

# Infliximab for Sarcoidosis

Your treating pulmonologist has discussed the use of infliximab with you. In this leaflet, you will find information about the effects and use of this medication. You will also read what to do if you experience side effects. However, this leaflet is not a substitute for the official package insert. If you have any questions after reading this leaflet, you can ask your treating physician.

## What is sarcoidosis and why are you prescribed infliximab?

In people with sarcoidosis, there is a disorder of the immune system that leads to damage to the body. It arises from an uncontrolled reaction of the immune system to an as yet unknown trigger in patients who are susceptible. This leads to accumulations of inflammatory cells, also called granulomas.

Because the cause of sarcoidosis is unknown, treatment focuses on suppressing the immune system. This leads to a reduction in the accumulation of inflammatory cells. As a result, symptoms and the risk of complications that may occur with the disease are reduced.

Unfortunately, the disease is not cured by treatment with medication. Infliximab can be given if a previous treatment with prednisone has not worked. 'Biologicals' or 'biosimilars' such as infliximab are very expensive and are therefore not prescribed lightly. Most patients can be treated well with a combination of prednisone and medications such as methotrexate and azathioprine.

## How does infliximab work?

Infliximab is a drug that blocks a specific inflammatory protein. This protein is called tumor necrosis factor-alpha (TNF- $\alpha$ ) and plays a role in inflammation. These are the same types of inflammation seen in sarcoidosis. By inhibiting this inflammatory protein, we try to reduce the symptoms of the disease, such as shortness of breath. Infliximab often works quickly, usually within a few weeks. Because the manifestation and severity of the disease vary greatly from person to person, the effect of infliximab and the body's response to the medication also differ per individual. Unfortunately, not everyone experiences sufficient benefit. If there is no improvement 4 months after starting treatment, your treating physician will usually choose to stop the medication.

## **What is the dosage and how is infliximab administered?**

Infliximab is a medication that you receive via an infusion, or in specific cases as subcutaneous injection. The dosage depends on your weight. It is administered in the day care department where you are seen.

The medication is given once every 6 weeks. During an infusion, you will be admitted for about 4 hours. After this, you can go home.

## **What are the side effects?**

The pharmacy's package insert lists all side effects of infliximab that have ever occurred.

### **The most common side effects are:**

- skin rash
- headache.

### **Side effects that sometimes occur:**

- infections
- reduced production of white blood cells.

### **Rare side effects (between 0.1% and 0.01% of users):**

- Nervous system disorders (multiple sclerosis (MS), optic neuritis, Guillain-Barré syndrome)
- Skin tumor (basal cell carcinoma or squamous cell carcinoma).

### **When should you contact your treating physician?**

If you suspect serious side effects, you should stop taking infliximab. Therefore, contact your treating physician if you experience:

- severe sore throat with fever
- fever
- chills
- signs of infection:  
such as feeling ill; fever; (increased) coughing with sputum; pain when urinating;  
persistent diarrhea
- signs of nervous system problems (for example, if you cannot move a limb).

## **What monitoring is needed when using infliximab?**

Sometimes liver function and blood cell production are disturbed. To detect this at an early stage, your treating physician will regularly have your blood tested. This is done according to a strict schedule. The first time is 1 week after starting infliximab. Further, with stable findings, every two weeks. This continues until 8 weeks after starting the medication. Afterwards, your treating physician will gradually reduce these checks to once every 4 months.

## **When should you not use infliximab?**

- with infections
- if your heart does not function well (heart failure)
- if you have been diagnosed with cancer in the past 5 years
- if you have multiple sclerosis (ms).

## **Can you use infliximab with other medications?**

You can use infliximab with almost all medications. Always inform your general practitioner and treating specialist(s) about which medications you use and for what purpose.

### **What is the effect on fertility, pregnancy, and breastfeeding?**

It is very important to inform your treating physician if you want to become pregnant or are already pregnant. As far as is known, infliximab does not affect the fertility of men and women. There is little data on the use of infliximab during pregnancy and its effects on the child. The available data indicate that the use of infliximab is probably safe for mother and unborn child up to a gestational age of 12 weeks. Until more data are available, personal advice is given. This depends, among other things, on the activity of the disease. This may mean that sometimes it is advised to stop infliximab when you wish to become pregnant, sometimes as soon as there is a positive pregnancy test. In some cases, temporarily stopping infliximab is not (safely) possible. In that case, your treating physician will discuss the pros and cons of continuing infliximab during (planning) pregnancy with you so you can make an informed choice.

### **Are you undergoing surgery or another (dental) procedure?**

There may be an increased risk of infection after surgery when using infliximab. Discuss this with your doctor if you need to undergo surgery or a dental procedure. Inform the person performing the procedure that you are being treated with infliximab.

### **What else should you know?**

- Before you can start infliximab, we must be sure that you do not have tuberculosis (TB) and/or chronic hepatitis B and C (liver inflammation).
- Infliximab should not be administered if you have a serious infection. If you have symptoms that may indicate an infection, such as high fever, severe shortness of breath, or coughing with sputum, consult your doctor. This also applies to (risk of) sexually transmitted diseases (STDs). In case of infections, infliximab must be (temporarily) stopped.
- During the use of infliximab, vaccination with live, attenuated viruses and bacteria is discouraged. These include vaccinations against mumps, measles, and rubella (MMR), yellow fever, oral polio vaccine, oral typhoid vaccine, and BCG. A flu shot is allowed. Inform the doctor or nurse who prescribes your vaccinations that you use infliximab.
- Check your skin on arms, legs, head, and neck annually. If you notice any skin abnormalities, it is wise to consult your general practitioner.

### **Are you going on holiday soon?**

- Planning a trip  
Be careful when traveling to areas where you have an increased risk of infections. Discuss this with the travel agency and get information from your regional Public Health Service (GGD), the Tropical Medicine Center, or the National Coordination Center for Travel Advice (LCR).
- Infliximab and vaccinations  
If you use infliximab, you must not receive vaccination with live, attenuated viruses and bacteria. These include vaccinations against yellow fever, oral polio vaccine, oral typhoid vaccine, and BCG. Inform the doctor or nurse who prescribes your vaccinations that you use infliximab.
- Medication passport and English patient letter  
If you are traveling, it is wise to take an overview of all your medications (medication passport) with you. You can request this from your pharmacy. You will then have a document for possible checks by customs. You can also use this in case of loss of medication or when you consult a doctor abroad. For infliximab, a separate medication passport is required. You can

request this 2 - 4 weeks before departure from your treating physician. If you need medical help abroad, it is important that you can tell the healthcare provider which disease(s) you have, which medications you use, and how your own doctor can be reached if needed. You can request an English letter from your treating physician for this. Please contact your treating physician well in advance (4 - 6 weeks before departure).

## **Do you have any questions?**

If you have any questions or doubts, please contact the Pulmonary Diseases outpatient clinic using the contact details known to you.

For more information about the treatment of sarcoidosis at Amsterdam UMC, visit the Amsterdam UMC-website.