

Intravenous Immunoglobulin



A PATIENT GUIDE TO DEMAND MANAGEMENT

Intravenous Immunoglobulin

What is Intravenous Immunoglobulin?

Immunoglobulin is a mixture of blood proteins called antibodies that are made by the immune system. Antibodies are formed 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 can be extracted from donor blood and are used to treat a number of medical conditions. It is usually given to patients as an intravenous infusion when it is called intravenous immunoglobulin (IVIg).

How does IVIg work?

The body uses antibodies as a means of regulating immune responses. In some medical conditions, such as autoimmune conditions, the body's immune system becomes overactive and starts attacking one or more body tissues such as; nerves, muscles or skin. IVIg is used as a treatment for these conditions by reducing and altering the immune systems response.

In other conditions the immune system cannot make the antibodies needed to fight infectious diseases. IVIg replaces these antibodies so that the body can defend itself against infections and helps prevent longer-term organ damage.



Detailed information on how IVIg is administered, including dose, side effects and risks can be found in the patient information leaflet (PIL) which accompanies every vial of IVIg. Please refer to the PIL or speak to your doctor or nurse directly if you have any further concerns.

Why are some hospitals having problems obtaining IVIg?

Occasionally hospitals cannot obtain as much IVIg as they would like to treat patients. The reasons for this are:

- i. There is a global shortage of IVIg, because there are fewer blood donors and more patients who need IVIg
- ii. Sometimes temporary shortages are caused by difficulties with production
- iii. IVIg is being used to treat an increasing number of diseases and so limited supplies have to go further

How can the availability of IVIg be improved?

In July 2006, the Department of Health held a review to consider the future supply of IVIg to the NHS. As part of the review, discussions were held with doctors and nurses, patient groups and IVIg suppliers. The review recommended new ways to buy and administer IVIg to ensure that in the future the NHS receives the supplies of IVIg that it needs.



However, it is likely that the UK will need more IVIg than the worldwide suppliers can provide. Therefore, the Department of Health has produced national guidelines to help advise doctors and hospitals on how patients should be treated when IVIg supply is low.

What does this mean for me?

IVIg treatment is essential in some conditions. The new national clinical guidelines recommend which patient groups should receive IVIg as a priority. For these patients hospitals will always ensure that their treatment is continued even when IVIg supplies are low.

For other medical conditions there may be alternative treatments available. For such patients, IVIg may not be used at times of shortage, so that IVIg can be reserved for those patients where no alternative is available.

The new national guidelines will also ensure that the reason you receive IVIg is reviewed every year. At your review your doctor will assess if your condition has improved as a result of the IVIg treatment. You will only continue to receive IVIg if it is shown to be effective in treating your condition. If IVIg is not effective for you then you will stop receiving it and your doctor will recommend an alternative which may be more beneficial. Your doctor will continue to monitor you and how you are responding to the new course of treatment.

What if I have worries about the use of availability or use of IVIg in my individual circumstance?

If you have any concerns, you should discuss these with your doctor. However, the new national guidelines and the introduction of a new national database of patients receiving IVIg have been designed so that patients for whom IVIg is crucial do receive it, even in times of shortage.

The Department of Health is planning to fund new research into alternatives to IVIg, for patients for whom IVIg has not been effective. In the future, this will help provide patients with additional treatment options.

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Additional sources of Information

For further information please go to:
Department of Health Immunoglobulin website
immunoglobulins@dh.gsi.gov.uk

Primary Immunodeficiency Association
Alliance House, 12 Caxton Street,
London, SW1H 0QS.
www.pia.org.uk

ITP Support Association
'Synehurste', Kimbolton Road, Bolnhurst,
Bedfordshire, MK44 2EW
www.itpsupport.org.uk

GBS Support Group
GBSSG, LCC Offices, Eastgate, Sleaford, NG34 7EB
Tel: 0800 374 803
www.gbs.org.uk

Kawasaki Support Group
13 Norwood Grove, Potters Green, Coventry,
West Midlands, CV2 2FR
Tel: 024 7661 2178
www.patient.co.uk/leaflets/kawasaki_support_group.htm