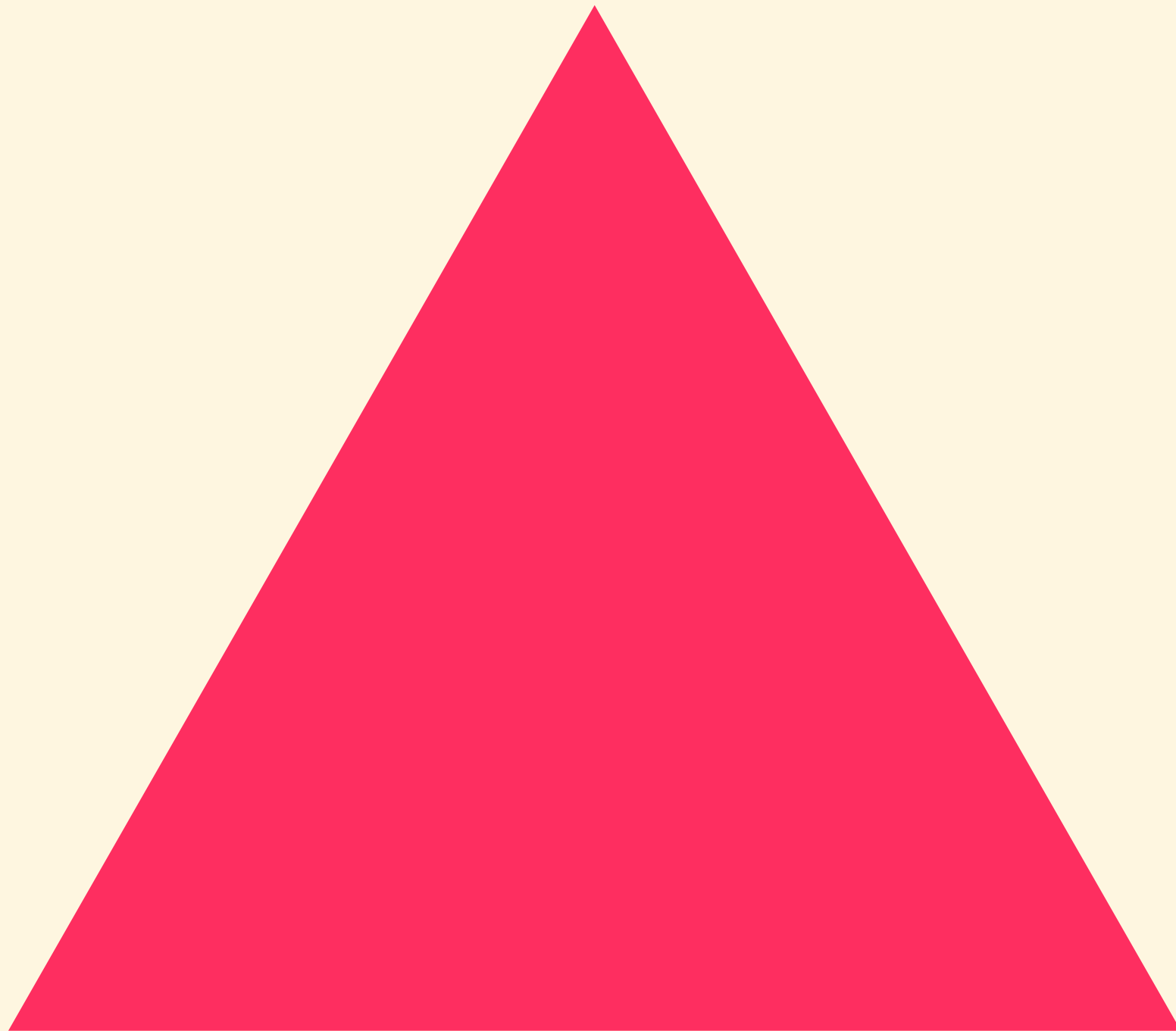


— with Michael Jay Garner

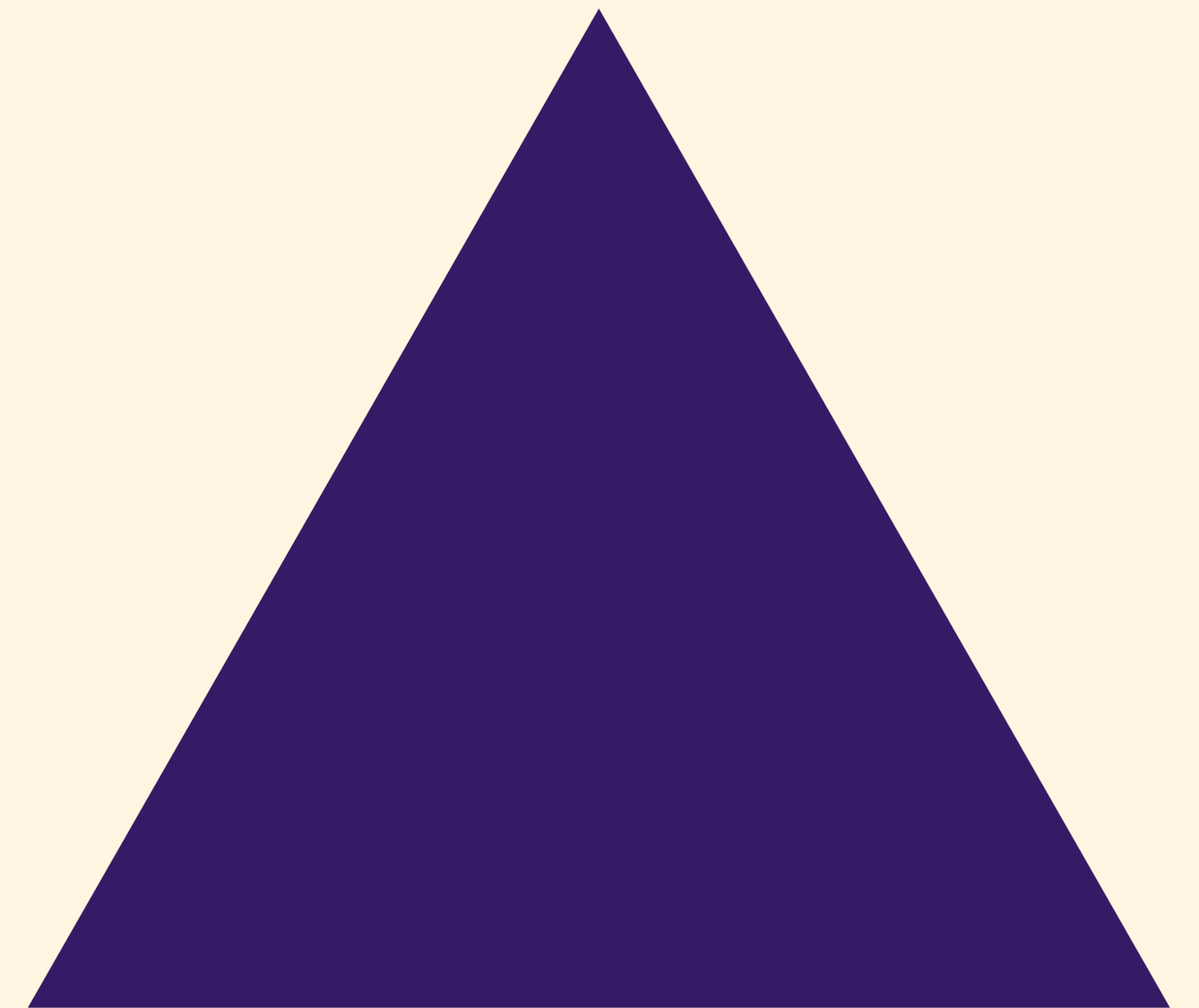
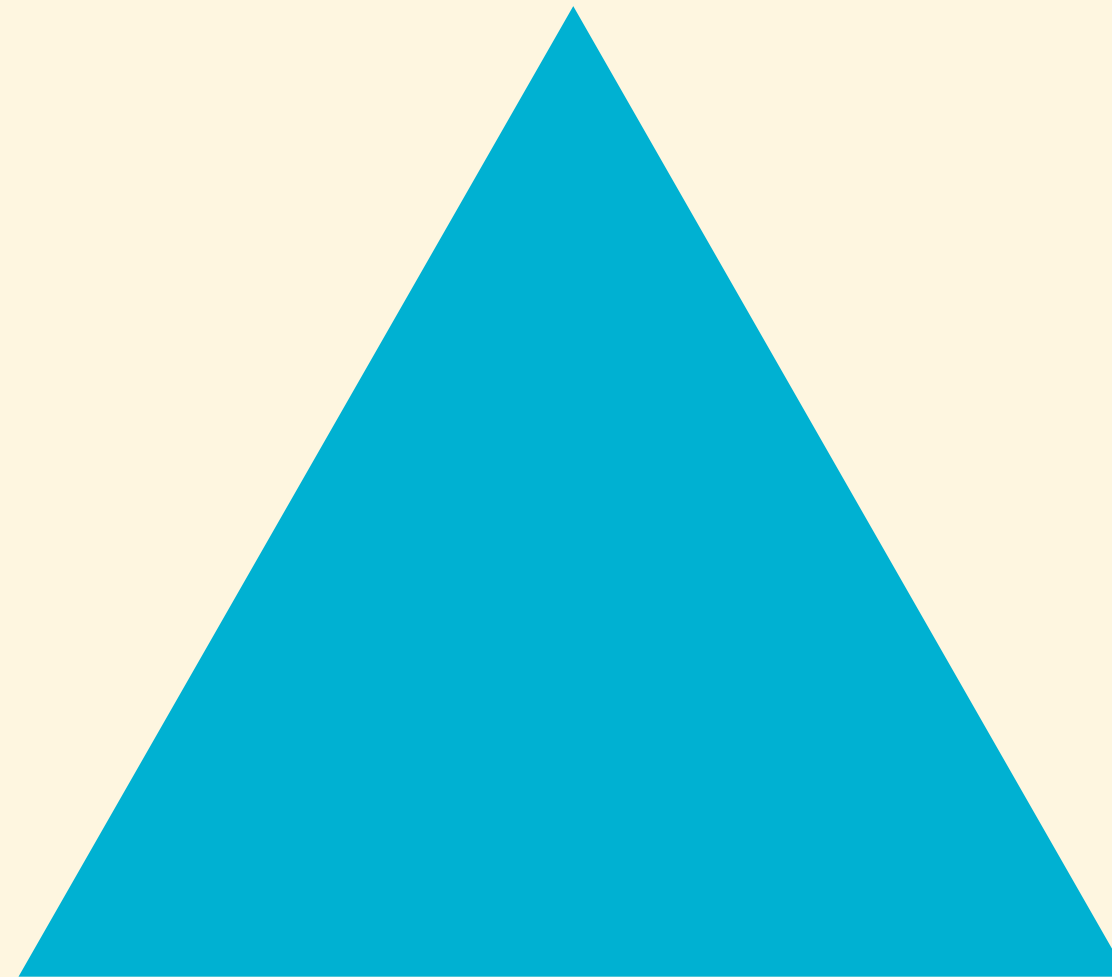
Avoid Jargon



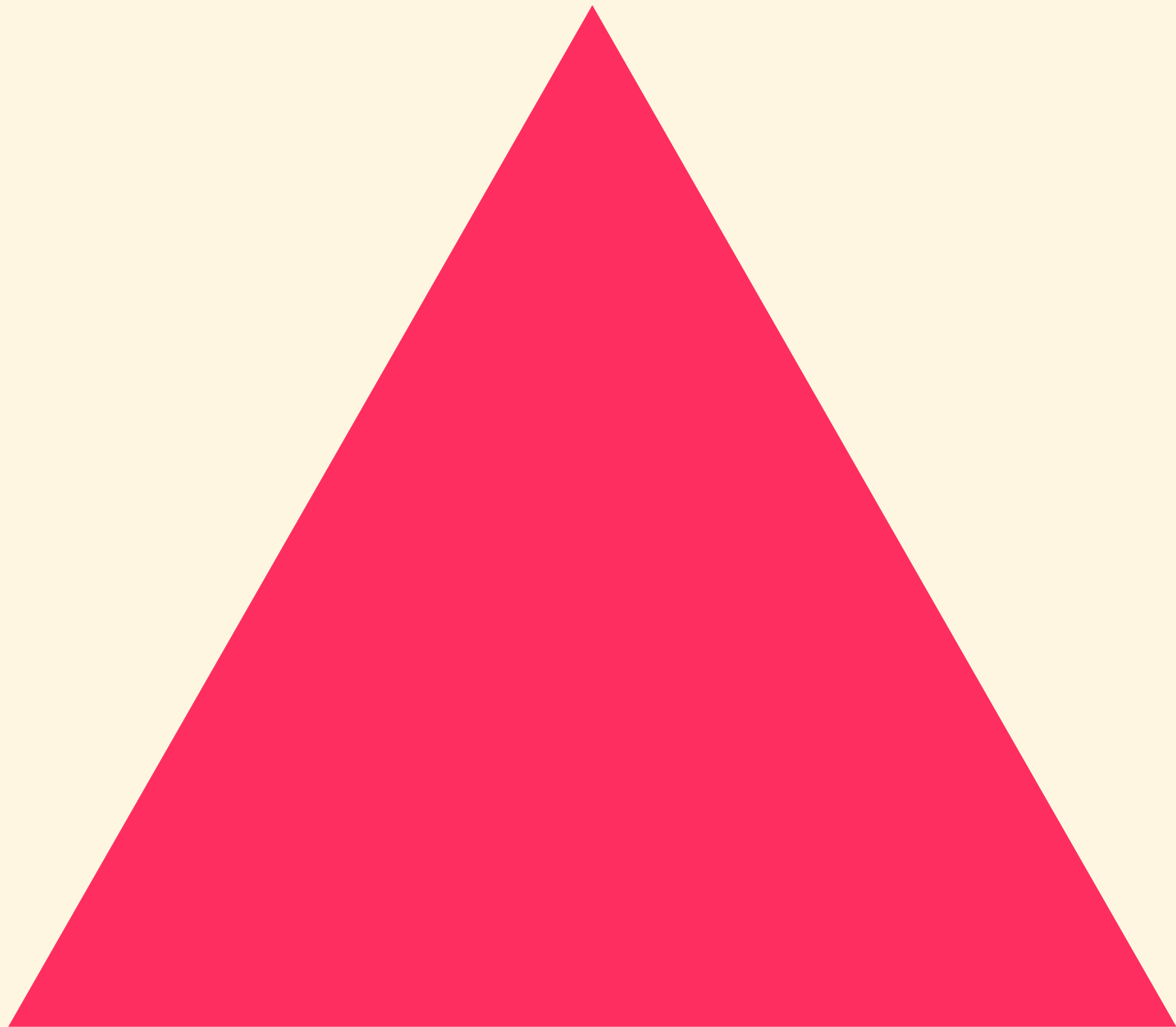
**Avoid
Jargon**



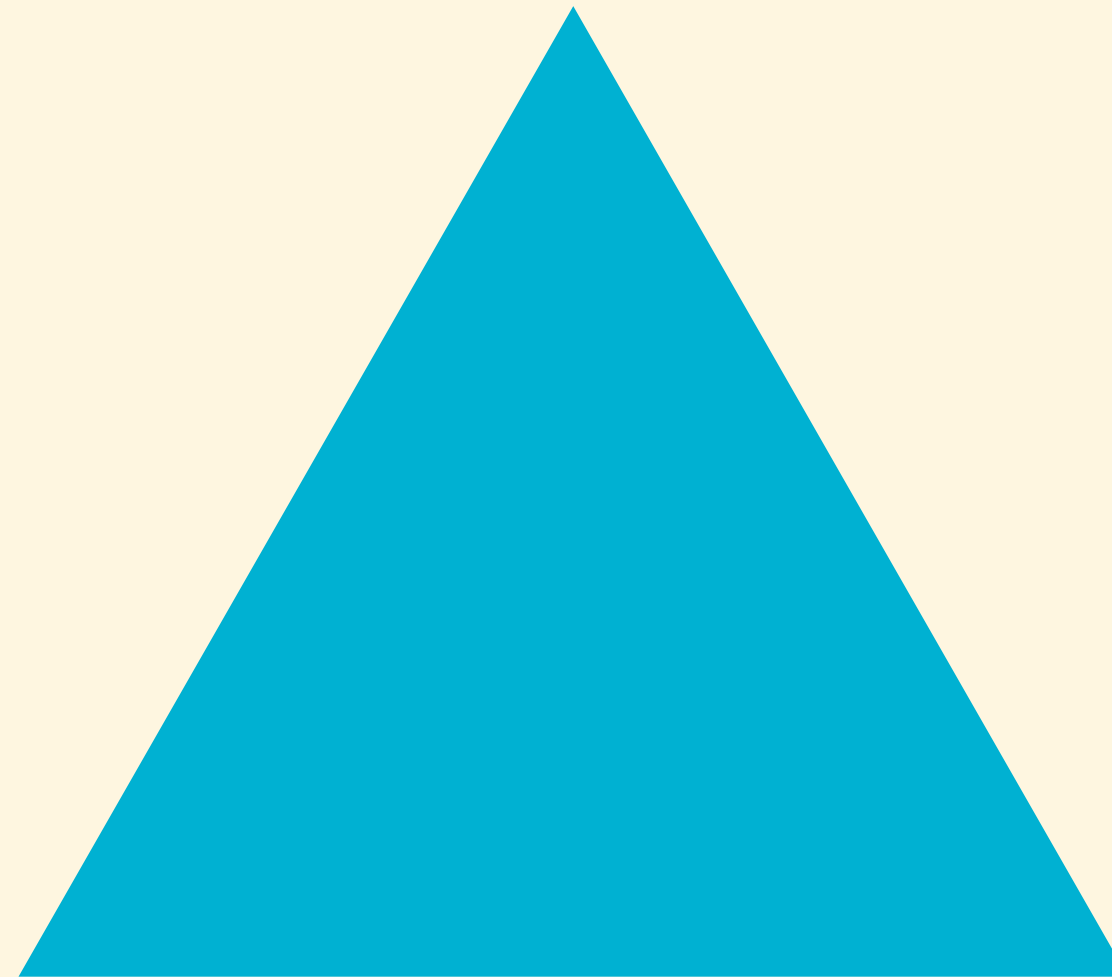
**Keep it
Linear**



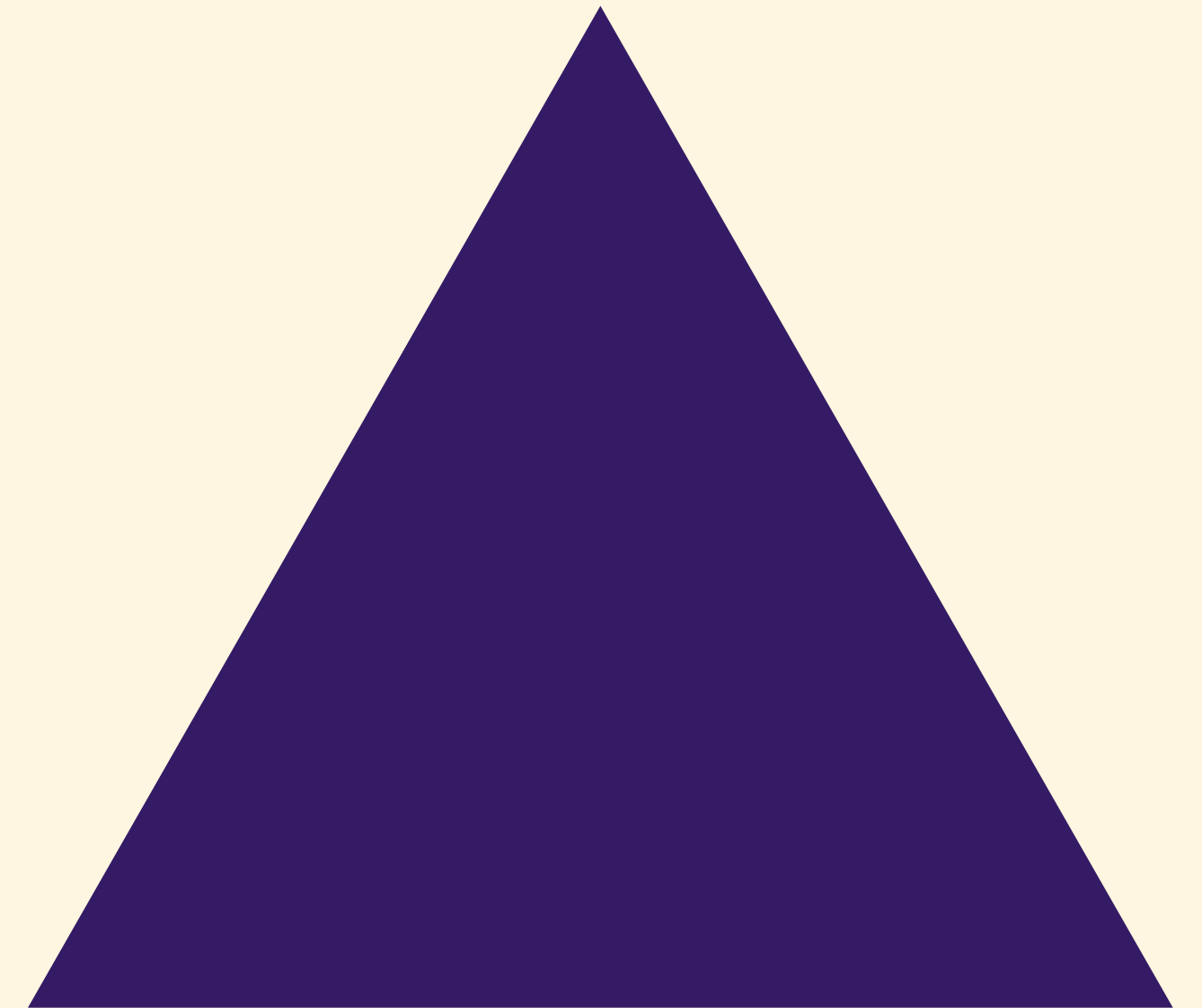
**Avoid
Jargon**



**Keep it
Linear**



**Trim the
Fat**



Two Sentence Challenge

What is your chronic
condition? Don't forget cause
AND effect.



Adapting the story to the “ask”

- Audience
- Situation
- Specific Request



A group of people are gathered in a meeting or workshop. In the foreground, a woman with long brown hair, wearing a white shirt and a gold necklace, is looking towards the right. Next to her is a woman with dark hair and a red patterned scarf, smiling. To the right, a man with short dark hair is looking towards the women. In the background, other people are visible, including a man in a plaid shirt. A large, semi-transparent circular graphic is overlaid on the image. It features a solid white circle with a dashed white circle inside it. Four white dots are placed on the dashed circle at the top-left, top-right, bottom-left, and bottom-right positions. Four white lines, each starting from a dot and extending outwards, cross at the center of the circles. The text "YOUR STORY" is written in large, white, sans-serif capital letters across the center of the image, with "YOUR" on the top line and "STORY" on the bottom line.

YOUR STORY

Overview of Upcoming Webinars

- March 13 – Legislative Briefing
- April 24 – What Does Health Care Access Mean? A Patient Panel
- May 22
- August 28
- September 25
- October 23
- November 13

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Thank you for joining us!

REMINDER:

This webinar is part of a series of educational webinars presented by the Hemophilia Council of California.

A recording and slides will be available in a few weeks at

<http://www.hemophiliaca.org/education/webinars/>

NEED HELP?

Contact **Lynne Kinst** at (916) 572-7771 or lkinst@hemophiliaca.org