

Patient information

Romiplostim for Refractory Chronic Immune Thrombocytopenia Purpura (ITP)

Haematology Liverpool

What is romiplostim?

Romiplostim belongs to a group of medicines called thrombopoietin (TPO) receptor agonists. They work by stimulating the cells in the bone marrow to produce more platelets in your blood. This should prevent bleeding and bruising associated with ITP. Romiplostim may not return your platelets to normal levels, but it may increase them and improve your symptoms.

Romiplostim is only available from the hospital team and must be collected from the Lloyds pharmacy in the hospital.

Who should not take romiplostim?

- if you are allergic to romiplostim or any of the other ingredients of this medicine.
- if you are allergic to other medicines that are produced by DNA technology using the micro-organism *Escherichia coli* (E. coli).

Warnings and pre-cautions

Talk to your doctor or pharmacists about all your health conditions before starting romiplostim, particularly if:

- You have liver problems.
- You or a member of your family has ever had a blood clot or if you are at risk of having blood clots.
- You are pregnant or trying to get pregnant.
- You are breastfeeding or plan to breastfeed.
- If you have another blood condition known as myelodysplastic syndrome (MDS); taking romiplostim may worsen MDS.

Some patients on romiplostim have experienced dizziness. Although this dizziness only lasted a short period of time, be aware that it could affect your ability to drive or operate machinery.

Side effects

As with any medication, romiplostim is associated with side effects, although not everyone gets them. The most common side effects are:

- Headaches
- Allergic reactions
- Infection in the nose, sinuses, throat and upper airways (upper respiratory tract infection)

In some cases, **more serious side effects can occur**, such as blood clots. The signs of a blood clot include:

- swelling, pain, heat, redness, or tenderness in your leg,
- sudden shortness of breath, especially with sharp pain in the chest or rapid breathing.
- pain in the tummy, swollen tummy or blood in your stools.

If notice any of these symptoms, please contact your doctor immediately or go to the nearest hospital emergency department.

These are not the only possible side effects, and more are listed in the package leaflet.

Reporting of side effects

If you have any side effects, talk to your doctor, pharmacist or nurse. This included any possible side effects not listed in the package leaflet. You can report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard.

Taking other medications

Tell your doctor or pharmacist if you have been taking, have recently taken or might take other medications including over the counter medications, vitamins and herbal supplements.

In particular, tell your doctor if you are taking any of the following medications:

- Anticoagulants or antiplatelets, used to prevent blood clots.
- The contraceptive pill or hormone replacement therapy.

If you are taking other medications for ITP e.g. steroids, these may be stopped or reduced when given together with romiplostim.

Pregnancy and breastfeeding

Pregnancy

Romiplostim is not recommend during pregnancy. If you are pregnant or trying to get pregnant, ask your doctor or pharmacist for advice before starting romiplostim. If you are a woman who could get pregnancy, you must use reliable contraception whilst taking romiplostim. Contact your doctor straight away if you get pregnant whilst taking romiplostim.

Breastfeeding

Romiplostim is not recommend whilst breastfeeding. If you are breastfeeding or plan on breastfeeding, ask your doctor or pharmacist for advice before taking romiplostim.

How to take romiplostim

Before starting treatment, your doctor will measure your platelet count. Romiplostim will be given as a once weekly injection under the skin (subcutaneous) by a trained nurse. Your dose will depend on your weight and may be changed based on your platelet count.

Once your platelet count is under control, your doctor will regularly check your blood. Your dose may be adjusted further to maintain long term control of your platelet count. If you do not respond to treatment with romiplostim, your doctor will stop treatment.

Self-administering romiplostim

After suitable training, your doctor may allow you to inject romiplostim yourself. Your doctor, nurse or pharmacist will show you how to do this. Do not inject yourself with this medicine if you are unsure how to. Always use romiplostim exactly how your doctor has told you. It is still important you are followed up regularly with your doctor, to determine if this treatment is working or if another treatment needs to be considered. The vials of romiplostim powder must first be dissolved using the vial of liquid in the box. The leaflet in the box has detailed instructions on how to prepare and administer your dose. You will be shown how to do this and should follow these steps for each dose. There is also a video available that shows you all of the steps, ask the team to show you this if you would find it useful.

The number of millilitres you need to inject will be shown on the label when you collect your supply from pharmacy. Sometimes we might adjust your dose in between you collecting supplies from pharmacy, we should always tell you the number of millilitres this new dose is equal to. If you want to calculate the number of millilitres yourself then you can do so with the following calculation:

Your dose / 500 = number of millilitres to inject
ie 180micrograms / 500 = 0.36 millilitres

Even if you are prescribed a dose that is equal to the size of the vial (ie 500 micrograms or 250 micrograms) it is essential that you still measure the number of mls and not use the full vial. Each vial contains slightly more romiplostim than is needed to ensure it can be measured accurately for each dose.

Storing romiplostim

If you are injecting romiplostim yourself, you will be given a supply to take home. Romiplostim must be stored in the fridge. The boxes for romiplostim are very bulky and some people prefer to remove the vials from the box and store in the fridge separately, if doing this you must ensure these stay clean to avoid cross contamination.

If your fridge malfunctions or your supply is left out at room temperature, you must contact the team who will advise what to do.

Travelling with romiplostim

You can travel while you are receiving treatment. Romiplostim may be removed from the fridge and stored at room temperature for up to 30 days in the original carton (no warmer than 25 C). If you are planning to travel abroad or for a long period, talk to the haematology team who will be able to provide practical advice.

Disposing of romiplostim

You will be given a sharps bin when you are started on romiplostim, this should be used to dispose of all used vials and needles.

When your sharps box is full, and you need to dispose it you need to re-order a new sharps bin via your GP practice and arrange disposal of your full sharps box by one of the following methods depending on where you live:

| | |
|-------------------------------|--|
| Liverpool and Knowsley | Please inform your own GP practice to forward your details to the city council |
| St Helens | Contact the council direct on 01744 676 789 or visit their website |
| Sefton | Contact the council direct on 0345 1400845 |
| Wirral | Please inform GP practice and they will suggest the nearest pharmacy to arrange disposal |

Any patients living outside these areas please enquire at your GP practice directly.

Missed doses

If you have missed a dose of romiplostim, speak to your doctor about when you should have your next dose.

If your doctor has allowed you to self-inject and you forgot to give yourself an injection, you should inform your doctor immediately.

Taking too much or too little Romiplostim

Your doctor will ensure you receive the right amount of romiplostim. If you have been given more or less romiplostim than you should have, you may not have any physical symptoms, but your platelet count may change to very high or low. Your doctor will monitor you for any signs or symptoms of this, and you will be given the appropriate treatment if needed.

If your doctor has allowed you to self-inject and you use more or less romiplostim than you should have, then inform your doctor immediately or go to the nearest hospital emergency department.

Stopping treatment

Do not stop this medication unless your doctor tells you to. If you want to stop for any reason, please discuss this with your doctor. Be aware if you stop romiplostim, a low platelet count may reoccur.

If you have any further questions about the use of this medicine, ask your doctor, pharmacist or nurse.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information

For further information please contact

Haematology Liverpool

Tel: 0151 706 3397

Text phone number: 18001 0151 706 3397

Author: Haematology Liverpool

Review date: April 2027

All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

يمكن توفير جميع المعلومات المتعلقة بالمرضى الموافق عليهم من قبل انتمان المستشفى عند الطلب بصيغ أخرى، بما في ذلك لغات أخرى وبطرق تسهل قراءتها وبالحروف الطباعية الكبيرة وبالصوت وبطريقة برايل للمكفوفين وبطريقة مون والإلكترونية.

所有經信托基金批准的患者資訊均可以其它格式提供，包括其它語言、易讀閱讀軟件、大字體、音頻、盲文、穆恩體 (Moon) 盲文和電子格式，敬請索取。

در صورت تمایل میتوانید کلیه اطلاعات تصویب شده توسط اتحادیه در رابطه با بیماران را به اشکال مختلف در دسترس داشته باشید، از جمله به زبانهای دیگر، به زبان ساده، چاپ درشت، صوت، خط مخصوص کوران، مون و بصورت روی خطی موجود است.

زانباریی پیوهندیدار بهو نهخوشانهی له لایمن تراستهوه پهمند کراون، نهگمر داوا بکریت له فورماتهکانی تردا بریتی له زمانهکانی تر، نیزی رید (هاسان خویندنهوه)، چاپی گهوره، شریتی دهنگ، هیلی موون و ئلیکترۆنیکی ههیه.

所有经信托基金批准的患者信息均可以其它格式提供，包括其它语言、易读阅读软件、大字體、音頻、盲文、穆恩體 (Moon) 盲文和电子格式，敬請索取。

Dhammaan warbixinta bukaanleyda ee Ururka ee la oggol yahay waxaa marka la codsado lagu heli karaa nuskhado kale, sida luqado kale, akhris fudud, far waaweyn, dhegeysi, farta braille ee dadka indhaha la', Moon iyo nidaam eletaroonig ah.