

Paul and Colleen's Story—Making a Difference in the Community (TRANSCRIPT)

VO Please see Important Safety Information and Indication at 3:40.

Paul I remember the first time it happened. I started to get this weird feeling. My eye just started flickering, and I'm like, something's wrong. I couldn't control my body. I couldn't talk. I was terrified. My name is Paul, I am 19 years old, and I live in Maple Shade, New Jersey.

Colleen Paul was diagnosed with epilepsy when he was 12 years old. I'm Colleen, I'm Paul's mom. I'm also Paul's caregiver.

Paul Growing up with epilepsy, it was tough, you know.

Colleen He could just be in the middle of anything and he would have a seizure. He could have as many as four and five in a day.

Paul I did have seizures in school. People didn't know what it was. I did get bullied because of it.

Colleen He said to me, "Mom, why me?" That's like rough, like how do you answer something like that?

Paul Epilepsy is always in the back of my mind. I always, you know, fear that I'm gonna have a seizure. Music is a big part of my life. I have too many records. It really calms me down and it relieves a lot of stress.

Colleen For people with epilepsy, they need to have a great circle of friends and family and people that will go the extra mile and support them.

Paul My treatment journey has been long.

Colleen We saw several different doctors. We tried several different medicines, different combinations of medicines. He had so many side effects.

Paul Unfortunately for me, many of the medications didn't really work well, which meant that I continued to have seizures.

Colleen I just thought, how's this poor kid gonna navigate life while he's still having all these seizures? I'm a strong-willed Irish mom, and my goal was to do anything I could for Paul. I found out about XCOPRI.

Paul After we discussed it with my doctor, he said it would be worth for me to try XCOPRI. Since I've started XCOPRI I have had very few seizures. Having less seizures means that I can go out more, I can do more stuff, because I don't have to be locked inside because all these seizures and my mom's worried. I'm not really gonna let epilepsy control me. I wanna see what else is out there.

Colleen I feel like he can just be so much more independent and have such a sense of freedom, and I can just relax a little bit and take a breath for the first time in a really long time.

Paul I am very involved with the epilepsy community. Paul's Law came about when I was 12 years old.

Colleen There were some states working on epilepsy laws related to seizure first aid in schools.

Paul The law would state that teachers and aides would know what to do when a seizure is happening. There's 12,000 kids in New Jersey who have epilepsy, and I'm like, well, I'm not alone with this.

Colleen Paul's Law passed in New Jersey in 2020, and it protects 12,000 children in schools with epilepsy. I'm very proud of Paul. I'm proud of what he's done for other people, and I'm extremely proud of his determination and not giving up.

Paul By sharing my story, I hope that people know that they are not alone with epilepsy.

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 or life threatening 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 healthcare 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.

Liver problems: XCOPRI may cause liver problems. Your healthcare provider will do blood tests to check your liver before you start XCOPRI and while you take XCOPRI if needed. Tell your healthcare provider right away if you have any symptoms of liver problems, such as: yellowing of the skin and eyes (jaundice), nausea, vomiting, unusual darkening of the urine, or feeling tired or weak.

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 healthcare provider about the best birth control method to use.**

Talk to your healthcare 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 1888-233-2334 or go to www.aedpregnancyregistry.org.

Talk to your healthcare 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 1800FDA1088 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.

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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