

General information brochure for teenagers and adolescents with ITP

(Immuun Trombocytopenie)



Patiëntenvereniging
Nederland



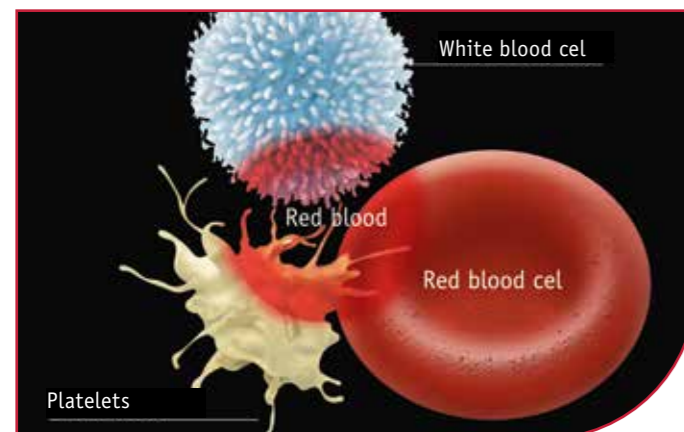
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Introduction

Perhaps you had been bruising easily and had frequent nose bleeds for a while. And then the doctor told you, 'You have ITP.' You may very well have many questions right now.

This booklet is intended to answer any questions you may have about immune thrombocytopenia, the disorder that is generally known as ITP. Reading all about the disorder will help you become more familiar with it and reduce your anxiety in case of certain symptoms or events. Being well informed enables people to better handle (chronic) disease.



This is what we want to contribute to with this booklet. If you have recently been diagnosed with ITP, it may seem scary initially, especially if you had never heard of it.

Once you know a bit more about ITP, you will find out that it does not have to be as bad as it initially seemed. Sure, there may be things you will have to change in your lifestyle, but most people with ITP live normal lives. There is no need to go on a diet, quit exercising, or stop going out.

What you do have to do, however, is accept that you have ITP and be more careful about contact sports or in other situations where you could sustain injuries or wounds. Other than that, by all means live your life as normal. Besides, the ITP may disappear on its own.

You will, especially in the beginning, have to make regular trips to the hospital for blood tests and doctor's appointments. There is a very small chance of complications or an underlying other condition. If you have any further questions or would like more information, ask your doctor, the Dutch ITP Patients' Association (ITP Patiëntenvereniging Nederland), or the ITP Expertise Network.



1. Everything you need to know about Immune Thrombocytopenia

What is ITP?

ITP is a disorder where your immune system is compromised for some reason and makes antibodies that attack your own blood platelets (which are also known as thrombocytes). This causes your platelets to be broken down faster than normal. It is, therefore, a form of autoimmune disease. Even though your bone marrow makes new platelets, it cannot keep up, which leads to a shortage of platelets.

ITP occurs both in men and in women and can arise at any age, both during childhood and at an older age. ITP is sometimes caused by another disease. We call this 'secondary ITP.' Secondary ITP may be treated differently because the treatment will then often be targeted on the underlying condition.

What exactly does it mean?

ITP involves a shortage of platelets in the blood, which is called 'thrombocytopenia' (thrombocyte = platelet; penia = shortage). Normally, platelets clot together in the blood around a wound to first stop the bleeding. If you don't have enough platelets, there may be more bleeding or the bleeding may go on for longer than normal.

What are the symptoms of ITP?

The first symptoms you will notice are unexpected bruises, which are often painless, or nose bleeds or bleeding gums. Girls may experience heavier menstrual bleeding or have longer periods. Fatigue is also a possible symptom of ITP. After successful treatment, most young people stop experiencing symptoms.

How can the doctor tell it's ITP?

First of all, the doctor will base their diagnosis on what you have told them (frequent nose bleeds or you bruise easily). ITP is supported by a blood test (and exclusion of other diseases). The normal platelet count varies by age, but anything over 150×10^9 per litre of blood is generally considered normal. With ITP, the platelet count is often under 100, but it can also be even lower than that, down to less than 3.

How can I be sure that it is not something else?

The blood test looks not only at the platelet count, but also looks at other results, such as amount of red blood cells and white blood cells. If these are also out of the ordinary, your doctor will run more tests. In almost all cases, an ITP diagnosis is not the start of another disease, such as leukaemia (a form of blood cancer). With those disorders, the blood test generally also reveals abnormalities in the red or white blood cells. Sometimes ITP may be part of a more general immune system disorder (secondary ITP). In that case, however, there will also be other symptoms, such as skin problems or painful joints. This can be examined through a lab test, especially when the patient has had ITP for a long time.

Why do you develop ITP?

ITP is an autoimmune disease, but there is no real insight into what triggers it. When you have an autoimmune disease, it means that your defences (your immune system) are not working properly. Your defences will then not only attack pathogens (viruses or bacteria), but also healthy parts of your body. In the case of ITP, your defence system attacks your own blood platelets.

In some cases, ITP develops after a virus infection, such as a throat infection or a cold. We also know that ITP can arise after another autoimmune disease (in 8.7% of cases). But in most cases, ITP develops without doctors being able to find out what caused it.

Did I catch it somewhere?

No, you didn't catch it somewhere. ITP is not an infectious disease. It is not an allergy either.

Can I pass ITP on to my children?

No, that is not possible. It is not like the colour of your eyes, which is hereditary. What we do know is that autoimmune diseases can run in a family. Since ITP is an autoimmune disorder, this also goes for ITP. But even then, the chance of that happening is very small. There are 2 to 3 new cases of ITP on every 100,000 persons in the Netherlands on an annual basis. This means roughly 500 new ITP patients a year, of which 125 to 150 are children. This makes ITP a rare blood disorder.

Does ITP affect my immune system in any other way?

No, not directly. ITP alone does not make you more susceptible to viral or bacterial infections. It does not increase the chance of you developing malignant immune system diseases such as leukaemia. If ITP is part of another disease or if you have to be on immune system suppressive medication for a prolonged period of time, this may compromise your general protection against infections. Your doctor will always discuss this with you and give you advice.



2. To treat or not to treat

Do I need treatment for my ITP?

In most cases, ITP does not require any treatment, because the symptoms automatically disappear in 75%-80% of children within a year. Also, taking medicine can sometimes lead to more problems than the ITP itself causes.

Whether or not to treat ITP depends not only on your platelet count, but mostly on whether you have bleeding problems or whether there are indications that ITP may be part of another disease (secondary ITP).

Needless to say, the doctor will want to know how your disease is progressing. You will, therefore, need regular check-ups. This is what we call 'watchful waiting', which means check-ups but no medication. Your doctor will advise you on what is the best option for you.

Whether or not you need treatment is something that will always be discussed with you and your parents before any treatment is started. Furthermore, the treatment plan can always be changed once treatment has started. This may be necessary when the side effects are more severe than initially hoped or when the treatment is not having the expected effect.

Treatment will depend on your age, your symptoms, and your personal preferences. Most people under the age of 18 are treated by a paediatrician, but if you are over 18, you will be treated by a specialist in internal medicine or by a haematologist (a doctor who specialises in blood diseases). The paediatrician, paediatric haematologist and you/your parents will assess together whether you need treatment, and if so, what treatment.

What treatment options are there?

Support treatments:

- Iron supplements in case of iron deficiency due to excessive blood loss
- Tranexamic acid in case of nose bleeds or heavy menstrual blood loss
- Contraceptive pill in case of heavy menstrual bleeding

Treatment for a low platelet count:

- Corticosteroids, such as prednisone
- Immunoglobulins directly into one of your veins through a drip (Intravenous immunoglobulin therapy (IVIG))

In some cases, such as when you have a tendency to bleed easily, it may be necessary to choose other kinds of therapy. This is called '2nd-line therapy.' Again, there are multiple options:

- Thrombopoietin receptor agonists (TPO-RAs). This is a substance that triggers the bone marrow to make extra blood platelets. Examples of commonly used TPO-RAs include romiplostim (Nplate®), which you have to inject into the fat underneath your skin every week, and eltrombopag (Revolade®), which is a pill you have to take daily.
- Rituximab (MabThera®). This medicine slows down part of your immune system so that fewer platelets will be broken down.
- MMF (CellCept®) or sirolimus (rapamycin®). These medicines are also immune system inhibitors that reduce the rate at which platelets are broken down.

It is often hard to predict which medicines are the most effective in which ITP patients. The doctor will go over your options with you and your parents.

If medication turns out not to work or to be insufficiently effective, another option may be to remove your spleen (splenectomy). This can help because the spleen plays an important part in the breaking down of your platelets. An important downside to having a splenectomy is that living without a spleen makes you more susceptible to certain bacterial infections, which can be serious if they are not treated properly (see the Splenectomy section for further details).

Additionally, there must always be a treatment plan ready for high-risk situations, such as when you need to have a tooth pulled at the dentist, when you need surgery, when you have a bleed that does not stop on its own, or when you have had a hard fall that causes you, your parents, or the doctor to worry about a possible major bleed. When these kinds of things happen, you must always consult with a doctor. In case of life-threatening bleeding, a combination of the medicines mentioned above is often prescribed and a platelet transfusion may be carried out.

If you have any further questions about these treatment options, you can always turn to your doctor and/or the ITP Expertise Network for advice.

Are the medicines dangerous?

Prescription medication is subject to stringent testing before being released and the side effects are stated in the insert. It is important that you read the insert, but do bear in mind that not everyone will experience one or several of the side effects listed.

To give you an idea of what to expect it is good to know that corticosteroids can lead to mood swings, sleeplessness, increased appetite, and weight gain. Other side effects, such as a moon face (a swollen, round face), diabetes, high blood pressure, skin changes, and osteoporosis, will not occur if you take corticosteroids for under 2 weeks. If you use them for longer than that, the doctor will monitor for these side effects.

If you receive intravenous immunoglobulin therapy (IVIG), you may experience an allergic reaction when the medicine is administered. In that case, the immunoglobins will be administered at a slower rate or the therapy will be stopped altogether. Sometimes it helps to take allergy medication (antihistamines) or corticosteroids before the next dose of immunoglobins is administered. After the drip, you may develop a (severe) headache, nausea, shivers, or a flu-like feeling with a slight fever. These symptoms will pass.

Long-term prednisone, CellCept®, rapamycin® and rituximab use comes with specific potential side effects. Seeing as these medicines are not prescribed as often, we will not go into these side effects here.

Does treatment always work?

Every person is unique. What works for one person may be less effective for another. It may take a while for your treatments to be set up correctly for you. Try to be patient. If treatment with medication is unsuccessful, a splenectomy may ultimately be considered, depending on the severity of your symptoms. Sometimes, however, the platelet count remains low for a long time despite treatment.

Splenectomy

A splenectomy is the surgical removal of your spleen. It is very important to think carefully about this and get advice from your doctor and/or the ITP Expertise Network.

A splenectomy is almost always performed laparoscopically, which means that the surgeon will not make any cuts, and under general anaesthesia. The idea behind performing a splenectomy in case of ITP is to increase your platelet count. The ITP makes antibodies that stick to your platelets, causing the spleen to filter them out of your blood. Removing the spleen can prevent this from happening. However, a splenectomy is almost never done in young people because young people often recover from ITP without treatment.

Once the spleen has been removed, there is a greater chance of infections and fever. Therefore, you will be put on antibiotics for at least 2 years as a precaution. After that, it is important to always have antibiotics 'on hand.' Getting an annual flu jab is also recommended. Before the surgery, you have to get a pneumococcal and a meningococcal vaccine, as well as other vaccines, and these will have to be repeated as necessary. The pneumococcal vaccine will be repeated every 3 years. In 2018, the Dutch public health authority (RIVM) changed its advice, recommending more vaccinations than they previously did. If your spleen was removed before 2018, you may need certain catch-up vaccines. After a splenectomy, you should check the guidelines every 3-5 years to see if there have been any changes. Discuss this with your doctor.

For details, see the website of the Dutch public health authority (RIVM) <https://lci.rivm.nl/richtlijnen/asplenie>.

Will a splenectomy help?

In 60%-70% of people who have had a splenectomy, the treatment worked, albeit only temporarily in some cases. Since you cannot put the spleen back once it has been removed, doctors will always first try to solve the problem using other treatment options. But these other treatments are never 100% effective in all patients either.

Could alternative medicine help?

As yet, there has not been any proper research done into alternative medicine. Not into its efficacy, and not into the side effects. Think carefully before starting an alternative medicine treatment. And make sure you tell your doctor about your alternative step.

What about if the ITP does not go away?

A distinction is often made between

- new acute ITP (under 3 months)
- persistent ITP (the ITP is active for longer than 3 months but under a year)
- chronic ITP (active for over a year)

Of all children with ITP, roughly 40% recover within 3 months and a further 40% recover within 1 year. Around 20% of these children will have ITP for longer than a year. Of the latter group some will still recover, but it is hard to say after how long.

There are many people who live happy and normal lives with chronic ITP. Chronic does not mean that the ITP cannot go away. The word 'chronic' does not mean either that the ITP is severe, it merely means that you have it for longer than a year. You can have mild chronic ITP and lead a very normal life in many respects, but you may also experience more serious symptoms.

If your ITP does not resolve, you will find that you eventually learn to manage it well. You get used to the fact that ITP is simply a part of you. You will often gradually become able to do more things than in the beginning. The platelets that you do have are of excellent quality and do what they have to do very well. In most cases, your life will then return to being reasonably normal.



3. In case of emergency

Emergencies

Most people with ITP never have an ITP-related emergency. That said, it is good to know when you should go to the hospital's accident and emergency department, so as to prevent you from worrying unnecessarily.

If you somehow sustain a hard blow to the head or have a severe headache, and you feel nauseous and your eyesight is deteriorating, you should go to the hospital right away. In such cases, it is important to check for bleeding in your head. If there is indeed bleeding in your head, don't panic. They will count your platelets and put you on a (different) treatment to correct it rapidly.

If you are suffering a bleed that cannot be stopped, call an ambulance or have someone take you to the hospital for immediate treatment. Make sure the receptionist is told that you have a blood disorder and that you need treatment fast.

If you were in an accident and need first aid, always tell the emergency responders that you have ITP.

Fever

If your spleen has been removed, always seek medical assistance when you get a fever (a temperature above 38.5°C or a temperature above 38°C with shivering). A fever may mean that you have an infection that requires (additional) antibiotics. This is important because infections are potentially more serious when you don't have a spleen.

How should I stop a nose bleed?

First blow your nose thoroughly once. Next, squeeze the side of your nose, just below the bone, but above your nostrils. Sit still for five minutes, bent forward slightly so that the blood does not flow into your throat. Then slowly release your nose and stay seated for another five minutes.

You could use xylometazoline (Otrivin®) nose drops or spray in case of a nose bleed. This will make the blood vessels in the nasal mucosa contract, which helps stem the bleeding. In case of a very severe nose bleed and that goes on for longer than 30 minutes, call your doctor. You may be prescribed tranexamic acid (Cyklokapron®) for a few days.

Allergies such as hay fever can trigger nose bleeds, so always make sure you properly manage your allergy.

Don't hesitate to call your doctor or GP when you are experiencing unusual symptoms or have concerns about your health, they are there to look out for your well-being.

4. Friends and school

Interacting with friends

Perhaps you find it hard to accept that you feel different from your friends and classmates, and perhaps you don't want to tell them that you have ITP. The information about ITP provided in this booklet will help you decide whether or not to explain it to your friends.

What do I tell my friends?

Tell your friends not to be afraid to be around you. ITP is not infectious. They don't have to change their behaviour towards you in any way, because you are the same person as you were before you were diagnosed with ITP. What they do need to know, however, is that you bruise easily. And if you are in a (road) accident and they are also on the scene, they must remember to tell the emergency responders that you have ITP. On the website of the expertise network, you can make and print an SOS card (<https://itp-expertise.net/wat-te-doen-bij-spoed/>). It is also a good idea to create a Medical ID on your smartphone. A Medical ID contains your diagnosis (immune thrombocytopenia) and phone numbers for family members who can be called when something happens to you.

Do I have to tell my school about my ITP?

That would be a good idea. The Dutch ITP Patients' Association has a letter with tips about ITP that you can make available to fellow students at your school or give to your tutor (see 'brochures' on the website www.itp-pv.nl). When you experience severe fatigue, for example, don't hesitate to tell your tutor/student counsellor.

Can I still do PE and/or sports?

There's no simple 'yes' or 'no' answer to this question. It depends on various factors, including your platelet count and your tendency to bleed easily. If you only have bruises and petechiae (tiny spots of bleeding under the skin), you can still do a lot of sports. There is no reason for you not to be able to go swimming, running, or engage in other sports that don't involve physical contact with others.

Do be careful, however, with contact sports, such as boxing and taekwondo, and certain extreme sports. The basic rule is that it is okay for you to practise, but not to be a sparring partner to someone else. If you are very good at PE and sports, and you like it a lot, you'll want to be able to get back to it as soon as possible.

You can also consider wearing personal protection in certain cases. You could wear a helmet when you go cycling or roller blading. That's not weird at all, professional cyclists always wear a helmet, so why wouldn't you? When you go back to doing sports, gradually increase the intensity and closely monitor what effect it is having on your bleeding before you take the next step.

If you are not sure, think something is too dangerous, or are afraid of injuries or bleeds, talk to your doctor to get tailored advice.



Do I have to tell anyone else?

Your dentist needs to know that you have ITP. If you see any other medical practitioners, such as a physiotherapist, it would be a good idea to let them know as well. You could give them a leaflet with general information about ITP. Other than that, use your common sense to decide whom to tell about your ITP.

Are there any jobs I can't do?

Young people generally have light jobs on the side. This is not a problem. If you are unsure about whether or not it is okay to do a certain job, talk to your doctor about it and listen to your body. It may be good for your employer to know about your disorder. You could also consider giving them a leaflet with general information about ITP.

Riding an electric scooter or moped, or driving a car

You can ride a scooter or a moped or drive a car, or take driving lessons, with ITP. Always make sure to wear a helmet when riding and to wear a seatbelt in the car.

5. Living with ITP

I'm still scared that I won't live very long

There is no evidence that suggests that people with ITP live shorter lives than others. The only risk of an early death is in case of heavy bleeding, but that's very rare. In fact, the risk of premature death is much greater if you smoke, drink a lot of alcohol, or use laughing gas or other drugs than because of having ITP.

Do I have to change my lifestyle?

Not drastically. After you have just been diagnosed, you may be unsettled for a while and perhaps scared to get bleeds or insecure about what lies ahead. After that initial period, you will generally find a way to live with it.

Sometimes I feel depressed because I have ITP

Living with ITP sometimes presents new challenges and you might feel as though you are on an emotional roller coaster. It is not strange that you feel sad, disappointed, upset, or angry, but most people with ITP quickly learn to deal with it. Perhaps you would like to share your concerns or feelings with a family member, a good friend, or your doctor. You can also talk to fellow ITP patients on the forum or website or on the ITP Patients' Association's special Facebook page. You can overcome all your frustrations if you focus your attention on what you can do instead of on your limitations. Remember that there is always a chance that the ITP will go away, and keep that in mind.

Why does my family not understand how I feel?

People who have ITP generally don't look sick. If you have younger siblings, they may wonder what all the fuss is about. Especially when they don't see anything wrong with you, except maybe a few bruises. They may find it hard to understand what you are going through, so talk to them. Everything will become a lot easier for everyone when the emotions are clear.

If you still live at home, your parents may also have their own problems. They may worry about you and try not to let on to you how worried they are, because they think that will make it worse for you. On the other hand, you may not be willing to discuss your problems with your parents, because you want to be less dependent or don't want to burden them with your concerns.

Our advice is to talk about it anyway, so that you all understand each other. If you really don't want to talk to you parents about it, find someone else to share your concerns with. If you have recently been diagnosed with ITP, your parents will probably want to be there for you and learn about the disorder together with you. Even if you are an adult and your parents no longer go with you to your appointments with the specialist, it is still nice to keep them (and other family members and friends) informed.

Do my parents have to come with me to my doctor's appointments?

This depends entirely on your age and the kind of relationship you have with your parents. Under Dutch law, your parents are medically responsible for you until age 12, meaning that they are the 1st point of contact for the doctor. From age 12 to 15, you and your parents have

joint responsibility for your health. This means that you and your parents both have to see the benefits of and approve a treatment together with the doctor. From age 16 onwards, you are personally responsible under Dutch law, meaning that you are authorised to choose your treatment yourself, in consultation with your doctor. But in some cases that's far from simple! And then it is nice to have your parents by your side, so that you can discuss it. In fact, it is always a good idea to take someone with you to your doctor's appointments. Two heads remember more of what the doctor said than one.

It can also be useful to write down in advance what you want to tell or ask the doctor. During an outpatient appointment, you easily forget to mention things. Don't hesitate to speak up when you don't know what certain medical terms mean. If there is anything you don't understand, ask what it means. This way, you will have a better understanding of what you have and what the doctor wants. And if you think of any questions later, you can often call your doctor.



I'm very tired

Some people who have ITP can feel very tired. It is not yet known exactly why this happens. Luckily, we do know now that this can be a symptom of ITP. Try to bring some regularity to your life. It can also help to keep exercising. Listen to your body when you feel severe fatigue. Rest in time, but also make sure you keep up your physical fitness. If you gradually lose your ability to do things or gradually do less, this will in the long term reduce your fitness and affect your sleeping pattern.

I'm scared of needles

Jab anxiety is perfectly normal. No one likes to get a jab. Take comfort in the fact that you're not the only one. However, most young people with ITP get used to blood tests and eventually overcome their fear of needles. That being said, your anxiety may be to such an extent that it causes you to sweat profusely, feel light-headed, faint, and experience other stress symptoms.

What can help is to drink lots of water and eat well before the jab. Try to relax, and try to take deep breaths. Focus on a distraction, such as a video on your phone or listen to music. Whatever you do, make sure you mention your fear of needles at the lab and to your doctor, so that they can find a suitable solution for you personally.

6. Medication, diets and vacations

How about medication?

If you are prescribed medication for a condition other than ITP, you are advised to remind your doctor that you have a low platelet count. In some cases, ITP can get worse because of certain medicines. Also, your ITP meds may not go together well with the other medication. The dosage will then have to be adjusted temporarily.

Remember that acetylsalicylic acid (Aspirine®) or other NSAIDs, such as ibuprofen (Advil®), naproxen (Aleve®) or diclofenac (Voltaren®), may aggravate your symptoms because they reduce the effectiveness of the small number of platelets that you do have. There are many medicines that contain NSAIDs, especially cold and flu medicine. Always ask your pharmacist to check for that.

Instead of NSAIDs, you can use acetaminophen (paracetamol), but always follow the dosage instructions from the insert. If acetaminophen does not sufficiently alleviate the problem, ask your doctor to prescribe an alternative. The only NSAIDs that are allowed are the selective COX-2 inhibitors, such as celecoxib or etoricoxib (Arcoxia®).

Is there anything I cannot eat or drink?

No. Unless you have another medical condition that limits your diet, there is absolutely no reason not to be able to eat and drink whatever you want. That said, a healthy and varied diet is always recommended.

Alcohol should not be a problem for people with ITP, provided that you limit yourself to one or a couple of glasses at most. Alcohol makes blood vessel dilate, which makes them more susceptible to bleeding.

As far as drugs are concerned, everyone knows how dangerous doing drugs can be. XTC can impede blood from coagulating, which means that XTC is very bad for people with ITP.

How about vaccinations?

People with ITP can get vaccinated as normal. If your platelet count is under 50, vaccines should preferably be injected under the skin (subcutaneously) instead of into the muscle (intramuscularly). Some vaccines can only be administered intramuscularly. This is essentially safe, provided that the platelet count is higher than 10. The injection site must then be pressed firmly for 10 minutes (no rubbing).

If you, for your ITP, go on a Rituximab drip, corticosteroids, or other medication that suppresses your immune system, it is recommended to leave at least three months between that treatment and any vaccination(s). If not, the vaccines might not be as effective. Aside from that, live attenuated vaccines cannot be administered at all during a treatment with the above medicines. This will in some cases apply to vaccines you need for a far-away holiday and before you get a splenectomy. Make sure you always discuss this with your doctor.

7. For girls

What about periods?

Teenage girls who have ITP will find that their periods can last much longer and cause heavier than normal bleeding. If you are experiencing this, tell your doctor. The doctor may decide to give you tranexamic acid (Cyklokapron®) to take when you have your period (which will improve your blood's coagulability). Or a hormone preparation ('the pill') to temporarily regulate your menstruations.

You may also be referred to a gynaecologist to discuss further options. If this is a male doctor and you don't feel comfortable with that, don't hesitate to ask for a female doctor.

Make sure you always have clean underwear/clothes with you when you have heavy menstrual bleeding. You could, for example, keep extra clothes in your locker at school/work. Then you won't have to remember to bring clothes every time.

Can I get pregnant while I have ITP?

There is a chance that the ITP will have resolved by the time you want to get pregnant. If not, there is still no need to worry. There have been many women with ITP who have given birth. It is, however, always a



good idea to discuss this with your haematologist before trying to get pregnant. They will consult with the gynaecologist to assess what would be best for you.

If you have a very low platelet count, you are advised, though, to have your baby at the hospital. A hospital is better equipped to deal with any unexpected bleeding in relation to the delivery, but also because your baby may in some cases need to be delivered with extra care. It is also important that your baby be checked over immediately after the birth. Some babies also have thrombocytopenia temporarily because the ITP antibodies were transferred through the placenta. In some cases, the baby has to be put on medication temporarily. Make sure you discuss this with your haematologist.

8. When travelling

Can I go on holiday or take part in (foreign) excursions?

Of course you can, but do take a few precautions. Here are a few things to bear in mind:

Before you go:

- Do you need any vaccinations for your trip, such as against hepatitis or typhoid fever? Remember that if you are on certain medication it is sometimes best to wait three months after this medication has ended before getting vaccinated (see point 6: What about vaccinations?)
- Try to find out what they call ITP in your destination country in case you experience problems. The ITP Patients' Association has a letter in English you can take with you. This letter is available for download on our website (www.itp-pv.nl).
- Check where the nearest doctor and hospital are near your (holiday) location, for in case of an emergency.
- If you are not travelling with your parents, make sure someone in your party knows that you have ITP.

After departure: enjoy yourself and try to forget about your ITP.

Am I okay to fly?

The cabin pressure on a commercial aircraft is constant. Even during turbulence, the pressure will remain constant. The whole process of increasing pressure during take-off and reducing pressure (down to the

normal level) on the descent is gradual and there is virtually zero chance of this causing bleeding.

You can ask your practitioner if you can bring medicines for an emergency, such as tranexamic acid (Cyklokapron®) or xylometazoline (Otrivin®), which is often prescribed for nose bleeds and bleeding gums

Platelet counts are less important than a visible/noticeable tendency to bleed easily. With chronic ITP without symptoms, flying does not seem to be much of a problem. On the other hand, however, it is recommended to think about what to do if problems do arise, either during a flight or during your stay. Discuss this with your doctor.

9. What else?

Will my acne worsen because of the ITP?

ITP will not make acne any worse, but steroids will. Bleeding spots may bleed for longer. Your doctor can help you or refer you to a skin specialist (dermatologist).

Can I get a piercing or a tattoo?

If your platelet count is under 50, getting your ears (or another part of your body) pierced is advised against because it will be hard to stop the bleeding. The same goes for tattoos, whereby the bleeding can cause the tattoo to convert into a bruise. Hopefully your ITP improves soon and you can again think about whether you want a tattoo or piercing after all. If you had your ears pierced before you got ITP, there is nothing to worry about.

Shaving and hair removal

If you cut yourself while shaving, it may take a bit longer for the bleeding to stop. Therefore, use an electric or safety shaver to prevent cuts. Hair removal may lead to bruising. Removing eyebrow hairs by their roots (epilation) may cause bruises or bleeds, but using hair removal creams is fine.



10. In closing

We hope you have found all this information useful. If there is anything that is not clear to you, please let us know! And if you have any further questions, please email them to info@itp-pv.nl. We will do our best to answer them.

You can also find us on Instagram and Facebook: ITP Patiëntenvereniging Nederland. There is also a private Facebook page that only members can access. You can communicate with other members with ITP there.

Furthermore, the patients' association tries to organise an annual day where you can meet other young people with ITP.

Website: www.itp-pv.nl

Email: info@itp-pv.nl

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Dutch ITP Patients' Association

The Dutch ITP Patients' Association (ITP Patiëntenvereniging Nederland) was founded in May 2003. Every year, a number of information sessions are organised to explain medical developments and give patients the opportunity to exchange experiences with each other. The association also publishes a newsletter 3 times a year. For more information and other brochures, please visit our website www.itp-pv.nl. Our website also provides details of how to support our association.



Patiëntenvereniging
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