

# Bexarotene for cutaneous T-cell lymphoma (CTCL)

Information for patients





We have prescribed you the medicine bexarotene, also known as Targretin, for the treatment of your cutaneous T-cell lymphoma (CTCL).

This leaflet has been written to answer some of the questions you may have about this treatment. If you have any further questions about this treatment or your condition, please speak to your Consultant or Lymphoma Clinical Nurse Specialist (CNS), or ask for a copy of the leaflet 'Cutaneous T-cell lymphoma' (from the British Association of Dermatologists).

## What is bexarotene?

Bexarotene belongs to a group of medicines known as retinoids, which are related to vitamin A. It comes as a soft capsule, which you swallow. Each capsule contains 75mg of bexarotene.

Bexarotene is used to treat people with CTCL, including mycosis fungoides (MF) or Sézary syndrome (SS). The exact way in which it works is not known, but it has been proven to prevent the growth of tumour cells, which stops your tumour from developing further. It can also improve symptoms, such as itching.

## Before starting bexarotene therapy

Your Consultant will discuss your treatment plan and options with you before you decide which treatment to have. If you start bexarotene, we will:

- measure your weight and height. This is to work out the surface area of your body, to make sure we prescribe you the correct dose.
- organise a blood test, before you start treatment
- discuss the likely effects of the treatment and the importance of regular blood tests, monitoring of blood test results and attending follow-up appointments
- answer any questions you may have
- discuss the support services available to you
- give you your drug monitoring booklet and set up your treatment plan in the Oral Chemo clinic
- give you details of who to contact if you have any problems or questions in between your follow-up appointments.

## How do I take the medicine?

The number of capsules you need to take each day will depend on your individual circumstances. We will discuss this with you in more detail before you start the treatment.

Bexarotene should be taken as a single daily dose, with or immediately after a meal. You should take it at the same time each day, for example at breakfast. Do not eat grapefruit or drink grapefruit juice while you are taking bexarotene. This can affect how the medication works.

## What should I do if I forget to take the bexarotene?

If you forget to take your dose at the usual time, take it with your next meal that day. If you are unable to take it on the same day, just take your daily dose the next day as normal.

Do not take a double dose to make up for a missed dose from the previous day.

If you are not sure what to do, contact your Lymphoma CNS, Haematology or Dermatology Consultant or specialist treatment centre pharmacist.

## Are there any side effects?

### **Very common side effects**

- low white blood cell count, which can increase your risk of infections.

If you have a temperature of 37.5°C or above, or if you feel cold and shivery, please contact Haematology Triage.

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- headache, tiredness or fatigue
- skin reactions after starting treatment, such as dry skin and an increase in flaking of skin on your hands and feet.

Please speak to your Consultant or Lymphoma CNS if you develop any of the above symptoms.

### **Other very common side effects include:**

- raised levels of fat in the blood (cholesterol and triglycerides)
- low thyroid hormone level (explained later in this leaflet).

## **Common side effects**

- nausea and vomiting
- diarrhoea
- dry or abnormal sensations of the eyes
- insomnia
- joint, bone and muscle aches.

## **Uncommon side effects**

If you develop symptoms of muscle pain, weakness and/or abdominal (tummy) pain, you may be at risk of pancreatitis. This is an inflammation (swelling) of your pancreas, which can cause further health problems if it is not treated.

It is important that you report any aches or pains to your Lymphoma CNS or to Haematology Triage.

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## How can I help to reduce the potential side effects?

- Eat low fat foods.
- Exercise regularly.
- Do not eat grapefruit or drink grapefruit juice.
- Use a moisturiser/emollient regularly on your skin and avoid soaps, as they can make your skin dry. Ask your Consultant or Lymphoma CNS about soap substitutes and ask for our 'Emollients' leaflet.
- Do not sunbathe or use sunbeds. Bexarotene is a photosensitive drug, which means it makes your skin more sensitive to light. Avoid direct exposure to sunlight as much as possible. If your treatment plan includes PUVA (photochemotherapy or ultraviolet A light therapy), we will adjust your dose of bexarotene.
- Do not take vitamin A supplements, as this will affect how well the bexarotene works.

## Bexarotene and pregnancy

You must not be pregnant or breast feeding before starting this therapy. You (or your partner, if you are a man) must also not become pregnant while you are taking the treatment, as bexarotene could harm your unborn baby. There are no known risks if you are male and your partner is already pregnant, but you may want to wear a condom anyway.

For this reason, if you or your partner is of child-bearing age you must use reliable contraception (birth control) continuously while taking bexarotene.

It is recommended that you and your partner begin using contraception at least one month before starting the therapy and continue for at least one month after it has stopped. We recommend that two reliable forms of contraception are used together, including one non-hormonal type (such as condoms), as bexarotene may affect how well oral contraceptives work (e.g. the pill). You should discuss this further with your GP or Lymphoma CNS.

If you are a woman of child-bearing age, you will be asked to consent to having a pregnancy test a week before starting the medicine, then each month during the therapy and one month afterwards, to confirm you are not pregnant. Your Consultant will discuss this with you and inform your GP, so that regular pregnancy tests can be organised.

## Will I need any other treatment?

You may have other treatments, such as psoralen and PUVA or chemotherapy at the same time as taking bexarotene. Your Consultant will discuss this with you when deciding on the best treatment option for you. Do not stop taking your bexarotene while having other treatment, unless you are told to by your Consultant.

As mentioned earlier in this leaflet, bexarotene reduces the activity of your thyroid gland, lowering thyroid hormone production. This can cause symptoms such as tiredness, constipation and sensitivity to the cold.

Bexarotene also increases the levels of fat in your blood, including cholesterol and triglycerides. Over time, these fats can be deposited in your arteries (blood vessels), making them narrower and less elastic.

Because both of these side effects can cause other problems, we may give you medicines to correct these side effects at the same time as prescribing the bexarotene.

Fenofibrate and atorvastatin lower the fats in the blood known as cholesterol and triglycerides. Levothyroxine helps to increase the level of thyroid hormone in the blood.

You will need to have regular blood tests to monitor the effects of your different tablets. At first, this will be done every week. When your blood results are stable and the most effective dose has been reached, the blood tests can be carried out monthly.

The blood tests need to be taken after fasting (not eating and drinking). You should not eat or drink anything for 12 hours before the blood tests, although you can take small sips of water and can continue to take your regular medications (unless told otherwise). For example, if your blood test is at 9.00am, you should have had nothing to eat or drink from 9.00pm the evening before (apart from sips of water).



You can have the blood tests at any of the Oxford University Hospitals' phlebotomy departments, but if it is easier for you they can be carried out at your GP's surgery or local hospital.

If your GP has been asked to organise your blood tests, we will get the results from the local hospital to which they will be sent.

## How long will I need to take bexarotene?

It may take two to three months or longer before you notice the benefits of bexarotene, but you can continue to take it for as long as you feel it is helping you. Your Consultant or Lymphoma CNS will arrange follow-up appointments to review and assess whether the treatment is working for you.

If you stop taking bexarotene, you will still need to have regular fasting blood tests. The results of these tests need to be reviewed by your Consultant or Lymphoma CNS. This is so that medication started at the same time as your bexarotene therapy (such as fenofibrate, atorvastatin or levothyroxine) can be stopped gradually to allow your body to readjust.

## Is there anything else I need to know?

Bexarotene can interact with a number of medicines, so please tell the person who prescribes you this medicine about any other or new medicines you are taking, including antibiotics and herbal or over-the-counter medicines. Bexarotene doesn't interact with alcohol.

## Where can I get a repeat prescription?

You should have been prescribed enough bexarotene to last you until your next appointment. However, if you do run out, please contact your Lymphoma CNS or Consultant with a copy of your most recent blood test results.

If you run out of the medication started with your bexarotene treatment (such as fenofibrate, atorvastatin, or levothyroxine), please see your GP. Take your drug monitoring booklet with you to your appointment, so that they can give you a prescription.

## How to contact us

The Lymphoma CNS's are available for non-urgent support and advice. They can also help by liaising between you, your relatives, your GP and the hospital doctors.

### **Anya Aspinall**

Email: [anya.aspinall@nhs.net](mailto:anya.aspinall@nhs.net)

### **Tracy Mitchell-Floyd**

Email: [t.mitchell-floyd@nhs.net](mailto:t.mitchell-floyd@nhs.net)

Tel: **01865 235 283**

(8.00am to 4.00pm, Monday to Friday)

You may need to leave a message, but we will call you back as soon as we can. Please leave your name, date of birth and telephone number.

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALS@ouh.nhs.uk**

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