

New Daily Persistent Headache

## Celebrating NDPHaware's 2 year Anniversary

It's been an interesting and exciting 2 years. We started NDPHaware after years of frustration on the lack of research and effective treatments available to this community. Our goals for research, education and advocacy got off to a fast start, which is the opposite of what I was told, that nonprofit work takes time and goes slowly. Maybe we just got lucky from connecting with Clusterbusters and meeting Dr Burish who offered to be part of the NDPH Patient Experience Survey - or maybe things are naturally lining up to make real progress in better understanding and treating our condition.

Since starting NDPHaware, we have much to celebrate and be proud of:

- 1. Launched our website and Facebook page
- 2. Invited to be a member of <u>CHAMP</u>, Coalition For Headache And Migraine Patients
- 3. Attended <u>Headache on the Hill</u>, virtually
- 4. Supported <u>Clusterbusters</u> at their annual conferences
- 5. Worked with Migraine World Summit
- 6. Attended <u>American Headache Society</u> conferences to advocate for research
- Launched the NDPH Patient Experience Survey with the support of Dr Burish from UT/ Houston Will Erwin Headache Research Center along with 4 other Headache Specialists. (See initial impressions of data link). We anticipate 2 papers coming out of the survey deep dive into the data.
- 8. We are now officially a registered 501 (c) (3) non profit organization.

Next steps are to continue sharing data from our survey and advocating for more research on NDPH. We are actively talking with multiple pharma companies and encouraging them to test their existing medicines for NDPH so we can learn more about what works best for our community. Research is a long process, which is why it's so important that we are pushing for it now.

In order to build on what we've accomplished over the past 2 years, we need your help. To be blunt, we need your support in the form of donations, ensuring NDPH is present at headache conferences where the leading headache researchers and pharmaceutical companies are making decisions about future research targets and priorities.

Our fundraising goal is \$5000 by the end of the year. All donations go 100% towards achieving our goals. NDPHaware is run by unpaid volunteers.

No amount is too small and we appreciate whatever you are able to contribute.

## Click to Donate

If your employer offers matching charitable donations, this is a great way to maximize your support. Let me know if you need any documentation.

## **NDPHaware Survey 1st Impression**

Thank you for your support, Alan