The Chronic Advocate: How I Found New Purpose Through Advocacy

I'm Not Sick. I'M MEDICALLY COMPLEX.

Jenn Heater
Professional Patient, Advocate, Writer
My Story: It Started With A Rare Disease…

- Diagnosed w/ Cushing’s Disease Senior Year of College
- Caused by a Pituitary Tumor
- 1st Brain Surgery in 2000
- 2nd Surgery 2009
- 3rd Surgery in 2015
The Grieving Process

Old Life

New Reality
Turning to Advocacy
Writing as an Outlet

• My first step was creating a blog and sharing my story

• From there I started to gradually talk about what everyday life was like with migraine and chronic illness
Tell Your Story

Telling Your Story is Powerful

- American Migraine Foundation
- National Headache Foundation
- US Pain INVisible Project
- Chronic Migraine Awareness
- HealthyWomen
- Migraine Again
- Migraine.com
Finding Organizations Whose Mission Appeals to You

• US Pain Foundation
• Association of Migraine Disorders (Shades for Migraine)
• Chronic Migraine Awareness
  • ARMS (Advocates Removing Migraine Stigma)
• Clusterbusters
• Move Against Migraine
• migraine.com
• Migraine Again
My Chronic Brain

- Online Magazine, Published 3 times a year
- Large print
- Volunteer staff all have migraine
- Features articles about new medications/devices, patient stories, art, recipes, advocacy
Advocacy is....

• Policy Based/Deals with Elected Officials
• Writing letters to your representatives
• Contacting Reps through social media
• Participating in events like Headache on the Hill and The Headache & Migraine Policy Forum

...BUT THAT’S NOT ALL THAT ADVOCACY IS
Advocacy is Also...

@BreatheMia
@thedizzycook
@nickidoesart
In Person Events

• Miles for Migraine
• US Pain Trainings
• Retreat Migraine
• Headache on the Hill
Migraine Community Covid Resources

- New Pediatric Migraine Resource Center - developed by the 2019 class of AHS Emerging Leaders. This group of providers audited the population needs and existing content and designed the topics to ensure the pediatric population is well supported.
- Managing Migraine During COVID-19 - tailored resources curated from the experts in the headache and migraine field to support those living with migraine during the pandemic.
- A weekly wellness series via Facebook Live for the migraine community to provide support during the pandemic. Please tune in to AMF's social channels to see the programming: Facebook, Instagram.

- Spotlight on Migraine Podcast episode "Navigating the COVID-19 Pandemic as a Migraine Patient"

- Facebook Live Chat/Support Group, Hosted on Migraine Meanderings - Thursdays at 1pm PT through end of May (may be extended)
Some Last Thoughts

1. Advocacy is for Everybody
2. There is Room in This Community For Everyone
3. Don’t Forget to Advocate for Yourself
4. We all have Something to Contribute to Advocacy, Your Delivery System May Just be Different than Mine
CHRONIC MIGRAINE DOESN’T DEFINE ME

KEEP FIGHTING STRONG BEAUTIFUL WARRIOR

Artwork by Amanda Ingrassia