

# Information for patients and carers

Home Therapy with Subcutaneous Immunoglobulin

Please read this leaflet as well as the others listed at the end. If you have any questions please ask the neuromuscular nurse, your consultant, or a member of the day treatment centre staff.

### What is SCIG?

Subcutaneous immunoglobulin (SCIG) is a blood product made from pooled plasma from many different people. SCIG preparations contain antibody molecules dissolved in a sterile solution. It is made so that it is suitable for subcutaneous injection (i.e., injection under the skin). Most products contain additives to help keep the antibody molecules stable during storage.

It is most likely that you are already being treated with IVIG and are familiar with this treatment, but you can remind yourself of the details by reading our related documents: 'Patient information-home therapy with intravenous immunoglobulin (IVIG)'. This gives details on what IVIG is and the potential side effects of treatment.

SCIG is a method of administering immunoglobulins which can be done at home by yourself, or a family member. An injection is given subcutaneously under the skin of the abdomen or thigh. Here the immunoglobulin is slowly absorbed into the blood stream and carried around the body. Only small volumes are given at any one time (10-20mls) so it has to be given more frequently than intravenous immunoglobulin. This is usually weekly. When using an infusion system, each treatment typically lasts between 45-90 minutes depending on the product used.

# Benefits of home therapy

- It is more convenient
- It does not require a trip to the hospital or a nurse to administer it
- You can choose to administer it when you like, although you will need to do this when there is another responsible adult around

- it is quick and easy to do
- You will not need to take time off work to attend the hospital for infusion
- It is safer than IVIG, with a lower incidence of serious side effects
- It usually gives more stable levels of immunoglobulin in your blood. If you have a tendency for your symptoms to become worse prior to each dose this may be reduced by switching from IVIG to SCIG

# Risks / Disadvantages of home therapy

- Local site reaction; can feel mildly painful, itchy, swollen or unpleasant following injection. This usually recovers within an hour or two; and most people find that this effect stops after a few weeks as the skin adapts
- There will not be immediate medical or nursing cover in the event of a reaction; however, the risk of a serious problem is small
- You will need to find adequate space to store the immunoglobulin safely (this may require storage in a fridge which will be provided)

## The training programme:

Self-administration involves an initial trial dose to assess if you can tolerate it, followed by a short training program of approximately 4-6 weeks. The training program involves attending a weekly clinic where you will be taught the background to this therapy and will be shown how to safely administer subcutaneous immunoglobulin. If a relative or carer is to be trained to help you administer SCIG, then they will need to accompany you for all weekly training sessions. At the end of this training period, when both you and the trainer are happy with your progress, you will be free to self-administer SCIG at home. A home visit will be carried out at the time of the initial treatments by the neuromuscular nurse to identify any problems or issues that may arise.

# **Supplies**

At the end of the training period the home care provider will supply you with all the medication and equipment you need for the first 3 months, and then you will receive regular supplies from the company. The SCIG comes in a variety of bottle sizes; usually 2g (10ml) or 4gm (20ml) but this can vary depending on the product.

# What happens once I am self-administering at home?

You must fill in the infusion diary, recording the batch numbers of the infused immunoglobulin bottles to keep for 5 years at home.

All batch numbers from your immunoglobulin are recorded on the national immunoglobulin database by the specialist nurse, so you will need to send batch numbers to the nurse via telephone or email on the same day of your infusion.

The care of your condition and its treatment remain under the supervision of the neurology team.

We will see you in the home therapy clinic every 3-6 months; you will need to attend your GP surgery or hospital for blood samples (FBC, U&E and LFT) to be taken every 3 months. If you have any problem between appointments, you can contact us via the telephone number or e-mail address below.

# What to do if you have an adverse reaction?

Subcutaneous IG has a lower incidence of side effects and allergic reaction than when given IV. However, it is important to be aware of the risks and how to recognise and manage any problems should they arise. You will be given a separate leaflet called: 'Subcutaneous immunoglobulin (SCIG) at home - what to do if you have an adverse reaction'. As with IVIG treatment in the hospital we recommend that you

ensure good fluid intake during and after treatment, ideally between 2 to 3 litres of fluid on the day of treatment, and on the day before and the day after treatment.

The most common side effect is local itching and irritation at the site of the injection. This usually resolves on its own, but taking antihistamines and paracetamol before or shortly afterward can help this.

If you have any symptoms which affect other parts of your body, such as headaches, shivering, or nausea, if the symptoms are mild and go away after you have taken antihistamines and paracetamol, it is safe to continue the injection. It is important to always have antihistamines in your house; these are cheap and readily available from your local pharmacist or supermarket. However, if the symptoms continue you should stop the injection immediately and remove the needle. if the symptoms become worse, or if you experience chest pain or shortness of breath, then seek immediate medical advice.

Remember - you must not infuse if you have an infection. If you are unsure, delay your infusion and phone the neuromuscular nurse for advice.

# Contact numbers for help or advice:

Neuromuscular specialist nurse 01772 523412

Brock infusion suite 01772 523248

Neurology ward at Royal Preston Hospital (out of **01772 524312** hours urgent advice)

#### Other relevant leaflets

- Information sheet about intravenous immunoglobulin (IVIG) in the treatment of acute and chronic neurological diseases
- Subcutaneous immunoglobulin (SCIG) at home what to do if you have an adverse reaction.
- Patient information home therapy with intravenous immunoglobulin (IVIG)

## Sources of further information

www.lancsteachinghospitals.nhs.uk www.nhs.uk www.accessable.co.uk www.patient.co.uk

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Please ask a member of staff if you would like help in understanding this information.

This information can be made available in large print, audio, Braille and in other languages.

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