## Patient & Family Guide

## Ustekinumab (Stelara®) Therapy for Crohn's Disease



### Ustekinumab (Stelara®) Therapy

Your healthcare provider believes treatment with a medicine called ustekinumab may help to manage your Crohn's disease. The brand name for ustekinumab is Stelara®.

In this pamphlet you will find 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 your healthcare provider gives you.

#### What is ustekinumab?

Ustekinumab is a prescription medicine used to treat adults with moderate to severe Crohn's disease who have already taken other medicine that did not work well enough or was not tolerated.

#### How does it work?

White blood cells go to different tissues in your body as part of your natural immune response to fight infections.

When you have Crohn's disease, your immune system cannot tell the difference between foreign substances (from outside your body) and your own body's tissues.

Inflammation and other symptoms of Crohn's disease are caused by a higher number of white blood cells entering your intestine and higher levels of two naturally occurring proteins in the body called interleukin 12 (IL-12) and interleukin 23 (IL-23).

Ustekinumab blocks these proteins to lower the inflammation caused by Crohn's disease.

#### How is ustekinumab given?

You will start your ustekinumab treatment with a one-time intravenous (IV) infusion through a small flexible tube inserted (put) into one of your arm's veins by a healthcare provider. The infusion takes about 1 hour and will help to lower your symptoms.

To continue your treatment, you will then get the drug through subcutaneous (under the skin) injections, usually in the front of your thigh or abdomen (belly), every 8 weeks to keep your symptoms under control.

Ustekinumab cannot be taken by mouth because your digestive system would destroy the drug.

Your healthcare provider or clinic will help you inject your first dose and make sure you are ready to self-administer (inject on your own) the medicine at home.

Do not try to inject this medicine on your own until you completely understand how to do it.

# Precautions before you start ustekinumab

- Before starting ustekinumab treatment, precautions can be taken to lower risks.
   Taking these precautions often results in successful treatment with very few downsides.
- You will have a tuberculosis (TB) skin test, chest X-ray, and blood work to check for TB or other active infections.
- Your healthcare provider may suggest that you update your vaccinations. These may include tetanus, varicella (chicken pox), or pneumococcal (pneumonia) vaccines.
- Be sure to tell your healthcare provider if you are allergic to latex because the ustekinumab needle cover is made of latex.

#### While taking ustekinumab

- Avoid live vaccines (vaccines that have a weakened form of a virus in them) while being treated with ustekinumab because of higher infection risk. If you are due for vaccinations or plan to be vaccinated, tell your healthcare provider.
- Be sure to tell your healthcare provider about any other health problems you have because ustekinumab may make them worse.
- Have regular blood work and check-ups with your healthcare provider.

What are your questions?
Please ask. We are here to help you.

#### What side effects can ustekinumab cause?

Like any medicine, ustekinumab has possible side effects, such as:

- Infections in your nose, throat, or windpipe
- > Headache
- Tiredness
- > Joint pain
- Nausea (feeling sick to your stomach)
- Itching
- > Vomiting (throwing up)
- > Vaginal yeast infections
- Urinary tract infections
- Redness at the injection site

Ustekinumab targets your immune system, and may increase your chance of getting infections, cancer, serious allergic reactions, and a rare condition called reversible posterior leukoencephalopathy syndrome.

# Be sure to tell your healthcare provider if you have any of the following symptoms:

- > Fever or chills
- Cough or hoarseness
- › Lower back or side pain
- Painful or difficult urination (hard to pee)
- > Headache
- Seizures
- Confusion
- > Vision problems

### Call 911 or go to the closest Emergency Department if you have any of these symptoms that start all of a sudden:

- > Rash
- Itching
- Trouble breathing
- Chest pain
- Swelling in your face, throat, legs, or feet

### Pregnancy and breastfeeding

- Tell your healthcare provider right away if you are pregnant, plan to become pregnant, or become pregnant while taking ustekinumab.
- It is not known if ustekinumab will hurt your unborn baby.
- Tell your healthcare provider if you are breastfeeding or plan to breastfeed. It is thought that ustekinumab passes into your breast milk.
- You and your healthcare provider will need to talk about the possible benefits and risks before you take this medicine while pregnant or breastfeeding.

This pamphlet is just a guide. Please talk to your healthcare provider about your questions. We are here to help you.

#### **Important**

- Always talk with your healthcare provider about other medicines you are taking, including prescription and non-prescription (over-the-counter) drugs and herbal or vitamin supplements.
- If you notice any serious side effects that do not go away, it is important to tell your healthcare provider right away so changes can be made.
- Usually, symptoms of side effects can be taken care of with other medicines, but lowering your ustekinumab dose or stopping treatment may be needed.
- Talking with your healthcare provider when you notice any changes in side effects will help you pick the treatment that will work best for you.

Notes:			

#### Looking for more health information?

Find this pamphlet and all our patient resources here: http://library.nshealth.ca/PatientGuides
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For more information go to http://library.novascotia.ca

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#### Nova Scotia Health Authority www.nshealth.ca

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

If you have any questions, please ask your healthcare provider.

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

