

The use of intravenous immunoglobulin (IVIg) in dermatology

This leaflet aims to answer your questions about having intravenous immunoglobulin (IVIg) to treat your skin condition.

If you have any questions or concerns, please speak to a doctor or nurse caring for you.

What is IVIg?

Immunoglobulin is a mixture of blood proteins called antibodies that are made by the immune system (the body's own defence system). Antibodies are produced when the immune system comes into contact with foreign substances that cause infections, such as viruses or bacteria. These antibodies protect us from infection.

Immunoglobulins (antibodies) can be taken out of donor blood and used to treat a number of medical conditions. It is usually given as an infusion into a vein (intravenous infusion) which is called IVIg.

Although IVIg is licensed in the UK, it is not specifically licensed for the treatment of autoimmune skin conditions. There is however evidence from trials that it may be of benefit in people with immunobullous disease or dermatomyositis and it is an accepted treatment in the UK which we have experience of using within Guy's and St Thomas' NHS Foundation Trust. The leaflet, **Unlicensed medicines – a guide for patients**, has more information about unlicensed medicines. If you would like a copy, please ask your doctor, nurse or pharmacist. Alternatively you can call the pharmacy medicines helpline – contact details are at the end of this leaflet.

How does IVIg work?

The body uses antibodies as a way of regulating immune responses. In some medical conditions, such as autoimmune conditions like immunobullous disease and dermatomyositis, the body's immune system becomes overactive and starts attacking its own tissues (for example nerves, muscles or skin). IVIg is used as a treatment for these conditions as it helps to reduce the immune response. IVIg doesn't work straight away. It may take up to 12 weeks to become effective.

How is IVIg given?

1. It is given as an infusion into a vein in your arm through a cannula (a small needle) every day for up to 5 days. Treatment will take place under supervised conditions in the outpatient infusion suite at Guy's Hospital.

2. Your doctor will work out the dose of IVIg most suitable for you and the number of days it will be administered over. This will depend on your medical condition. Each infusion will be given over a few hours but the exact duration will vary from person to person.
3. During the infusion you are observed closely and will have your blood pressure, pulse and temperature checked regularly.

IVIg can be given as a 'one-off' course or you may need to have repeated courses every month. Your doctor will let you know if you need to have more than one course of treatment.

There are no dietary restrictions, however it is recommended that you stay hydrated before treatment.

Will I feel any pain?

You may feel some discomfort when the cannula is placed in a vein in your arm. This should only last for a few seconds and then wear off. If you continue to feel discomfort or notice swelling around the cannula please tell your nurse.

Are there any side effects?

As with all medicines IVIg can cause side effects, however not everybody gets them.

Mild reactions usually occur within the first 30 minutes of the start of the infusion and include headache, fever, chills, nausea and vomiting, skin rash, back pain or muscular aches. If these occur the infusion will be slowed down or stopped as necessary and the symptoms usually settle quickly. Urticaria (raised, itchy areas of skin) has also been reported in some rare cases.

Very rarely people can experience severe allergic reactions such as a fall in blood pressure and anaphylactic shock. This will usually happen within seconds or minutes of the beginning of the infusion. The infusion is given by appropriately trained staff, under the supervision of your dermatology team. We will be monitoring you closely and you will be treated promptly if such reactions occur, and the infusion will be stopped.

For a complete list of side effects, please refer to the manufacturer's leaflet supplied with this medicine. If you have any questions or concerns about potential side effects, please speak to the doctor or nurse caring for you.

Safety

When medicines are made from human blood or plasma, certain measures are put in place to prevent infections being passed on to patients. These include:

- careful selection of blood and plasma donors to make sure those at risk of carrying infections are excluded
- testing of each donation and pools of plasma for signs of virus/infections
- steps included by the manufacturers in the processing of the blood or plasma that can inactivate or remove viruses.

Despite these measures, when medicine prepared from human blood or plasma is administered, the possibility of passing on infection cannot be totally excluded. This also applies to any unknown or emerging viruses or other types of infections. The measures taken **are** considered effective to protect against HIV, hepatitis B and hepatitis C virus transmission.

It is important to note that once you have been given IVIg, you are no longer able to donate blood.

Can I take other medicines alongside IVIg?

IVIg does not usually interfere with other medications. However, you must tell your doctor, specialist nurse or pharmacist if you take any other medications, including medicines obtained without a prescription, herbal remedies or if you have received any vaccinations in the last three months.

IVIg may impair the effect of live vaccines, as it may contain antibodies to measles, varicella and other viruses. Therefore if you have been treated with IVIg, you should not have any live vaccines for at least three months after the end of your treatment. If you need to have any vaccines following your IVIg treatment, please seek advice from your doctor or nurse.

Is IVIg safe in pregnancy and breast-feeding?

Before using this medicine, please tell your doctor or pharmacist if you are pregnant, planning a pregnancy or are breast-feeding.

As the safety of IVIg in pregnancy and during breastfeeding has not been established, the manufacturers recommend that it is used with caution. However, clinical experience with immunoglobulins suggests that no harmful effects on the course of pregnancy, or on the foetus and the neonate are to be expected. Immunoglobulins are excreted into the milk and may contribute to the transfer of protective antibodies to the newborn.

Will IVIg affect driving and/or the use of machinery?

There are no indications that immunoglobulin preparations may impair the ability to drive and/or use machines.

Will I have a follow-up appointment?

You will have a follow-up appointment in the immunobullous clinic every three months – this may be more frequent at the start. You will be reviewed by one of the doctors in the outpatient infusion suite at Guy's Hospital each time you come in for an infusion

Contact us

If you have any questions or concerns about IVIg, please contact Dr Groves' team on **020 7188 6279/7847** or the Guy's Infusion Suite helpline on **020 7188 5896** (Monday to Friday, 9am to 5pm).

Out of working hours the dermatology on-call team can be contacted through the hospital switchboard by calling

020 7188 7188 – state 'bleep desk' and then ask for bleep 2010.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

t: 020 7188 8801 **e:** pals@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953

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t: 111

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w: www.nhs.uk

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t: 0848 143 4017 **e:** members@gstt.nhs.uk

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