

## **Advocacy Connection Team (ACT)-Now Educational Program for Headache Fellows and Patients/Caregivers: Assessment of Educational Objectives**

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### **Abstract**

**Objective:** The aim of this project was to assess for improvement in knowledge of migraine and headache disorders as stigmatized diseases and comfort in participating in advocacy as it relates to these conditions.

**Background:** The Advocacy Connection Team (ACT)-Now program is an educational program offered through the non-profit advocacy organization, Miles for Migraine. It is designed to teach headache fellows and patients advocacy skills.

**Methods:** The 2021 ACT-Now cohort was administered a set of 11 pre-course survey questions identifying their role (healthcare provider/headache fellow or patient/caregiver), baseline knowledge of migraine related disability and stigma, and baseline engagement and comfort with advocating. The post-course survey questions were the same other than the addition of one question assessing knowledge of migraine-related disability and additional questions addressing comfort levels advocating with insurance and policy makers as well as creating an advocacy plan.

**Results:** Compared to pre-survey, participants were able to correct identify epidemiological data about migraine. There was also an increase in the comfort level of participants in advocacy activities including coming up with an advocacy action plan.

**Conclusion:** These surveys demonstrate that ACT-Now is highly effective at improving advocacy skills in a mixed cohort of patients and headache fellows, giving them the skills to create advocacy plans and engage with other patients and physicians, payers and policy makers to create a more understanding, equitable and compassionate world for persons with migraine and other headache diseases.

### **Introduction**

Headache disorders are very common and can be incredibly disabling. Migraine affects over 1 billion people in the world and tension type headache affects nearly 2 billion people.<sup>1</sup> Migraine is

also one of the most common diseases worldwide and is the second most disabling based on years of life lived with disability.<sup>1</sup> However, despite its prevalence and level of disability, people with headache disorders are underdiagnosed, undertreated and these disorders are understudied, compared to other comparable diseases. It is postulated that one of the reasons for this lack of public awareness is due to the stigma of migraine and other headache disorders. Stigma is described “a characteristic, trait, or diagnosis that is used to discredit an individual and leads to prejudice, discrimination, and loss of status.”<sup>2</sup> Negative personal, societal and structural stigma has prevented migraine and other headache disorders from being treated as the severe, disabling neurobiological diseases they are. Stigma leads to a decrease in public education on headache disorders and is why people are less likely to seek care for their symptoms. Even when individuals do seek medical care, they are less likely to be appropriately diagnosed and treated. NIH funding for research on migraine and headache disorders falters compared to the disease burden, especially when compared to other disease states that are as common or disabling.<sup>3</sup>

Advocacy has become one of the main methods of combating stigma. Advocacy in its most basic form is public support for a cause. Migraine advocacy is achieved through a combination of educational and institutional interventions to decrease stigma toward the disease and improve care for patients living with it. Advocacy can range from bedside education to political activism.<sup>4</sup> Miles for Migraine is a nonprofit organization focused on advocacy for migraine and other headache disorders. In addition to fundraising for research and training providers, it provides educational sessions for patients, providers, and caregivers. Miles for Migraine also sponsors local support groups to bring the migraine community together.

The Advocacy Connection Team (ACT)-Now program is an educational program offered through Miles for Migraine. It is designed to teach headache fellows and patients advocacy skills. This program includes nine sessions over the course of one year. Instructors include physician and non-physician content experts in headache advocacy, stigma, equitable access to quality healthcare, underserved populations, and navigation of insurance claims and denials. The curriculum is based in part on the American Academy of Neurology Palatucci Advocacy Leadership Forum (PALF), with additional teaching on stigma and the relationship between disease advocacy and resource allocation. At the end of the course, students are encouraged to engage in an advocacy project. After the pilot year, we decided to determine the effectiveness of

this program in creating better migraine and headache disorder advocates that will then move on to help further promote increased research, training, education, and decrease the stigma migraine and other headache diseases.

## **Methods**

We conducted surveys at the beginning and end of the second cohort of ACT-Now students (2021-2022), shown in Appendix 1. The goal of the surveys was to assess baseline epidemiologic information and familiarity with advocacy as it relates to headache/migraine and to determine if comfort levels and knowledge about the practice of advocacy as part of headache medicine improved by the end of the course. Participation was optional.

## **Participants**

The pre-questionnaire had 67 respondents, of which 21 (31%) were headache fellows from Miles for Migraine supported fellowship programs; the post-survey had 40 respondents, of which 22 (55%) were headache fellows. Other subjects included people with migraine and family members or caregivers of people with migraine.

Prior to starting the course, 36/69 (53%) of respondents had been involved in some type of advocacy work. The types of advocacy people had been involved in ranged from formal meetings such as Headache on the Hill and Neurology on the Hill, engagement in other organizations such as Coalition for Headache and Migraine Patients (CHAMP), American Headache Disorders Association (AHDA), social media, and other non-headache related advocacy.

## **Statistical Analysis**

Still in process as of 6/12/23

## **Results**

In the pre-survey, there were 69 participants (14 fellows, 55 patients or caregivers) and in the post survey there were 40 participants (22 fellows, 18 patients or caregivers). Survey responses are listed in Table 1.

**Table 1. Responses to pre and post survey**

Question	Response	Pre-survey Number (%)	Post-survey Number (%)	Probability
In terms of years of life lived with disability, migraine ranks ___ globally.	Correct	32 (46.4%)	23 (57.5%)	p<0.05
	Incorrect	37 (53.5%)	17 (42.5%)	
Prior to starting this course, were you engaged in any advocacy initiatives?	Yes	36 (52.2%)	21 (52.5%)	p=NS
	No	33 (47.8%)	19 (47.5%)	
How comfortable do you now feel advocating?	Very comfortable	16 (23.2%)	25 (62.5%)	p<0.001
	Somewhat comfortable	45 (66.2%)	15 (27.5%)	
	Not comfortable	8 (11.6%)	0 (0%)	
Do you know how you would go about advocating?	Yes	19 (26.1%)	36 (90%)	p<0.05
	No	50 (73.9%)	4 (10%)	
Do you know how to make an advocacy plan?	Yes	8 (11.6%)	37 (92.5%)	p=NS
	No	61 (88.4%)	3 (7.5%)	
Have you prepared your elevator speech on migraine or headache disorders?	Yes	26 (37.7%)	35 (87.5%)	p<0.01
	No	43 (62.3%)	5 (12.5%)	
Do you feel you know who your targets are for advocacy?	Yes	27 (39.1%)	36 (90%)	p<0.0001
	No	42 (60.9%)	4 (10%)	
Do you know how to find out about advocacy organizations to help you decide which advocacy programs you would want to participate in?	Yes	25 (36.2%)	36 (90%)	p<0.001
	No	44 (63.8%)	4 (10%)	
Do you understand why migraine is a stigmatized disease?	Yes	67 (97.1%)	40 (100%)	p=NS
	No	2 (2.9%)	0 (0%)	
Migraine is the ___ most common disease worldwide.	Correct	n/a	9 (22.5%)	n/a
	Incorrect	n/a	31 (77.5%)	
How comfortable are you giving your elevator speech?	Very Comfortable	n/a	22 (55%)	n/a
	Somewhat comfortable	n/a	16 (40%)	
	Not comfortable	n/a	2 (5%)	
How comfortable are you advocating with insurance companies?	Very comfortable	n/a	12 (30%)	n/a
	Somewhat comfortable	n/a	24 (60%)	
	Not comfortable	n/a	4 (10%)	
How comfortable are you advocating with policy makers?	Very comfortable	n/a	11 (27.5%)	n/a
	Somewhat comfortable	n/a	23 (57.5%)	
	Not comfortable	n/a	6 (15%)	
Have you created a plan that reflects the population you are advocating for?	Yes	n/a	27 (67.5%)	n/a
	No	n/a	13 (32.5%)	
How comfortable are you with creating an act of advocacy/project	Very comfortable	n/a	20 (50%)	n/a
	Somewhat comfortable	n/a	19 (47.5%)	
	Not comfortable	n/a	1 (2.5%)	
How comfortable are you creating an act of advocacy/plan that addresses health disparities?	Very comfortable	n/a	6 (16%)	n/a
	Somewhat comfortable	n/a	24 (60%)	
	Not comfortable	n/a	10 (25%)	

For the one epidemiologic question asked in the pre-course survey and two asked in the post-course survey. The number of participants correctly identifying how common migraine ranks as a disease worldwide, showed improvement before and after the program.

After completing the program, respondents became significantly more comfortable advocating. The percentage of the cohort who were “not comfortable” advocating went from 11.7% at the beginning of the course to 0%. The proportion of participants who felt “very comfortable” advocating went from 23.2% to 62.5%. Pre-course, 26.1% (18/69) of participants felt they knew how to go about advocating, post course 90% (36/40; p-value \*\*\*). Pre-course 11.6% (8/69) endorsed knowing how to make an advocacy plan, post course 92.5% (p-value \*\*\*). All of these differences were highly statistically significant.

Participants became more comfortable with their elevator speeches. Pre-course, 36.7% of the class endorsed having prepared an elevator speech. Post-course 87.5% had (p-value \*\*\*). Comfort levels in delivering an elevator speech were not assessed in the pre-course survey; however, in the post-course survey, only 5.0% were “not comfortable” giving their elevator speech. The percentage of students who felt they knew their targets for advocacy increased from 39.1% to 90.0% (p-value <0.0001).

We asked our learners how comfortable they were advocating with insurance companies in the post-course survey only. At the end of the course, 30.0% reported feeling “very comfortable” and only 10.0% were “not comfortable” advocating with insurance companies. Similarly, at the end of the course, 57.5% of respondents were “somewhat comfortable” and 27.5% were “very comfortable” advocating with policy makers.

At the conclusion of the ACT-Now course, 67.5% had created an advocacy plan for the population for whom they were advocating. 90.0% of respondents knew how to find advocacy organizations to help them with their advocacy goals. Furthermore, all respondents felt they understood why migraine was a stigmatized disease. Only 2.5% of respondents were “not comfortable” creating an advocacy project, while 47.5% were “somewhat comfortable” and 50% were “very comfortable”. At the conclusion of the ACT-Now program 25.0% were “very comfortable” creating an advocacy plan that addresses health disparities, 60.0% were “somewhat comfortable” and 15% of respondents were “not comfortable”.

Course participants commented positively on the course, the curriculum, the speakers, and the breakout groups.

## **Discussion**

We identified 3 categories of outcomes measured – epidemiologic knowledge of migraine disease, comfort levels engaging in advocacy, and preparation for advocacy in action. Questions pertaining to each category are seen in Appendix 1. After completing the ACT-Now program, class participants had increased epidemiological knowledge, increased comfort levels regarding advocating, and have begun to create their own advocacy plans. In particular, they showed increased confidence in specific skills in advocacy such as elevator speech, picking appropriate targets, and understanding the current healthcare system as to be able to navigate it and advocate for systemic changes.

An elevator speech is a very short summary of one's situation that is an opportunity to frame a listener's understanding for an "advocacy ask." For example, the elevator speech of a person with migraine may include a brief synopsis of their current diagnosis, level of disability due to the condition, a statistic on the prevalence of migraine and/or associated disability, and finally the "ask." Having a good elevator speech is critical to successfully advocating and has successfully been used and endorsed for communities involved in advocacy of mental health disorders.<sup>5</sup> As a result of the ACT-Now course, participants became enormously more confident in their elevator speeches

At the conclusion of the ACT-Now course, a majority of the cohort had created an advocacy plan. Respondents knew how to identify advocacy organizations to help them with their projects. All respondents felt they understood why migraine was a stigmatized disease. Very few respondents were not comfortable creating an advocacy project, and half were very comfortable. At the conclusion of the ACT-Now program most participants were comfortable creating an advocacy plan that addressed health disparities.

The importance of these skills cannot be overemphasized. Advocacy is not traditionally required in medical school or residency curriculum. Many medical schools offer at least one course on advocacy, but these tend to be elective rather than mandatory.<sup>6</sup> The Accreditation Council for Graduate Medical Education (ACGME) has categorized advocacy for "systems change that

enhances high-value, efficient, and effective patient care” as Level 5 under the Physician Role in Health Care Systems for neurology residents.<sup>7</sup> However, this does not guarantee that any given neurology resident has exposure to or is formally taught how to advocate for their patients. Similarly, patients must often learn how to become their own advocates which can be met with resistance by the healthcare system. There are no formal training programs in headache disorder advocacy dedicated toward medical trainees, specifically fellows, prior to the ACT-Now program. While the Palatucci Advocacy Leadership Forum provides an excellent framework for clinicians to obtain advocacy skills for the broader range of neurological disorders, the ACT-Now program specifically is targeted for headache fellows. Even more unique is that this program combines fellows with patient advocates as well, reinforcing that advocacy should be done with patients in addition to for patients.

## Conclusion

These surveys demonstrate that ACT-Now is highly effective at improving advocacy skills in a mixed cohort of patients and headache fellows, giving them the skills to create advocacy plans and engage with other patients and physicians, payers and policy makers to create a more understanding, just and sympathetic world for persons with migraine and other headache disorders.

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## Appendix 1.

Pre and post questionnaires distributed to ACT-Now participants in 2021-2022 year.

<b>Pre-Course Survey Questions</b>
Are you a current headache fellow, patient, or other?
In terms of years of life lived with disability, migraine ranks _____ globally?
Prior to starting this course, were you engaged in any advocacy initiatives?
How comfortable do you feel advocating?
Do you know how you would go about advocating?
Do you know how to make an advocacy plan?
Have you prepared an elevator speech for migraine or other headache disorder?
Do you know who your targets are for advocacy?
Do you know how to find out about advocacy organizations to help you decide which advocacy programs you would participate in?
Do you understand why migraine is a stigmatized disease?
<b>Post-Course Survey Questions included the Pre-Course Questions with the addition of the following:</b>
Migraine is the _____ most common disease worldwide?
How comfortable are you giving your elevator speech?
How comfortable are you advocating with insurance companies?
How comfortable are you advocating with policy makers?
Have you created a plan that reflects the population you are advocating for?
How comfortable are you with creating an act of advocacy or an advocacy project?
How comfortable are you creating an act of advocacy or plan that addresses healthcare disparities?