

# FOR PATIENTS WITH LYSOSOMAL ACID LIPASE DEFICIENCY (LAL-D) AND THEIR CAREGIVERS YOUR GUIDE TO INFUSIONS WITH KANUMA® (sebelipase alfa)



Actor portrayal

## IMPORTANT SAFETY INFORMATION INCLUDING BOXED WARNING & INDICATION

### What is the most important information I should know about KANUMA?

Life-threatening allergic (hypersensitivity) reactions, including anaphylaxis may occur in people who receive enzyme replacement therapies (ERT), including KANUMA. Anaphylaxis has occurred during the early course of enzyme replacement therapy and after extended duration of therapy.

**Please see Important Safety Information on [pages 1 & 2](#) and full [Prescribing Information](#) for KANUMA (sebelipase alfa), including Boxed WARNING regarding hypersensitivity reactions including anaphylaxis.**

  
**Kanuma®**  
(sebelipase alfa) | 20mg/  
intravenous infusion 10mL

## IMPORTANT SAFETY INFORMATION INCLUDING BOXED WARNING & INDICATION (cont'd)

Seek immediate medical care if you have any of these signs or symptoms that may be related to a severe allergic reaction:

- Rash such as hives; may also include itching
- Difficulty breathing, shortness of breath, tightness in the chest, and wheezing (noises while breathing)
- Dizziness or feeling faint
- Tingling and swelling around the mouth, in your throat, or eyes
- Fast heartbeat
- Very low blood pressure
- Sweating
- Loss of consciousness
- Flushing or temporary reddening of the skin (usually on the face)
- Agitation or irritability

Administration of KANUMA should be supervised by a healthcare provider knowledgeable in the management of hypersensitivity reactions including anaphylaxis.

### Allergy to Eggs or Egg Products

Tell your doctor if you have had a severe allergic reaction to eggs or egg products, as people with a known history of egg allergies were excluded from clinical trials.

### Common Side Effects

The most common side effects in people treated with KANUMA are:

- Infants with rapidly progressive LAL Deficiency presenting within the first 6 months of life ( $\geq 30\%$ ): diarrhea, vomiting, fever, stuffy or runny nose, anemia, cough, swelling of the nose and throat, and hives.
- Pediatric and adult patients with LAL Deficiency ( $\geq 8\%$ ): headache, fever, sore throat, swelling of the nose and throat, weakness, constipation, and nausea.

These are not all the possible side effects of KANUMA. Call your healthcare provider for medical advice about side effects.

Tell your doctor if you are pregnant or plan to become pregnant or are breastfeeding or plan to breastfeed.

Tell your doctor about all the medications you take, including prescription and over-the-counter drugs, vitamins, and herbal supplements.

**To report SUSPECTED SIDE EFFECTS, contact Alexion at [1-844-259-6783](tel:1-844-259-6783) or the FDA at [1-800-FDA-1088](tel:1-800-FDA-1088) or [www.fda.gov/medwatch](http://www.fda.gov/medwatch).**

## INDICATION

### What is KANUMA® (sebelipase alfa)?

KANUMA is a prescription medicine that is used to treat people with a diagnosis of lysosomal acid lipase (LAL) deficiency. It is administered as an infusion under the supervision of a healthcare provider.

**Please see Important Safety Information on pages 1 & 2 and full [Prescribing Information](#) for KANUMA (sebelipase alfa), including Boxed WARNING regarding hypersensitivity reactions including anaphylaxis.**



# STARTING TREATMENT WITH KANUMA<sup>®</sup> (sebelipase alfa)

You may have questions about starting your KANUMA treatment. Be sure to discuss your questions with your doctor. Use this brochure as a guide.

Inside, you will find

**Information about KANUMA** ([pages 4-5](#))

**What to expect before, during, and after your infusions**  
([pages 6-7](#))

**Support for people with LAL-D** ([pages 8-9](#))

Talk to your doctor if you have questions about KANUMA or LAL-D. For additional support or questions about KANUMA or LAL-D, contact the OneSource<sup>™</sup> patient support program at [1-888-765-4747](tel:1-888-765-4747). See [page 8](#) for more details.

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Actor portrayal

# ABOUT KANUMA<sup>®</sup> (sebelipase alfa)

## What is KANUMA?

KANUMA is a prescription treatment for people with a diagnosis of Lysosomal Acid Lipase Deficiency (LAL-D).

## What does KANUMA do?

Patients with LAL-D are born with a missing or dysfunctional enzyme that is important for your body. This enzyme, called lysosomal acid lipase (LAL), plays an important role in a key part of your body's cells, called lysosomes, by breaking down fatty material. Buildup of fatty material can cause continuous damage that may affect the function of many organs throughout your body. KANUMA helps to replace the LAL enzyme that is missing or not working correctly.

## How is KANUMA administered?

KANUMA is administered by intravenous (IV) infusion. An IV infusion is a way of delivering medicine directly into your bloodstream. KANUMA is given once every other week in children and adults, and once weekly in infants.

## What is the recommended dosage of KANUMA?

For infants with rapidly progressive LAL-D presenting within the first 6 months of life, the recommended starting dosage of KANUMA is 1 mg/kg of body weight given by IV infusion once weekly. For infants under 6 months who do not respond to this dose, the doctor may increase the dosage to 3 mg/kg of body weight once weekly. For patients who do not respond to this dose, the doctor may further increase the dosage to 5 mg/kg once weekly.

For children and adults presenting with LAL-D, the recommended dosage of KANUMA is 1 mg/kg of body weight given by IV infusion once every other week. For patients who do not respond to this dose, the dosage may be increased to 3 mg/kg once every other week.

KANUMA is administered by IV infusion.

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## How long will my infusion last?

Your KANUMA® (sebelipase alfa) infusion will last at least 2 hours, though your doctor may decide to increase or decrease your infusion time.

## Where will I go for my infusions?

Your doctor will talk with you about when and where your infusions will happen. They may be scheduled in his or her office, a hospital, or a specialized infusion center.

## Do I need to get all of the infusions recommended by my doctor?

Yes. LAL-D is a genetic disease, which means that your body's makeup does not allow it to produce a properly functioning LAL enzyme. KANUMA is intended to replace the LAL enzyme that does not work correctly or may be missing. Talk to your doctor about the importance of staying on treatment.

## When will I know if KANUMA is working?

You may not feel KANUMA working. Your doctor will monitor your care and review the appropriate test results.

## Does KANUMA have side effects?

In infants with rapidly progressive disease presenting within the first 6 months of life treated with KANUMA, the most common side effects are diarrhea, vomiting, fever, stuffy or runny nose, anemia (low red blood cells), cough, swelling of the nose and throat, and hives.

In pediatric and adult patients treated with KANUMA, the most common side effects are headache, fever, sore throat, swelling of the nose and throat, weakness, constipation, and nausea.



Actor portrayal

# PREPARING FOR YOUR KANUMA<sup>®</sup> (sebelipase alfa) INFUSIONS



## BEFORE YOU GO

Bring these items to your first appointment:

- Your insurance card and ID (you may also want to call ahead to see if there are any other documents you will need)
- Items that may make you feel more comfortable (for example, a favorite pillow or blanket) during your infusion



## WHEN YOU GET THERE

At the start of your appointment, you will:

- Check in with a receptionist who will look at your insurance card and ID, and may ask you to fill out some paperwork
- Meet with a healthcare provider, who may ask a few questions and check your blood pressure, temperature, breathing, pulse, and weight, as well as make other assessments
- Get set up in the space where you will be getting your infusion

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## DURING YOUR INFUSION

- First, a healthcare provider will set up the IV equipment; if you are uncomfortable with needles, talk with your healthcare provider or doctor about strategies to make you feel more comfortable
- Once the infusion starts, your KANUMA® (sebelipase alfa) treatment will continue for at least 2 hours (though your doctor may decide to increase or decrease your infusion time)
- Tell your healthcare provider right away if you feel anything out of the ordinary or if you notice any of the following reactions during or after your infusion: rash such as hives (may also include itching), difficulty breathing, shortness of breath, tightness in the chest, and wheezing (noises while breathing), dizziness or feeling faint, tingling and swelling around the mouth, in your throat, or eyes, fast heartbeat, very low blood pressure, sweating, loss of consciousness, flushing or temporary reddening of the skin (usually on the face), or agitation or irritability.



## AFTER YOUR INFUSION

- The IV or other device will be removed when the infusion is complete
- After your infusion, you may be asked to stay awhile so your healthcare provider can check your blood pressure, temperature, and pulse; if you do not feel well, let your healthcare provider know right away
- Tell your doctor or get medical help right away if you experience any of the following severe signs or symptoms at any time during or after your infusion: rash such as hives (may also include itching), difficulty breathing, shortness of breath, tightness in the chest, and wheezing (noises while breathing), dizziness or feeling faint, tingling and swelling around the mouth, in your throat, or eyes, fast heartbeat, very low blood pressure, sweating, loss of consciousness, flushing or temporary reddening of the skin (usually on the face), or agitation or irritability.

Your infusion team is there for you if you have any questions or need assistance.

  
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(sebelipase alfa)  
intravenous infusion | 20mg/  
10mL



# ONESOURCE™ SUPPORT SERVICES



With our experience and resources, we're here to help you feel supported every step of the way. Here's an overview of the services we offer.



## Education

**When you have questions about LAL-D or KANUMA® (sebelipase alfa), we'll work to find the answers.** Your dedicated Case Manager can provide you with:

- Educational materials about LAL-D
- Details about KANUMA
- Information about LAL-D



## Health Insurance Navigation

**Health insurance can be complicated. We're here to help make sense of it all.** Your Case Manager can help by:

- Providing information that explains your insurance coverage for KANUMA
- Addressing financial concerns or gaps in coverage

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### Community Connections

**With OneSource™ by your side, you'll never have to go it alone.**

Connect with others in the rare disease community who understand your experience. We can share information about:

- In-person and online meetings and events specific to your condition
- Support and resources
- Advocacy groups
- A peer-to-peer program called Peer Connects

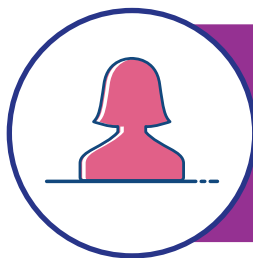


### Ongoing Support

**When life takes a turn, OneSource is ready to keep you on track.**

Your Case Manager is ready to help:

- Work with your healthcare provider to ensure you keep receiving your medicine as prescribed
- Guide you through insurance changes
- Navigate your treatment through life events, such as getting married, starting a new job, moving, or traveling



Get connected with your OneSource Case Manager by calling **1-888-765-4747**, Monday through Friday, 8:30 AM to 8 PM (ET) or visit the website at [www.alexiononesource.com](http://www.alexiononesource.com).

# MORE WAYS TO COUNT ON ONESOURCE™

## Alexion CoPay Program

Here are some additional services we provide to help support you with KANUMA® (sebelipase alfa)



### Financial Assistance

**We can provide information about resources available that may be able to help cover the costs for KANUMA.**

If you have Medicare, Medicaid, or another federal- or state-funded insurance plan, we can connect you to third-party resources that may be able to help with financial assistance.

If you have commercial insurance, you may be eligible for the **Alexion OneSource CoPay Program**, which may be able to help cover some out-of-pocket treatment costs.

### To be eligible, you must:

- ✓ Be signed up for patient services through OneSource
- ✓ Have commercial insurance
- ✓ Be prescribed KANUMA for an FDA-approved indication
- ✓ Reside in the United States or its territories

**Talk to your healthcare provider or OneSource Case Manager for more information about financial assistance.**

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# YOUR INFUSIONS WITH KANUMA® (sebelipase alfa)

- **KANUMA is an FDA-approved treatment for LAL-D.** KANUMA is administered by intravenous (IV) infusion and is available through a prescription
- **Your healthcare team will help you schedule your infusions with KANUMA.** Your infusions may take place in your doctor's office, a hospital, or a specialized infusion center
- **When you arrive, a healthcare provider will get you settled and set up your IV.** Once your IV is set up, the infusion begins and will last at least 2 hours, though your doctor may decide to increase or decrease your infusion time
- **After your infusion, the IV will be removed and your healthcare provider will check in with you.** Your healthcare provider may check your blood pressure, temperature, and pulse
- **Talk to your doctor about the importance of receiving regular infusions with KANUMA**

Get connected with your OneSource™ Case Manager by calling [1-888-765-4747](tel:1-888-765-4747), Monday through Friday, 8:30 AM to 8 PM (ET) or visit the website at [www.alexiononesource.com](http://www.alexiononesource.com).

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To learn more, visit [kanuma.com](http://kanuma.com)

**ALEXION®**  
AstraZeneca Rare Disease

**ONESOURCE®**  
Personalized Patient Support from Alexion

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