In November 2017, 180 people living with migraine wrote to ICER with heart-wrenching details of their real-life struggles with migraine disease. This outpouring of information helped ICER to better understand the pain and challenges of migraine disease, and the desperate need for access to better preventive medicines.

The second Public Comment period is now open through May 8, 2018 and we need to amplify our voices even louder before ICER issues their final report. **Let’s shoot for 250 written patient submissions!**

**Background:** The Institute for Clinical and Economic Review (ICER) is assessing the new class of CGRP inhibitor medicines for migraine prevention. It is anticipated that these medicines will begin to come to market in the second half of 2018.

Insurance companies will use ICER’s final report (as well as other information) when determining if they will cover these new medicines, what tier the medicines will be in on the plan’s formulary, and what types of prior authorization or step therapy will be required. All of this will heavily impact the access migraine patients have to this new class of medicines.

**Current Status:** The ICER review is a nine-month process. Patient information along with data submissions from various stakeholders informed the [Draft Evidence Report](https://icer.org) that ICER published on April 11.

We are now in a second Public Comment period until May 8. All input ICER receives during this current period will be shared with the voting panel members who vote on the final
report. Unfortunately, ICER has denied our request that a migraine patient and a headache specialist doctor be included on this voting panel – so the voting panel truly does not have a personal or specialist understanding of migraine disease.

Even if you wrote to ICER during an earlier stage in this process, it is vital that you submit another letter to ensure that it is seen by the voting panel.

Call to Action: Patient input must be received by Tuesday, May 8, 2018. This is your story to tell and a chance to be heard and advocate. Everyone’s story will be different, but it’s important that we all emphasize key points to show that we are a strong and united community.

Know that many stakeholders, including migraine patient advocacy leaders, are weighing in on technical aspects of academic studies, clinical data and health economic modeling. As a person with migraine, you are uniquely qualified to help ICER understand the personal impact of migraine disease.

We need migraine patients to write ICER to ensure they understand how painful and disabling migraine disease is, how limited in effectiveness current treatments are, and how great the need is for patient access to new and more effective preventive medicines.

Below is guidance for what we encourage you to share in your submission and how to submit your letter.

Have Questions? Patient Advocate Katie M. Golden is playing a leading role organizing the patient responses during this Public Comment period. If you have questions, you can contact Katie through her blog, Golden Graine.

GUIDANCE ON PATIENT SUBMISSIONS DURING PUBLIC COMMENT PERIOD DUE BY MAY 8, 2018

For your submission, we encourage you to succinctly cover the following four points (1-2 paragraphs per point):

1) Share your migraine journey (when did you first start experiencing migraine attacks, what does a migraine attack feel like to you, how often do you experience migraine attacks, etc.).
   • Detail is important. Don’t be afraid to be graphic. What is most important to you – reducing your migraine frequency, lessening the severity or increasing your functional ability?
   • Share what migraine disease has taken away from your quality of life and how you would value a new and potentially better treatment.

2) Describe the negative/disabling impact that migraine has in your life.
   • What are you unable to do now that you used to be able to do?
• How have you had to alter your lifestyle due to migraine – impact on education, work, family life, etc.

3) Detail how existing migraine medicines fail to fully treat your migraine disease and have many unwanted side effects.
   • List medications, supplements, surgeries, neurostimulators, and complementary alternative methods that you have tried or are currently using.
   • Convey what the downsides are of your current treatment regimen. Detail how existing migraine medicines fail to fully treat your migraine disease and have many unwanted side effects.

4) Call on ICER to appropriately value your pain and disability, and support both episodic and chronic migraine patients in having access to these new CGRP inhibitor medicines.
   • Share any access issues you’ve experienced. These include being denied medications prescribed by your doctor, being forced to change medications (non-medical switching), being required to try other medications before obtaining approval (step-therapy) or inability to afford needed medicines.
   • State the need for better treatment options and access to them.

Submissions must be made via email following a few important rules:
   • Your letter must be in the form of a Word document attachment (not in the body of your email or as a PDF attachment)
   • Your letter cannot exceed 5 pages
   • Your letter must be written with Times New Roman, 12-point font size

Your letter attachment must be emailed to publiccomments@icer-review.org by Tuesday, May 8. (Please also send your letter to info@headachemigraine.org so we can track how many letters have been submitted.)

Note that all letters submitted during the Public Comment phase, including those submitted by individual patients, will be posted publicly to the ICER website and will be shared with members of the voting panel. Only share information that you are comfortable being posted publicly online.

YOUR PATIENT VOICE TRULY MATTERS AND WE THANK YOU FOR TAKING THE TIME TO WRITE ICER AND BE HEARD!