

Your Welcome Booklet...



... for the Akcea Connect™
Patient Support Program

 **Tegsedi**™
(inotersen) injection
254 mg/1.5 mL

AKCEA™
THERAPEUTICS CANADA 

Welcome to the Akcea Connect™ Patient Support Program

Getting started with your PrTEGSEDI™ treatment

This booklet contains some useful materials about TEGSEDI™ to help you along your treatment journey. Remember – the Akcea Connect™ Patient Support Program and your Nurse Case Manager are here for you every step of the way.

TEGSEDI™ is used for the treatment of stage 1 or stage 2 polyneuropathy in adult patients with hereditary transthyretin amyloidosis (hATTR).

For more information on the Akcea Connect™ Patient Support Program, please contact us by:



1-833-327-0723



support@akceaconnect.ca

Or visit our website at akceaconnect.ca

Table of contents

hATTR

- 06 Hereditary transthyretin amyloidosis (hATTR)
- 08 Your family tree
- 10 Talking to your loved ones about your diagnosis

Akcea Connect™ overview

- 11 Akcea Connect™ is here to help
- 12 Your Nurse Case Manager: Supporting you throughout your treatment with TEGSEDI™

TEGSEDI™

- 13 How TEGSEDI™ works
- 14 Akcea Connect™ offers injection training for TEGSEDI™ patients and caregivers
- 15 A step-by-step injection guide for you or your caregiver
- 20 Storing TEGSEDI™
- 21 Serious warnings and precautions
- 22 TEGSEDI™ and laboratory monitoring
- 23 TEGSEDI™ may lower the level of vitamin A in your body
- 24 Possible side effects of TEGSEDI™



Your Akcea Connect™ Nurse Case Manager,

.....
Julie Sadonoja



Peer Mentor Program

27 Join our Peer Mentor Program today!

Living with hATTR

28 Lifestyle tips for patients living with hATTR

For your caregiver

30 Akcea Connect™ supports caregivers

Resources & FAQ

33 Available resources for Canadians with hATTR

34 Akcea Connect™ is committed to Canadians on TEGSEDI™

35 FAQs you can discuss with your Nurse Case Manager

36 Notes

Hereditary transthyretin amyloidosis (hATTR)

What is hATTR?

In hATTR, a change or mutation in the gene alters the structure of a protein in your body called transthyretin (TTR). This causes the TTR protein to fold into an unusual shape or clump together and build up in the body. This buildup of TTR protein can stop the organs in your body from working properly.

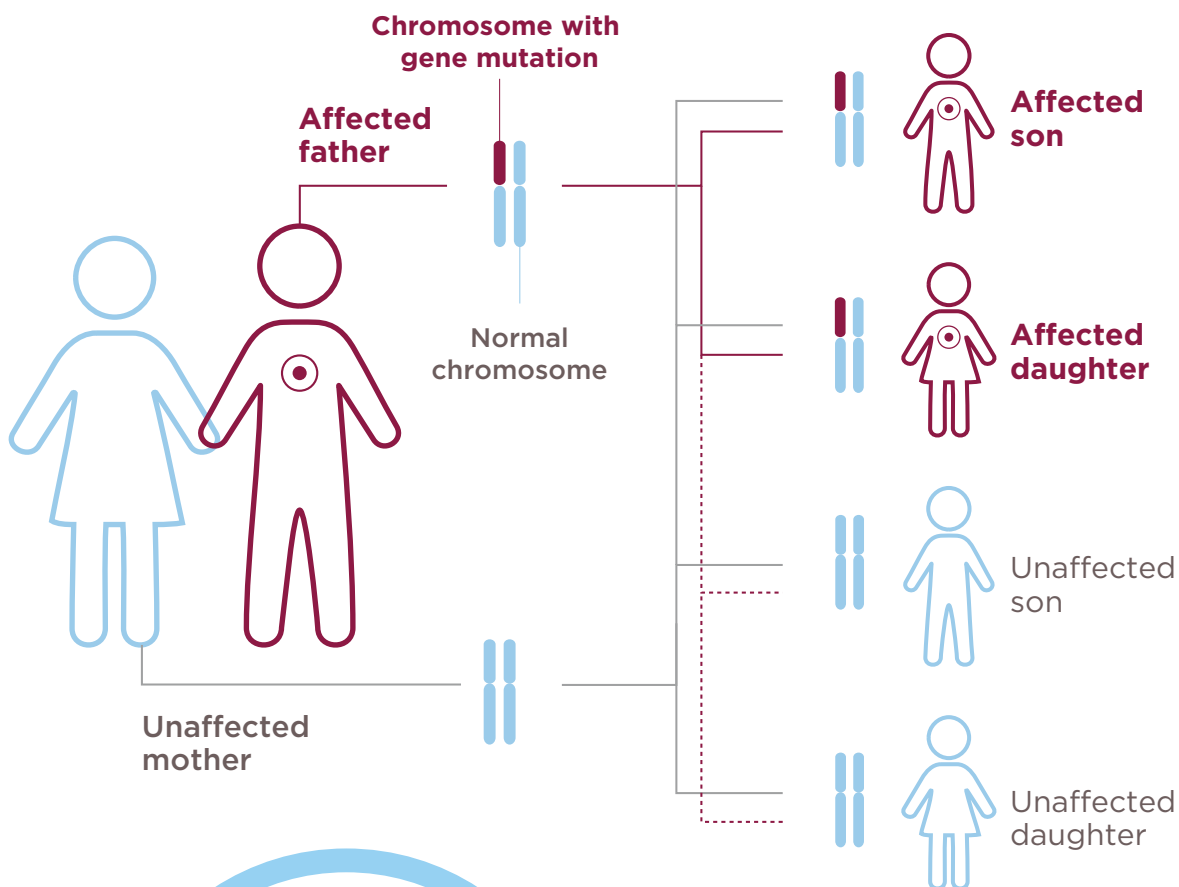
Why do I have hATTR?

hATTR is inherited in an autosomal dominant pattern.

- One copy of the altered gene in each cell is sufficient to cause the disorder.
- In most cases, an affected person inherits the mutation from one affected parent.



Autosomal dominant inheritance example



Your doctor may have used genetic testing to confirm your diagnosis. This will also help determine your risk of passing this genetic disorder on to your children.

Your family tree

Fill out your family tree below and track the inheritance of the *TTR* gene mutation throughout your family where possible. This exercise can help you outline who in your family has tested positive for the *TTR* gene mutation who may be at risk of passing along the gene or who has been diagnosed with hATTR. For more information, ask your doctor or consider discussing your family tree with a genetic counsellor.

First Generation

Grandparent

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Grandparent

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Grandparent

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Grandparent

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Second Generation

Aunt/Uncle

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Aunt/Uncle

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Aunt/Uncle

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Parent

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Parent

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Aunt/Uncle

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Aunt/Uncle

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Aunt/Uncle

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Your Generation

Cousin

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Cousin

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Cousin

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Sibling

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

YOU

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Sibling

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Cousin

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Cousin

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Cousin

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Next Generation

Niece/Nephew

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Niece/Nephew

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Niece/Nephew

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Child

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Child

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Child

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Niece/Nephew

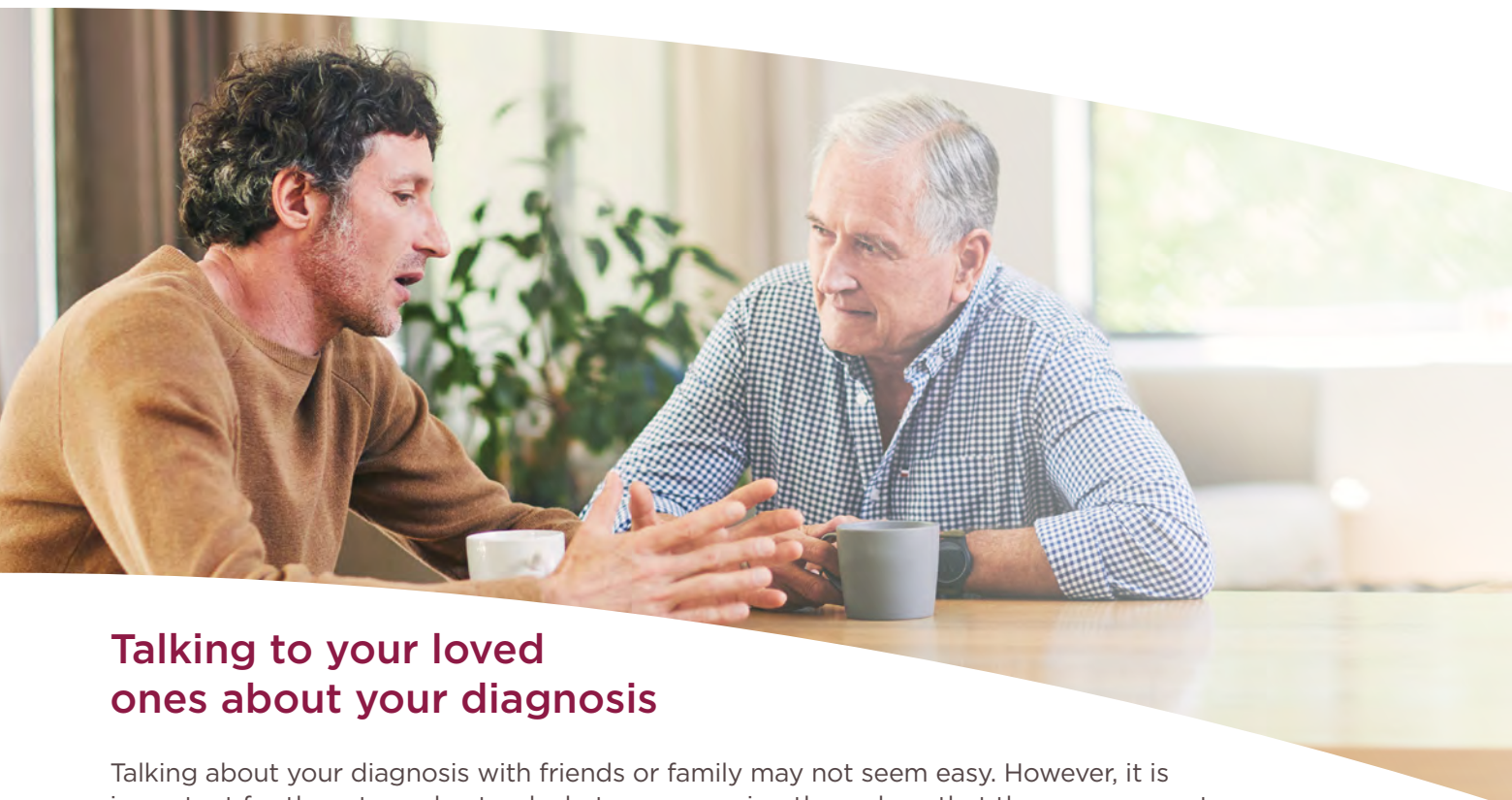
☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Niece/Nephew

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown

Niece/Nephew

☐ Diagnosed with hATTR
☐ Positive for *TTR* gene mutation
☐ hATTR status unknown



Talking to your loved ones about your diagnosis

Talking about your diagnosis with friends or family may not seem easy. However, it is important for them to understand what you are going through so that they can support you throughout treatment.

You may want to think about the environment in which to have this conversation, and when you want it to take place. Make sure you are in a setting that is comfortable and that you leave enough time, so you do not feel rushed. It may also be helpful to write down what you want to say ahead of time so you can bring up the points that matter most to you.

During this discussion, understand that the people in your support system may have questions. Remember that there are resources available to help you and your loved ones understand your diagnosis and support you on your treatment journey.

Talk to your healthcare provider to find out what services, such as genetic counselling, may be available for you. Gaining access to these services may help answer questions about this inherited disease.

Questions or comments to discuss with your Nurse Case Manager

AKCEA CONNECT™ is here to help

As part of ongoing commitment, Akcea Connect™ is proud to offer a variety of services to support you and help answer questions you may have. You will also have tools in your own Akcea Connect™ backpack, which contains a training mat, a demo device and more!



Education

Offering comprehensive education, resources and navigation support services specific to hATTR and TEGSEDI™.



Injection training & administration support

Offering injection training and administration support services in your home or through a specialty clinic network. Before using TEGSEDI™, your healthcare provider should show you or your caregiver how to use it the right way. If you or your caregiver have any questions, ask your healthcare provider.



Blood draw & urine testing services

Offered in your home or through a specialty clinic network.

- Results are communicated directly to your healthcare provider.



Pharmacy services

Coordinating the dispense and delivery of TEGSEDI™ through a dedicated pharmacy network or your preferred pharmacy.



Patient support calls

If you request it, you will receive regular support calls to answer your questions and to remind you to continue taking TEGSEDI™ as prescribed.



Reimbursement navigation

Assessing your coverage options and facilitating payer coverage requirements.



Financial assistance

Investigating reimbursement options and eligibility for financial assistance for you.

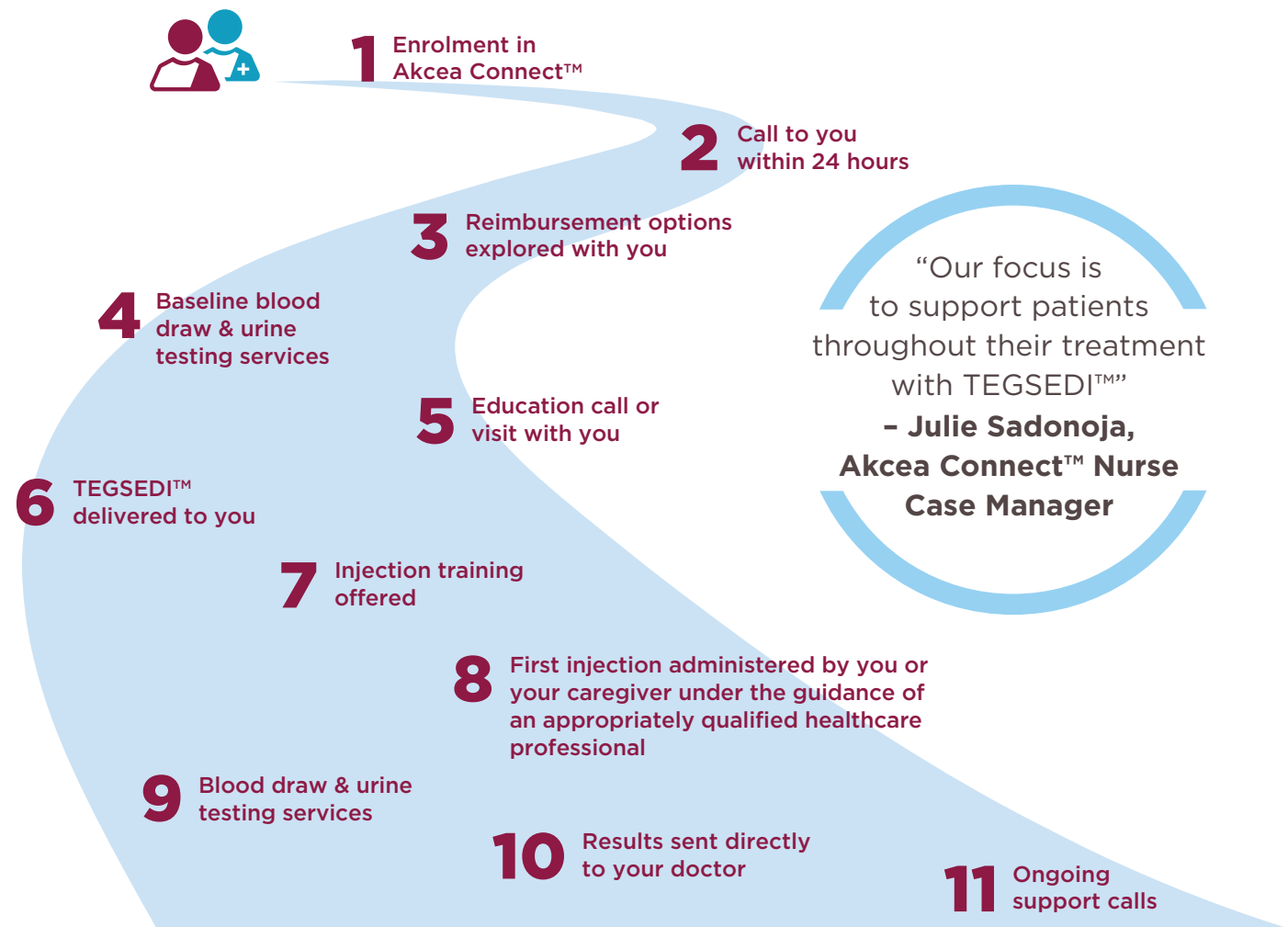
While hATTR is a rare disease, you are not alone. Our program is meant for anyone with hATTR that is taking TEGSEDI™ and is enrolled in **the Akcea Connect™ Patient Support Program.**

Your Nurse Case Manager: Supporting you throughout your treatment with TEGSEDI™

Akcea Connect™ is staffed by a dedicated Nurse Case Manager who is here to assist you, your family or caregiver, and your healthcare team. Our Nurse Case Manager will collaborate directly with you and your healthcare team and help answer your questions during treatment.

Field nurses will perform blood draws and collect samples based on what your doctor has requested. These services are available to you at a location of your choice, including your home, workplace, or a clinic, and the results are sent directly to your doctor. Akcea Connect™ can even help to coordinate these services through specialty clinic networks while you may be traveling.

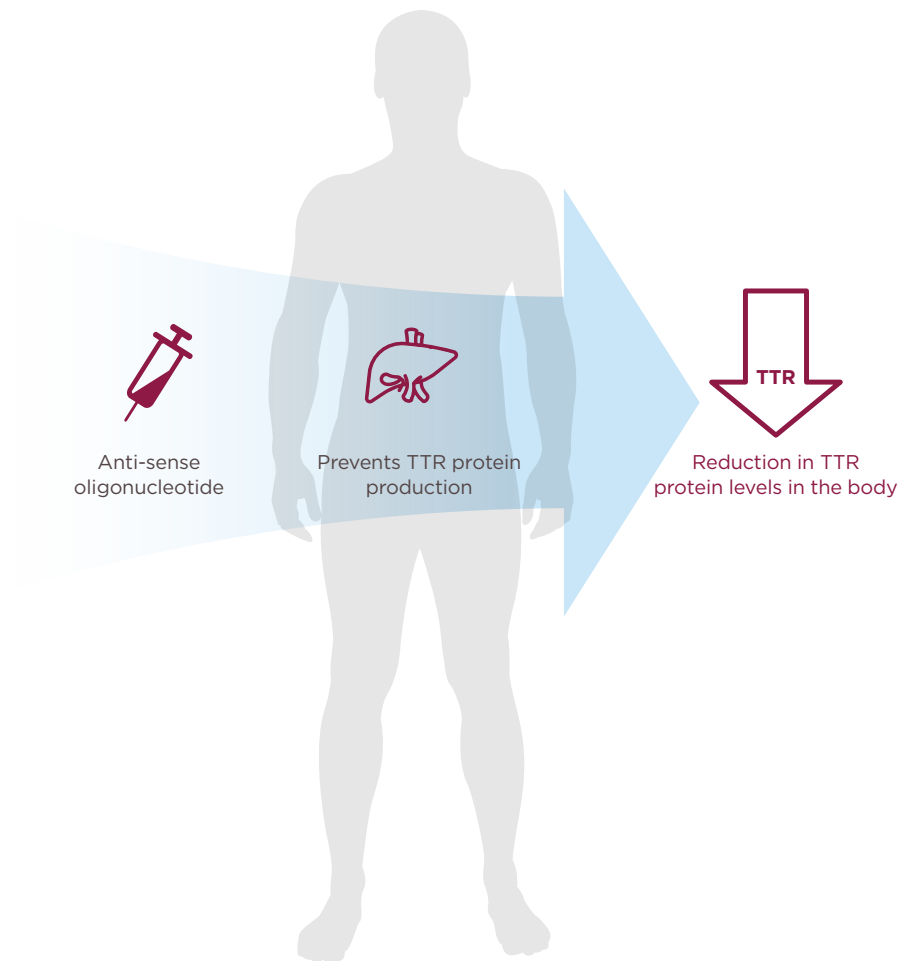
Touchpoints and support services offered by your Akcea Connect™ Nurse Case Manager



Treatment with TEGSEDI™

How TEGSEDI™ works

TEGSEDI™ belongs to a group of medicines called **anti-sense oligonucleotides**. It helps to reduce the levels of TTR proteins in the body by **preventing TTR production** by the liver.



Questions or comments to discuss with your Nurse Case Manager

Akcea Connect™ offers injection training for TEGSEDI™ patients and caregivers

The Akcea Connect™ Patient Support Program Team is equipped to offer injection training and administration support services in your home or through our speciality clinic network. The goal of injection training is to prepare you or your caregiver to administer TEGSEDI™ by yourselves.

Learning the proper injection technique is a very important step when beginning TEGSEDI™ treatment. Before using TEGSEDI™, your healthcare provider should show you or your caregiver how to use it the right way.

For additional injection training support, please contact
the Akcea Connect™ Patient Support Program at:



1-833-327-0723





A step-by-step injection guide for you or your caregiver

Before using TEGSEDI™, your healthcare provider should show you or your caregiver how to use it the right way. If you or your caregiver have any questions, ask your healthcare provider. If you have any questions after reading this guide, please discuss them with your doctor and healthcare team.

Please note: the information included in this injection guide is NOT meant to replace your doctor's instructions or the complete instructions for use included in the Patient Medication Information section of the TEGSEDI™ Product Monograph. Read the instructions for use in the Patient Medication Information leaflet before you start using your TEGSEDI™ prefilled syringe and each time you get a repeat prescription.

Injecting TEGSEDI™

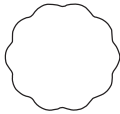
- Make sure that TEGSEDI™ is at room temperature (20°C to 25°C) at the time of the injection.
- Choose a different spot each time you inject TEGSEDI™ and make sure not to inject through clothing.
- **Do not** share your syringe with another person or re-use your syringe.

Warnings

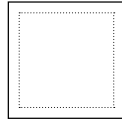
- **Do not** share your syringe with another person or re-use your syringe.
- **Do not** use if dropped onto a hard surface, if damaged, or if the needle is bent.
- **Do not** shake or freeze the prefilled syringe.
- **Do not** use if the expiry date on the side of the syringe body has passed.
- If any of the above happens, **throw away** the prefilled syringe in a puncture-resistant (Sharps) container and use a new prefilled syringe.
- **Do not** remove needle cap until you have reached Step 6 of these instructions and are ready to inject TEGSEDI™.

Prepare

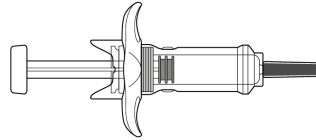
1 Gather supplies



1 Gauze Pad or
Cotton Ball



1 Alcohol
Wipe



1 TEGSEDI™ Prefilled
Syringe

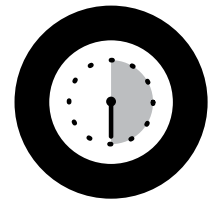


1 Sharps
Container

Do not perform the injection without all the supplies listed.

2 Prepare to use your TEGSEDI™ prefilled syringe

- Remove the plastic tray from the carton and check the expiry date.
- Let TEGSEDI™ warm up at room temperature (20°C to 25°C) for at least 30 minutes before giving the injection.
- Remove the syringe from the tray by holding onto the syringe body.



Do not use if the expiry date has passed.

Do not warm the syringe in any other way. For example, **do not** warm in a microwave or hot water, or near other heat sources.

Do not move the plunger.

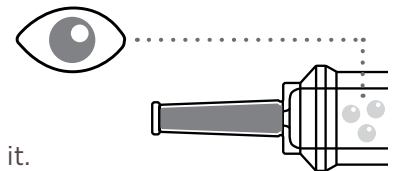
Do not remove the syringe from the tray by holding onto the needle cap or plunger.

3 Check the medicine in the syringe

- Look in the inspection area to check that the solution is clear and colourless or slightly yellow in colour. It is normal to see air bubbles in the solution. You do not need to do anything about it.

Do not use the product if the solution shows haziness, particulate matter, discolouration or leakage.

If the solution looks hazy, has particulate matter, discolouration or leakage, throw the prefilled syringe away in a puncture-resistant (Sharps) container, and use a new prefilled syringe.



4 Choose the injection site

- Choose an injection site on your abdomen or the front of your thigh.

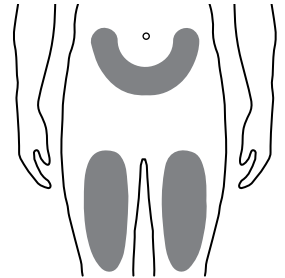
Do not inject into the 3 cm area around the belly-button (navel).

Do not inject into the same site each time.

Do not inject where skin is bruised, tender, red or hard.

Do not inject into scars or damaged skin.

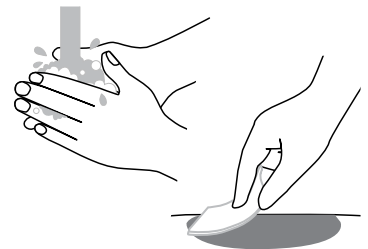
Do not inject through clothing.



5 Clean the injection site

- Wash your hands with soap and water.
- Clean the injection site with an alcohol wipe in a circular motion and let the skin air dry.

Do not touch the area again before injecting.



Inject

6 Remove the needle cap

- Hold the syringe by the body, with the needle facing away from you.
- Remove needle cap by pulling it straight off. **Do not** twist it off.
- You may see a drop of liquid at the end of the needle. This is normal.
- Keep your hands away from the plunger to avoid pushing the plunger before you are ready to inject.

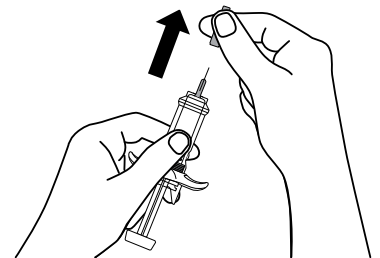
Do not remove the needle cap until right before you inject.

Do not pull the cap off while holding the syringe by the plunger. Always hold by the body of the syringe.

Do not let the needle touch any surface.

Do not remove any air bubbles from the syringe.

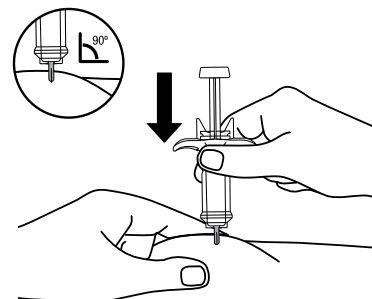
Do not put the needle cap back onto the syringe.



7 Insert the needle

- Hold the syringe in one hand.
- Hold the skin around at the injection site as your healthcare provider has instructed you. You should either gently pinch the skin at the injection site or give the injection without pinching the skin.
- Slowly insert the entire needle into the chosen injection site at a 90° angle until fully inserted.

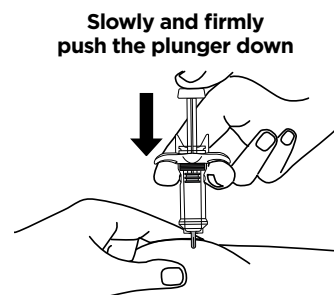
Do not hold the syringe by the plunger or push against the plunger to insert the needle.



8 Start the injection

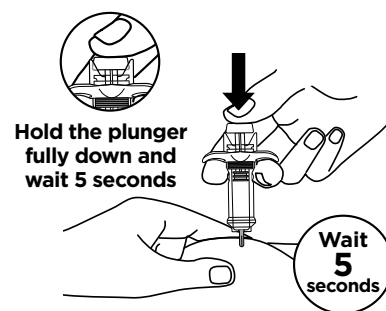
- Slowly and firmly push the plunger all the way down until the medicine is injected. Make sure the needle stays fully inserted in the injection site while you are injecting the medicine.
- It is important to fully push the plunger all the way down.
- Your syringe may make a click sound as you push the plunger down. This is normal. This **does not** mean that the injection is finished.
- The plunger can feel stiffer towards the end of the injection. You may need to press a little harder on the plunger to make sure you have pushed it as far as it will go.

Do not let go of the plunger.



9 Push the plunger down

- Push firmly on the plunger at the end of the injection. Hold the plunger fully down and wait for 5 seconds. If you let go of the plunger too quickly, you may lose some of the medicine.
- The plunger will start to lift automatically which means that the plunger has been pushed fully down.
- Press down again if the plunger does not start to lift automatically.



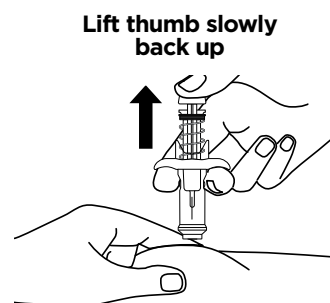
10 Complete the injection

- Slowly pull up on the plunger and let the safety spring push the plunger up automatically.
- The needle should now be retracted safely inside the syringe, and the safety mechanism spring visible on the outside of the plunger.
- When the plunger comes to a stop, your injection is complete.
- If the plunger does not rise up automatically when you release the pressure, it means the safety spring did not activate and you should push the plunger again but harder.
- Throw away the cap and syringe into the puncture-resistant (Sharps) container right away.

Do not pull the plunger up by hand. Lift the whole syringe straight up.

Do not try to replace the cap on the retracted needle.

Do not rub the injection site.



Disposal and care

- **Do not** throw away the prefilled syringe in your household waste.
- Discard the used TEGSEDI™ prefilled syringe in a Sharps disposal container right away after use.
- You will need to follow your community guidelines for the right way to dispose of your Sharps disposal container.



Usual dose

- 284 mg/1.5 mL inotersen injected just below your skin once a week.
- Your doctor may change how often you inject your dose depending on the results of your platelet count.
- Each prefilled syringe contains one dose and is for one-time use only.
- Use the entire contents of the syringe.
- Choose the same day of the week to have your dose.
- Your doctor will recommend taking Vitamin A while on TEGSEDI™.

Storing TEGSEDI™



2°C to 30°C

- TEGSEDI™ may be stored unrefrigerated (2°C to 30°C) in the original container for up to 6 weeks.
 - If not used within the 6 weeks, throw TEGSEDI™ away.



- Store TEGSEDI™ in the refrigerator at 2°C to 8°C in the original container and protect from light.



30 minutes

- Let TEGSEDI™ warm up at room temperature (20°C to 25°C) for at least 30 minutes before giving the injection.
 - Other warming methods should **NOT** be used (for example, do not warm in a microwave, or hot water or near other heat sources).

Serious warnings and precautions

TEGSEDI™ can lower the platelet count in your blood. Some patients taking TEGSEDI™ have also developed glomerulonephritis. This is a condition where your kidneys do not work properly. Therefore, before you start TEGSEDI™ and while you are using it, you will need regular blood and urine tests done by a medical lab or field nurse for your doctor to assess the effects of TEGSEDI™ on your platelet counts and kidneys.

Decreased platelet count (thrombocytopenia):

TEGSEDI™ can lower the platelet count in your blood. Your doctor should monitor you every 2 weeks while you are taking TEGSEDI™ and for 8 weeks after you stop taking it. This is especially important if you are elderly (since you may be at a greater risk of bleeding), or taking medicines to prevent the formation of blood clots or platelets or those that lower your platelet count.

If you experience or notice:

- unusual or prolonged bleeding (such as a rash of red spots on your skin, spontaneous bruising or bleeding in your eye)
- stiffness in your neck or
- an unusual severe headache

Call your doctor right away.

Tell your doctor before you take TEGSEDI™, if you take blood thinners or medications that may lower the platelet count such as acetylsalicylic acid and warfarin.

Glomerulonephritis/kidney problems:

It is important to know that treatment with TEGSEDI™ may cause glomerulonephritis (kidney inflammation), which is a condition where your kidneys do not work properly. Your doctor will check how well your kidneys are working before you start TEGSEDI™, regularly while you are taking TEGSEDI™, and for 8 weeks after you stop taking it.

Symptoms of glomerulonephritis are:

- Foaming urine
- Pink or brown coloured urine
- Blood in the urine
- Passing less urine than usual




Some patients taking TEGSEDI™ have also developed a decline in how well their kidneys are working without having had glomerulonephritis.

Tell your doctor if you are taking any medicines that damage the kidneys or affect kidney function, for example sulfonamides, aldosterone antagonists and some types of painkillers.

TEGSEDI™ and laboratory monitoring

Before you start TEGSEDI™ and while you are using it, you will need regular blood and urine tests done by a medical lab or field nurse. Regular monitoring will help your doctor detect potential side effects and take appropriate actions if they occur.

Laboratory tests

| | | Prior to starting treatment | During treatment |
|---|--|-----------------------------|--|
|  | Blood tests to check platelet count | ✓ | Every 2 weeks or more often if needed, and continue for 8 weeks after stopping TEGSEDI™ |
|  | Blood and urine tests to check kidneys | ✓ | Every 3 months* or more often if needed as clinically indicated, based on a history of kidney disease and/or renal amyloidosis, and for 8 weeks after stopping TEGSEDI™ |
|  | Blood tests to check liver | ✓ | 4 months after treatment and once per year thereafter |

* Patients with urine protein to creatinine ratio (UPCR) ≥ twice the upper limit of normal, or estimated glomerular filtration rate (eGFR) <60 mL/min, which is confirmed on repeat testing and in the absence of an alternative explanation should be monitored every 4 weeks or more often.

**Make your
laboratory testing
one of your priorities.
Regular monitoring is
an important part
of your TEGSEDI™
treatment.**

TEGSEDI™ may lower the level of vitamin A in your body

If you experience symptoms of low vitamin A before starting TEGSEDI™, your doctor will recommend you take a vitamin A supplement. Once your symptoms are gone, your doctor will start you on TEGSEDI™.

TEGSEDI™ may decrease the levels of vitamin A in your body and you may need to take a vitamin A supplement while on it. Your doctor will tell you the correct dose of vitamin A for you.

Look out for the symptoms of low vitamin A, which include:

- Dry eyes
- Poor vision
- Decreased night vision
- Hazy or cloudy vision

Talk to your doctor right away if you are pregnant, think you may be pregnant or are planning to become pregnant. TEGSEDI™ may affect your levels of vitamin A and low or high levels of vitamin A can harm the baby. If you are of child-bearing age, you should use a contraceptive method while on this treatment.



Possible side effects of TEGSEDI™

These are not all the possible side effects you may feel when taking TEGSEDI™. If you experience any side effects not listed here, contact your healthcare professional. Prior to starting your TEGSEDI™ treatment, be sure to ask your doctor for advice on how to manage the side effects. For a complete list of side effects, please consult the Patient Medication Information section of the TEGSEDI™ Product Monograph.

Very common side effects include the following:

- Thrombocytopenia (low levels of platelets which are blood cells that help your body form clots to stop bleeding)
- Anaemia (reduction in red blood cells which can make the skin pale and cause weakness or breathlessness)
- Vomiting or nausea
- Diarrhoea
- Constipation
- Injection site erythema (redness around the injection site), injection site pruritus (injection site itching) or injection site pain
- Fatigue
- Oedema peripheral (swelling of the ankles, feet or fingers)
- Pyrexia (increase in body temperature)
- Chills (feeling cold)
- Myalgia (muscle aches/pain) or arthralgia (joint pain)
- Headache

Common side effects include the following:

- Eosinophilia (an increase in the number of white blood cells called eosinophils in your blood which help fight infection)
- Chest pain or heart disorders, such as atrial fibrillation (an irregular heart beat that may increase your risk of stroke, or heart-related complications) or congestive cardiac failure (a condition in which the heart does not pump blood as effectively as it should, often associated with shortness of breath, weakness and swelling of the legs and ankles)
- Balance disorder, or vertigo (feelings of spinning or being off balance or unsteady)
- Hypothyroidism (low level of thyroid hormone which can cause fatigue, feeling cold, weight gain and poor memory and concentration)
- Eye disorders, such as cataracts (clouding of the eye lens which can lead to decreased vision), ocular hyperaemia (white part of the eye is bloodshot) or vitreous floaters (visual spots that resemble grey or black specks and can drift across the eyes)
- Dry mouth
- Abdominal distension (swelling or bloating of the belly)
- Gastroesophageal reflux disease (this occurs when acid in the stomach flows back into the food pipe causing heartburn)
- Flu like symptoms such as high temperature, aches and chills
- Peripheral swelling (swelling of the lower legs or hands)
- Injection site reaction (inflammation or damage to the tissue around the injection site), injection site bruising, swelling, discolouration, rash, haemorrhage (excessive bleeding from the injection site) haematoma (a solid swelling of clotted blood at the injection site) or induration (hardening of the area around the injection site)
- Upper respiratory tract infection (infection in the mouth, nose, throat or voice box)
- Asymptomatic bacteriuria (the presence of bacteria in the urine that does not cause symptoms)

- Skin infection, abrasion or lesion (scrape, graze, abnormal lump, or sore on the skin)
- Localized infection (an infection that affects a specific part of the body or organ)
- Gastroenteritis viral (infection in the stomach and intestines caused by a virus. Symptoms may include diarrhea, cramps and vomiting)
- Contusion (bruise)
- Limb injury
- Platelet count decreased (decrease in platelets which are blood cells that help your body form clots to stop bleeding)
- Changes to your blood and urine tests (this may indicate infection or liver or kidney damage)

These are not all the common side effects of TEGSEDI™. Please consult the Patient Medication Information leaflet that came with your medication for more information.

Serious allergic reaction (symptoms such as swelling of the face, lip or throat, rash, itchiness, hives, difficulty breathing or wheezing) can occur (frequency unknown). Stop taking TEGSEDI™ and seek immediate medical help if you experience these symptoms.

You may experience fatigue and flu-like symptoms such as high temperature, aches and chills during your treatment with TEGSEDI™. These are common side effects you that may occur as a result of treatment. If you develop flu-like symptoms, contact your doctor right away.

Questions or comments to discuss with your Nurse Case Manager

Join our Peer Mentor Program today!

Connect with someone who can relate

The Akcea Connect™ Patient Support Program now offers a Peer Mentor Program to help Canadian patients with hATTR.

Peer Mentors are here to help support you and other Canadians with this rare disease. They are available to share with you their personal experiences with this rare disease, starting treatment and their ongoing experience, as well as lifestyle tips that have helped them throughout their journey.

**Speak with
an Akcea Connect™
Peer Mentor today.
They may understand
what you're going
through and are
here to help.**



**Caring
mentors.**



**Dedicated
family members.**



**Patient
advocacy groups.**

All of these help make the community of this rare disease stronger together.

Ask your Nurse Case Manager to help you get connected to the people and resources that are available to help support you.

To connect and participate in the Akcea Connect™ Peer Mentor Program, call your Nurse Case Manager at 1-833-327-0723 or email support@akceaconnect.ca.

Questions or comments to discuss with your Nurse Case Manager

Lifestyle tips for patients living with hATTR

Once you move past the initial diagnosis, there are lifestyle changes you can make to help assist you with some of the challenges you may face with your diagnosis. Here are some tips to help you understand your diagnosis and take care of yourself:

- **Understand your condition**

- Learn everything you can about your diagnosis and how it affects you. Ask your doctor or see page 33 for a list of resources available to Canadians living with hATTR.

- **Recognize your emotions**

- Exercising, listening to music, or spending time with friends are ways to help manage stress and emotions you may feel. When you find a technique that works for you, incorporate it into your routine.

- **Join a support group**

- Reach out to others in your community by joining a support group where you can meet other people with similar experiences.

- **Manage relationships**

- Some friends or family may not understand the challenges you are facing. Try to focus on the relationships that matter most to you.

Questions or comments to discuss with your Nurse Case Manager



Akcea Connect™ supports caregivers

At Akcea Connect™, we understand that caregivers may play a special role in the lives of patients diagnosed with hATTR. As a caregiver, it is important to remember to take care of yourself and your needs first.

Taking steps to relieve stress and spend time for yourself can help you be kind to yourself while caring for a loved one. Here are some tips to manage stress and take care of yourself:

- **Ask for and accept help**

- Make a list of ways others can help you and allow them to assist you with tasks you feel comfortable with.

- **Join a support group for caregivers**

- At support groups, you can meet with other people with similar experiences and get support from your community.

- **Stay organized**

- Make to-do lists and set routines to help you maintain control.

- **Take time for yourself**

- Stay in touch with family and friends make sure to spend time every day doing something you enjoy.

- **See your doctor for regular checkups**

- Although you may be helping care for someone else's health, make sure to check in with your own doctor and manage your health.

Questions you may ask as a caregiver

What does it mean to be a caregiver?

A caregiver is anyone who provides care for another person in need. This person may be a child, an aging parent, a husband or wife, a relative, friend, or neighbour.

How does being a caregiver affect my health?

Being a caregiver may feel stressful. It is important to take care of yourself first so that you can take care of others.

Are there any caregiving support services that can help me?

Services such as meal delivery, home healthcare services, or legal and financial counseling may help you stay on top of these tasks. See page 11 to see how the Akcea Connect™ Patient Support Program can assist patients with hATTR and their caregivers with many of these services.

How can I stay informed and learn more about hATTR?

There are many resources available to learn more about hATTR. See the following page for a list of helpful resources.

Questions or comments to discuss with your Nurse Case Manager

Available resources for Canadians with hATTR

The Canadian Amyloidosis Support Network

www.thecasn.org

Canadian Organization for Rare Disorders

www.raredisorders.ca

Orphanet (Canada Page)

www.orpha.net/national/CA-EN/index/homepage/

Regroupement québécois des maladies orphelines (RQMO)

www.rqmo.org

Please consult the Patient Medication Information leaflet that came with your medication for more information on TEGSEDI™. This leaflet is only a summary and will not tell you everything about this drug. Talk to your healthcare providers about your medical condition and treatment and ask if there is any new information about TEGSEDI™.

Also, this booklet is not meant to replace the advice of your doctor. For any additional information regarding your treatment or condition, speak with your healthcare providers.



Akcea Connect™ is committed to Canadians on TEGSEDI™

The Akcea Connect™ Patient Support Program is a complimentary support program offered by Akcea Therapeutics Canada to assist patients on TEGSEDI™. Akcea Connect™ is committed to helping support patients, their families, and their healthcare team.

Akcea Therapeutics Canada is proud to offer its complimentary Akcea Connect™ Patient Support Program, which provides various resources to help assist you during your treatment journey. The goal of the program is to help you feel empowered about your healthcare through education.

* The Akcea Connect™ Patient Support Program is sponsored by Akcea Therapeutics Canada and administered through its third-party provider, Innomar Strategies™. The program administrator is required to collect, use and store your personal information in accordance with applicable privacy laws.



FAQs you can discuss with your Nurse Case Manager

What is hATTR?

To understand more about your diagnosis, see page 6 of this booklet. A list of additional resources for Canadians with hATTR are available for you on page 33 of this booklet.

I am nervous about telling my friends and family about my diagnosis, what should I do?

It is important for those in your support system to understand your diagnosis. For more advice on talking to your loved ones about your diagnosis, see page 10 of this booklet.

How can Akcea Connect™ help me?

Akcea Connect™ is here to support you throughout your treatment journey. To read more about the support services and training materials offered by Akcea Connect™, see page 11 of this booklet.

How does TEGSEDI™ work?

TEGSEDI™ helps to reduce the levels of TTR proteins in the body by preventing TTR production by the liver. To understand more about how TEGSEDI™ works, see page 13 of this booklet.

I am not prepared to administer the TEGSEDI™ injection, do you offer injection training?

Akcea Connect™ offers in-person injection training for you or your caregiver. To read a step-by-step injection guide, see page 15 of this booklet.

What laboratory tests will be performed throughout my TEGSEDI™ treatment?

Your Akcea Connect™ Nurse Case Manager will coordinate with you and your doctor to schedule and perform the laboratory tests required throughout your TEGSEDI™ treatment. To learn more about what tests will be performed and why they are necessary, see page 21 of this booklet.

What if I travel during my TEGSEDI™ treatment?

Akcea Connect™ can coordinate with you and your healthcare team while you travel to manage laboratory tests required throughout your treatment. To learn more about our support services, see page 11 of this booklet. For more information on TEGSEDI™ laboratory tests, see page 21.

What tools are available to help me follow my treatment schedule?

Be sure to fill out your TEGSEDI™ Dosing and Appointment Tracker to help you navigate through your treatment with TEGSEDI™, keep track of your dosing schedule, and more.

What is the Peer Mentor Program and who is it for?

Akcea Connect™ offers a Peer Mentor Program to help you connect with other Canadians living with hATTR. To learn more about this service and for lifestyle tips for patients living with hATTR, see pages 27 and 28 of this booklet.

Notes



Printed in Canada.
AKCEA Therapeutics, Inc.

