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

Katie MacDonald

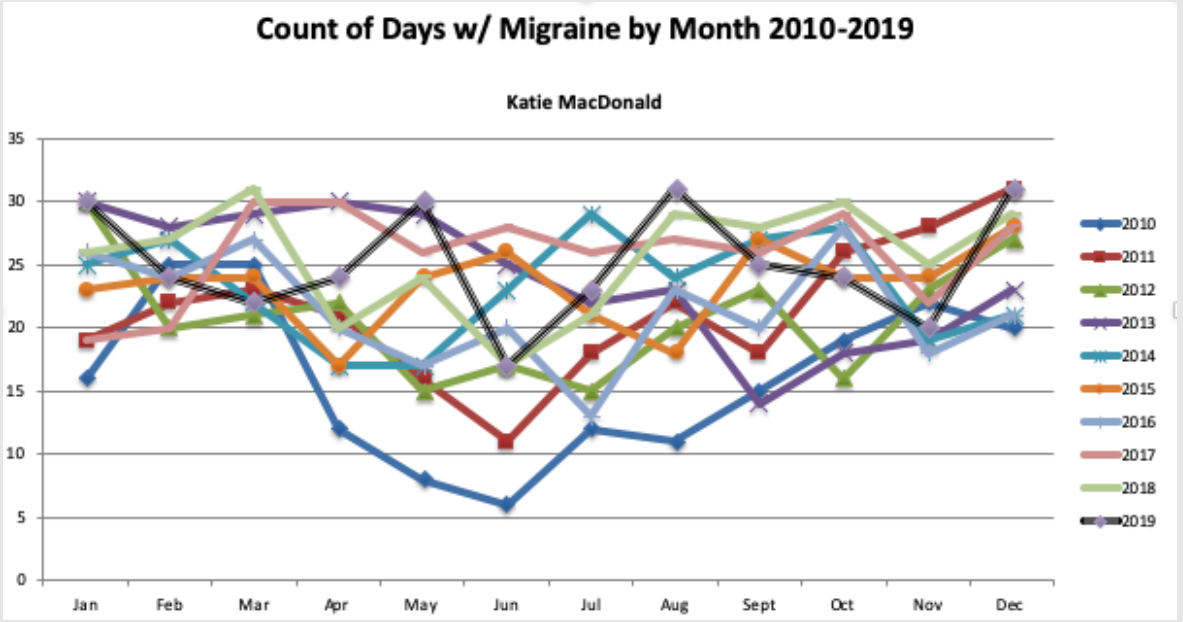
Agenda

- 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

Turning Points

2013
HCNE

2015
HOH

2016
LEFT CAREER

2016
MILES FOR MIGRAINE

2017
AHDA

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

Resources:

AMERICAN MIGRAINE FOUNDATION

ASSOCIATION OF MIGRAINE DISORDERS

ARE YOU AWARE? CHRONIC MIGRAINE AWARENESS, INC.

CLUSTERBUSTERS

HSG Cluster Headache Support Group

the daily headache

Danielle Byron Henry Migraine Foundation

GOLDEN GRAINE

The Headache & Migraine POLICY FORUM

healthy women

Hope for Migraine Community
- CGRP & Emerging Treatments -

MigraineAgain

Migraine.com

Migraine is a Disease

The Migraine Diva

migrainepal

MIGRAINE WORLD SUMMIT

MILES FOR MIGRAINE

NATIONAL HEADACHE FOUNDATION

PAF Patient Advocate Foundation
Solving Insurance and Healthcare Access Issues | since 1996

Alliance for Headache Disorders Advocacy

MIGRAINE RESEARCH FOUNDATION
Opening doors to a cure

U.S. PAIN FOUNDATION

spinal csf leak FOUNDATION
because your dura maters®

Thank you

Questions?

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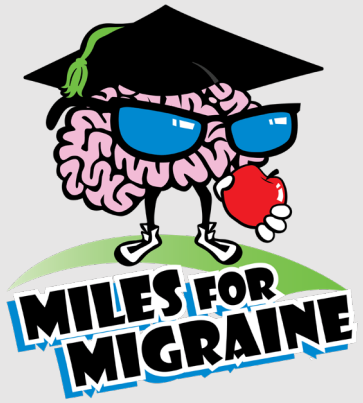

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