

## What will it take to move the needle? *A Patient's Perspective*

Katie MacDonald, Alliance for Headache Disorders Advocacy

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## Agenda

- My Story
- My Thoughts on Moving the Needle
- Resources

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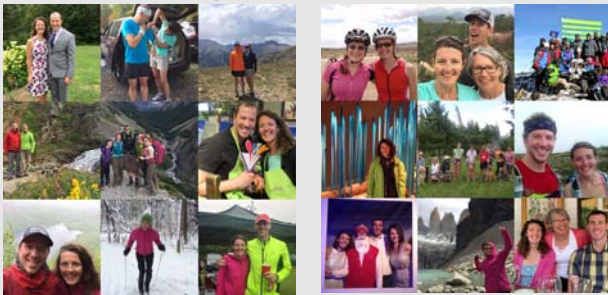
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## Personal Story



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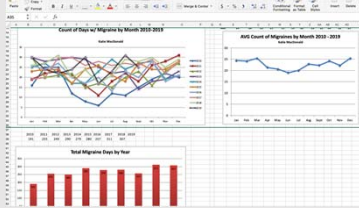
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## Personal Story

- Diagnosed at 14
- Chronic for last 9 years



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## Personal Story

- Journey through treatments
- Frustrated, difficult patient turned advocate
  
- HCNE 2013
- HOH 2015
- Left Corporate Job – June 2016
- Miles for Migraine 2016
- AHDA 2017

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## Lessons Learned

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## 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
- Patients 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

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## Moving the needle through ADVOCACY

- Learning that my HA specialist was 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

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## Moving the needle through ADVOCACY

- Miles for Migraine
  - In-person events
    - Walk, Run or Just Relax
    - Education Days
    - Youth Camps
    - Migraine Community Groups
    - Meet-ups
  - Discussing Stigma & Advocacy
  - Providing Resources



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### Moving the needle through **ADVOCACY**

- How can providers promote advocacy?
  - Encourage patients to share their story
  - Talk to patients about how you are involved
  - Make your patient base aware of events
  - Champion communication within your health network
  - Become a mentor
- How do you currently promote advocacy?

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### 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

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### Other Ideas

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### Moving the needle through Providers

- De-emphasize role of Headache Specialists
- More education to fields like:
  - Primary Care
  - NP
  - OBGYN
  - ENT
  - Optometry
  - Emergency / Urgent Care
  - School Nurses

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### A few more ideas

- Large employers to offer education on invisible illness.
- Engage with the episodic migraine community
- Fewer organizations with clearer focus
- Palatucci program for patients

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### Resources to introduce to patients:

- Step 1: Coalition for Headache and Migraine Patients (CHAMP)
- Step 2: Miles for Migraine
- Step 3: Alliance for Headache Disorders Advocacy (AHDA)
  
- Encourage in person events over social media

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## Resources to introduce to patients:



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**Thank you**  
Questions?

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