

# The Power of Perseverance: Overcoming Epilepsy's Challenges with Fewer Seizures

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August 1, 2024 By JenVon Cherry, Founder of Epitome of Epilepsy

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Since I was a young girl, I've been navigating the unpredictable waves of epilepsy after being diagnosed when I was in kindergarten. I faced numerous challenges that shaped my character, as well as my future. From the onset, I grappled with a lack of support in school, struggles with entering and succeeding in the workplace and lack of resources within my community. As a child, school was a series of relentless obstacles. As an adult, my career suffered from constant misunderstandings with employers who couldn't grasp the complexities of my condition, like my forgetfulness and the need to ask questions repeatedly. One of the most heart-wrenching impacts was the realization that I would not be able to have children, due to medication-induced pre-menopause. This experience pushed me to fight not just for myself but for others enduring similar struggles, particularly in Black and Brown communities where I feel the need is greatest.

My own experience is not out of the ordinary, as there are 3 million adults in the United States who have active epilepsy. Recognizing and understanding the complexities of epilepsy allows us to appreciate the courage it takes to face each day, constantly wondering and worrying if a seizure will occur. It involves navigating doctors' appointments, adjusting treatments, and confronting the social stigmas attached to the condition.

The fear of the unknown is an ever-present theme in my life with epilepsy. The constant worry that a seizure will occur, or the stress involved with trying a new medication. However, despite these tribulations, I've learned it's important to focus on hope rather than fear. This shift in perspective provides me with the confidence to explore new treatment options and move closer to a life with fewer seizures.

Through working with my doctor, who focuses on my needs with a patient-centric approach, I was introduced to [XCOPRI](#) (cenobamate tablets) CV, a prescription medication approved for the treatment of partial-onset seizures in adults 18 and older.

Like any medication, XCOPRI has risks and benefits. Do not take XCOPRI if you are allergic to it or have a genetic problem (called familial short QT syndrome) that affects the electrical system of

the heart. XCOPRI can have serious side effects including serious allergic reaction which may affect organs and other parts of your body like the liver or blood cells. XCOPRI may cause problems with the electrical system of the heart (QT shortening). Antiseizure drugs, including XCOPRI, may cause suicidal thoughts or actions in a very small number of people, about 1 in 500. Call your doctor right away if you have suicidal thoughts or actions, or new or worsening depression, anxiety, or irritability. XCOPRI may cause problems that affect your nervous system, including 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.

These are not all of XCOPRI's side effects. We encourage you to read the Important safety information included at the end of this article.

While for some patients, the possibility of eliminating their seizures may seem out of reach, incorporating XCOPRI into my own treatment plan has resulted in seizure reduction.

To those diagnosed with epilepsy, my advice is simple: take it one day at a time. I want you to know that despite the challenges, living with epilepsy can indeed be fulfilling. Advocating for yourself is crucial—not only in securing the best medical care but also in everyday life.

Looking ahead, I am committed to working to raise awareness of epilepsy within the Black community. This has always been a passion of mine; in fact, back in high school, I knew I wanted to start a non-profit. Today, I'm the founder of Epitome of Epilepsy, an organization dedicated to serving those affected by epilepsy in all communities in Charleston, South Carolina, through education, inspiration, and advocacy. Through that, I am actively involved in launching a scholarship program for students with epilepsy, organizing conferences with doctors to foster better understanding, and establishing partnerships with Historically Black Colleges and Universities (HBCUs). Additionally, through my personal project, the "Jewels of Epilepsy" plaques, I aim to honor those who contribute significantly to our community.

My life's journey is a testament to resilience and hope. For myself, I'd love to hit the five-year mark of being seizure-free. As I work towards this milestone, my message is clear and resolute: There is a rich, rewarding life beyond the shadows of epilepsy. Let your voice be heard and push yourself to conquer the world. Embrace your challenges and advocate for a world of better support and deeper understanding. Looking back at the little JenVon who was timid and lonely, I'm proud of JenVon today, who is living out a dream I never thought possible.

Please read important safety information below. Talk to your neurologist or epileptologist about how XCOPRI might be right for you, and visit [XCOPRI.com](https://www.xcopri.com) to hear more stories from others like me.

**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](http://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](http://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 full [Prescribing Information](#) and [Medication Guide](#).

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<http://beta.docker.realhealthmag.com/article/power-perseverance-overcoming-epilepsys-challenges-fewer-seizures>