

Drug information  
**Belimumab**

**BELIMUMAB**  
is used to treat lupus (SLE)

**VERSUS**  
**ARTHRITIS**

## Introduction

Belimumab is a drug that can help prevent your condition causing damage to your body. You can discuss the benefits and risks of taking belimumab with healthcare professionals before you start treatment, so you're able to make an informed decision.

## What is belimumab and how is it used?

Belimumab (trade name Benlysta) is a type of drug called a biological therapy. In lupus, the immune system produces harmful antibodies that attack the body's own tissues. Belimumab works by reducing the activity of the blood cells, called B-cells, that produce these antibodies. This reduces the inflammation that causes the symptoms of lupus.

If belimumab works for you, you should start to notice the benefits within six months of starting treatment.

Belimumab can be prescribed by a consultant rheumatologist for adults with lupus. It's usually given alongside other treatments for lupus. Belimumab won't be started if you haven't tried other treatments appropriate for your condition first.

## Is belimumab suitable for me?

Your doctor may decide not to prescribe belimumab if you're pregnant or breastfeeding, or if:

- you have an infection or you've had repeated or serious infections in the past
- you've had mental health problems such as depression or thoughts of suicide
- your lupus affects your kidneys or nervous system

- you have HIV
- your B-cell or antibody levels are low
- you've had any kind of transplant
- you've had cancer.

You'll have blood tests to check your antibody and possibly your B-cell levels before treatment and every few months from then on. Your doctor may also check for previous hepatitis infection as belimumab may increase the risk of hepatitis coming back.

Your doctor may decide not to prescribe belimumab if you're being treated with another drug that targets B-cells, such as rituximab, or if you're on drugs such as cyclophosphamide that can affect the production of blood cells.

## **When and how do I take belimumab?**

Belimumab is given through a drip into a vein, called an intravenous infusion, in hospital. It usually takes about an hour. The first three infusions will be two weeks apart, and after that they'll be given monthly.

Because it's a long-term treatment, it's important to keep taking belimumab, unless you have severe side effects:

- even if it doesn't seem to be working at first
- even when your symptoms improve (to help keep your condition under control).

If you haven't noticed any improvement in your symptoms after six months, your doctor may decide to discontinue the treatment.

## Possible risks and side effects

As with all drugs, belimumab can sometimes cause side effects, but many people won't have any problems.

Some people may have a reaction to belimumab, usually during or just after having an infusion. These aren't usually serious but, occasionally, the infusion may have to be stopped.

The person giving the infusion will be looking out for any problems but you should tell them straight away if you feel sick, feverish, dizzy or short of breath or if you have a headache, rash, itching or sudden swelling.

You may be offered paracetamol and drugs called antihistamines, which may help to reduce the risk of these reactions.

Sometimes people have side effects a few days after the infusion. Contact your healthcare team if you have any new symptoms such as:

- diarrhoea or feeling sick
- fever
- headaches or facial swelling
- muscle pains
- difficulty sleeping
- depression
- infections

Tell your rheumatology team if you have symptoms that may indicate an infection – such as a sore throat or runny nose, persistent cough or stomach upsets.

You should also tell your rheumatology team if you develop chickenpox or shingles or come into contact with someone who has chickenpox or shingles. You may need antiviral treatment.

In very rare cases, people treated with belimumab have developed a serious infection called progressive multifocal leukoencephalopathy (PML), which affects the brain. You must see your doctor straight away if you notice any of the following:

- problems with memory or thinking clearly
- dizziness, loss of balance or difficulty walking
- speech problems
- loss of vision.

### Tips to reduce your risk of infection

- Try to avoid close contact with people you know have an infection.
- Wash your hands regularly and carry around a small bottle of antibacterial hand gel.
- Keep your mouth clean by brushing your teeth regularly.
- Stop smoking if you're a smoker.
- Make sure your food is stored and prepared properly.
- Try to keep your house clean and hygienic, especially the kitchen, bathrooms and toilets.

It's recommended that you carry a biological therapy alert card. Then anyone treating you will know that you've had belimumab and that your antibody levels may be low. Ask your rheumatology team for a card.

## **Taking other medicines**

Belimumab is usually prescribed alongside other drug treatments for lupus, but may interact with some other medicines. Check with your doctor or pharmacist before starting any new medicines, and remember to mention you're on belimumab if you're treated by anyone other than your usual rheumatology team.

Don't take over-the-counter or herbal medicines without discussing this first with your healthcare team.

## **Vaccinations**

You should discuss vaccinations, including any you may need if you're planning to travel abroad, with your rheumatology team. If possible, it's best to have any vaccinations you may need before you start belimumab.

Live vaccines aren't usually recommended once you've started on belimumab or in the 30 days before starting belimumab. Live vaccines include measles, mumps and rubella (MMR), tuberculosis (BCG), yellow fever and shingles vaccines.

Pneumococcal (new-mow-kok-al) vaccines, which help to protect against pneumonia, and yearly flu vaccines – except for the nasal flu vaccine – are fine and are usually recommended. However, these may not be quite so effective if you have them after starting belimumab.

## **Having an operation**

If you're planning to have an operation, you should discuss with your specialists whether you need to stop or delay any of your drug treatments for a time before and after surgery.

## Alcohol

You can drink alcohol while on belimumab but keep within the recommended limits for adults of no more than 14 units per week – unless your doctor advises a lower limit.

## Fertility, pregnancy and breastfeeding

There's limited information available about the effects of belimumab in pregnancy. Women who could become pregnant should use effective contraception while being treated with belimumab and for four months after stopping treatment.

It's not yet known whether belimumab passes into human breast milk, so you should talk to your rheumatology team if you're thinking of breastfeeding.

There is currently no information available on the possible effects of belimumab on male and female fertility.

This leaflet is a guide to belimumab, its benefits and potential side effects. If there's anything else you'd like to know about this drug, just ask the healthcare professionals in charge of your care.

## Thank you!

A team of people helped us create this booklet. We would like to thank Veena Patel, James Taylor, Gail Melling and Neil Snowden for helping us with reviewing this booklet.

We would also like to give a special thank you to the people who shared their opinions and thoughts on the booklet. Your contributions make sure the information we provide is relevant and suitable for everyone.

**FAMILIES**  
**FRIENDS**  
**DOCTORS**  
**RESEARCHERS**  
**DONORS**  
**FUNDRAISERS**  
**VOLUNTEERS**  
**VERSUS**  
**ARTHRITIS**

Registered Charity No 207711  
Scotland No SC041156  
© Versus Arthritis 2019

**Versus Arthritis**

Copeman House  
St Mary's Court  
St Mary's Gate  
Chesterfield S41 7TD

Tel 0300 790 0400  
calls charged at standard rate

[www.versusarthritis.org](http://www.versusarthritis.org)  
[enquiries@versusarthritis.org](mailto:enquiries@versusarthritis.org)

Follow us:



VA2285