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~~short term~~ *long-term* support for haemophilia

JASMINE GARCIA
USA
Glanzmann's thrombasthenia

Together we are driving
change in haemophilia

Understanding Glanzmann's Thrombasthenia

Patient information

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What is Glanzmann's thrombasthenia (GT)?

In individuals with GT, blood clotting does not work properly. The blood needs various blood components in order to clot, the most important being blood platelets. These platelets clump together to form a blood clot, and to do this, they need specific proteins known as glycoproteins. When you have GT, a specific glycoprotein called glycoprotein 2B/3A (also written GPIIb/IIIa) is missing or insufficient. This means that platelets will not form a strong clot and are therefore unable to stop bleeding.

Why do people get GT?

GT is a rare genetic disorder that affects approximately 1 in 1 million people. It is passed on by both parents and can occur in both men and women.

Signs and symptoms?

Common

- Easy bruising
- Nosebleeds or gum bleeding
- Heavy menstrual bleeding

Other, more severe symptoms

- Swelling, pain and warmth around a joint
- Inability to straighten or bend a joint
- Headache or neck ache
- Drowsiness or loss of consciousness
- Sensitivity to light
- Upset stomach
- Vomit that is black and syrupy or bright red
- Red- or black-coloured stools



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Stay healthy

Take care of your health:

To help prevent further health problems:

- Have your bleeds treated and tell your doctor how frequently they occur, even if bleeding is minor. Losing just 5 ml blood per day deprives the blood of 2.5 mg iron and may lead to anaemia (iron-poor blood).
- Maintain good dental hygiene.
- Avoid anti-inflammatory drugs (such as aspirin, ibuprofen, naproxen), which may affect platelets.
- Avoid intramuscular injection.
- Discuss sports activities with your doctor and consider avoiding sports associated with a risk of injury.

Recommendations given by your doctor:

Their purpose is to maintain your health. GT can be a severe disease, but with the right treatment and support, it can be properly managed.

- If you are diagnosed with iron deficiency, take your medication for as long as prescribed.

Special note for women:

- A hormone replacement therapy may help to manage heavy menstrual bleeding.
- Discuss ways to prevent bleeding during and after pregnancy/childbirth with your doctor.



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Inform others

Because it is rare, GT often goes undiagnosed. Unlike other rare coagulation disorders, there is not a lot of information available to help people with GT to understand their disease. With a better understanding of your condition, you will help yourself and other patients with GT.

For further information and references about GT and haemophilia, visit the World Federation of Hemophilia (WFH) website at www.wfh.org.

In an emergency, please keep in mind that GT is a rare disease, which means that some doctors may not be familiar with it.

- Make sure to always carry your emergency health card with you, showing your condition.
- Inform doctors, medical staff and relatives about your condition.
- Inform your school (teachers or other persons in charge) in cooperation with your haemophilia treatment centre.

Treatment options

Treatment depends on what type of bleed you have.

Minor injuries such as gum bleeding, or nosebleeds, may be treated effectively with local measures such as pressure, nasal packing, or medication administered locally, such as fibrin glue. Treatment options for more serious bleeds and surgery include platelet transfusions or medicines supporting the blood clotting process.

Please remember: A better understanding of GT can help to stop minor bleeds. In the case of severe bleeds or injury, you should go to the nearest haemophilia treatment centre.



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Novo Nordisk established HaemCare™ to support people with haemophilia, their families, as well as their attending physicians, carers and therapists.

HaemCare™ is part of the international Changing Haemophilia® initiative.

With HaemCare™, we offer a comprehensive range of services and are available to answer your questions or provide suggestions at any time.

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