What Will It Take To Move The Needle?
A Patient’s Perspective

Katie MacDonald
Agenda

• My Story
• Moving the Needle
• Resources
Personal Story
Personal Story

• Diagnosed at 14
• Chronic for last 9 years
Personal Story

- Journey through treatments
- Frustrated, difficult patient turned advocate
Lessons Learned
Lessons Learned

• There is no cure and treatments are limited.
• We need advocates on our side and we need to learn to advocate
• Importance of expectation setting
• Providers are frustrated by lack of treatments too
• People with migraine should not expect advocacy to be someone else’s job
• It’s better to participate and pay the price, then to miss out…and pay the same price
Moving the Needle
What is ADVOCACY

Self Advocacy
• Self Care
• Asking questions
• Asserting your needs and rights
• Speak up for yourself
• Educate yourself

Individual Advocacy
• Sharing your diagnosis
• Wearing a shirt – spark conversation
• Sharing knowledge
• Writing a letter or blog post
• Tell your story

Systems Advocacy
• Sign a petition
• Connect with your Members of Congress
• Changing laws and policies
Moving the needle through ADVOCACY

My Experience

• Mom

• Learning that my HA specialist = patient care + research + advocacy

• First HOH was a life changer
  • Patients and Providers speaking together
  • Being in same place with other people who had migraine
  • Having my story heard
  • Gaining confidence in sharing that I have migraine
Moving the needle through ADVOCACY

Miles for Migraine
• In-person events
  • Walk, Run or Just Relax
  • Education Days
  • Youth Camps
  • Community/Support Groups
  • Meet-ups
• Discussing Stigma & Advocacy
• Providing Resources
Why is ADVOCACY the path?

- Gives purpose to disease
- Connects people with common interests
- Lessens isolation
- Improves function
- The more we talk, the more people understand
Resources:

- Step 1: Coalition for Headache and Migraine Patients (CHAMP)
- Step 2: Miles for Migraine
- Step 3: Alliance for Headache Disorders Advocacy (AHDA)

- In-person events over social media
Thank you
Questions?
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