



## St John's Institute of Dermatology Skin Cancer Services

# Bexarotene treatment for your cutaneous T-cell lymphoma (CTCL)

We have prescribed you the medicine bexarotene, also known as Targretin<sup>®</sup>, for the treatment of your CTCL. This leaflet answers 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 doctor or clinical nurse specialist (CNS), or ask for a copy of our leaflet, **About your skin condition: cutaneous T cell lymphoma**.

An information leaflet is provided by the manufacturer in each box of medicine. It is important that you read both the drug manufacturer's leaflet and this information sheet.

### What is bexarotene?

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

Bexarotene is used to treat patients with CTCL, including those with Mycosis Fungoides (MF) or Sezary Syndrome (SS). The exact way it works is not known, but we believe it prevents the growth of tumour cells, so it stops your tumour from developing further. It can also improve symptoms, such as itching.

### Before starting bexarotene therapy

Your doctor will discuss your treatment plan and options with you before you decide which treatment to have. If you choose to take bexarotene, you will need to see your skin cancer CNS. The nurse 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 baseline blood test.
- discuss with you the implications of this treatment, the importance of regular blood tests, monitoring of blood test results and attending follow-up appointments.
- give you dietary and well-being advice.
- 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.
- 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 at your outpatient appointment.

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.

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

If you forget to take your dose at the usual time, take it with your next meal on the same 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 CNS, doctor or specialist treatment centre pharmacist.

## Are there any side effects?

### Very common side effects

- Low white blood cell count (susceptibility to chills and fever)
- Headache, tiredness or fatigue
- Skin reactions on starting treatment – for example, dry skin and an increase in scaling.

Please speak to your doctor or 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. This is explained further overleaf.

### Common side effects

- Nausea and vomiting
- Diarrhoea
- Dry or abnormal sensations of the eyes
- Insomnia
- Joint, bone and muscle ache.

### 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 not treated. It is therefore important to report any aches or pains to your doctor or CNS.

**If you are in severe pain, go straight to your nearest accident and emergency (A&E) department. Take a list of your medicines and your drug monitoring booklet, if you have one.**

## Limitations of bexarotene

You must not be pregnant or breast feeding before starting this therapy, or become pregnant while on treatment, as bexarotene could harm your unborn baby. For this reason, women and men whose partner is of child-bearing age must use reliable contraception (birth control) continuously while taking bexarotene. It is recommended that you begin using contraception at least one month before starting therapy and continue for at least one month after therapy has stopped.

We recommend that women use **two** reliable forms of contraception together, including one non-hormonal type (for example condoms), as bexarotene may reduce the efficacy of oral contraceptives. You should discuss this further with your doctor or CNS.

Women of child-bearing age will be asked to consent to having a pregnancy test once week before starting the medicine, monthly during the therapy and one month afterwards, to confirm they are not pregnant. Your prescribing doctor will discuss this with you and inform your general practitioner (GP) so that regular pregnancy tests can be organised.

## Will I need any other treatment?

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

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, for example 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. Both fenofibrate and atorvastatin lower the fats known as cholesterol and triglycerides in the blood, while 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 therapeutic dose of the medication is achieved, the blood tests can be performed monthly.

These blood tests need to be taken after fasting. You should not eat or drink anything for twelve hours before the tests, although you can take small sips of water. For example, you may have the blood test late morning, when you have had nothing to eat or drink from midnight (apart from water). You can have the blood tests at St Thomas' Hospital, but if this is easier for you, they can be performed at your GP surgery or local hospital.

**If your GP has been asked to organise your blood tests, then they will fax the results to your skin cancer CNS (our fax number is 020 7188 4392).** If you have the blood tests arranged by your consultant at your local hospital, then the specialist looking after you there should be able to monitor your results.

You will need to have:

- full blood and differential white cell count
- **fasting** lipids, including cholesterol, triglycerides, high density lipoproteins (HDL) and low density lipoproteins (LDL)
- thyroid function tests (thyroxine level as well as thyroid stimulating hormone called TSH)
- biochemical profile, including liver and renal function tests
- creatinine Kinase (CK)
- amylase.

## 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 doctor or 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 doctor or CNS as before. This is so that medication started at the same time as your bexarotene therapy, for example fenofibrate, atorvastatin or levothyroxine, can be stopped gradually.

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

- Eat low fat foods.
- Exercise regularly.
- Do not eat or drink grapefruit/juice. This interferes with how the medication works.
- Do not sunbathe or use sun beds. Bexarotene is a photosensitive drug, which means it is sensitive to light. Minimise direct exposure to sunlight as much as possible and avoid sun lamps. If your treatment plan includes PUVA, your medication will be taken into consideration.
- Do not take vitamin A supplements, as bexarotene is a type of vitamin A.

## Is there anything else I need to know?

Bexarotene can interact with a number of medicines, so please tell the doctor or CNS who prescribes the medicine about any other medicines you are taking, including antibiotics, herbal or over-the-counter medicines. **Please see the manufacturer's leaflet for guidance on how to store your medicines.**

## 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 CNS or doctor with a copy of your most recent blood test results.

If you run out of the medication started with your bexarotene treatment, for example fenofibrate, atorvastatin, or levothyroxine, please see your GP. Take your drug monitoring booklet with you to your appointment, so that you can obtain a prescription.

## Contact us

Your CNS is available for support and advice, and can also help by liaising between patients, relatives, GPs and hospital doctors. Support from a CNS is available for all patients as soon as they have been diagnosed.

### Patient pathway coordinator

Becky Roles

t: 020 7188 7188 ext 51633 (Monday to Friday 9am–5pm)

e: [rebecca.roles@gstt.nhs.uk](mailto:rebecca.roles@gstt.nhs.uk)

## Useful organisations

### Macmillan Cancer Support

**w:** [www.macmillan.org.uk](http://www.macmillan.org.uk)

**t:** 0808 808 00 00

### Department for Work and Pensions benefit enquiry line

**w:** [www.dwp.gov.uk](http://www.dwp.gov.uk)

**t:** 0800 882200

### Cutaneous Lymphoma Foundation

**w:** [www.clfoundation.org](http://www.clfoundation.org)

### Cancer Research UK

**w:** [www.cancerhelp.org](http://www.cancerhelp.org)

**t:** 0808 8004040



**Dimbleby Cancer Care** is the cancer support service for Guy's and St Thomas'. They have drop-in information centres, and also offer complementary therapies, psychological support and benefits advice.

Drop-in information centres are located at Guy's in Oncology Outpatients (Ground floor, Tabard Annexe) and at St Thomas' on the Lower Ground Floor, Lambeth Wing.

**t:** 020 7188 5918 **e:** [RichardDimblebyCentre@gstt.nhs.uk](mailto:RichardDimblebyCentre@gstt.nhs.uk)

**Pharmacy medicines helpline** - For information about any medicines that you have been prescribed at Guy's and St Thomas' hospitals, you can speak to the staff caring for you or call our helpline.

**t:** 020 7188 8748 9am to 5pm, Monday to Friday

**PALS** - To make comments or raise concerns about the Trust's services, please contact our Patient Advice and Liaison Service (PALS). Ask a member of staff to direct you to PALS or:

**t:** 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**Language support services** - If you need an interpreter or information about the care you are receiving in the language or format of your choice, please get in touch using the following contact details:

**t:** 020 7188 8815 **fax:** 020 7188 5953 **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

**Knowledge & Information Centre (KIC)** - For more information about health conditions, support groups and local services, or to search the internet and send emails, please visit the KIC on the Ground Floor, North Wing, St Thomas' Hospital.

**t:** 020 7188 3416

### Become a member of your local hospitals, and help shape our future

Membership is free and it is completely up to you how much you get involved. To become a member of our Foundation Trust, you need to be 18 years of age or over, live in Lambeth, Southwark, Lewisham, Wandsworth or Westminster or have been a patient at either hospital in the last five years.

To join, please call 0848 143 4017, email [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk) or visit [www.guysandstthomas.nhs.uk](http://www.guysandstthomas.nhs.uk)

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