

What is Advocacy?

As physicians, advocacy is what we do:

- Seeing patients

- Research

- Fighting insurance companies

- Teaching students and residents

 - *this is why I hate that hospitals have “patient advocates”

As People with Disease (Patients?), self and community advocacy

- Personally rewarding, both practically and healthy

- Rewarding to the Community

 - Reducing stigma

 - Supporting research

 - Education

 - Support groups

Advocacy, both professional and patient, is a tool to magnify our ability to impact the lives of people with headache disorders beyond what we can do seeing them one at a time in clinic and beyond just taking care of our physical needs.

Professional advocacy: GME funding, reimbursement, NIH funding, etc.

Headache on the Hill

Neurology on the Hill

AAN Calls to Action

Patient advocacy: Access, education, insurance coverage, drug costs etc.

Headache on the Hill

Public awareness

Patient education

Support Groups

Advocacy is Engaging



Advocacy is Healthy!



Advocacy is Rewarding!



**Advocacy isn't
always successful!**

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MISTAKES

IT COULD BE THAT THE PURPOSE OF YOUR LIFE IS
ONLY TO SERVE AS A WARNING TO OTHERS.

My Personal Advocacy Journey

- From WV – returned and shocked by inadequate treatment of headache disorders
- PALF – 2011
- NOH, HOH
- GRC to Advocacy Committee
- Advocacy Engagement Subcommittee
- Runnin' for Research to Miles for Migraine
- Botox and Medicaid
- CGRPs and Medicaid

Advocacy as a patient or care-giver:

Where to start?

Passion

Skill

Finding time

Value

Convincing your boss/spouse/kids...

Finding your team

Suggestions for getting started

Miles for Migraine – you have already started

Talk to your provider about opportunities locally

Educate yourself about headache disorders

Email or call your state and national representatives – nothing specific, just say you have Migraine or other headache disorder and that you hope they will support initiatives related to this, like NIH funding, drug pricing, etc.

Apply for Headache on the Hill in 2022.

Advocacy Action Plans

Once you have a goal, you need a plan. Without a plan, you are just counting on luck. If you were lucky, you wouldn't have a headache disorder. So you need a plan.

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“To raise money to be used for Headache and Migraine Research by organizing a 5K race and 1 mile walk.”

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“Migraine affects 36 million people in the US and Migraine and other Headache conditions are often severely disabling and costly to individuals and society. Research in these areas is limited in large part due to a lack of funding.”

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It's ok if things change over time, but having steps keeps you focused

Allow for modifications over time

1. Get approval of AHMA to organize race under its umbrella x
 2. Select name of race x
 3. Select site of race x
 4. Select date of race x
 5. Organize a race committee x
 6. Notify iplayoutside.com x
 7. Select timing company x
- 8-15: etc.

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Target Audience/People Needs

Who do you need/want to help you with this project?

Tie each person/audience to an action item if only needed for part

Assume people will agree, don't take it personally when they don't

Resources Needed:

Money, space, time, stuff...

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Success Measures:

This one may be the most important
Have lots of success measures. Even silly ones. Checking a success box is wildly motivating to keep moving forward.

Conclusions:

Advocacy is needed

Advocacy is hard

Advocacy is fun

Advocacy is rewarding

Advocacy isn't your job or responsibility

Do what you are passionate about and what you are good at

Advocacy can change your life and someone else's life