



PRIMARY IMMUNODEFICIENCIES

SCIG INFUSIONS A PRACTICAL GUIDE FOR PATIENTS



INTRODUCTION

This booklet explains how to administer your subcutaneous immunoglobulin replacement therapy.

Primary immunodeficiencies (PIDs) are rare diseases that occur if various components of the immune system are either missing or not functioning correctly. PID patients who are not able to produce enough antibodies (immunoglobulins, IGs) are often prescribed IG replacement therapy to provide them with improved protection from infections.

This type of therapy involves administering a solution containing IGs that have been purified from blood plasma donated by healthy individuals. The medication can be delivered either intravenously (IVIG) into a vein or subcutaneously (SCIG) into the fatty layer under the skin. With training and support, adults, young people and children can learn to administer SCIG themselves at home.

This booklet will guide you through the typical steps involved in delivering SCIG infusions (it is not aimed to replace instructions you receive from your healthcare provider). It will help you when you are learning the process and it will also serve as a useful reminder when you are more experienced. Some of the steps are more complex than others – however, they are all important and should be followed with care every time.

Safety notes

- Only administer your SCIG after training and approval from your healthcare provider.
- Before proceeding, make sure you have read and understood any information given to you by your healthcare provider.
- Make sure you keep your therapy journal up-to-date and take it with you whenever you visit your healthcare provider.
- Ensure you store all your supplies carefully according to the instructions.
- Always throw away any unused product remaining in your vials in your sharps box after each infusion.
- If you experience any side-effects that concern you, talk to your healthcare provider.

ABBREVIATIONS

IG	Immunoglobulin
IVIG	Intravenous immunoglobulin
PID	Primary immunodeficiency
SCIG	Subcutaneous immunoglobulin

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WHAT WILL I NEED?

You will usually need the following equipment:

Vials of SCIG	Alcohol wipes
Infusion pumps and tubing	Tape and/or transparent dressing
Subcutaneous needles or catheter sets	Sharps container
Syringes	Gloves
Transfer needles/spikes	Treatment journal or app

There may be a choice of SCIG products and infusion pumps, as well as types of needles, and needle sets (multi-site or single-site). It is also possible to administer your SCIG without an infusion pump using the rapid manual push method. Your healthcare provider will be able to advise on the best options and products for you.

If you require an infusion pump, the following factors may be important for you to discuss:

- Costs – initial costs, maintenance costs
- Additional equipment – some pumps require that you use specific supplies with them, e.g. syringes, tubing
- Power source – batteries, mains power or manual
- Portability – size, weight
- Infusion rates – maximum performance, variable or not variable
- Fluid capacity per syringe
- Simplicity
- Reliability.

STAGES OF SELF-ADMINISTRATION

The process of SCIG self-administration can be split into a number of stages:

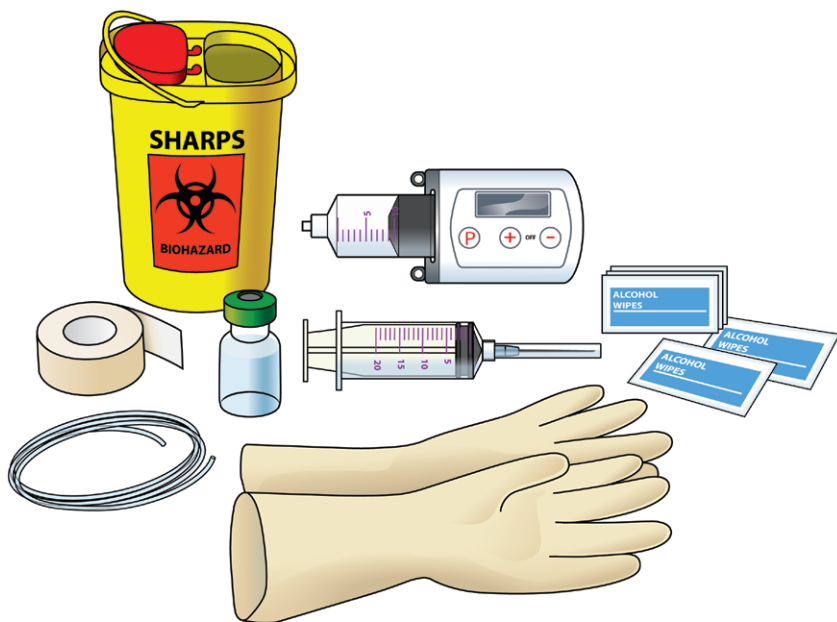
1.	↓	Set up your equipment
2.	↓	Select your infusion site
3.	↓	Prepare your infusion site
4.	↓	Run your infusion
5.	↓	Record your infusion
6.	↓	Tidy up!

Contact your healthcare provider if you have any questions about your PID or the infusion process.

1. SET UP YOUR EQUIPMENT

The first step of the process is to prepare all of your equipment.

- 1) Gather together all your equipment.
- 2) Clean your table or surface with alcohol wipes.
- 3) Thoroughly wash and dry your hands then disinfect them using your alcohol wipes. Put on gloves if advised by your healthcare provider.
- 4) Get your infusion pump ready by following the manufacturer's instructions.
- 5) Inspect your vial(s):
 - a. Does the SCIG look right? It should be the correct colour and free of particles.
 - b. Do not use it if the seal is damaged or the expiration date has passed.



6) Prepare your syringe:

- Clean the vial stopper with an alcohol wipe and let it dry.
- Attach the transfer needle to your syringe and pull out the plunger to fill it with air.
- With the vial upright on a flat surface, insert the needle into the centre of the stopper.
- Check that the tip of the needle is not in the liquid then push down the plunger to inject air into the vial.
- With the needle still inserted, turn the vial upside down.
- Slowly pull back on the plunger to fill the syringe with the required amount of medicine.
- Take the filled syringe and needle out of the vial.
- Carefully take off the needle and throw it away in your sharps container.
- If you are using more than one vial, repeat the process.

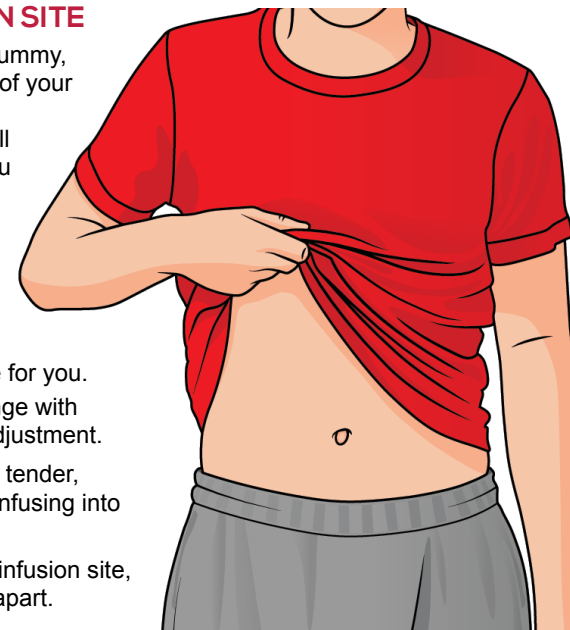
7) Connect your filled syringe to the administration tubing.

- Gently push on the syringe plunger until the tubing is nearly full, being careful not to let the medicine reach the tip of the tube needle.

Once you have everything ready, the next step is to select an infusion site (or sites) on your body where the needle(s) is to be inserted.

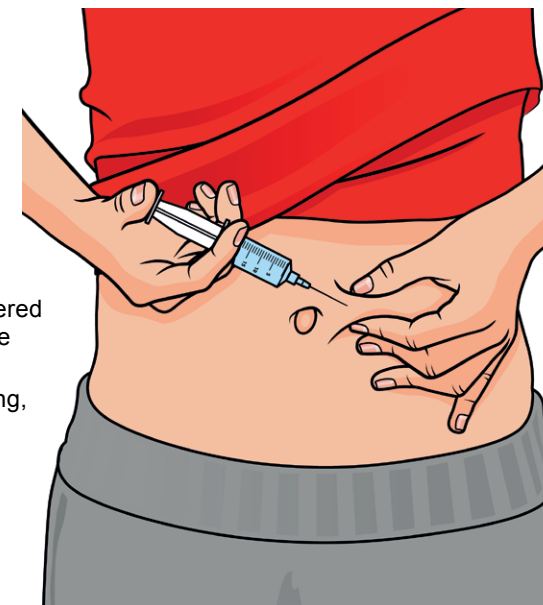
2. SELECT YOUR INFUSION SITE

- Select a site (or sites) on your tummy, thigh, upper arm or the outside of your upper leg/hip for your infusion (your healthcare provider will tell you how many infusion sites you need to use).
 - Only infuse up to 20 ml per site to reduce the risks of infusion site reactions.
 - Trial and error may be required until you find the best site(s) and infusion time for you.
 - Your choice of site may change with weight loss/gain and dose adjustment.
- Never infuse where your skin is tender, bruised, red or hard and avoid infusing into scars, tattoos or stretch marks.
- If you are using more than one infusion site, be sure sites are at least 5 cm apart.



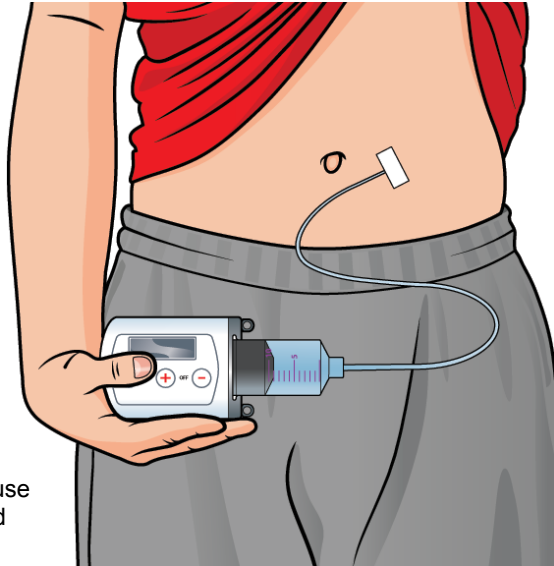
3. PREPARE YOUR INFUSION SITE

- Clean your infusion site with an alcohol wipe and allow it to dry completely.
- Lift a skin fold, insert the needle into the tissue below your skin and secure it with tape, if needed.
- Make sure the needle has not entered a blood vessel by gently pulling the plunger back on your syringe.
 - If you see any blood in the tubing, throw away the needle and tubing and select a new site.
 - If you have multiple infusion sites, clamp the tubing for that site, remove the needle and continue infusing only at sites with no blood return issues.



4. RUN YOUR INFUSION

1. Connect your infusion pump by following the manufacturer's instructions.
2. Set the infusion rate as per your healthcare provider's advice.
3. Turn on the infusion pump.
4. Add ice, a warm or cold compress (whichever you prefer) or anaesthetic cream to reduce any pain or discomfort when inserting the needle or while the infusion is running.
5. It may help the medicine to infuse more easily if you move around during your infusion.



5. RECORD YOUR INFUSION

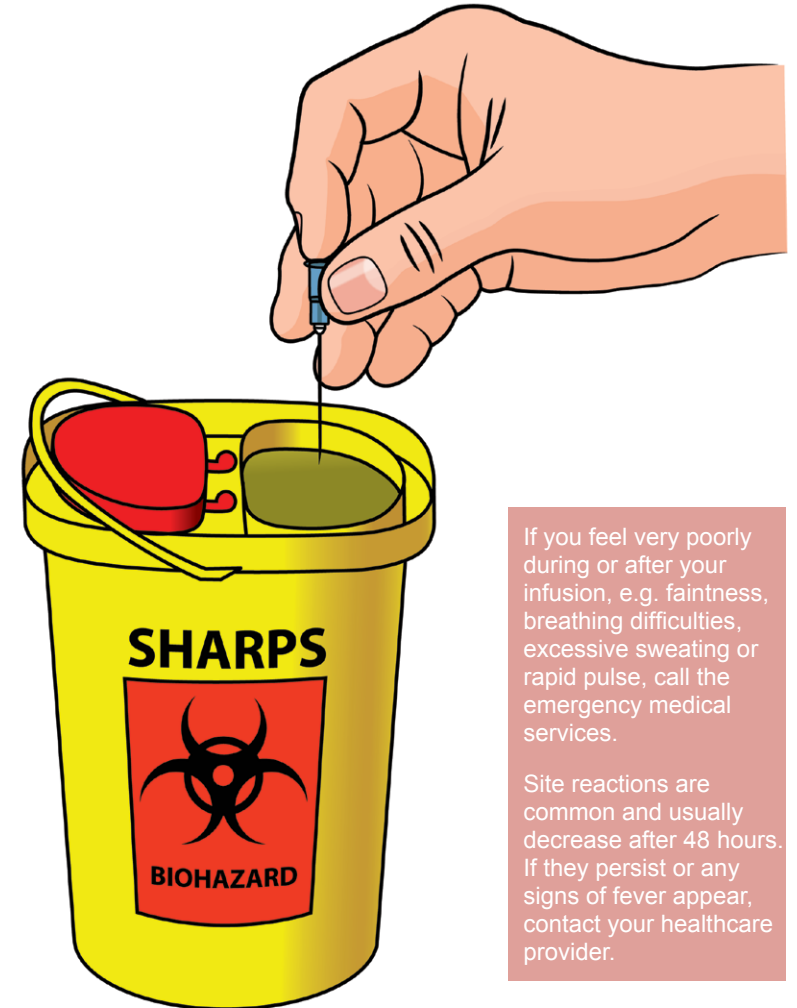
1. It is important to record information about your infusion in your printed or electronic therapy journal.
2. Make sure that you record the date and time of each infusion, the serial number of the vials, the infusion rate and the amount of medicine that you infused, as well as any issues.
3. Be sure to tell your healthcare provider if you have had any problems with your infusion.
4. Your journal will be really useful so take it to any medical appointments.



6. TIDY UP!

Time to tidy up! When your infusion has finished:

1. Turn off your infusion pump when all the medicine has been infused.
2. Take off the tape and remove the needle from the infusion site. Place sterile gauze or a plaster over the site.
3. Discard used vials (even if there is left over liquid in them) and any disposable supplies, in your sharps container.
4. Clean and store your infusion pump.



If you feel very poorly during or after your infusion, e.g. faintness, breathing difficulties, excessive sweating or rapid pulse, call the emergency medical services.

Site reactions are common and usually decrease after 48 hours. If they persist or any signs of fever appear, contact your healthcare provider.

TROUBLESHOOTING

PROBLEM	POSSIBLE SOLUTION
Local skin reactions (redness, swelling, itching)	<p><i>Skin reactions at the infusion site are common and mostly mild. The amount of swelling usually relates to the volume of fluid being infused and should resolve slowly over 48 hours. If more swelling than expected occurs or if it takes longer than normal to go away, try the following:</i></p> <ul style="list-style-type: none"> • Decrease the volume per site and/or increase the infusion time for your next infusion. • Is the needle too short? Change to a longer one or another brand. • Are you allergic to the tape or dressing? Consider changing to paper/hypoallergenic tape. • Try to ensure that the needle is dry when you insert it into your skin. Medicine on the tip of the needle can sometimes cause a skin reaction • Practice and perfect your technique for priming the tubing and placing and removing the needle. • Try using gentle massage or a warm/cold compress (according to your preference) after your infusion. • Try applying a steroid cream to the infusion site during and after infusion.
Leaking at site	<p><i>Leaky sites can be caused by a variety of factors, including choice of infusion needles, needle placement, needle length and technique. If you experience leaking at your infusion site, consider the following:</i></p> <ul style="list-style-type: none"> • Is the needle fixed securely? • Is there enough fatty tissue at your infusion site? • Is the needle too short? • Is the infusion volume too high?
Discomfort with needle	<ul style="list-style-type: none"> • Is the needle too long and irritating the abdominal wall or muscle? Switch to a shorter or another type of needle. • Try using a catheter that allows the introducer needle to be removed. • Consider applying an anesthetic cream before you insert the needle.

PROBLEM	POSSIBLE SOLUTION
Long infusion times	<ul style="list-style-type: none"> • Check the quality of your tubing and needle • Discuss the number of sites you are using and the volume per site with your healthcare provider. • Ensure your infusion site is appropriate, e.g. do not inject into skin that has scar tissue. • Check the following: your infusion rate settings, tubing size and length matches infusion rate, needle gauge, pump function, battery function, etc.
Anaphylactic reactions	<ul style="list-style-type: none"> • Discontinue treatment immediately and seek medical attention.



FURTHER INFORMATION AND SUPPORT

This booklet has been produced by the International Patient Organisation for Primary Immunodeficiencies (IPOPI). Other booklets are available in this series. For further information and details of PID patient organisations in 52 countries worldwide, please visit www.ipopi.org.

Provided by



Supporting families affected by primary and secondary immunodeficiency

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

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