PATIENT & CAREGIVER EDUCATION

Belimumab

This information from UpToDate® Lexidrug™ explains what you need to know about this medication, including what it's used for, how to take it, its side effects, and when to call your healthcare provider.

Brand Names: US

Benlysta

Brand Names: Canada

Benlysta

What is this drug used for?

- It is used to treat lupus.
- It is used to treat kidney problems caused by lupus.

Prefilled syringes:

- If your child has been given this form of this drug, talk with the doctor for information about the benefits and risks. Talk with the doctor if you have questions or concerns about giving this drug to your child.

What do I need to tell the doctor BEFORE my child takes this drug?

- If your child is allergic to this drug; any part of this drug; or any other drugs, foods, or substances. Tell the doctor about the allergy and what signs your child had.
- If your child has had a severe skin reaction like Stevens-Johnson syndrome (SJS) or toxic epidermal necrolysis (TEN) with this drug.
- If your child has an infection.
- If your child has nervous system problems caused by lupus.
- If your child is using another drug like this one. If you are not sure, ask your child's doctor or pharmacist.
- If your child has had a vaccine in the past month.

This is not a list of all drugs or health problems that interact with this drug.

Tell the doctor and pharmacist about all of your child's drugs (prescription or OTC, natural products, vitamins) and health problems. You must check to make sure that it is safe to give this drug with all of your child's other drugs and health problems. Do not start, stop, or change the dose of any drug your child takes without checking with the doctor.

What are some things I need to know or do while my child takes this drug?

All products:

- Tell all of your child's health care providers that your child is taking this drug. This includes your child's doctors, nurses, pharmacists, and dentists.
- Have your child's blood work and other lab tests checked as you have been told by the doctor.
- Your child may have more chance of getting an infection. Some infections have been deadly. Have your child wash hands often. Have your child stay away from people with infections, colds, or flu.
- Make sure your child is up to date with all vaccines before treatment with this drug.
- Talk with the doctor if your child has recently had a vaccine or before your child gets any vaccines. Vaccine use with this drug may either raise the chance of an infection or make the vaccine not work as well.
- This drug may lower how well the immune system works. Drugs that do this may raise the risk of certain types of cancer. If you have questions, talk with the doctor.

If your child is or may be sexually active:

- If your child may become pregnant, have your child use birth control while taking this drug and for 4 months after the last dose. If your child gets pregnant, call the doctor right away.
- If your child used this drug while pregnant, tell the baby's doctor.

If your child is breast-feeding a baby:

- Tell the doctor if your child is breast-feeding a baby. You will need to talk about any risks to the baby.

Vials (for IV infusion):

- Infusion reactions have happened with this drug. These have happened on the same day as the infusion. Tell your child's doctor if your child has any bad effects during or after the infusion.

What are some side effects that I need to call my child's doctor about right away?

WARNING/CAUTION: Even though it may be rare, some people may have very bad and sometimes deadly side effects when taking a drug. Tell your child's doctor or get medical help right away if your child has any of the following signs or symptoms that may be related to a very bad side effect:

- Signs of an allergic reaction, like rash; hives; itching; red, swollen, blistered, or peeling skin with or without fever; wheezing; tightness in the chest or throat; trouble breathing, swallowing, or talking; unusual hoarseness; or swelling of the mouth, face, lips, tongue, or throat. Rarely, some allergic reactions have been deadly.
- Signs of a very bad skin reaction (Stevens-Johnson syndrome/toxic epidermal necrolysis) like red, swollen, blistered, or peeling skin (with or without fever); red or irritated eyes; or sores in the mouth, throat, nose, or eyes.
- Signs of infection like fever, chills, very bad sore throat, ear or sinus pain, cough, more sputum or change in color of sputum, pain with passing urine, mouth sores, or wound that will not heal.
- Signs of a urinary tract infection (UTI) like blood in the urine, burning or pain when passing urine, feeling the need to pass urine often or right away, fever, lower stomach pain, or pelvic pain.
- New or worse behavior or mood changes like depression, anxiety, acting on dangerous impulses, thoughts of hurting others, or thoughts of suicide.
- Chest pain or pressure.
- Slow heartbeat.

- Muscle pain.
- Dizziness or passing out.
- Shortness of breath.
- Cold sweats.
- Severe upset stomach or throwing up.
- A severe brain problem called progressive multifocal leukoencephalopathy (PML) may happen with this drug. It may cause disability or death. Tell the doctor right away if your child has signs like confusion, memory problems, depression, change in the way your child acts, change in strength on 1 side is greater than the other, trouble speaking or thinking, change in balance, or change in eyesight.

What are some other side effects of this drug?

All drugs may cause side effects. However, many people have no side effects or only have minor side effects. Call your child's doctor or get medical help if any of these side effects or any other side effects bother your child or do not go away:

All products:

- Trouble sleeping.
- Headache.

- Upset stomach.
- Diarrhea.
- Nose or throat irritation.
- Pain in arms or legs.

Auto-injectors:

- Irritation where the shot is given.

These are not all of the side effects that may occur. If you have questions about side effects, call your child's doctor. Call your child's doctor for medical advice about side effects.

You may report side effects to your national health agency.

How is this drug best given?

Give this drug as ordered by your child's doctor. Read all information given to you. Follow all instructions closely.

Auto-injectors:

- It is given as a shot into the fatty part of the skin on the top of the thigh or the belly area.
- Keep giving this drug to your child as you have been told by your child's doctor or other health care provider, even if your child feels well.

- If you will be giving your child the shot, your child's doctor or nurse will teach you how to give the shot.
- Give this drug on the same day each week or the same day every 2 weeks as you were told by your child's doctor.
- Before using this drug, take it out of the refrigerator and leave it at room temperature for 30 minutes.
- Do not heat or microwave.
- Do not shake.
- Move the site where you give the shot with each shot.
- Do not give into tender, bruised, red, or hard skin.
- This drug is colorless to slightly yellow. This drug may also be clear to slightly pearly. Do not use if the solution changes color or is cloudy, leaking, or has particles.
- Do not use this drug if it has been dropped or if it is broken.
- Throw syringe away after use. Do not use the same syringe more than one time.
- Throw away needles in a needle/sharp disposal box. Do not reuse needles or other items. When the box is full, follow all local rules for getting rid of it. Talk with a doctor or pharmacist if you have any questions.

Vials (for IV infusion):

- It is given as an infusion into a vein over a period of time.
- Other drugs may be given before this drug to help avoid side effects.

What do I do if my child misses a dose?

Auto-injectors:

- Give a missed dose as soon as you think about it.
- After giving a missed dose, keep giving on your child's normal day or start a new schedule based on the day the dose is taken.
- Do not give 2 doses on the same day.
- If you are not sure what to do if your child misses a dose, call the doctor.

IV infusion:

- Call your child's doctor to find out what to do.

How do I store and/or throw out this drug?

Auto-injectors:

- Store in a refrigerator. Do not freeze.
- Store in the original container to protect from light.
- If needed, this drug can be left out at room temperature for up to 12 hours before use. Throw away any part not

used after 12 hours.

- Protect from heat and sunlight.
- Do not put this drug back in the refrigerator after it has been stored at room temperature.

Vials (for IV infusion):

- If you need to store this drug at home, talk with your child's doctor, nurse, or pharmacist about how to store it.

All products:

- Keep all drugs in a safe place. Keep all drugs out of the reach of children and pets.
- Throw away unused or expired drugs. Do not flush down a toilet or pour down a drain unless you are told to do so. Check with your pharmacist if you have questions about the best way to throw out drugs. There may be drug take-back programs in your area.

General drug facts

- If your child's symptoms or health problems do not get better or if they become worse, call your child's doctor.
- Do not share your child's drug with others and do not give anyone else's drug to your child.
- Some drugs may have another patient information

leaflet. If you have any questions about this drug, please talk with your child's doctor, nurse, pharmacist, or other health care provider.

- If you think there has been an overdose, call your poison control center or get medical care right away. Be ready to tell or show what was taken, how much, and when it happened.

Consumer Information Use and Disclaimer

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If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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