Interferon treatment for your cutaneous T-cell lymphoma (CTCL)

You have been prescribed the medicine interferon alpha-2a, also known by its brand name Roferon®-A, for the treatment of your cutaneous T-cell lymphoma. This leaflet answers some of the questions you may have about this treatment. If you have any questions about your condition, please speak to your doctor or nurse 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 manufacturer’s leaflet and this information sheet.

What is interferon?

Interferon is a medicine that contains an antiviral agent called interferon alfa-2a. This substance is similar to the proteins that your body naturally produces to protect you against viral infections. It is used to treat cutaneous T-cell lymphoma because it prevents the growth of cancer cells, and therefore slows the growth of your cancer (tumour).

It is supplied as a solution in a cartridge and is injected into your body.

Before starting interferon therapy

Your doctor will discuss your treatment plan and options with you before you decide which treatment to have. If you choose to have interferon, you will need to see the skin cancer clinical nurse specialist (CNS). The nurse will:

- organise a baseline blood test
- discuss with you the benefits and side effects of this treatment, and the importance of regular blood tests and attending follow-up appointments
- advise and demonstrate how and when to give the therapy
- discuss the support services available to you
- offer dietary and well-being advice
- answer any questions you may have
- discuss your treatment and monitoring plan, and give you your drug monitoring booklet
- 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?

Interferon is given as an injection beneath the skin. This is known as a subcutaneous injection. The injection can be given by your doctor or nurse, or we may teach you how to inject the medicine yourself. It is important that you only use the medicine as your doctor or CNS instructs you to.

If you will be injecting the medicine yourself, we will prescribe an injection pen, as interferon is supplied in cartridges. A manual is supplied with the pen, which gives you detailed instructions on how to use both the pen and cartridge. You must read this manual carefully before using the pen. Each cartridge contains enough solution for several doses, so you will be able to use it several times. You should write the date on the label supplied when you start a new cartridge and you must use each cartridge within 28 days. You should not try to inject the medicine yourself unless you have received training. Your nurse will give you training on how to operate the pen and on the injection technique when you collect your prescription from the pharmacy.

We will also give you a supply of sterile needles that fit onto the pen. You must use a new, clean, sterile needle each time you give yourself a dose.

Interferon needs to be stored in the fridge. Please see the manufacturer’s leaflet on how to store medication safely.

How do I know how much to inject?

Your doctor will consider your individual needs such as your medical history, illness and well-being, and will discuss the recommended dose with you. If you are self-injecting the medicine, you must not change the prescribed dose yourself. Your doctor will give you a follow-up appointment and will review your dosage. You can contact your CNS between appointments for extra support.

When should I take the medication?

If you are self-injecting the medicine, it is best to do this before going to bed. This way, you can sleep off the side effects (outlined below). You may wish to take painkillers beforehand to reduce any side effects and help you get to sleep. Please discuss this with your CNS or doctor.

What should I do if I forget a dose?

If you forget a dose, take your normal dose the next time it is due. Never give yourself a double dose to make up for one you have missed. If you are not sure what to do, contact your GP, pharmacist, CNS or doctor.

Are there any side effects?

Common side effects include:
- Flu-like symptoms such as aches and pains, tiredness and chills
- Loss of appetite, nausea, diarrhoea, weight loss
- Dry skin, a rash
- Cold sores
- Hair thinning
Rare side effects include:

- Vertigo (fear of heights)
- Convulsions
- Coma
- Impotence
- Intestinal bleeding
- Kidney, heart, lung and liver abnormalities
- Depression, feeling sad or worthless
- Suicidal thoughts – if you have this, contact your doctor immediately.

If you are concerned about these or any other side effects, please contact your pharmacist, CNS or doctor.

Limitations of interferon

You must not be pregnant or breast feeding before starting this therapy, or become pregnant during it. Interferon could harm your unborn baby. For this reason, women and men whose partner is of child bearing age must use contraception (birth control) continuously while taking interferon and for a period after finishing the medication. We recommend using two reliable forms of contraception together. You should discuss this further with your doctor, pharmacist or CNS.

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

Will I need any other treatment?

Your doctor may combine your interferon treatment with other forms of medicine, such as Targretin® (bexarotene). In such cases, you may experience additional side effects. Your doctor and CNS will explain these to you and arrange for you to have blood tests to monitor your progress.

What blood tests do I need and how often do I need to have them?

To monitor the effects of your interferon treatment you will need to have a blood test once a month. We will perform a full blood and differential white cell count, and a biochemical profile, including liver and renal function tests.

If your GP is able to organise your blood tests, then the results must be faxed to your skin cancer CNS on 020 7188 4392. Alternatively, if your GP is monitoring your blood results, please make sure you have copies of the results and bring them with you when you attend clinic. If your blood tests are organised at your local hospital, the specialist there should be able to monitor your results.

How long will I need to take interferon?

If you respond well to the medicine, your doctor will discuss with you the possibility of continuing treatment on a maintenance dose. This means that you will only need to take the amount of interferon required to maintain stability of your condition.
What else do I need to tell my doctor?

Please make sure you tell your doctor if you have:

- an allergy to interferon
- a history of heart disease
- a history of kidney or liver disease
- a bone marrow disorder
- epilepsy
- a psychiatric illness or psychiatric difficulties
- psoriasis
- an autoimmune disease, for example, thyroid dysfunction
- had an organ transplant
- a blood disorder
- if you may be pregnant.

Please also bring a list of the medications you are taking.

Where can I get a repeat prescription?

You should have enough interferon to last you until your next appointment. If you run out, please contact your CNS or doctor at St Thomas’ Hospital. Alternatively, if you are under the care of a dermatologist at your local hospital, please contact him/her for a repeat prescription. You will need to take a copy of your latest blood test results.

About St John’s Institute of Dermatology

St John’s Hospital for Diseases of the Skin was founded in 1868 and later grew to include an institute for postgraduate studies in dermatology.

In 1990 both institutions became a part of St Thomas’ Hospital and were renamed St John’s Institute of Dermatology. In 1995, the Dermatology Department from Guy’s Hospital was also incorporated into St John’s. St John’s is the largest dermatology department in the UK and the only postgraduate dermatology teaching institute in the UK.

St John’s exists to provide clinical excellence in the teaching and treatment of common and rare skin conditions as well as providing world-renowned research into skin diseases as a part of Kings College London.

Contact us

If you have any questions or concerns about interferon, please contact your clinical nurse specialist (CNS):

Alison Baker 020 7188 7188 (bleep 0542) Mon–Fri 8–4pm
Ian Gosling 020 7188 7188 (bleep 0541) Mon–Fri 8–4pm
Cath Morgans 020 7188 7188 (bleep 1251 Mon–Thurs 8–6pm

To bleep a member of staff, please call the hospital switchboard on 020 7188 7188 and ask for the bleep desk. Ask for the relevant bleep number and wait for a response. This will connect you directly to the person you are looking to contact.

Out of hours please call the hospital switchboard 020 7188 7188 and ask for ‘dermatology on call’.
Further sources of information

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.
\textbf{t:} 020 7188 8748 9am to 5pm, Monday to Friday

Patient Advice and Liaison Service (PALS)
To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:
\textbf{t:} 020 7188 8801 at St Thomas’ \quad \textbf{t:} 020 7188 8803 at Guy’s \quad \textbf{e:} pals@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.
\textbf{t:} 020 7188 3416

Language support services
If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.
\textbf{t:} 020 7188 8815 \quad \textbf{fax:} 020 7188 5953

NHS Direct
Offers health information and advice from specially trained nurses over the phone 24 hours a day.
\textbf{t:} 0845 4647 \quad \textbf{w:} www.nhsdirect.nhs.uk

NHS Choices
Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.
\textbf{w:} www.nhs.uk

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:
\textbf{t:} 0848 143 4017 \quad \textbf{e:} members@gstt.nhs.uk \quad \textbf{w:} www.guysandstthomas.nhs.uk