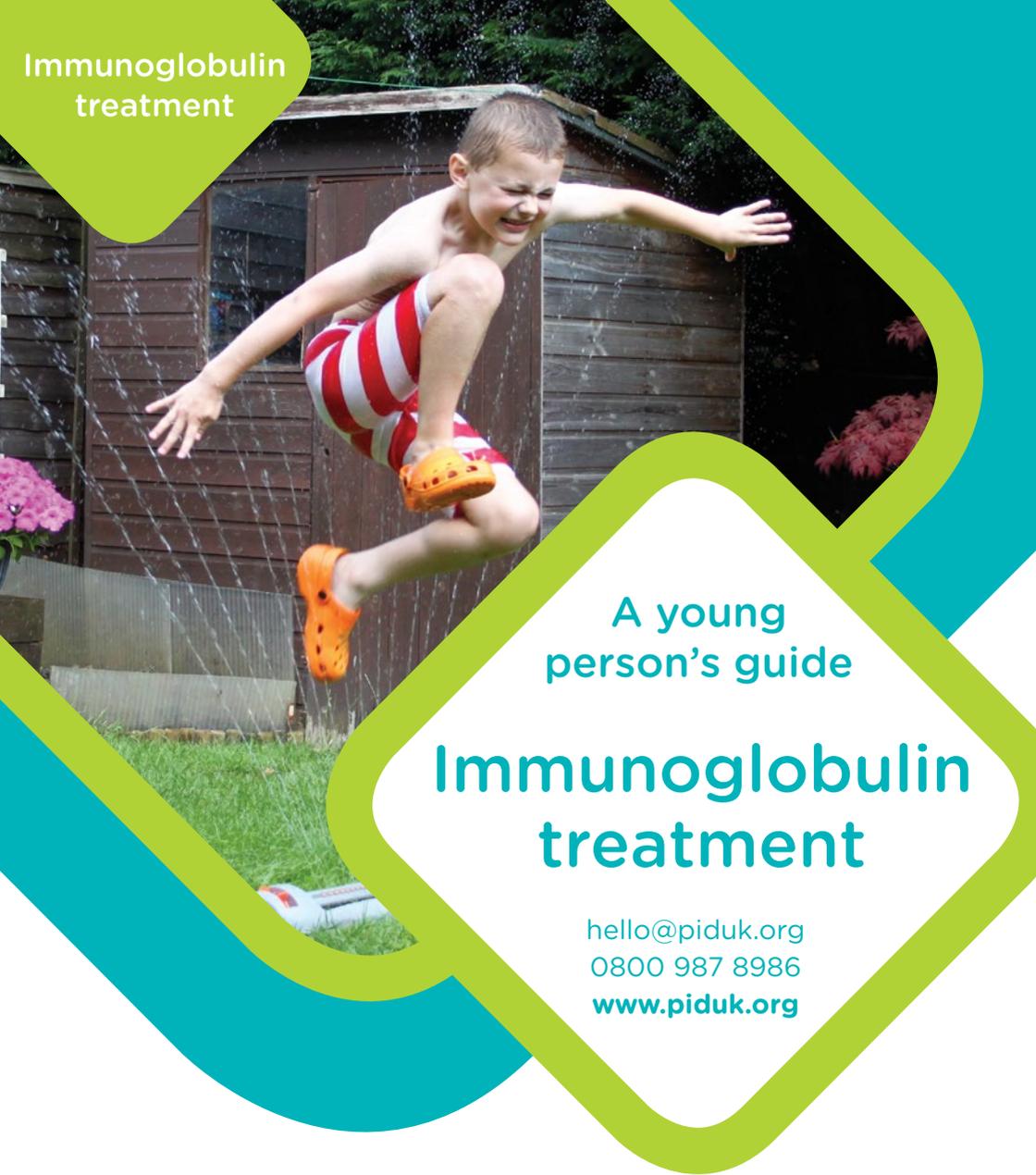


Immunoglobulin
treatment



A young
person's guide

Immunoglobulin treatment

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Great Ormond Street 
Hospital for Children
NHS Foundation Trust

THE

CHILDREN'S HOSPITAL

 **PID UK**
Supporting families affected
by primary immunodeficiencies



Introduction

Your doctor would like you to have some treatment to help keep you healthy. It is called immunoglobulin (pronounced 'imm-you-no-glob-you-lin'). This leaflet will help you to understand a bit more about this treatment.

About this leaflet

This leaflet has been produced by PID UK in conjunction with Great Ormond Street Hospital and the Great North Children's Hospital. It is designed to help answer the questions young people may have about immunoglobulin therapy as a treatment for their primary immunodeficiency. The information should not, however, replace advice from your immunology team of doctors and nurses.

We would like to thank the young people and parents who provided feedback on the content of this leaflet.

Immunoglobulin treatment - a young person's guide
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What is immunoglobulin?

Immunoglobulin - let's call it Ig for short - is a mixture of proteins that are a natural part of our body's defence (immune system) against germs. Germs are tiny things that make us sick by growing inside us, causing chest infections, chickenpox or other illnesses. To help us fight germs, special cells should make Ig to coat the germ and mark it out for destruction. Another word for Ig is 'antibody'.



Why do I need Ig treatment and what good will it do me?

The tests doctors have been doing have told them that your body is not making its own Ig properly. This means you may not be able to fight off germs easily and your body may need some Ig support. There are different reasons for not being able to make Ig. Sometimes doctors can find out these reasons, but sometimes they can't. Whatever the reason, there is a treatment to replace the missing Ig, which will help you fight off germs.

Ig can be obtained from other people, by using their blood. After people donate their blood at special centres, Ig is separated from it and can be given to you like a medicine. This Ig will then do the job of protecting your body from infection.

How will I get Ig?

Ig can't be taken as a pill or syrup because it would be digested (broken down) in our stomach like food, and it wouldn't get into our bodies. Instead, Ig has to be put straight into the body by an injection. Unfortunately, this means that it is necessary to use a needle or a cannula, which is a thin plastic tube through which the Ig is injected - there is no other way. The Ig goes just under the skin (also called 'subcutaneous') or into a vein. When Ig is given into the skin it's called SCIG. When it's given into a vein it's called IVIG.

Where and when will I get it?

IVIG is usually given in hospital. First, the doctor or nurse will ask you some questions and examine you to make sure you are well that day. If you don't already have one, they will put a cannula into one of your veins (often on the back of your hand) - if you prefer, they will use cream or spray so you won't feel it go in. Then, they will connect the cannula to a 'drip' - some tubing that runs through a pump from a bottle of Ig. The pump gives you the right amount of IVIG, slowly at first and then faster. Usually it takes a few hours to have IVIG, 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! When you are connected to your IVIG you need to stay on the hospital ward, but you can go home after if you are feeling ok. Most people need to have their IVIG once every three weeks, to keep their Ig levels up.

SCIG is given in hospital the first few times but later on it is often safe to have it at home. It's given through thin needles that are put into the skin on your tummy or thigh each time, usually at two separate sites. Your dose/amount of Ig is gradually injected over an hour using small pumps connected to fine tubes attached to the needles. This does make lumps under the skin but don't worry because these gradually go down over the next day; they aren't painful but can sometimes be a bit red. Although this sounds uncomfortable it's actually fine and many children just like you have this type of treatment to help them manage infections and germs too. Usually SCIG is given once a week and your nurse will encourage you to move around as normal while it's infusing or to sit and relax while doing something you enjoy.

Are there any side effects?

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

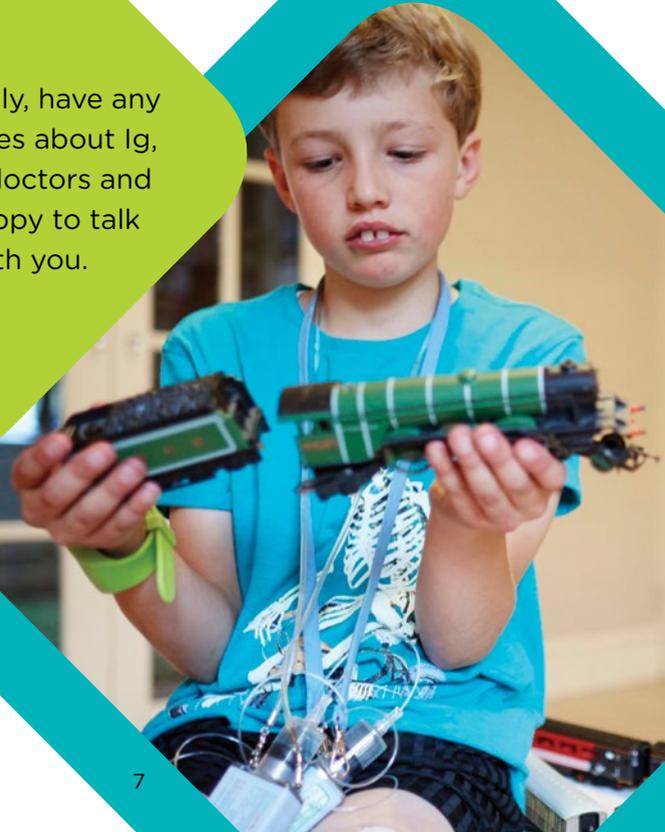
The first is that sometimes people get a rash, a fever or a headache while their infusion is running or soon after. This might mean the infusion is being given too quickly, or maybe you were already poorly that day. The nurses will slow down the infusion and give you medicines to treat the reaction, which will get better. This occasionally happens with IVIG, but hardly ever with SCIG. It can happen after the infusion once you are home, but your nurse will give you information about how to manage any infusion side effects, such as a headache.

The other sort of side effect is catching an infection from your Ig. This is because it is made from other people's blood. Back in the twentieth century, there was sometimes a problem with blood transfusions, which could carry germs from person to person. Nowadays, more is known about how to do this treatment and lots of steps are taken to make sure the Ig is safe for you and other people who need it. It's important that you have your Ig because it stops you from getting infections.

Anything else I should know?

Having Ig is just one part of staying healthy. You may need other treatments, such as antibiotics and physio, to keep your chest in good shape. Every few months you will need to see a specialist doctor called an immunologist. You will need 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.



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.



About Primary Immunodeficiency UK

**Primary Immunodeficiency UK
(PID UK) is a national organisation
supporting individuals and families affected
by primary immunodeficiencies (PIDs).**

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

Our website at www.piduk.org provides useful information on a range of conditions and topics, and explains the work we do to ensure the voice of PID patients is heard.

If we can be of any help, please contact us at hello@piduk.org or on **0800 987 8986**, where you can leave a message.

Support us by becoming a member of PID UK. It's free and easy to do via our website at www.piduk.org/register or just get in touch with us. Members get monthly bulletins and newsletters twice a year.

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

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