The Chronic Advocate: How I Found New Purpose Through Advocacy

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I'm Not Sick.

I'M MEDICALLY COMPLEX.

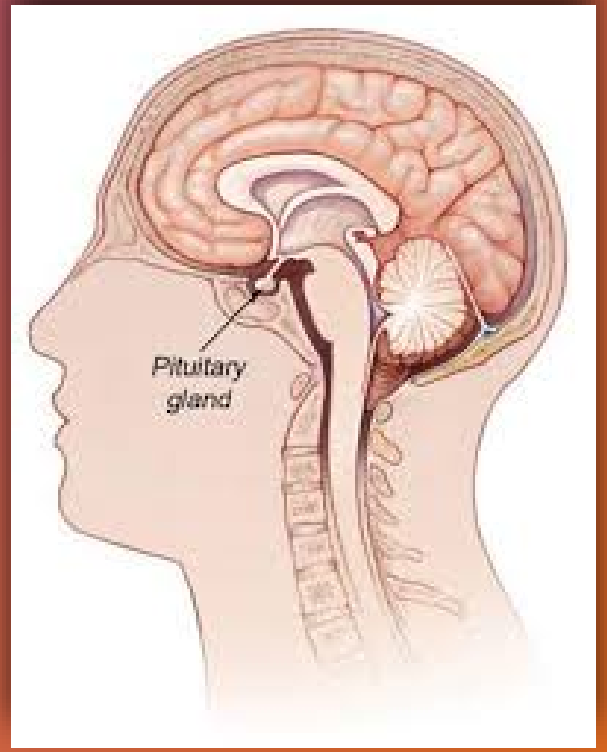
talesofamedicaloddity.com

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

Chronic Migraine Awareness

SF Miles for Migraine

Headache on the Hill

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

The Mighty

When I Wasn't Well Enough to Attend My 20-Year High School Reunion

Tonight is my 20-year high school reunion. That sentence alone is enough to give pause to anyone who has ever uttered it. I'm not able to attend because I am chronically ill, and at this point, committing to anything more than a doctor's appointment or a trip to the store usually ends up being a lose-lose for me.

Tell Your Story

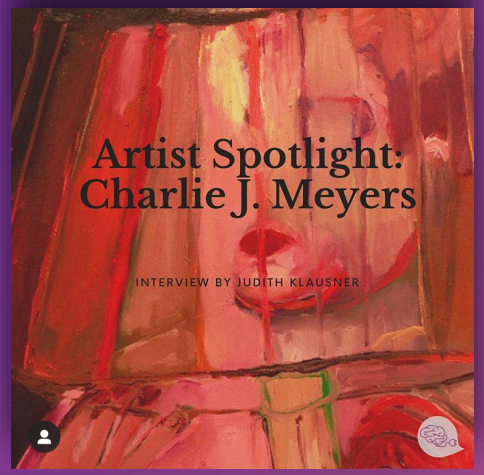
Telling Your Story is Powerful

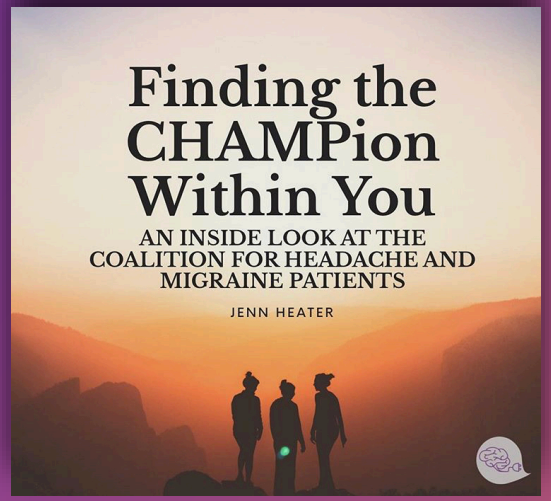
- American Migraine Foundation
- National Headache Foundation
- US Pain INVisible Project
- Chronic Migraine Awareness
- HealthyWomen
- Migraine Again
- Migraine.com

Finding Organizations Whose Mission Appeals to You

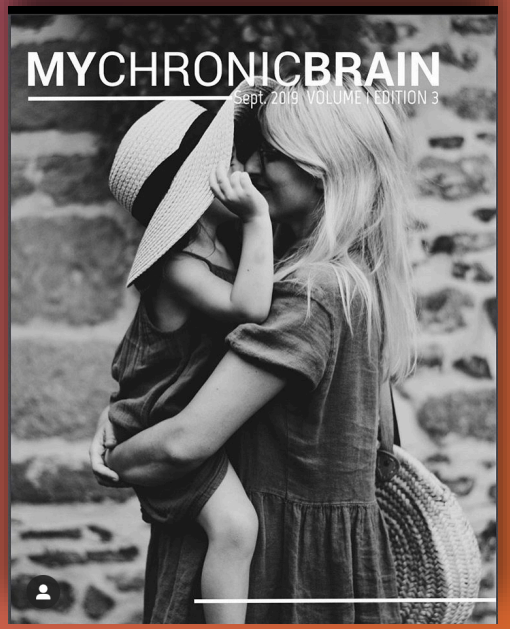
- US Pain Foundation
- Association of Migraine Disorders (Shades for Migraine)
- Chronic Migraine Awareness
  - ARMS (Advocates Removing Migraine Stigma)
- Clusterbusters
- Move Against Migraine
- migraine.com
- Migraine Again

My Chronic Brain





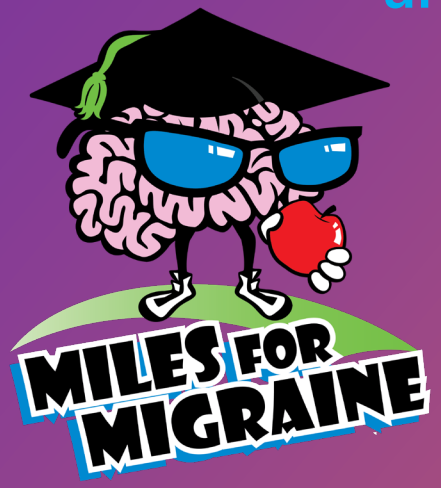
- Online Magazine, Published 3 times a year
- Large print
- Volunteer staff all have migraine
- Features articles about new medications/devices, patient stories, art, recipes, advocacy



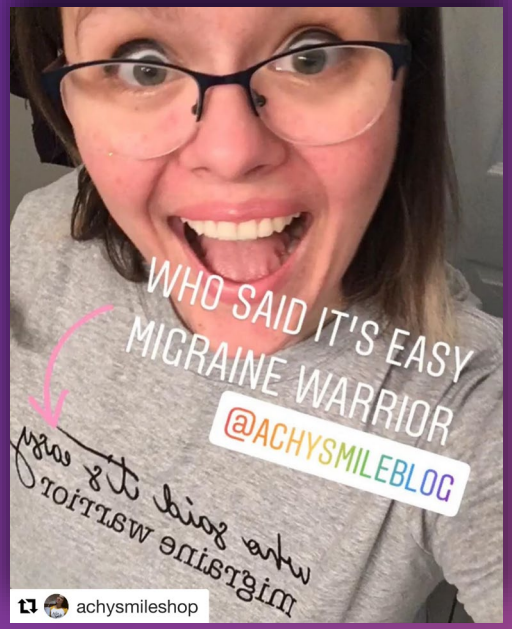
Advocacy is….

- 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

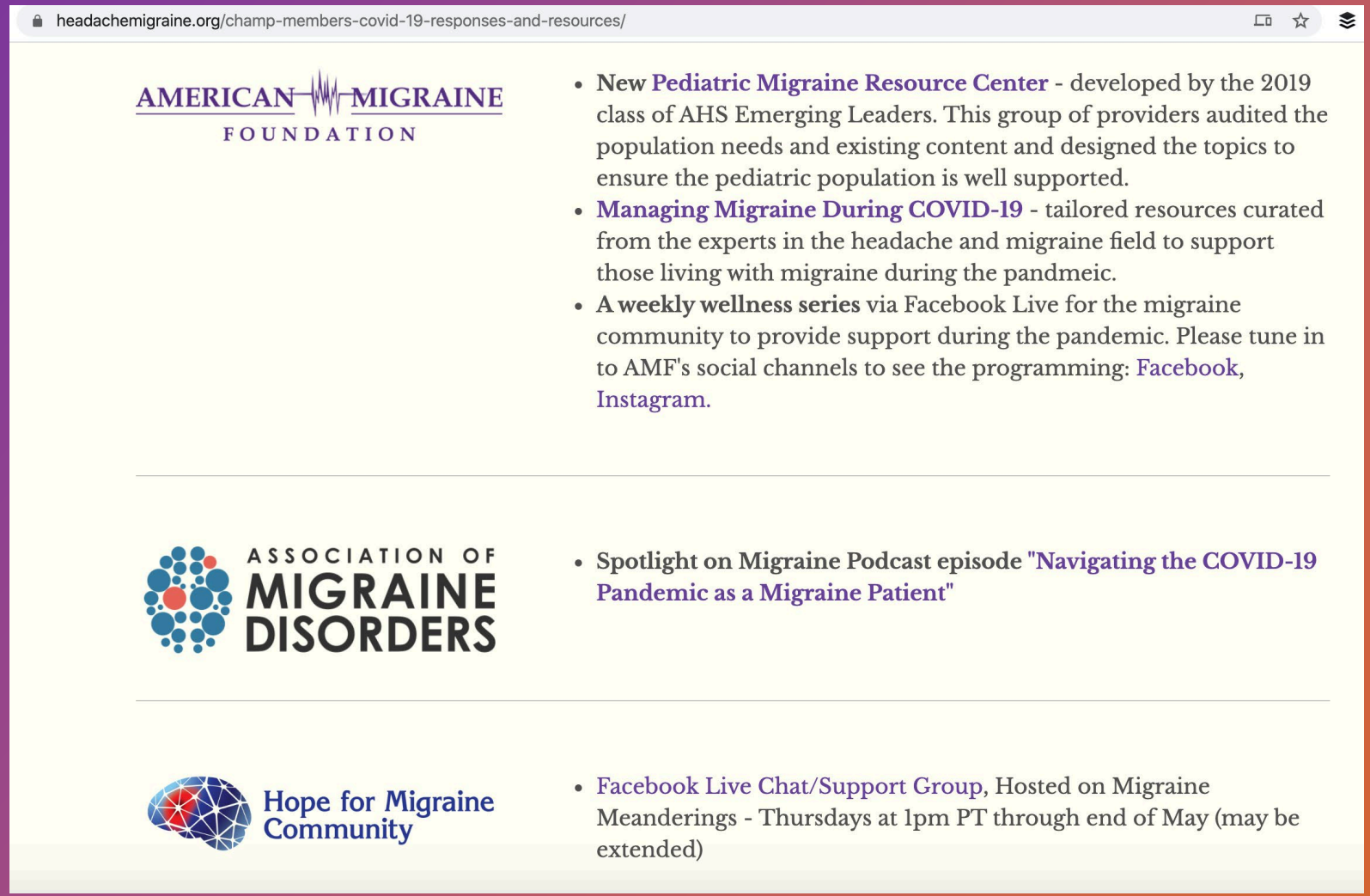
MCB Team #ShadesForMigraine

In Person Events

- Miles for Migraine
- US Pain Trainings
- Retreat Migraine
- Headache on the Hill

RETREATMIGRAINE

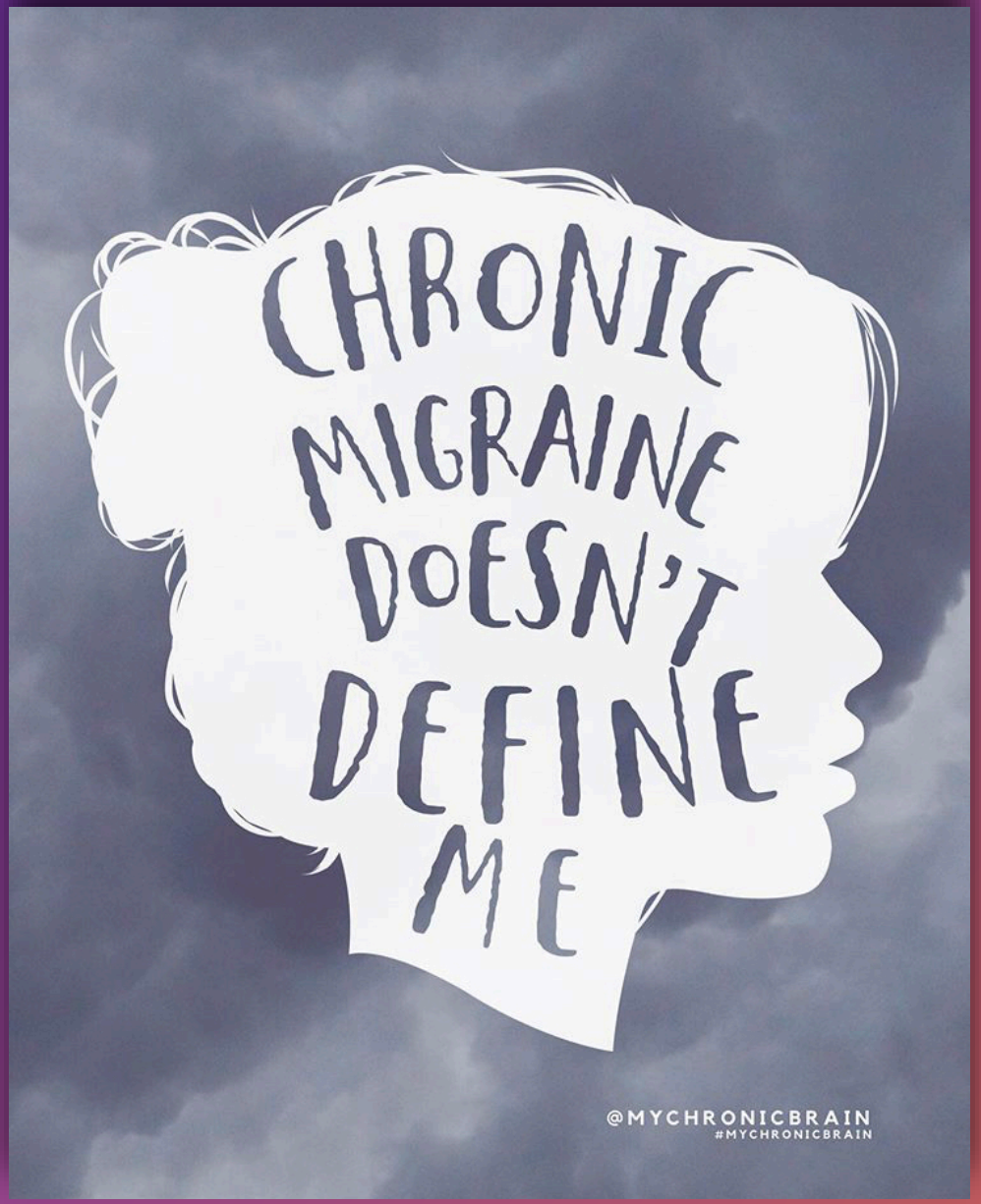
Migraine Community Covid Resources



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

MILES FOR MIGRAINE



Artwork by Amanda Ingrassia