

Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Immunoglobulin treatment in Neurology

This information sheet from Great Ormond Street Hospital (GOSH) explains what immunoglobulin is, why it is used in Neurology, how it is given and some of the possible side effects. Each person reacts differently to immunoglobulin and so your child may not suffer any of the side effects mentioned. If you are worried about any of these side effects, please ring one of the contact numbers on the fact sheet. If you have any questions or concerns, please ask your doctor, nurse or pharmacist.

What is immunoglobulin?

Immunoglobulin is also known as IgG or antibody. It is a blood product and is given often as replacement for people who are unable to make their own antibodies. It is the mainstay of treatment for patients affected by primary antibody deficiency and an essential component of treatment in other complex immunodeficiencies and some secondary immunodeficiencies including use during bone marrow transplant (BMT). Immunoglobulin is also used in other specialist areas including haematology, neurology and gastroenterology as an 'immunomodulator' where its mechanism of action is not well understood.

In Neurology it is often used to modulate the immune system in conditions where we recognise that the immune system has become mis-programmed and put the brain, eyes and spinal cord under attack. Some conditions we use it in are Guillain Barre syndrome, acute transverse myelitis, ADEM, optic neuritis, opsoclonus myoclonus, neuromyelitis optica and auto-immune encephalitis.

Evidence from trials has established IVIG as a first line of treatment for Guillain-Barre syndrome and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). It is also used as a reserve treatment in severe acute demyelination, such as Acute Disseminated Encaphomyelitis (ADEM) and Acute Transverse Myelitis (ATM) or for severe attacks of Multiple Sclerosis (MS).

Important background information

Immunoglobulin is a blood product made from pooled collections of human plasma; therefore with all IgG products there is a very small risk of transmitting infections such as hepatitis. To minimise this risk, all blood donors and IgG products are carefully screened, and manufacturing processes include virus inactivation steps against common viruses including HIV, Hepatitis B, and Hepatitis C. In the UK, most IgG products are made from US plasma. British plasma has not been used since 1998 due to the possible risk of variant Creutzfeld Jacob Disease (vCJD) for which there is no screening process at present.

The risks are very small and your doctor would have assessed that the benefits of the treatment outweigh the potential risk of infections from IgG.

How is it given?

Immunoglobulin can be given by infusion through a cannula into a vein (intravenously or IV). In some specialities, it can be given by subcutaneous infusions (SC) under the skin using a portable infusion pump or by hand. This is very unusual in Neurology, particularly as larger amounts of fluids are needed.

Intravenous immunoglobulin (IVIg)

Administering IVIg is dependent on having good venous access. It is often just given once, but infusions if needed regularly can be are administered every four weeks. All infusions should be started slowly and gradually increased to the maximum rate. IVIg can be administered at your local hospital as part of a shared care arrangement. Infusions normally take between three and four hours to complete depending on the dose given and how well your child tolerates the infusion.

What are the potential side effects of immunoglobulin therapy?

Reactions to immunoglobulin are rare but they are more likely to occur during the first few infusions. Reactions are more common with IVIg than SCIg. Possible side effects are described below, and your doctor or nurse will also explain these to you.

Important information

Your child is more likely to have a reaction to immunoglobulin if they have an infection. If your child is unwell when their infusion is due, please tell your doctor or nurse. The infusion may need to be delayed and the infection treated with antibiotics first.

Please tell the doctor or nurse if your child complains of any of the following side effects during the infusion as these symptoms can also be reduced by slowing or stopping the infusion and/or by giving your child medicines such as paracetamol or antihistamine.

During the infusion

Headache, fever, feeling sick and/or abdominal pain: These may occur during or after the infusion. They are common in older children. Please tell the doctor or nurse if your child complains during the infusion so we can slow or stop the infusion or give additional medicines.

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Allergic type reactions: Signs of an allergic reaction include skin rashes and itching, high temperature, shivering, redness of the face, a feeling of dizziness or headache, tightness or pain in the chest, and wheezing or difficulty breathing. Reactions may be mild to severe. If you see any of these signs, please report them to a doctor or nurse.

After the infusion

Flu-like symptoms: Your child may have a mild headache, fever, chills, aching joints and muscles. These symptoms normally disappear within 24 to 48 hours and can be treated with regular paracetamol. They are more common after the first few infusions. These symptoms occur mainly in patients receiving intravenous immunoglobulin.

Long-term risks: There is a very small chance of contracting an infection from receiving a blood product, as explained earlier in the leaflet. This is monitored by regular blood tests. If you require more information on this, please ask your doctor or nurse.

Useful numbers

Pharmacy Medicine Information: 020 7829 8608 GOSH Switchboard: 020 7405 9200 Neuroimmunology Clinical

Nurse Specialist team: 020 7405 9200 ext 5051 or 0460



Further information and support

- The MS Society supports people affected by multiple sclerosis and other demyelinating disorders. Call their helpline on 0808 800 8000 or visit their website at www.mssociety.org.uk
- You can call the Encephalitis Society on 01653 699 599 or visit their website at www.encephalitis.info
- The Transverse Myelitis Society may also be able to help. Their helpline number is 020 8568 0350 and their website is at www.myelitis.org.uk
- The British Trust for the Myelin Project supports researchers and other people with an interest in demyelinating disorders. You can call them on 0161 292 3191 or visit their website at www.myelinproject.co.uk
- The Guthy-Jackson Charitable Foundation in the United States supports people with Neuromyelitis Optica, as does the UK organisation NMO-UK. Visit their websites at www.guthyjacksonfoundation.org and www.nmo-ukresearchfoundation.org

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