# Kailey's Journey—Fighting Stigma, Seizures, and Hesitation (TRANSCRIPT)

**VO** Please see important safety information and indication at four eighteen (4.18)

**Alan** Kailey is our youngest daughter. She's a fantastic girl. She loves sports. She loves writing. She loves to travel.

Kailey I was diagnosed with epilepsy at 14 years old.

**Alan** We were at home when we first actually saw her seizure. I knew that she was going through a grand mal seizure only because I've seen it before in my line of work. It was very scary. Very, very scary.

**Kailey** I actually had a seizure every single day. This went on for years, I've been on multiple medications.

**Alan** And none of them seemed to work. When the doctor had mentioned that brain surgery might be a solution, she thought that maybe this was the way to go.

**Kailey** And I've had three brain surgeries.

**Alan** Impact was huge. We saw this very vibrant young girl come back from the surgery and she was nothing like she was before.

**Kailey** Throughout these treatments, I continued to have seizures. I was giving up hope.

**Alan** She's been a trooper. She fights every day. I know that.

**Kailey** My dad is my rock. We have the strongest bond ever.

**Alan** Because we talk and she tells me how difficult life is living with epilepsy. When her neurologist suggested Xcopri, we had our doubts.

**Kailey** I was very, very hesitant to start a new medication. I was like, is this one going to work? And it did. It finally did. Since starting Xcopri, I have been seizure free for over a year.

**Alan** The longest period of time since she's had epilepsy where she has not had a seizure.

**Kailey** Being seizure free is just amazing.

**Alan** We've been able to do so much more. We've been able to take walks. Go to the golf range. Go to the coffee shop. We see our normal Kailey again.

**Kailey** There definitely is a stigma. I have a blog and I fight the stigma. It's really important for people with epilepsy to have a network that helps them throughout their advocacy journey.

**Alan** She knows how hard it is that she wants to help other people. I've seen a lot in my life. I've seen a lot. I've seen a lot of brave men and women working alongside of me,

doing a lot of things that nobody could ever imagine. But when I see my daughter go through her battle with epilepsy, I think it trumps everyone. She fights every day to overcome epilepsy. And that, to me, I think, is one of the bravest things that I've ever seen and encountered.

# 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 <a href="https://www.aedpregnancyregistry.org">www.aedpregnancyregistry.org</a>.

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 <a href="https://www.fda.gov/medwatch">www.fda.gov/medwatch</a>.

#### **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 <u>Medication Guide</u>. This information does not take the place of talking with your healthcare provider about your condition or your treatment.

Please see full <u>Prescribing Information</u> and <u>Medication Guide</u>.