Caring at its best

University Hospitals of Leicester

# Having subcutaneous immunoglobulin (SClg) therapy at home to treat your immune disorder

Department of Immunology

Information for Patients

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# Introduction

The aim of this treatment is to replace missing antibodies to help you fight infections. People with immune deficiency can have immunoglobulin (Ig) therapy in 2 main ways:

- into the vein (intravenously IV)
- under the skin (subcutaneously SC)

We only offer training for subcutaneous immunoglobulin as part of the home therapy programme, as it carries very minor risks of adverse reaction and SC infusions can easily be managed at home by yourself or with a friend or relative.

To start with, all immunoglobulin treatments will take place in hospital under the care of a clinical immunologist and a specialist nurse. After 6 to 8 infusions, if you have had no serious adverse reactions to treatment and you meet all the criteria, you will be offered entry to the home therapy programme.

### What is the home therapy programme?

The home therapy programme is a series of teaching sessions which will prepare you to have your treatment (known as infusions of subcutaneous immunoglobulin (SCIg)) at home.

There are 2 ways in which immunoglobulin can be infused subcutaneously (SCIg):

- via a pump which automatically administers the medication. You do this once a week, and it takes about 2 hours.
- daily manual push (without a pump) this involves you manually pushing a syringe at a steady speed allowing the medication to be administered slowly. You do this 3 or 4 times a week, and it takes 10 to 15 minutes each time.

#### Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk



Both methods use the same technique for preparation for your infusions. The decision on which method to use will be discussed with you at your clinic appointment. The nurse will go through both techniques and you will have the opportunity to choose the technique which suits you best.

# What will the programme cover?

- An overview of SCIg therapy and home therapy.
- How to prepare the infusion.
- How to give the infusion.
- What to do if you have an adverse or unwanted reaction.
- Completing the infusion.
- What to do if you have a needle injury.
- How to dispose of equipment safely.
- Recording your treatments correctly.
- Recording any infection you may have had and any treatments taken such as antibiotics.

The specialist nurse will watch you perform the infusions, ask you some questions and give you a small written test at the end of the programme. This helps us to see if we have explained everything clearly and to check that you can carry out the therapy safely.

# What is the criteria for the home therapy programme?

#### You must:

- be self-motivated and willing to take on the responsibility of home therapy.
- have had no moderate or severe reactions to therapy in the last 4 to 6 months.
- have a telephone at the place you have the infusion.
- have the support of your General Practitioner (GP).
- agree to return to hospital based infusion if any moderate to severe reactions happen at home or if there are any problems with the home therapy programme.
- undergo Leicester's training course for home therapy and successfully complete all of the assessments within the course.
- sign an agreement saying that you are willing to take on responsibility for infusions at home using the home therapy procedure.
- have successfully completed at least 6 infusions under the supervision of a nurse who specialises in this type of treatment.
- have been advised of the procedure for prescribing and delivery of SCIg products before starting home infusions.

- agree to attend all outpatient review appointments in clinic.
- have yearly home visits by an immunology specialist nurse to assess your infusion technique.
- agree to do monitoring blood tests every 12 weeks.
- agree to send your infusion records to the nurse every 4 to 6 weeks.
- Please note, prescriptions cannot be renewed if you do not regularly attend your review appointments, and monitoring bloods and infusion records are not up to date.

### What support will I have at home?

Support will be provided by all members of the Home Therapy Team:

- Immunology Specialist Nurse via telephone, in clinic and home visits as needed.
- Consultant Clinical Immunologist or Immunology Specialist Registrar via telephone and in clinic.
- GP via telephone and in their surgery.
- Some delivery services also have 24 hour helplines if you are having problems with an infusion.

### What are the benefits of home therapy?

- Less time lost from work or school.
- You are in control of your therapy.
- Your treatment is more convenient and flexible.
- You are in a more relaxed and comfortable environment.
- You will spend less time waiting in hospital.
- You will spend less time travelling to and from hospital.

### **Patient comments**

- "Changing to subcutaneous home therapy was the best decision I made".
- "You are completely in control; your illness does not rule your life".
- "Full training is given and you are safe in the knowledge that you have the specialist staff at the end of a phone if you need advice or support and of course your GP. Go for it!".
- "I use the time to play scrabble, watch a film or have a meal".
- "It's much better at home because it can be done at any time to suit me. It is also more relaxing and much less time involved. Plus I don't have to go out when it's cold and it's very reassuring to know help (if needed) is always at the other end of the phone".

# **Contact details**

If you have any queries please talk to your specialist nurse or your consultant clinical immunologist - telephone: 0116 258 6702

# **Further information**

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Immunodeficiency UK produce a number of leaflets: <u>www.immunodeficiencyuk.org</u> Email: <u>hello@immunodeficiencyuk.org</u> Telephone: 0800 987 8986

If you have any questions write them down here to remind you what to ask when you speak to your nurse/ consultant:

اگر آپ کو یہ معلومات کسـی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔ علی هذه المعلومات بلغةٍ أخری، الرجاء الاتصال علی رقم الهاتف الذي یظهر في الأسـفل

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ਜੇ ਤੁਸੀ ਇਹ ਜਾਣਕਾਰੀ ਕਸਿੇ ਹੋਰ ਭਾਸ਼ਾ ਵਚਿ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਰਿਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦੱਤਿ ਗਏ ਨੰਬਰ `ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ। Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

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