RMCH Paediatric Immunology News

Manchester University NHS Foundation Trust

Issue 1 Winter 2025

Welcome to the first edition of the RMCH Paediatric Immunology annual newsletter! The purpose of this circular is to give you an idea of the service our department provides and make you aware of the resources available to patients with immune system disorders. We hope you enjoy reading it!

Department of Paediatric Immunology RMCH

History:

The department of Paediatric Immunology in Manchester was initiated in 1997 through the fundraising of the Drew family who noted a lack of services for children with immune deficiencies. In 1997 a monthly outreach clinic was established with Professor Andrew Cant from Newcastle. In 2002, Dr Peter Arkwright was appointed as the first Paediatric Immunologist at RMCH with support from the Specialist Nurse Sister Barbara Boardman. In 2009, Dr Stephen Hughes was appointed as a second Paediatric Immunologist, followed by Dr John Molloy in 2019.

Today:

The department has now grown to a staff of nine (Consultants, Resident doctors, Nurse specialists, Admin team). In addition to our own clinics, we do joint clinics at RMCH with colleagues from rheumatology, respiratory, gastroenterology and haematology.

We also conduct two outreach clinics at Royal Preston Hospital and Alder Hey Childrens Hospital. Currently we have 340 patients registered in our service.

Family Experience of an immune deficiency diagnosis

A diagnosis of an immune deficiency in a child can be a life changing experience for families. We are lucky to have one of our recently diagnosed patient's Pippa Vickers mother Sarah describe their journey in the immunology service. You may find some of their journey resonates with your own experiences.

"Our journey to becoming an immunology patient began when our daughter was 5 months old. She started getting coughs and colds which became constant and severe. We were frequent attenders to the GP and our local hospital, each time being told she was an unlucky child who was just catching lots of viruses as it was winter. Within a week of having some immunology bloods completed that showed low immunoglobulins, we were in clinic at Royal Manchester Children's Hospital. More tests were done and a week later Pippa had her first infusion of Immunoglobulins. She then started on weekly subcutaneous infusions which she has tolerated well.

Being told your child needs weekly infusions which involves you having to insert a needle into their skin is terrifying and feels impossible. However, with the support of the immunology nurses and medical team we felt empowered to do this. We received training with them at RMCH and continued to have support at home with our local community nurses until we felt confident to administer them alone.

The immunoglobulin infusions are now a part of our weekly routine. If we have any concerns at all the immunology team are always at the end of the phone and no question is considered too silly for them. Being scooped up and looked after by the immunology team has been life changing for us. We no longer have constant hospital admissions, and our daughter has gained weight, started walking, talking and smiling. For months we didn't know what her laugh sounded like as she was too poorly, we now know she has a delightful chuckle and personality.

This photo is from June 2025 before she started her immunoglobulins

This photo is from August 2025 - she had been on immunoglobulin treatment for about 8 weeks

Tell us more about yourself?
One of our consultants, Dr Stephen Hughes has kindly offered an insight into his work, inspirations and interests.

1. Why I decided to work in paediatric immunology
When I studied immunology at university, I was fascinated. As I began working as a doctor, I was drawn to paediatric immunology because it combines detailed science with the chance to make a real difference for children and families. The possibility of finding treatments that can cure or transform lives was – and still is – very exciting to me.

2. Interests outside work
Outside work, I belong to the Methodist Church, and I like to get involved in things that support other people. Recently I have been helping to set up a repair café where people can bring broken items to be fixed instead of thrown away (so, I have started collecting useful tools). Before that, I organised a community boardgames day (so, I have an amazing collection of brilliant board games), and before that I ran Who Let the Dads Out?, a group supporting fathers and young children (I have not felt any need to collect any more children).

3. Fun fact about Stephen
My PhD research was on an immune cell called the dendritic cell. They are so important and so well designed that no human immune deficiency has yet been found where dendritic cells are missing!

Vaccination advice for immunology patients

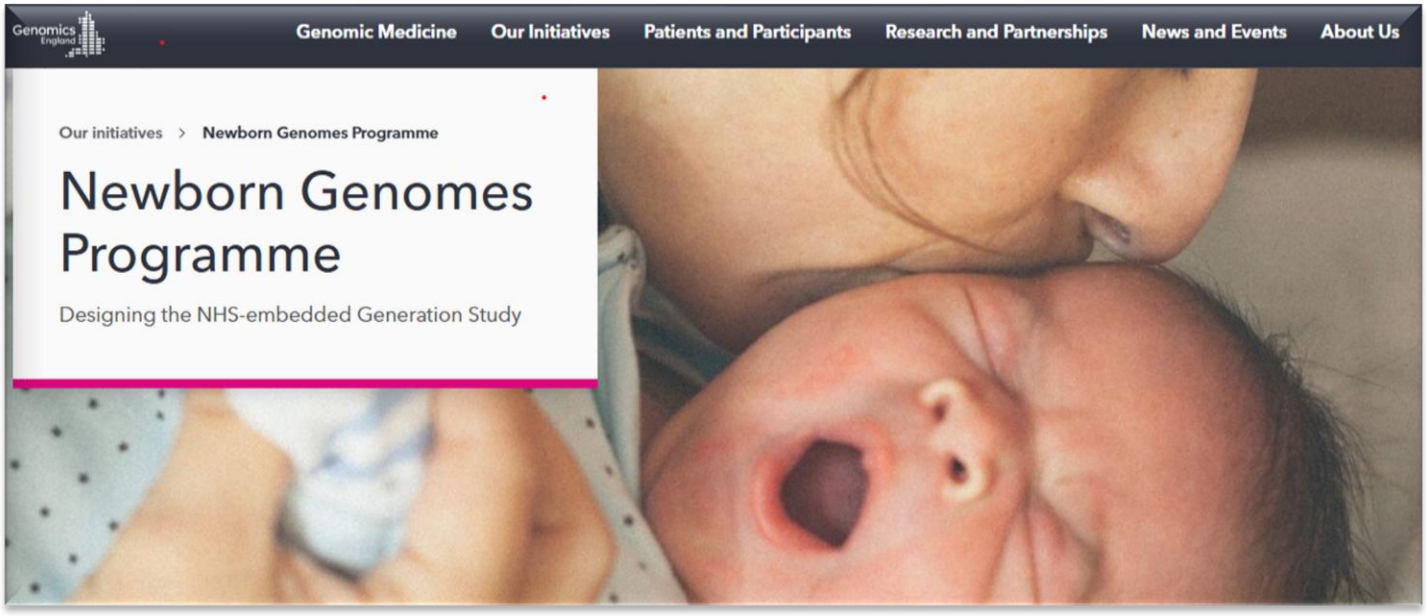
Vaccines protect us from many infections—and even some cancers—by training the immune system to recognise and fight germs. Your immunologist will have measured antibody levels after vaccines like tetanus to see how well the immune system responds.
For people who **cannot make antibodies**, regular **immunoglobulin treatment** provides ready-made protection against many common bacteria and viruses.
Even so, some vaccines are still worthwhile:
Flu vaccine: gives useful T-cell protection each year, even for patients on immunoglobulin. Family members should also be vaccinated to add another layer of defense.
COVID-19 vaccine: shown to benefit patients with antibody deficiencies—please have it when offered.
HPV vaccine: recommended for all adolescents with antibody or T-cell problems, using a full course of doses.

Immunology news/research update:

Dr. Arkwright brings up to date on exciting developments in the immunology world!

As we are all social animals, life is all about interacting and having fun with others: our family, our friends, our pets and also microorganisms. Some microbes such as “good bacteria” that live in our gut help us to remain healthy and well. Other bacteria and viruses such as golden Staph, E. coli, measles, flu and COVID can make us very sick. For most people vaccination is key to prevention serious infections.

In patients with immune deficiencies, it is only when we come across these microbes that we get ill. Modern medicine is now prioritising prevention. Rather than waiting until patients get ill and then having to see a doctor and sometimes go to hospital, it would be great to prevent us getting ill in the first place. The NHS have recently started a new screening program for genetic diseases, including immune deficiencies called the **Newborn Genomes Programme**. It is still in the early stages, but the hope is that all infants will soon be screened for genetic diseases of the immune and other systems so that they can be diagnosed before they get sick and therefore get treated early, some even get cured. Genetic testing is changing our ability to prevent and diagnose immune deficiencies. It is very exciting times! If you are interested, you can read more about it all at the following link: https://www.genomicsengland.co.uk/initiatives/newborns



Further information/resources/supports

Immunodeficiency UK

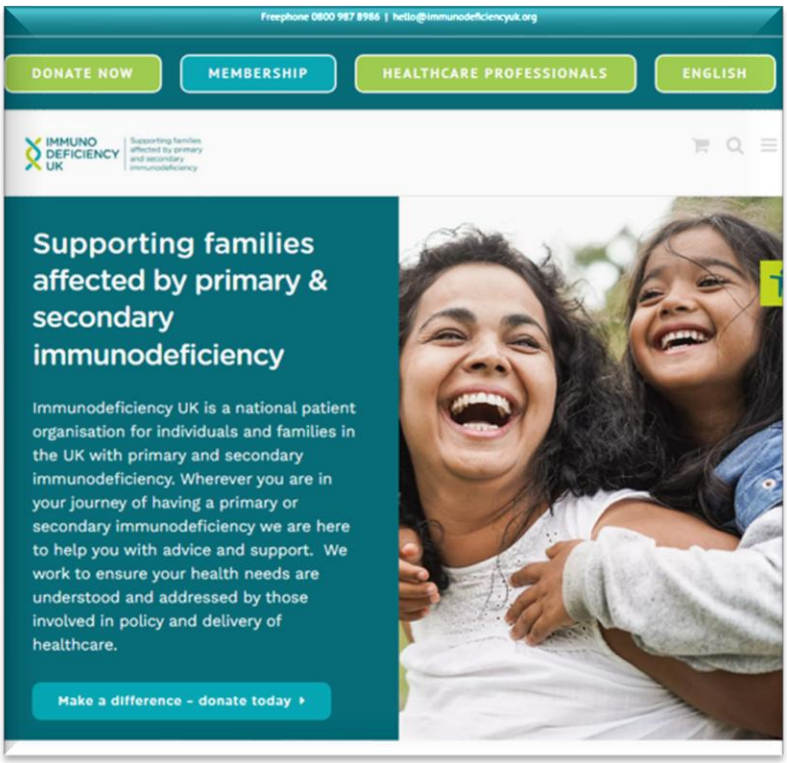
Immunodeficiency UK is a national charity supporting people affected by immunodeficiencies. The charity works to improve awareness of immunodeficiency and its impact, and advocates on the community's behalf on healthcare provision and access to specialised medicines. Whether you are newly diagnosed, caring for a loved one, or have been living with an immunodeficiency for many years, they aim to help you feel informed and supported.

By visiting their website, you can find information to help navigate the challenges you may be facing. Alongside people's stories of those affected, they have practical guides on living with immunodeficiency, including how to access COVID-19 medicines, and on topics such as travel insurance and employment rights at work.

You can also find booklets explaining the treatment and management of immunodeficiency and information on specific immunodeficiency conditions, as well as information for your GP and other healthcare professionals.

The charity has a helpline for those who need support, and each year, they hold mental health support events, acknowledging that having an immunodeficiency can take an emotional toll.

Membership of Immunodeficiency UK is free, with members receiving a monthly e-newsletter giving community news, health and research updates and details of events and surveys that may be of interest. You can sign up for membership at Membership - Immunodeficiency UK, and our helpline contact email is **hello@immunodeficiencyuk.org.**



Further resources:
Additionally, the websites below may also be of help:
https://cgdsociety.org/
https://www.haeuk.org/