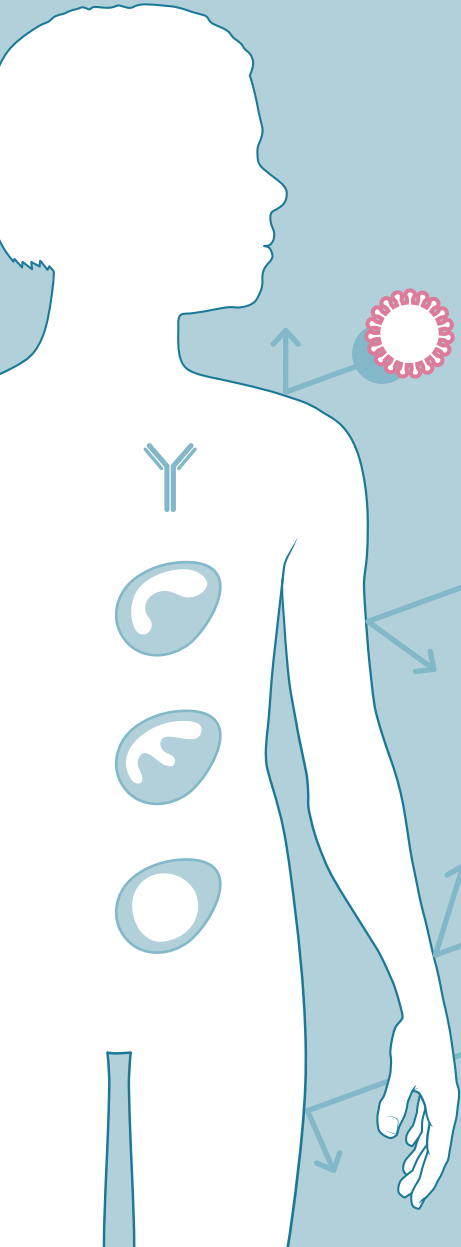




# The defense system



The body has a defense system.

The body's defense system is also called the **immune system**.

This system is the body's defense against, for example, **viruses** and **bacteria**.

The defense system protects the body with **antibodies** and **defense cells**.



# What can go wrong?

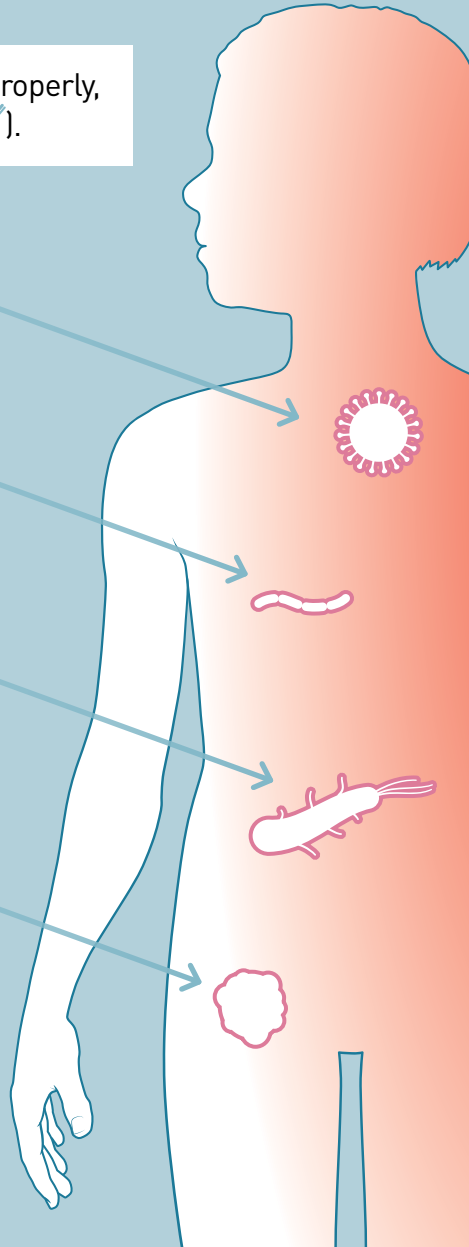
Sometimes the defense does not work properly, because there are too few **antibodies** (Y).

Bacteria and viruses can then infect the body, resulting

in illness.

The reason for this may be an immune system disorder.

An immune system disorder is also called '**immunodeficiency**'.





# Tests to determine whether you have an immune system disorder

In the hospital, the healthcare team will look at why your defenses are not working properly.

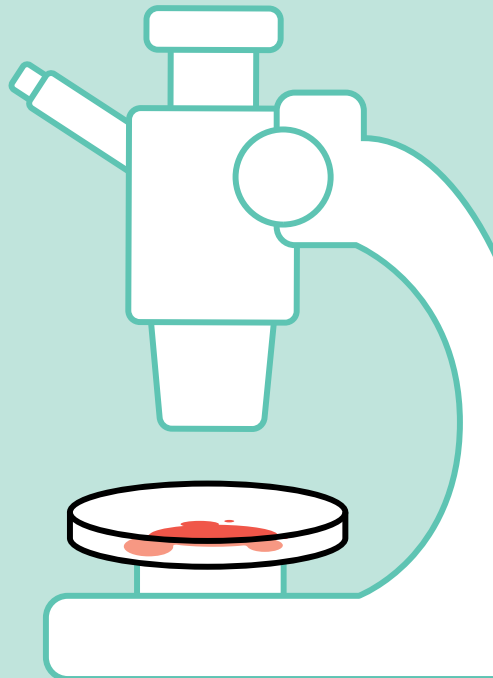
The following tests are possible:

## 1 Blood test

We examine your blood for antibodies and defense cells.

There are different types of **antibodies** and **defense cells** in the blood.

We investigate how many antibodies and defense cells are present and whether they are working correctly.





# Testing with a vaccination

2

## Vaccination



Sometimes testing involves a test vaccine. The **vaccine** is given through an **injection**.

First, we test your blood prior to vaccination.

Then you receive the vaccination.

**Approximately 4 to 6 weeks** after the vaccination, we test your blood again.

Then we see if you have formed antibodies from the vaccination. We call this a '**response**'.

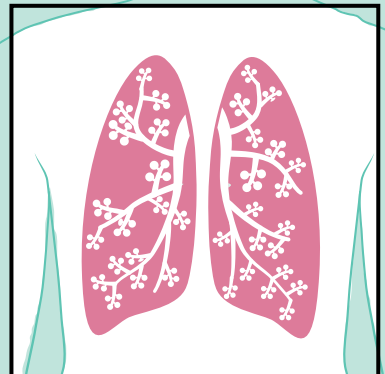
It enables us to see if your defense system is working properly.

3

## A lung x-ray or CT scan

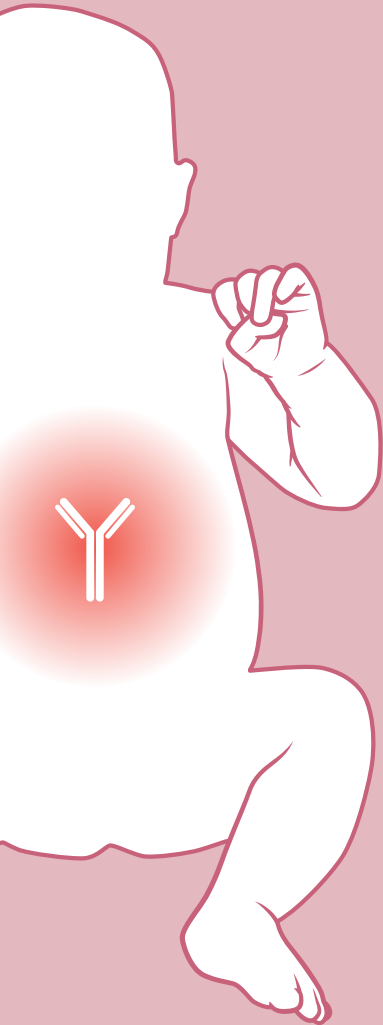
Sometimes further testing is needed.

For example, an investigation of the lungs. Sometimes **x-rays** or a **CT scan** of the lungs are also performed.





# An immune system disorder



There are over **400** different congenital immune system disorders.

They lead to a range of symptoms.

They are all of differing severity too.

**Congenital immune system disorders are rare.**

A congenital immune system disorder is called '**primary immunodeficiency**'.

The abbreviation is **PID**.

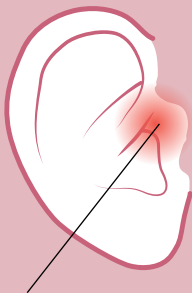
Symptoms caused by PID may not occur until advanced age. This is not the same for everyone.



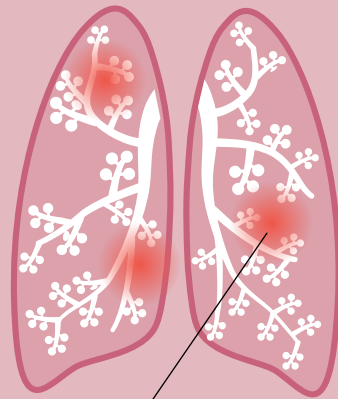
# Symptoms with an immune system disorder

Patients with an immune system disorder may have a wide range of symptoms, including:

- **Being frequently sick**
- **Infections, such as an ear infection or pneumonia**
- **Recurrent infections**
- **Fatigue**



Ear infection



Pneumonia

Do you want to learn more about immune disorders?

Or do you want to connect with other people with an immune system disorder?

The **dsai e.V. patient organization for congenital immunodeficiency** can help you with this.

[www.dsai.de](http://www.dsai.de)

or call them at 08074 8164

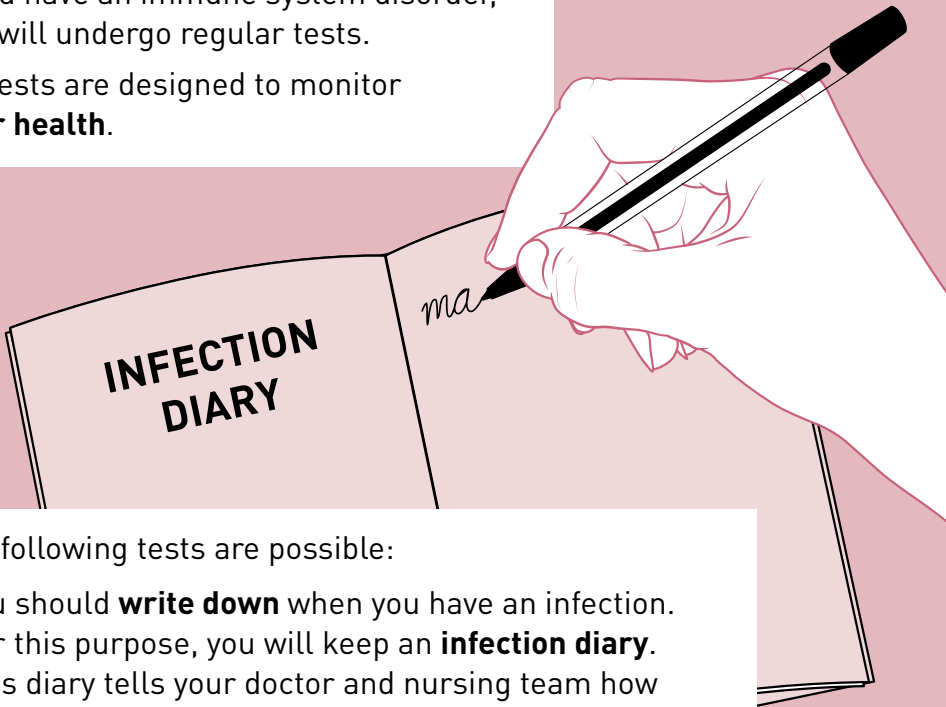




# An immune system disorder is present - what then?

If you have an immune system disorder, you will undergo regular tests.

All tests are designed to monitor **your health**.



The following tests are possible:

- You should **write down** when you have an infection. For this purpose, you will keep an **infection diary**. This diary tells your doctor and nursing team how many infections you have and how severe they are.
- You will regularly attend your doctor or hospital for check-ups.
- Your blood levels will also be checked regularly.
- Sometimes further testing is needed.



# Testing for pathogens

If you are sick, please **call** your doctor or nursing team.

The doctor or nursing team will want to know whether the disease has been caused by a bacterium or a virus. A culture medium can be used to check whether the disease has been caused by a bacterium or another pathogen.

The doctor can then also see which bacteria or pathogens are making you sick.



Sometimes the doctor prepares the **culture**. Sometimes you prepare the culture yourself. You then cough up some mucus and bring the mucus in a vessel to the doctor or hospital.

## When are you sick?

- You have a fever of more than 38 degrees Celsius
- You are coughing up mucus
- You have diarrhea
- You feel unwell

If in doubt, you can **ask** your doctor or nursing team about it **at any time**.



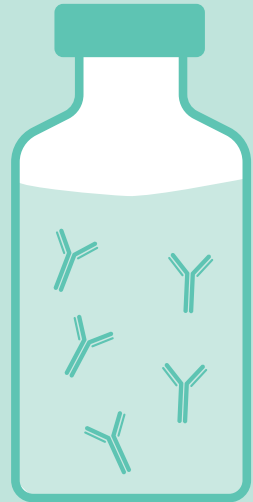


# Drugs for an immune system disorder

If you are sick, check with your doctor or nursing team to see if you need medicine.

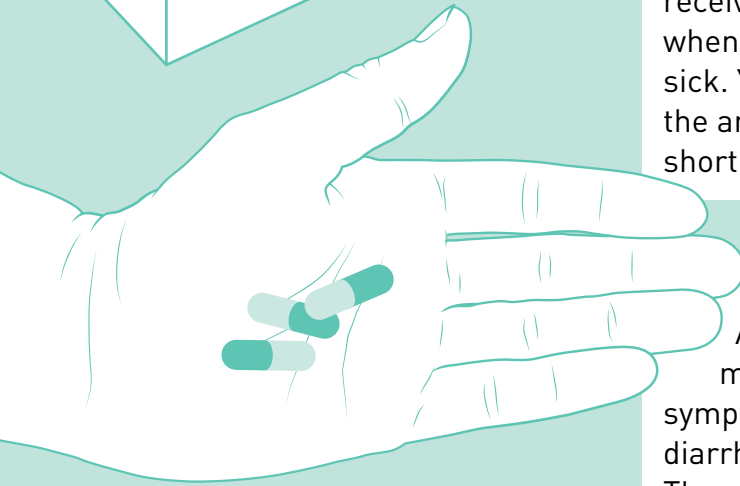
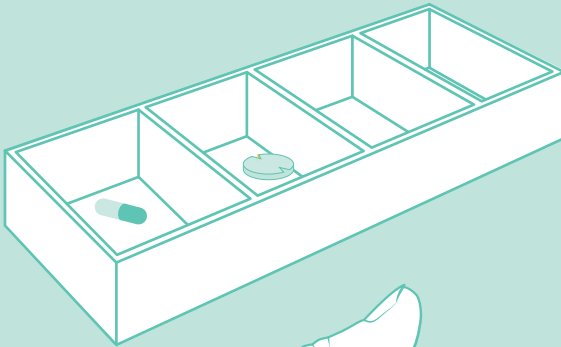
If you need medicine, there are the following options, for example:

- **Antibiotics**
- treatment with **immunoglobulins**





# Antibiotics



Antibiotics are medicines **against infections** caused by **bacteria**.

Sometimes you will receive antibiotics when you are already sick. You will often take the antibiotics for a short period of time.

Antibiotics may result in symptoms, such as diarrhea or nausea. These symptoms are called side effects.

Ask your doctor or nursing team about possible side effects.

You can also find the side effects in the **package leaflet**.



# Immunoglobulins



Immunoglobulins

**Immunoglobulins are antibodies** in the blood.

Antibodies help the body to recognize bacteria or viruses.

This way, the antibodies try to prevent you from getting sick.

People **with** a disorder that affects the immune system have **too few** antibodies.

People **without** an immune system disorder have **sufficient** antibodies.

They can donate their blood.

Immunoglobulins from their blood can help people with an immune disorder.

You will receive immunoglobulins, in order to prevent infections.

This does not mean that you will never become sick again.

Immunoglobulins do not cure the immune system disorder.

**You need repeated infusions of immunoglobulins.**



# Immunoglobulin treatment

You will receive the **first** treatment at the **hospital** or at your **doctor's practice**.

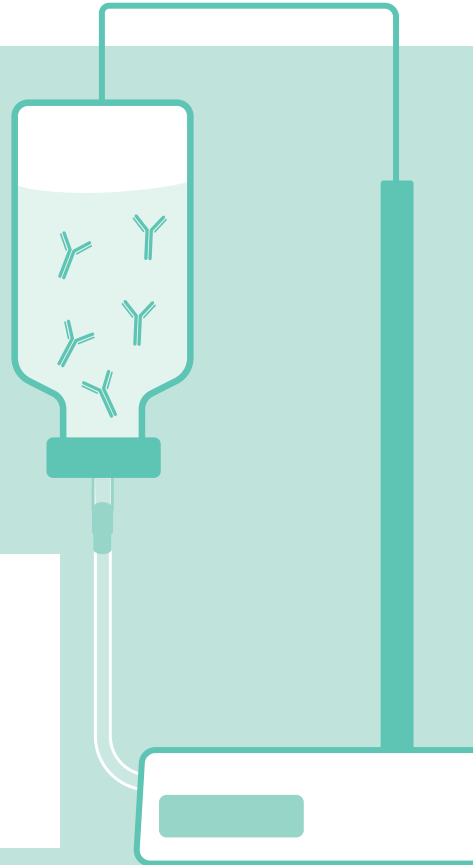
**If this works well**, you can continue the treatment independently **at home**.

You will receive **help** from a nursing team.

Immunoglobulins help to protect you against pathogens. However, the treatment may cause you to feel unwell. For example, you may get a headache or feel sick. **These symptoms are called side effects**.

Ask your doctor or nursing team about possible side effects.

You can also find the side effects in the **package leaflet**.









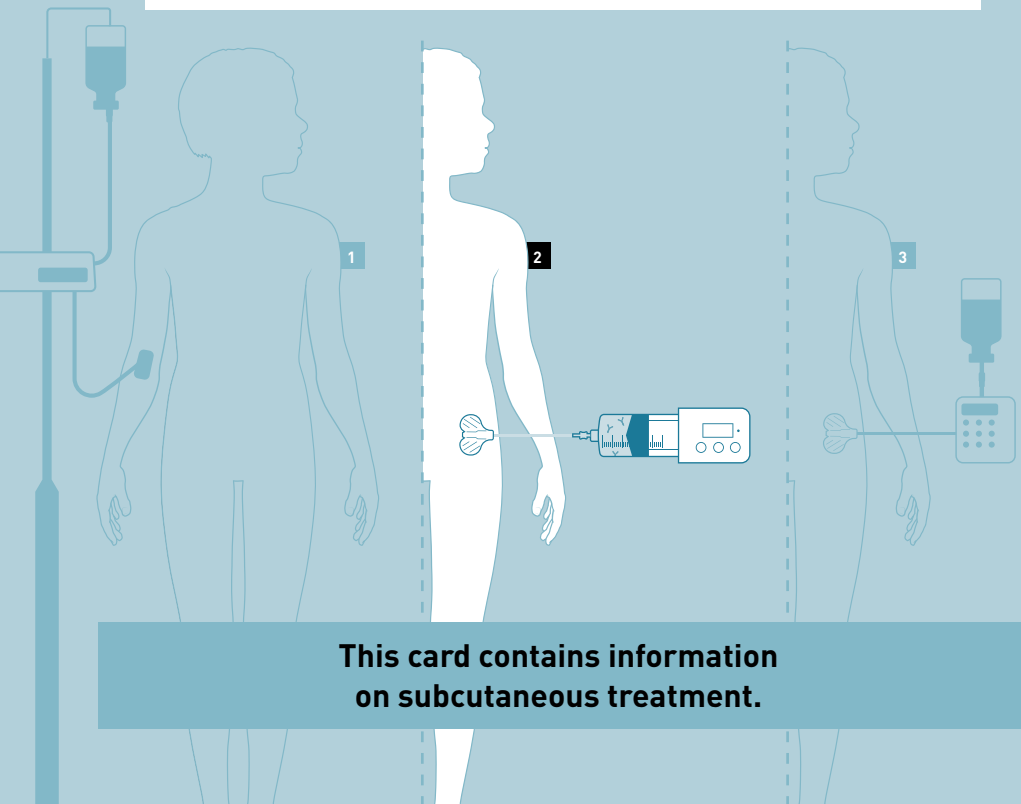
# The subcutaneous treatment (SCIg)

There are 3 ways to receive **immunoglobulins**.

Together with the doctor, you will decide which option suits you best.

The 3 ways to receive immunoglobulins are:

- 1 Intravenous (IVIg)
- 2 **Subcutaneous (SCIg)**
- 3 Supported subcutaneous (fSCIg)



**This card contains information  
on subcutaneous treatment.**



# The subcutaneous treatment (SCIg)

## 2 Subcutaneous

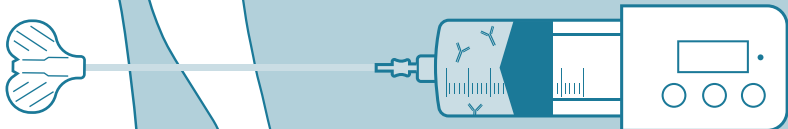
You will receive immunoglobulins via a thin needle under the skin.

This is called '**subcutaneous**'.

The abbreviation of this treatment is **SCIg**.

Usually, you will receive this treatment once or twice a **week or every other week**.

SCIg treatment lasts about **1 to 2 hours**.



**You can learn to administer the treatment independently at home.**







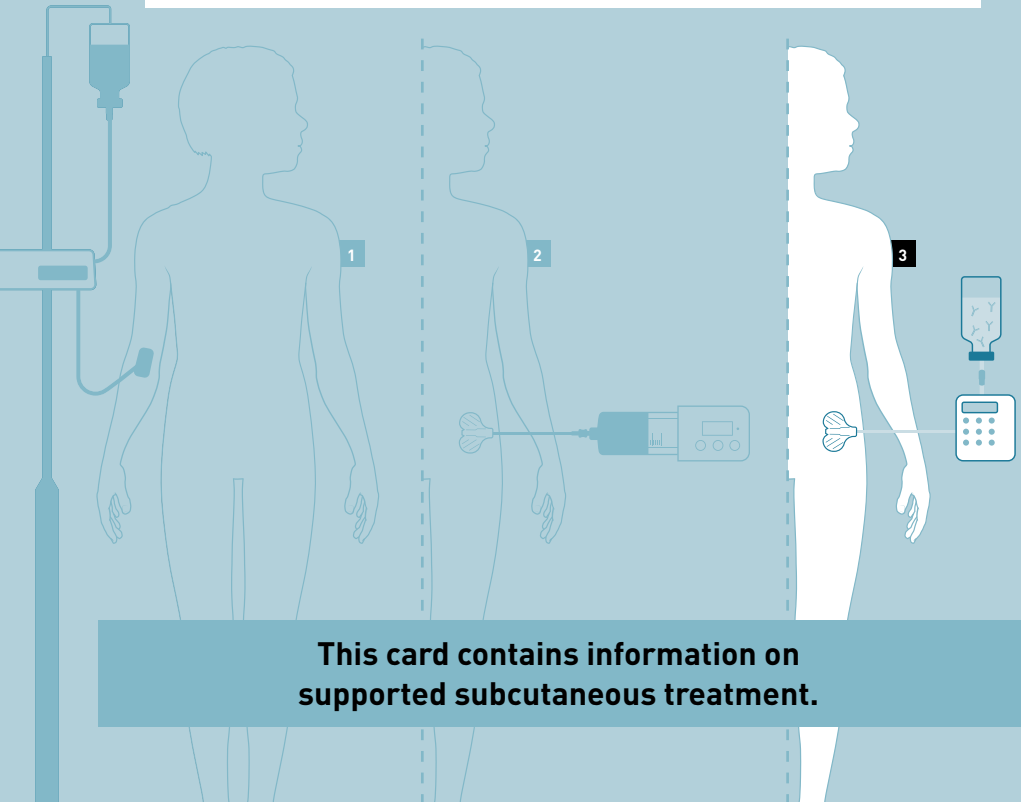
# The supported subcutaneous treatment (fSCIg)

There are 3 ways to receive **immunoglobulins**.

Together with the doctor, you will decide which option suits you best.

The 3 ways to receive immunoglobulins are:

- 1 Intravenous (IVIg)
- 2 Subcutaneous (SCIg)
- 3 **Supported subcutaneous (fSCIg)**



**This card contains information on supported subcutaneous treatment.**



# The supported subcutaneous treatment (fSCIg)

## 3 Supported subcutaneous

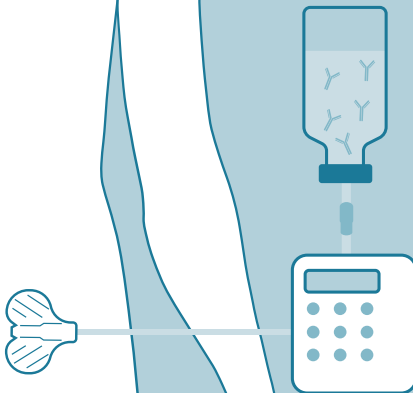
You will receive immunoglobulins via a thin needle under the skin.

By injecting an excipient under the skin, more immunoglobulins can be received.

This is called '**supported subcutaneous**'.

Usually, you will receive this treatment **every two to four weeks**.

Supported subcutaneous treatment takes about **1 to 2 hours**.



Excipients

**You can learn to administer the treatment independently at home.**



## Who can help me?



Many people can **help** you with treatment:

- Hospital doctors, such as:
  - An internist/infectologist
  - A pneumologist
  - An immunologist
  - An ENT doctor
  - A geneticist
- Nurses and healthcare practitioners
- Home nursing
- Primary care physician
- Pediatrician

**Together**, they will make sure that you get the treatment you need.

**Ask your doctor or nursing team who your first point of contact is.**



# Impact on your daily life

An immune system disorder has consequences for **everyday life**. For example, on your work, relationships, the choice to have children, or travel.

It is important that you talk **about your problems and questions**.

You can, for example, talk to your **doctor** or **nursing team**.

They are used to discussing these matters and they will try to help you.

**The patient organization can also help you with your questions.**

Do you want to learn more about immune disorders?

Or do you want to connect with other people with an immune system disorder?

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