# Frequently Asked Questions About KYGEVVI and TK2d



#### What is TK2d?

TK2d, or thymidine kinase 2 deficiency, is a mitochondrial disease. Mitochondria are parts of the cell responsible for making the energy that the body's organs need to function properly. Mitochondrial diseases happen when genetic mutations impact the mitochondria.

## What is early-onset TK2d?

Early-onset TK2d is when symptoms of TK2d start at 12 years old or younger. It is possible that someone developed symptoms as an infant or child but wasn't diagnosed until after age 12. This is still early-onset TK2d.

Symptoms may vary depending on the age of onset, but the main symptom is muscle weakness. It can show up as fatigue, trouble eating or breathing, and/or difficulty with motor skills like sitting up and walking. Symptoms can worsen over time.

#### What is KYGEVVI?

KYGEVVI is the first and only FDA-approved prescription medicine for the treatment of TK2d in adults and children with a symptom onset on or before 12 years of age.

### What are the possible benefits of KYGEVVI?

KYGEVVI may help patients with early-onset TK2d live longer after starting treatment.

# What are the possible side effects of KYGEVVI?

KYGEVVI may cause serious side effects including elevated liver enzyme levels. Increased liver enzyme levels in your blood are common with KYGEVVI. Your healthcare provider will do blood tests to check your liver enzyme levels before starting treatment and during treatment with KYGEVVI. Tell your healthcare provider right away if you develop any signs or symptoms of liver problems, including loss of appetite, pain on the right side of your stomach area, dark or amber-colored urine, yellowing of your skin or the white part of your eyes, nausea and vomiting, or itching.

KYGEVVI may cause stomach and intestinal (gastrointestinal problems). Diarrhea and vomiting are common with KYGEVVI, but may also be severe and lead to hospitalization. Tell your healthcare provider right away if you have diarrhea or vomiting during treatment with KYGEVVI that lasts longer than a few days.

The most common side effects of KYGEVVI include diarrhea, stomach area (abdominal) pain including pain in the upper stomach area, vomiting, and increased liver enzyme levels in your blood.

Please see the <u>Patient Information</u> for additional product information and the <u>Instructions for Use</u> for preparation and administration instructions.

# Frequently Asked Questions About KYGEVVI and TK2d (cont'd)

### How is KYGEVVI taken?

KYGEVVI should be taken orally or by feeding tube 3 times a day about 6 hours apart with food. Take or give KYGEVVI exactly as your doctor tells you. Please refer to the Instructions for Use for step-by-step instructions on how to dissolve the powder and take a dose of KYGEVVI oral solution.

## Once prescribed, is there a support program to help me get started with KYGEVVI?

ONWARD® is a personalized support experience built to get you started with KYGEVVI. After enrolling in ONWARD, your dedicated Care Coordinator\* and our exclusive specialty pharmacy partner, PANTHERX Rare, will work together to support you in many ways:

- PANTHERx Rare will work with your doctor and help coordinate directly with your insurance provider during the approval process
- At the same time, your Care Coordinator will explain potential financial assistance options and keep you updated on your status
- Once approved, your dedicated pharmacy team at PANTHERx Rare will remind you how to appropriately prepare and administer KYGEVVI and provide ongoing coaching and check-ins as you start treatment
- Your Care Coordinator will also stay in contact to provide resources and personalized support tailored to your needs and experiences during treatment

ONWARD is provided as a service of UCB and is intended to support the appropriate use of UCB medicines. ONWARD may be amended or canceled at any time without notice. Some program and eligibility restrictions may apply.

#### How do I enroll in ONWARD?

If you're prescribed KYGEVVI, talk to your doctor about enrolling in ONWARD.



<sup>\*</sup>ONWARD Care Coordinators do not provide medical advice and will refer you to your healthcare professional for any questions related to your treatment plan.

# **Frequently Asked Questions**

# About KYGEVVI and TK2d (cont'd)

# What other questions should I ask my doctor?

- How will I know if the treatment is working?
- Are there other things that can support my overall health while living with TK2d?
- Are there any dietary restrictions or guidelines I should follow?
- · Will physical therapy help me?
- What should I do if I notice a new symptom?
- How often should I be seen for follow-up visits?
- Is it safe for me to be around people who are sick or have infections?
- How can I best explain my condition to my friends, family, or coworkers?



# **Indication and Important Safety Information**

#### INDICATION

KYGEVVI is a prescription medicine used for the treatment of thymidine kinase 2 deficiency (TK2d) in adults and children with a symptom onset on or before 12 years of age.

#### IMPORTANT SAFETY INFORMATION

KYGEVVI may cause serious side effects including elevated liver enzyme levels. Increased liver enzyme levels in your blood are common with KYGEVVI. Your healthcare provider will do blood tests to check your liver enzyme levels before starting treatment and during treatment with KYGEVVI. Tell your healthcare provider right away if you develop any signs or symptoms of liver problems, including loss of appetite, pain on the right side of your stomach area, dark or amber-colored urine, yellowing of your skin or the white part of your eyes, nausea and vomiting, or itching.

KYGEVVI may cause stomach and intestinal (gastrointestinal) problems. Diarrhea and vomiting are common with KYGEVVI, but may also be severe and lead to hospitalization. Tell your healthcare provider right away if you have diarrhea or vomiting during treatment with KYGEVVI that lasts longer than a few days.

The most common side effects of KYGEVVI include diarrhea, stomach area (abdominal) pain including pain in the upper stomach area, vomiting, and increased liver enzyme levels in your blood.

Your healthcare provider may change your dose, temporarily stop, or permanently stop treatment with KYGEVVI if you develop certain side effects.

Before taking or giving KYGEVVI, tell your healthcare provider about all of your medical conditions, including if you have or have had liver problems. In addition, tell your healthcare provider if you are pregnant or plan to become pregnant. It is not known if KYGEVVI will harm your unborn baby. Also, tell your healthcare provider if you are breastfeeding or plan to breastfeed. It is not known if KYGEVVI passes into your breast milk. Talk to your healthcare provider about the best way to feed your baby if you take KYGEVVI. **Tell your healthcare provider about all the medicines you take**, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

These are not all of the possible side effects of KYGEVVI. Call your doctor for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088. You may also report side effects to UCB, Inc. at UCBCares® (1-844-599-CARE [2273]).

Please see additional information in the Patient Information Leaflet.



