Thriving with Migraine Through Advocacy

Angie Glaser

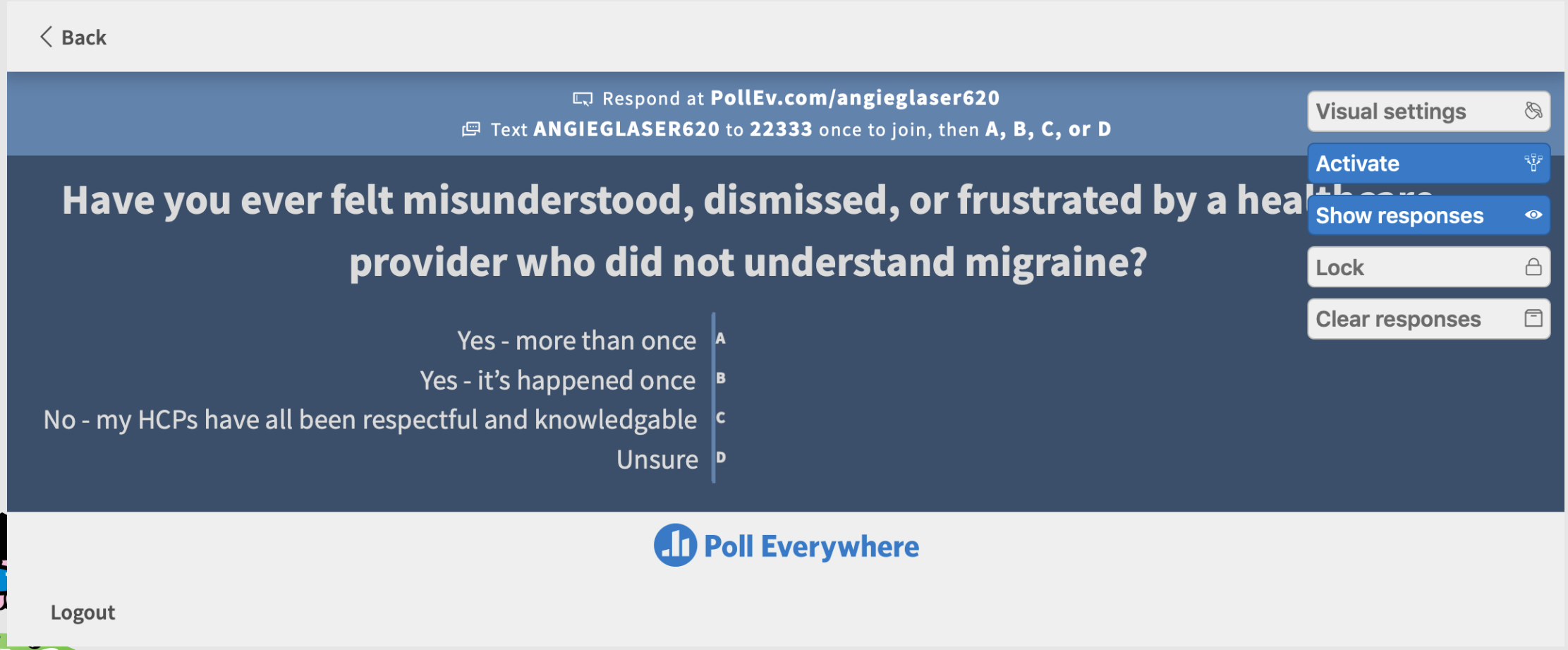
Patient, Advocate, Writer, Editor

MILES FOR MIGRAINE

Agenda

- Why Advocate? Audience Poll
- My Migraine Story
- How I Became a Migraine Advocate
- Getting Started with Advocacy
- Resources

Why Advocate?



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My Migraine Story (So Far)

- Diagnosed at age 3
- Episodic from ages 3-22 under the care of neurologists & a psychiatrist
- Migraine attacks became more frequent in late teens & early 20's
  - College & breaking into the workforce
- Refractory chronic migraine with chronic daily headache at age 24
  - Left my job & moved in with my parents
  - Saw a headache specialist for the first time and began to understand migraine as a disease
- Finally, a day without head pain - age 30

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What I Thought My 20s Would Look Like

Career!

Purpose!

Plans!

Celebrations!

Friends!

Travel!

What My 20s Actually Looked Like

Months spent in bed

Job loss

Grief

Extreme photophobia

Nausea, weight loss

Disability

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How I Became A Migraine Advocate

- Started a blog and twitter account to help grapple with grief and loss
  - The goal: validation and community.
  - The fuel: loneliness, anger, grief
- Paula Dumas, co-founder of MigraineAgain, reached out
  - I started working PT as an editor, became FT Feb 2020
- My work at MigraineAgain connected me to CHAMP and helped me break into advocacy world:
  - Attended Headache on the Hill, spoke at Miles for Migraine events and on the Migraine World Summit, attended industry events, and gave testimony during public meetings (ICER) and on Capitol Hill (AHDA, HMPF)

What My 20s Looked Like After Discovering Advocacy

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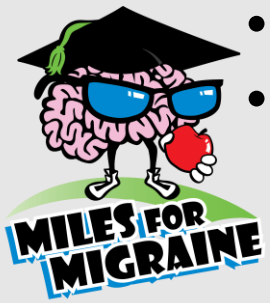
Flavor of Advocacy

- Raising Awareness
  - Speak up about your experience, on social media and real life
  - Write, blog, tweet, share on insta or facebook
  - Talk to the people in your life about how migraine affects you
  - Support orgs like Miles for Migraine by fundraising & attending events
  - Resist the urge to hide
- Lobbying for Change
  - Bring your message to the people in power
  - Headache on the Hill – attend in person or take part in virtual lobbying events
  - Migraine at Work – talk to your boss about your experience

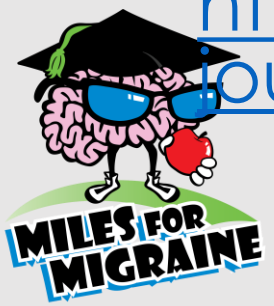
It takes privilege to advocate

- Advocacy usually requires:
  - Energy
  - Time
  - Knowledge
  - Heart
- Advocacy sometimes requires:
  - Money
  - Connections
  - Specialized skills
  - Ability to travel
  - An understanding workplace (thanks to stigma)



Getting Started with Advocacy - Resources

- Alliance for Headache Disorders advocacy - https://allianceforheadacheadvocacy.org/
- Coalition for Headache and Migraine Paitents (CHAMP) - https://headachemigraine.org/
- Migraine World Summit [Education]- https://migraineworldsummit.com/
- Migraine at Work - https://migraineatwork.org/
- Share your Migraine Journey on Migraine Again - https://www.migraineagain.com/share-your-migraine-journey/



Connect with Me

- Personal blog - http://chronicmigrainelife.com/
- Twitter - @winedarkme
- Instagram - @angelaglasses
- Migraine Again - https://www.migraineagain.com/