



Patient & Family Guide

2022

# Ustekinumab (Stelara®) Therapy



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# Ustekinumab (Stelara®) Therapy

Your IBD health care provider believes treatment with a medication called ustekinumab may help to manage your inflammatory bowel disease (IBD). The brand name for ustekinumab is Stelara®.

This pamphlet will give you basic information about ustekinumab to help you make an informed decision about whether or not to use this treatment. This pamphlet does not take the place of any information or instructions from your IBD health care provider.

## What is ustekinumab?

- Ustekinumab is a **biologic medication**.
- A biologic medication is a type of medication that treats inflammation (swelling).

## How does it work?

- When you have an infection, white blood cells go to different tissues in your body as part of your natural immune response.

- When you have Crohn's disease or ulcerative colitis, your immune system cannot tell the difference between foreign (from outside your body) substances and your own tissues.
- Inflammation and other symptoms of Crohn's disease and ulcerative colitis are caused by:
  - › a higher number of white blood cells entering your intestine.
  - › higher levels of 2 proteins (that are already naturally in your body), called interleukin 12 (IL-12) and interleukin 23 (IL-23).
- Ustekinumab blocks these proteins to lower inflammation.

## How is ustekinumab given?

- You will start your ustekinumab treatment with one intravenous (IV) infusion. This will help to lower your symptoms.
- The infusion will take place at a private infusion clinic in your area.
- The infusion takes about **one hour**.
- The medication is given through a small, flexible tube inserted (put) into a vein in your arm by an IBD health care provider.

- You will then get subcutaneous (under the skin) injections, usually in the front of your thigh or abdomen (belly), **every 8 weeks**. This will help to keep your symptoms under control.
- Ustekinumab **cannot** be taken by mouth because your digestive system would destroy it.
- The nurses at the infusion clinic will help you inject your first dose and make sure you are ready to self-inject (give yourself injections) the medication at home. If you do not feel that you can self-inject the medication, you can keep going to the infusion clinic for your injections.

**Do not try to inject this medication on your own until you fully understand how.**

## **How long will I need to take ustekinumab?**

- Ustekinumab can take up to 4 months to take full effect. Your IBD health care provider will check how you are responding to the medication and decide if you should keep taking it.

- It is very important that your IBD health care provider check your progress at regular visits to make sure this medication is working properly. You may also need regular blood tests. Ask your IBD health care provider when you can expect a follow-up appointment.
- You can check if the medication is working by monitoring your IBD symptoms or having your IBD health care provider do tests, like:
  - › Stool (poop) sample
  - › Colonoscopy (scope of the bowel)
 These tests will check if the medication has improved the inflammation.
- If the medication is working well and you are not having major side effects, your IBD health care provider may want you to stay on ustekinumab long-term (years) for your IBD.

## **How much does ustekinumab cost?**

- Biologic medications like ustekinumab are very expensive. They can cost thousands of dollars a month.
- The Patient Support Program for ustekinumab will work with your insurance company **or** Nova Scotia Pharmacare. Any part of the cost that is not covered by your insurance or Pharmacare is usually paid for by the Patient Support Program.

- A nurse coordinator with the Patient Support Program will stay in contact with you and your IBD health care providers. They will help you with any paperwork that may be needed to cover the cost of this medication.

## **Before you start taking ustekinumab:**

- Before you start taking ustekinumab, there are things you can do to lower your risks and help the treatment work better.
- You will have blood tests, a tuberculosis (TB) skin or blood test, and a chest X-ray. These tests will check for active infections.
- Your IBD health care provider may want you to update your vaccinations for:
  - › Tetanus
  - › Varicella (chicken pox)
  - › Pneumococcal (pneumonia)

**Be sure to tell your health care provider if you are allergic to latex.** The ustekinumab needle cover is made of latex.

## **While taking ustekinumab:**

- **Do not get any live vaccines (vaccines that have a weakened form of a virus in them) while taking ustekinumab.** You are at a higher risk of infection from the virus. If you are due for vaccinations or plan to be vaccinated, tell your IBD health care provider.
- **It is safe to get the yearly flu vaccine (flu shot) while taking ustekinumab.**
- Tell your IBD health care provider about any other health problems you have. Ustekinumab may make them worse.

## **What are the possible side effects of ustekinumab?**

Like any medication, ustekinumab has possible side effects. These include:

- › Infection in your nose, throat, or windpipe (tube that connects your throat and lungs)
- › Headache
- › Tiredness
- › Joint pain
- › Nausea (upset stomach)
- › Itchy skin
- › Vomiting (throwing up)
- › Vaginal yeast infection

- › Urinary tract infection
- › Redness at the injection site (where the needle is inserted)

Ustekinumab affects your immune system. It may increase your chance of getting:

- › An infection
- › Non-melanoma skin cancer
- › A rare condition called reversible posterior leukoencephalopathy syndrome. A very small number of patients taking ustekinumab got this neurologic syndrome. It went away when they stopped taking ustekinumab.

**Talk with a health care provider right away if you have any of the following symptoms:**

- › Fever (temperature above 38<sup>0</sup> C/100.4<sup>0</sup> F) or chills
- › Cough or hoarseness (rough feeling in your throat)
- › Headache
- › Pain in your lower back or side
- › Trouble urinating (peeing) or pain when you urinate
- › Confusion
- › Trouble seeing



- **If you think you have an infection, visit your primary health care provider (family doctor or nurse practitioner) or go to a walk-in clinic. It is important to tell them that you are taking ustekinumab.**
- If you get an infection while taking ustekinumab, tell your IBD health care provider. They will tell you if you should delay your ustekinumab treatment. If the infection becomes serious, your treatment may be stopped.

**Call 911 or go to the nearest Emergency Department right away if you suddenly have these symptoms of a serious allergic reaction:**

- › Rash
- › Itchy skin
- › Trouble breathing or shortness of breath
- › Chest pain
- › Swelling in your face, throat, legs, or feet

## **Pregnancy and breast/chest feeding**

- **It is important to tell your IBD health care provider if you are pregnant, or plan on getting pregnant, while taking ustekinumab.**
- **Ustekinumab is safe to use during pregnancy. Your IBD health care provider may adjust the timing of your treatments in the third trimester of your pregnancy.**

**Your baby may not be able to get any live vaccines (like the rotavirus vaccine) in their first year of life. It is very important to talk about this with your health care provider.**

- **You can start taking ustekinumab again shortly after you give birth. It does not pass into your breast/chest milk, so it is safe to breast/chest feed your baby.**

## Important:

- If you are prescribed any new medications while you are taking ustekinumab, ask your IBD health care provider or pharmacist about possible complications before starting the new medication. This includes prescription and non-prescription (over-the-counter) drugs, and herbal or vitamin supplements.
- **If you notice any serious side effects, or you have side effects that do not go away, it is important to tell your IBD health care provider right away.** You may have to lower your dose (the amount you take) or stop taking ustekinumab. They will make changes to your medication, if needed.
- Side effects can usually be helped with other medications, but you may need to lower your ustekinumab dose or stop taking ustekinumab.
- **It is important to talk with your IBD health care provider if you notice any changes in your side effects.** This will help you and your IBD health care provider pick the treatment that is best for you.

# Notes:

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## Looking for more health information?

Find this pamphlet and all our patient resources here: <https://library.nshealth.ca/PatientEducation>

Contact your local public library for books, videos, magazines, and other resources.

For more information, go to <http://library.novascotia.ca>

Connect with a registered nurse in Nova Scotia any time: call 811 or visit <https://811.novascotia.ca>

Learn about other programs and services in your community: call 211 or visit <http://ns.211.ca>

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*Please do not use perfumed products. Thank you!*

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The information in this pamphlet is for informational and educational purposes only.

The information is not intended to be and does not constitute health care or medical advice.

If you have any questions, please ask your health care provider.

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The information in this pamphlet is to be updated every 3 years or as needed.