

Your child's antibody replacement therapy at home

Children's Hospital

Information for Patients

Produced: October 2024

Review: October 2027

Leaflet number: 1544 Version: 1

Introduction

We give home immunoglobulin (antibody) therapy to children and young people with primary and secondary (which happen as a result of other treatment) immune deficiencies. These cause frequent infections despite regular use of oral antibiotics. Immunoglobulin treatment is antibodies that help the body to fight infection. This treatment should help you

- get fewer infections,
- miss less school
- reduce the chance of long term lung damage

The hospital's immunology team oversees your treatment. They make sure you get the immunoglobulin and equipment you need through the hospital and homecare companies.

The benefits of weekly subcutaneous infusions at home

Subcutaneous immunoglobulin (SCIg) infusions use a small needle. It goes into the fatty tissue just under your skin. The infusion usually takes about 1 hour. You will need to sit in one place during the infusions.

Benefits of doing this at home compared to hospital are:

- You can choose the time, for example, outside of school/working hours
- It takes less time. Once a week using more than one spot instead of every 3 weeks using one spot
- You are less likely to catch other infections from hospital.
- Much easier to place the needle for the infusion.

**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

The risks of immunoglobulin therapy

- **Infection risk:** It is a blood product. This risk is very low. All donors are screened, and the product is treated to kill viruses.
- **Allergic type reaction:**
 - This is more likely when starting therapy or swapping to a new product. At least 3 infusions are given in hospital. This is to manage this risk and make sure of safe practice.
 - If you are unwell it may be better to delay the infusion. Please talk to the immunology team.
 - Most reactions are mild. They can usually be managed with an antihistamine at home. Get urgent medical advice for reactions not responding to an oral antihistamine.
- **Blood clots:** Much less likely with subcutaneous therapy, and in children and young people, compared to adults.
- **Headaches and tiredness (fatigue):** Rare in children and usually passes quickly.

The benefits of treatment are greater than these risks.

The criteria for home therapy management

The child, young person and/or parent/carers **must**:

- Agree (consent) to treatment and the responsibility of home management
- Attend at least 6 monthly Out Patient follow up appointments
- Make sure that blood tests are taken every 12 weeks. These are usually taken at the daycare unit at the hospital.
- Fill out and send infusion records, batch numbers and any side effects or reactions each month

Training involves weekly attendance at the hospital for 6 weeks to:

- observe at least 1 infusion
- practice preparing and giving under guidance and supervision of qualified nurses
- learn about troubleshooting infusion problems, side effects and the importance of submitting infusion records and blood testing
- take part in a final practice test of competence
- Fill out a written multiple-choice test on immunoglobulin therapy, infections and side effects.

More information is available from:

The 'International Patients' Organisation for Primary Immunodeficiencies (IPOPI)

www.ipopi.org

Immuno Deficiency UK: www.immunodeficiencyuk.org

UK PIPS: www.ukpiips.org.uk

University Hospitals of Leicester NHS Trust

Department of Immunology

Telephone: 0116 258 6702

For any questions or problems, please contact:

Richard Cawthorn

Children's Immunology Nurse Specialist

Children's Hospital

University Hospitals of Leicester NHS Trust

Telephone: 0116 258 6711

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

Previous reference:

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk