# Starting and Staying on XOLREMDI

A Guide for Patients & Caregivers

#### WHAT IS XOLREMDI® (mavorixafor)?

XOLREMDI is an oral prescription medicine used in people 12 years of age and older with WHIM (warts, hypogammaglobulinemia, infections and myelokathexis) syndrome to increase the number of certain white blood cells (neutrophils and lymphocytes) circulating in the bloodstream.

Please see the full **Prescribing Information** and **Important Safety Information on page 11**.



### Take the Next Step to Help **Improve Immune Function**

Now that you and your healthcare provider have decided that XOLREMDI is right for you, it's time to get started.

XOLREMDI is an FDA-approved breakthrough therapy for use in people 12 years of age and older with WHIM syndrome. XOLREMDI targets the underlying cause of WHIM syndrome to increase the number of certain white blood cells in your bloodstream. Higher levels of white blood cells can help reduce infections.

To get the most out of your treatment, take XOLREMDI every day as prescribed by your healthcare provider.

#### In this guide:

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Side Effects→



Before taking XOLREMDI, tell your healthcare provider if you are pregnant, nursing, or plan to become pregnant. XOLREMDI can harm your unborn baby. You must use a reliable method of birth control (contraception) during treatment and for three weeks after you stop taking XOLREMDI. Talk to your healthcare provider about options for effective birth control and the best way to feed your baby while taking XOLREMDI.

Tell your healthcare provider if you have kidney, liver, or heart problems.



### **Taking** XOLREMDI® (mayorixafor)

#### Take XOLREMDI every day, as directed.

3 or 4 **CAPSULES** 



Swallow whole and do not open, break, or chew capsules\*



Once daily, every morning



After an overnight fast, 30 minutes before food

#### Staying on track

Consistency is key. Taking XOLREMDI daily, exactly as prescribed, is an important part of managing your condition. If you have questions about taking XOLREMDI, talk to your healthcare team to get the information you need.

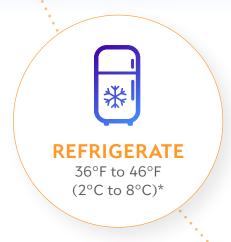


<sup>\*</sup>Your healthcare provider will prescribe your daily dosage of XOLREMDI based on your weight.

## Storing XOLREMDI® (mavorixafor)

#### Follow these guidelines for proper XOLREMDI storage:

- **1.** Unbox your XOLREMDI shipment and put the bottle in your refrigerator.
- **2.** Store XOLREMDI in its original bottle, with the top tightly closed to protect from moisture. Do NOT put XOLREMDI in a different pill box.
- **3.** Keep XOLREMDI refrigerated at all times.





#### Tip: Designate a spot

Storing XOLREMDI in the same place in your refrigerator every time can help simplify your morning routine and provide a visual reminder to take your medication.



#### Tip: Plan ahead for travel

You can take a trip and still stay on track with XOLREMDI. Talk to your healthcare provider about how to transport XOLREMDI and store your medication at your destination.



## What to Tell Your Healthcare Team

Before and while taking XOLREMDI, it's important to discuss any changes in your health or medications.



#### **Health updates**

#### Tell your healthcare team right away if you are:

- Diagnosed with kidney, liver, or heart issues
- Pregnant or planning to become pregnant
- Nursing or planning to nurse
- Planning a change in your birth control

Do not take XOLREMDI if you are pregnant as XOLREMDI can harm your unborn baby. Birth control is required while taking XOLREMDI and for three weeks after you stop taking XOLREMDI. Talk to your healthcare provider about options for effective birth control and the best way to feed your baby while taking XOLREMDI.



#### Your medications

Some medications and supplements should not be taken with XOLREMDI. If you are taking these medications while you are taking XOLREMDI, your healthcare provider may stop XOLREMDI, decide to change your dose, or monitor you more closely.

Give your healthcare team a list of all prescription and over-the-counter medicines, herbs, and dietary supplements you're taking. Update the list if anything changes. Avoid taking supplements that contain goldenseal or St. John's Wort, and avoid eating or drinking anything containing grapefruit. Interactions with XOLREMDI may occur.

### It's especially important to tell your healthcare team and pharmacist if you are taking or plan to start medication for:

- Depression or other mental health disorders
- Arrhythmia (abnormal heart rhythm)
- High blood pressure
  - Breast cancer
  - Pain management (opioids)



### What to Know **About Side Effects**

XOLREMDI side effects were studied in a 1-year clinical trial in 31 people with WHIM syndrome.

#### The most common side effects\* were:

- Low platelet count (thrombocytopenia)
- Rash (including a kind called pityriasis)
- Nasal irritation
- Nosebleeds
- Vomiting
- Dizziness

\*Experienced by more than 10% of people taking XOLREMDI and more often than by people taking placebo.

In patients with certain risk factors, XOLREMDI may cause a serious heart rhythm problem (QT prolongation).

These are not all the possible side effects of XOLREMDI.



#### **TALK TO YOUR HEALTHCARE TEAM**

Speak up if you have any side effects that bother you or prevent you from taking XOLREMDI as directed.

You are encouraged to report side effects of prescription drugs to the FDA at www.fda.gov/medwatch or by calling 1-800-FDA-1088. You may also call X4 Pharmaceuticals at 1-866-MED-X4MI (1-866-633-9464).



## **Establishing Your New**Treatment Routine

**Getting used to a new medication regimen can take time.** Creating a plan for taking XOLREMDI that you can stick to may be helpful in managing your condition.

#### Strategies for a smooth start



#### Make medication reminders

Set an alarm on your phone or tablet, put a note beside your bed, or stick a reminder on your refrigerator to take XOLREMDI when you wake up.



#### Schedule your morning

Allow enough time to wake up, take your medication, and wait 30 minutes before eating. Plan ahead so you aren't rushed.



#### Get support from loved ones

Ask for help and encouragement, whether it's assistance with remembering your medication or just someone to cheer you on. Your friends and family will want to be there for you.



#### Track your doses and your health

Use an electronic or paper tracker to check off each daily XOLREMDI dose and make note of how you're feeling to discuss with your healthcare provider.

STAY ON TRACK
WITH XOLREMDI
THROUGH THESE
HELPFUL RESOURCES



### **Getting Support Throughout Treatment**

#### **CONTACT X4CONNECT**

Call 844-X4CNNCT (844-942-6628) Monday to Friday, 8am to 8pm ET. We're here for you.



A patient support program that offers a range of services throughout your XOLREMDI treatment journey

#### Meet your team



X4 Nurse Educators\*

Provide one-on-one education and resources about XOLREMDI and living with WHIM syndrome to you and your family.



**X4Connect Care Coordinators** 

Help you understand insurance coverage and out-of-pocket costs, find financial support, and access XOI REMDI in case of insurance delays.



**X4Connect Specialty Pharmacists** 

Answer questions about your XOI REMDI treatment.



<sup>\*</sup>X4 Nurse Educators are employees of X4 Pharmaceuticals and do not work under the direction of a healthcare professional; they do not offer medical or treatment-related advice. For treatment and medical questions, you should contact your healthcare provider.

## Frequently Asked Questions About XOLREMDI® (mayorixafor)

#### **Taking XOLREMDI**

#### Why do I have to take XOLREMDI every day?

Consistency is key. Taking XOLREMDI daily, as prescribed, is an important part of managing your condition.

#### Why do I have to take XOLREMDI on an empty stomach?

Taking XOLREMDI along with food can reduce how much of the drug is absorbed by your body. Take XOLREMDI as directed, on an empty stomach after an overnight fast.

#### After I take XOLREMDI, how long should I wait before eating or drinking?

Wait at least 30 minutes after taking XOLREMDI before consuming food or beverages.

#### What happens if I accidentally eat or drink before taking XOLREMDI?

Taking XOLREMDI after eating or drinking can interfere with your body's ability to absorb the medication. Your healthcare team can give you directions on when to take your next dose of XOLREMDI.

#### What if I miss a dose of XOLREMDI?

If you miss a dose of XOLREMDI, take your next dose as scheduled the following morning, on an empty stomach. Do not take more than one XOLREMDI dose each day. Daily alerts can help you stay on track.

#### What if I have difficulty swallowing XOLREMDI capsules?

XOLREMDI gel capsules must be taken in their original form. Do not crush or open the capsules. Try taking sips of water both before and with each XOLREMDI capsule. Your healthcare team can provide additional tips if needed.



## Frequently Asked Questions About XOLREMDI® (mayorixafor) (cont'd)

#### Storing and handling XOLREMDI

#### Why does XOLREMDI need to be refrigerated?

To maintain stability, XOLREMDI must be stored at the standard refrigerator temperature of 36°F to 46°F (2°C to 8°C). Talk to your healthcare provider for specific instructions.

#### Why does XOLREMDI need to be stored in its original bottle?

The bottle for XOLREMDI is designed to protect the medication from moisture. XOLREMDI should be stored in the refrigerator in the original bottle with the top tightly closed.

#### How can I travel with XOLREMDI?

You can take a trip and stay on track with XOLREMDI. Plan ahead and talk to your healthcare team about how to transport and store XOLREMDI while traveling.

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#### Tips for caregivers of children aged 12+ taking XOLREMDI

- **1. Read through this booklet together**—Make sure your child knows how to take XOLREMDI and understands the refrigeration requirement.
- 2. Involve them in their XOLREMDI routine—Help your child take charge of managing their medication reminders by getting them their own medication tracker for checking off daily doses.
- **3. Encourage communication about treatment**—Discuss any questions your child has about XOLREMDI or its side effects. Have them keep a list of things to ask their healthcare provider.

## HAVE OTHER QUESTIONS ABOUT XOLREMDI?

Contact your healthcare team and get the answers you need.



### **Important Safety Information**

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#### IMPORTANT SAFETY INFORMATION

What should I tell my healthcare provider before taking XOLREMDI?

Before taking XOLREMDI, tell your healthcare provider if you are pregnant, nursing, or plan to become pregnant. XOLREMDI can harm your unborn baby. You must use a reliable method of birth control (contraception) during treatment and for three weeks after you stop taking XOLREMDI. Talk to your healthcare provider about options for effective birth control and the best way to feed your baby while taking XOLREMDI.

Tell your healthcare provider if you have kidney, liver, or heart problems.

Tell your healthcare provider about all the prescription and over-the-counter medicines you take, as well as vitamins and herbal supplements, such as goldenseal and St. John's Wort. XOLREMDI may affect the way other medicines work, and other medicines may affect how XOLREMDI works. It is especially important to tell your healthcare provider if you are taking a type of pain medicine called opioids or any medications for depression or other mental health disorders, abnormal heart rhythm, high blood pressure, or breast cancer. If you are taking these medications while you are taking XOLREMDI, your healthcare provider may stop XOLREMDI, decide to change your dose, or monitor you more closely.

You should not eat grapefruit or drink grapefruit juice while taking XOLREMDI.

#### What are the possible side effects of XOLREMDI?

In patients with certain risk factors, XOLREMDI may cause a serious heart rhythm problem (QT prolongation).

The most common side effects of XOLREMDI are low platelet count (thrombocytopenia), rash (including a kind of rash called pityriasis), nasal irritation, nosebleeds, vomiting, and dizziness.

These are not all the possible side effects of XOLREMDI. Tell your healthcare provider if you have any side effects that bother you or do not go away. For more information, ask your healthcare provider. You are encouraged to report side effects of prescription drugs to the FDA at <a href="https://www.fda.gov/medwatch">www.fda.gov/medwatch</a> or by calling 1-800-FDA-1088. You may also call X4 Pharmaceuticals at 1-866-MED-X4MI (1-866-633-9464).



## Have a Question? Contact X4Connect.

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