

JenVon's Story—Using Your Voice for Self-Advocacy (TRANSCRIPT)

VO Please see Important Safety Information and Indication at 3:50.

JenVon My name is JenVon. I'm 41 years old. I live in Charleston, South Carolina, and I've been living with epilepsy for almost 36 years. [Music] Living with a chronic illness can be difficult. It can. My first seizure happened when I was 6 years old. I was probably having 1 to 3 seizures a month; sometimes I would have cluster seizures, 4-5 seizures in one day. There was always this little [hand motion] on my shoulder called epilepsy tapping me to let me know that I was not like everybody else. For a long time, a really, really long time, it was hard for doctors to try and figure out what type of treatment worked best for me. It was difficult to learn at a young age how to manage the mood swings, the side effects. It really shaped my life. I don't think anyone realized how much this really affected me. Learning how to have a voice and stand up for yourself is extremely important. You have to find friends that are accepting. It's important to have people you can go to, to talk to. If you know anything about me, you know that my mom and I are best friends. She is literally my backbone. My man, my man, my man has really come into my life and just shown me what love looks like and having somebody like that in your corner is top tier. Being an advocate for yourself, I will say it a million times: it's the most important thing on any chronic illness journey. Having a doctor that listens to you, that hears you and can actually help you with treatment, is the best thing. I started taking XCOPRI 2 years ago when my doctor suggested it. At first I was like, no, I'm tired of being on a new medication. I had been on so many different medications that I was fearful of new side effects that I had never dealt with before. But he was adamant. Since I started taking XCOPRI, I've seen a significant reduction in my seizures. I've always wanted to reach that 1-year seizure-free mark. Having my seizures reduced helped me gain so much confidence and control over my life. I think that's something anybody who is living with epilepsy would like to have. The journey now is more about me using my voice and with my non-profit organization helping other people on the journey that are newly diagnosed and trying to understand their diagnosis. And the Black and brown community. We don't hear about epilepsy a lot. We don't talk about it a lot. And I'm really just trying to change that narrative. I hope I can inspire someone in my situation. I would really give [advice to] anyone going through this journey or newly diagnosed that life is possible. Life is possible.

IMPORTANT SAFETY INFORMATION and INDICATION for XCOPRI® (cenobamate tablets) CV

DO NOT TAKE XCOPRI IF YOU:

- Are allergic to cenobamate or any of the other ingredients in XCOPRI.
- Have a genetic problem (called Familial Short QT syndrome) that affects the electrical system of the heart.

XCOPRI CAN CAUSE SERIOUS SIDE EFFECTS, INCLUDING:

Allergic reactions: XCOPRI can cause serious skin rash or other serious allergic reactions which may affect organs and other parts of your body like the liver or

blood cells. You may or may not have a rash with these types of reactions. Call your healthcare provider right away and go to the nearest emergency room if you have any of the following: swelling of your face, eyes, lips, or tongue, trouble swallowing or breathing, a skin rash, hives, fever, swollen glands, or sore throat that does not go away or comes and goes, painful sores in the mouth or around your eyes, yellowing of your skin or eyes, unusual bruising or bleeding, severe fatigue or weakness, severe muscle pain, frequent infections, or infections that do not go away. **Take XCOPRI exactly as your healthcare provider tells you to take it. It is very important to increase your dose of XCOPRI slowly, as instructed by your healthcare provider.**

QT shortening: XCOPRI may cause problems with the electrical system of the heart (QT shortening). Call your healthcare provider if you have symptoms of QT shortening including fast heartbeat (heart palpitations) that last a long time or fainting.

Suicidal behavior and ideation: Antiepileptic drugs, including XCOPRI, may cause suicidal thoughts or actions in a very small number of people, about 1 in 500. Call your health care provider right away if you have any of the following symptoms, especially if they are new, worse, or worry you: thoughts about suicide or dying; attempting to commit suicide; new or worse depression, anxiety, or irritability; feeling agitated or restless; panic attacks; trouble sleeping (insomnia); acting aggressive; being angry or violent; acting on dangerous impulses; an extreme increase in activity and talking (mania); or other unusual changes in behavior or mood.

Nervous system problems: XCOPRI may cause problems that affect your nervous system. Symptoms of nervous system problems include: dizziness, trouble walking or with coordination, feeling sleepy and tired, trouble concentrating, remembering, and thinking clearly, and vision problems. **Do not drive, operate heavy machinery, or do other dangerous activities until you know how XCOPRI affects you.**

Do not drink alcohol or take other medicines that can make you sleepy or dizzy while taking XCOPRI without first talking to your healthcare provider.

DISCONTINUATION:

Do not stop taking XCOPRI without first talking to your healthcare provider. Stopping XCOPRI suddenly can cause serious problems. Stopping seizure medicine suddenly in a patient who has epilepsy can cause seizures that will not stop (status epilepticus).

DRUG INTERACTIONS:

XCOPRI may affect the way other medicines work, and other medicines may affect how XCOPRI works. **Do not start or stop other medicines without talking to your healthcare provider.** Tell healthcare providers about all the medicines you take, including prescription and over-the-counter medicines, vitamins and herbal supplements.

PREGNANCY AND LACTATION:

XCOPRI may cause your birth control medicine to be less effective. **Talk to your health care provider about the best birth control method to use.**

Talk to your health care provider if you are pregnant or plan to become pregnant. It is not known if XCOPRI will harm your unborn baby. Tell your healthcare provider right away if you become pregnant while taking XCOPRI. You and your healthcare provider will decide if you should take XCOPRI while you are pregnant. If you become pregnant while taking XCOPRI, talk to your healthcare provider about registering with the North American

Antiepileptic Drug (NAAED) Pregnancy Registry. The purpose of this registry is to collect information about the safety of antiepileptic medicine during pregnancy. You can enroll in this registry by calling 1-888-233-2334 or go to www.aedpregnancyregistry.org.

Talk to your health care provider if you are breastfeeding or plan to breastfeed. It is not known if XCOPRI passes into breastmilk. Talk to your healthcare provider about the best way to feed your baby while taking XCOPRI.

COMMON SIDE EFFECTS:

The most common side effects in patients taking XCOPRI include dizziness, sleepiness, headache, double vision, and feeling tired.

These are not all the possible side effects of XCOPRI. Tell your healthcare provider if you have any side effect that bothers you or that does not go away. For more information, ask your healthcare provider or pharmacist. **Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088** or at www.fda.gov/medwatch.

DRUG ABUSE:

XCOPRI is a federally controlled substance (CV) because it can be abused or lead to dependence. Keep XCOPRI in a safe place to prevent misuse and abuse. Selling or giving away XCOPRI may harm others and is against the law.

INDICATION:

XCOPRI is a prescription medicine used to treat partial-onset seizures in adults 18 years of age and older.

It is not known if XCOPRI is safe and effective in children under 18 years of age.

Please see additional patient information in the [Medication Guide](#). This information does not take the place of talking with your healthcare provider about your condition or your treatment.

Please see [Medication Guide](#) and full [Prescribing Information](#).