

Immunoglobulin
replacement



Immunoglobulin replacement

A guide for younger children



NHS

Great Ormond Street
Hospital for Children
NHS Foundation Trust

THE
great north
CHILDREN'S HOSPITAL



**IMMUNO
DEFICIENCY
UK**

Supporting families affected by
primary and secondary
immunodeficiency

About this leaflet

This leaflet has been made by Immunodeficiency UK, together with Great Ormond Street Hospital and the Great North Children's Hospital to tell you about immunoglobulin treatment for children with immunodeficiency. This information should be used together with advice from your own Immunology doctor or nurse.

We would like to thank the young people and parents who helped to make this leaflet.

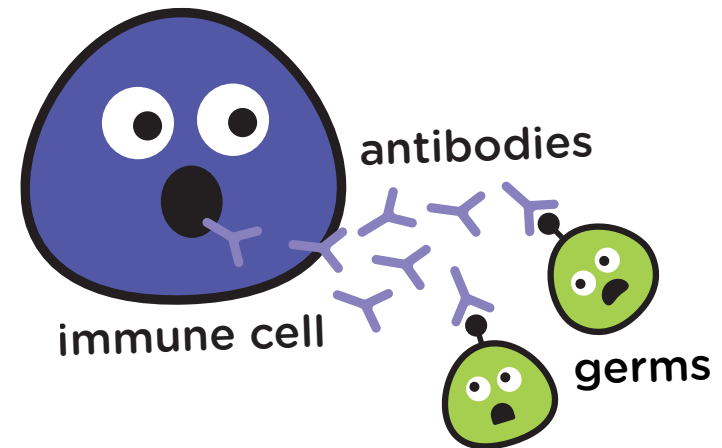


Introduction

Your doctor would like you to have a special medicine to help keep you healthy. It is called immunoglobulin (pronounced 'imm-you-no-glob-you-lin') or Ig for short. This leaflet will tell you about the Ig treatment. You should also talk to your doctor and nurse about it.

What is immunoglobulin?

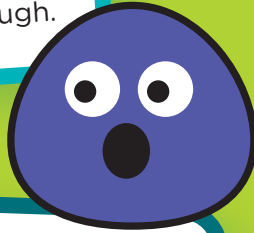
Immunoglobulin is a natural part of your body's defence (immune) system that helps to protect you against germs. Germs are tiny things which can cause an infection and make us ill. The immune system is like an army of different cells that have special ways to protect the body. Immunoglobulin is also known as antibodies.



Antibodies are made by special immune cells. The antibodies help to mark any germs that get into the body, so that the immune system can destroy them.

Why do I need Ig treatment?

You will have had blood tests which show that there's not enough antibodies in your body. There are many reasons why this might happen – often it is something that you are born with, or sometimes it's caused by special medicines you might have needed for a different medical problem. It's never because of anything that you have done though.



If your body cannot make enough of its own antibodies it means that you have less protection against germs – and this is why your doctor wants to give you Ig treatment. The Ig medicine is made up of antibodies from other people which will then do the job of protecting your body from infection.

The Immunoglobulin medicine is made up of lots of different antibodies which helps you fight infections.



How will I get Ig?

Ig can't be taken as a pill or syrup, it has to be put straight into the body. This means giving Ig through a small needle or thin plastic tube, either under the skin or into the blood. You can have numbing cream beforehand so that this doesn't hurt.

- If the Ig goes into the blood through a vein it is called '**intravenous Ig Infusion**' or IVIG for short.
- If the Ig goes under the skin it is called '**subcutaneous Ig infusion**' or SCIG for short.

To keep good Ig levels in the body that will keep you well you will need to have regular infusions.

Your health team will discuss with you and your family which way might be the best way for you to have the treatment.

Having immunoglobulin regularly helps keep you well.

Intravenous means into a vein.

Subcutaneous means under the skin.

Where and when will I get it?

IVIG is usually given in hospital. You will need to have a cannula (a small plastic tube which goes into a blood vessel/vein usually in the hand or the bend of the arm). You will be offered to have numbing cream or spray to help so this will not hurt. When you have the infusion the nurses will check your temperature, heart and breathing to make sure that everything goes well with the treatment.



Usually, an IVIG infusion takes a few hours so you might want to bring something to do, such as a book to read, a game to play or even some homework to complete. It is also good to drink a lot when you are having the infusion. Most children need to have their IVIG infusion every 3-4 weeks to keep their Ig levels up.

SCIG needs to be given in hospital at the beginning, but it can be given at home when someone has been trained to give the medicine. This could be a nurse, your mum or dad – and some children learn to do their own treatment too. The SCIG infusion is usually given through two thin needles that are put into your legs, or belly. You can have numbing cream or spray to help so this will not hurt.

An IVIG infusion is usually given every 3-4 weeks.

Having a numbing cream or spray can help with having Ig treatment.

SCIG is usually given once a week or every two weeks.

To help deliver all the Ig you need a small pump, or it might be injected by hand. Once all the Ig has been given the small needles are taken out. After treatment there will be lumps under the skin but don't worry this is normal and they will soon disappear. SCIG is usually given once a week or every two weeks.

There is also a different type of SCIG which is called facilitated-SCIG which can be given once a month and in bigger doses. You can talk to your team to find out if this would be an option for you.

Are there any risks?

Most people have no problems with their Ig treatment, but there are two sorts of risks that you should know about.

- **The first is that all medicines can have side effects.** This means that they can also have unwanted effects – as well as the good effects of protecting you from infections. This could be things like making you feel a bit sick or giving you a headache or skin rash. That may happen when you are having Ig treatment, but the person in charge of your treatment will be able to help if this happens.
- **The other risk is catching an infection from your Ig treatment.** This could happen if any germs got into the medicine, or into your body when giving the medicine. But, that risk is very small because all medicines are made and tested very carefully to make sure that they are safe for people. People who are trained to do your infusion will also know how to give the infusions in a clean and safe way so that no germs get into your body.

The infusions are given to protect you from getting serious infections – the risk of having Ig treatment is small, compared to the bigger, good effect that is normally seen.

It's important that you have your Ig because it protects you from getting infections.

Anything else I should know?



Having Ig is just one part of staying healthy. You may need other treatments too, such as antibiotics and physio to keep your chest in good shape. Every few months you will need to see your specialist team to have tests to check you are getting the right amount of Ig. These tests include blood tests, blowing tests (or lung function tests) and sometimes an X-ray or CT scan of your chest. These are nothing to worry about.

If you, or your family, have any questions or worries about Ig, the immunology doctors and nurses will be happy to talk them over with you.

My doctor is called: _____

My nurse is called: _____

Your doctors and nurses are there to help you with any questions you may have.



Tips & tricks



Wear comfortable and suitable clothes for having the infusions.



Make the treatment day a treat day - do something fun whilst having the treatment or afterwards.



Watch a film, play a game, have ice cream, go shopping, take a bike ride, play football, go to the cinema with a friend... what do you like doing?



It is good to drink a lot on your treatment day.



Tell your mum/dad or nurse/doctor if you are worried about anything or if you have any questions.

Glossary of terms

antibody – a type of protein (immunoglobulin) that is produced by certain types of white blood cells. Antibodies fight germs (mostly bacteria and viruses).

cannula – a small plastic tube that is inserted into a vein to give immunoglobulin or other treatments.

CT scan (also known as a CAT scan) – a specialised X-ray that gives pictures of the inside of the body.

immune deficiency – when the immune system's ability to fight infections doesn't work properly.

immune system – the parts of the body that protect against infection and disease.

immunoglobulins – proteins in the body that act as antibodies. They work to protect against and fight off infections. They are produced by specialist white blood cells and are present in blood serum and other body fluids.

immunologist – consultant specialising in the care of people with immune system problems.

infusion – delivery of treatment either into a vein (intravenous) or under the skin (subcutaneous).

intravenous – inside or into a vein; e.g. an immunoglobulin infusion may be given directly into a vein.

IVIG – intravenous immunoglobulin.

protein – one of the basic building blocks of life. Proteins make up the structure and determine the function of the cells that make up all the tissues of our bodies.

SCIG – subcutaneous immunoglobulin.

subcutaneous – meaning 'under the skin'. It also refers to anything relating to the loose tissue under the skin; e.g. an immunoglobulin infusion given straight into the tissue directly beneath the skin is said to be given subcutaneously.

Notes

Get in touch

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About Immunodeficiency UK

Immunodeficiency UK is a national organisation supporting individuals and families affected by primary and secondary immunodeficiency.

We are the UK national member of IPOPI, an association of national patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for PID patients worldwide.

Our website has useful information on a range of conditions and topics, and explains the work we do to ensure the voice of patients with primary and secondary immunodeficiency is heard. If we can be of any help, please email us or call on the number above, where you can leave a message.

Support us by becoming a member of Immunodeficiency UK. It's free and easy to do via our website. Members get monthly bulletins.

Immunodeficiency UK is reliant on voluntary donations. To make a donation, please go to www.immunodeficiencyuk.org/donate



Supporting families affected
by primary and secondary
immunodeficiency

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This booklet was made possible,
in part, by a grant provided by
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