2024 INTERVIEW SUMMARY SHEET

SPEAKER
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TITLE & ORGANIZATION
Director of Operations
Miles for Migraine

TOPIC

Migraine FOMO: Are You Missing Out?

KEY TAKEAWAYS

- It's important to talk about your worries and stresses related to migraine and seek support from trusted friends, co-workers, or partners. Talking with them may help you problem solve and release some of the tension that builds up from dealing with your attacks.
- You may think it's easier to not make plans at all rather than make plans and then cancel because of migraine symptoms. But social interaction is important for your overall well-being.
- Being realistic about what your body can handle may mean making a difficult decision to say no to something you really want to do.
- Even if you feel that you've let your co-workers down by missing an important deadline, you can still use the opportunity to educate them about migraine and specifically how it affects you.
- It may be tempting to compare your treatment plan and medications with what others are taking, but everyone with migraine is dealing with their own unique situation, and there are many different aspects to a treatment plan.
- The Alliance for Headache Disorders Advocacy is the largest migraine policy organization in the U.S. They sponsor Headache on the Hill, where advocates meet with congressional leaders.
- Miles for Migraine sponsors walk/run events to raise migraine awareness.
- One type of advocacy is to get involved on a federal policy level, driving change that will impact millions of people.
- A first step in advocacy is to develop your own elevator speech — learning to tell your own story about what you're living with and how you're experiencing it.
- Sharing information on social media is a good way to advocate.
- When you help others through advocacy you can increase your sense of worth and happiness.

TREATMENTS CITED

N/A

QUOTES

"You never know what people are dealing with kind of behind the curtain. We all have our external face and life that we present, but everyone is dealing with different challenges."

"I think one of the biggest lessons I've had is that I realized when I was not working and I was still dealing with daily attacks, that this really is a disease. It's not my work. It's not one stress."

"I think, for me, organization is really important, trying to stay organized, kind of knowing that at any time, I could have a bad attack and I don't know how long it's going to take me offline for."

"I think one of the biggest things is, you have to try to show up. So, don't hesitate to sign up for an event out of fear that you might have to cancel... Just give people a heads up ahead of time, and let them know that you live with migraine or headache disease, and that there's a chance you may need to cancel, but you really want to be there."

PRACTICAL STEPS

- Don't compare yourself to others. Everyone's migraine journey is different. Focus on doing the best you can for yourself.
- Take a multidimensional approach to treatment. Explore different aspects of your treatment plan to include behavioral health, lifestyle modifications, and support from your community.
- If you need to miss work or a personal event due to migraine, communicate your situation.
 Simply not showing up can perpetuate stigma.
 Use the opportunity to educate others about migraine.
- If your current healthcare provider isn't meeting your needs or listening to you, consider seeking a new doctor or treatment plan.
- Share new information of therapies you've learned about with your healthcare provider.