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

Political Advocacy
Advocacy is Healthy!
Advocacy is Rewarding!
Advocacy isn’t always successful!
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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Action Plan Steps:

Issue: What problem do I want to address/solve – spell it out, describe it

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

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Reason: Why is this important? Why do you care? Why should I care?

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Actions To Take: Describe each step, even if it seems minimal, from start to finish
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