



September  
Newsletter

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## Welcome to the September Immunodeficiency UK newsletter!

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Hello Immunodeficiency UK member and we hope the month is treating you well so far.

We have a lot to update you about in this month's newsletter.

Read on for our monthly news round up and, don't forget to [like us on Facebook](#) to get updates throughout the month.

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### COVID-19 Autumn booster dates and information



**England** – For those most at risk, including people with weakened immune systems, vaccinations and local invitations started on 11 September. You can now book your vaccine appointment via the National Booking System [National Booking Service - NHS Digital](#) . NHS England recommends people should be offered flu and COVID-19 vaccinations at the same time.

**Scotland** – Care home residents, people aged 75+ and people with weakened immune systems are being invited for COVID-19 boosters and flu jabs starting from 4 September. Invitations for other groups will follow. People should wait to be invited or prompted to book their jab(s) by NHS Scotland. Over 50s will receive a flu jab in Scotland, compared to only over 65s in England. Flu jabs for 50–64-year-olds will start from 4 September. [The coronavirus \(COVID-19\) vaccine | NHS inform](#)

**Wales** – the autumn booster programme started on 11 September. Vaccinations for flu and COVID-19 are to be rolled out to over 65s, at risk groups and those working or living with vulnerable people. [COVID-19 vaccination programme | GOV.WALES](#)

**Northern Ireland** – the autumn booster programme began on 18 September, starting with residents in care homes. [Get a COVID-19 vaccination in Northern Ireland | nidirect](#)

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## Access to COVID-19 treatments

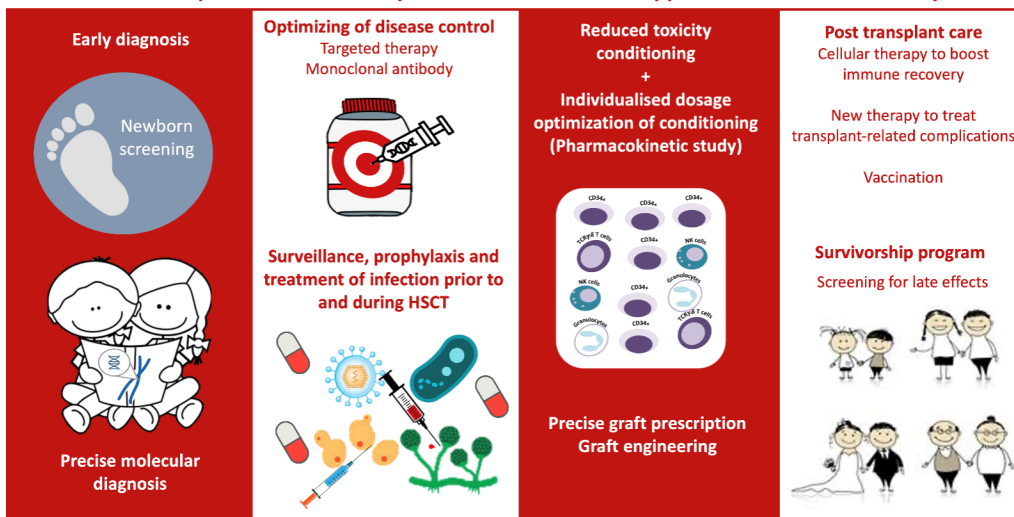
Updated information is now available with a list of integrated care board contact details for residents in England. The list was developed by joint working between Immunodeficiency UK, Blood Cancer UK, Lupus UK, Anthony Nolan and the National Kidney Federation.

[Immunodeficiency UK - Access to COVID-19 treatments](#)

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**The Haplo+4kids clinical trial to improve haploidentical donor stem cell transplant for children and adolescents with immunodeficiency**

**Towards Precision Medicine and a Personalised Approach to Haematopoietic Stem Cell Transplantation and Cellular Therapy for Inborn Errors of Immunity**



The Paediatric Immunology and Transplant teams at the Great North Children's Hospital in Newcastle and Great Ormond Street Hospital in London are preparing to start recruitment to an exciting clinical trial called Haplo+4kids, funded by the UK Medical Research Council.

The aim of this trial is to improve the transplant outcomes after a mismatched family or unrelated donor haematopoietic stem cell transplantation (HSCT; also known as a BMT) for children with inborn errors of immunity which is also known as primary immunodeficiencies. This trial is one of the important milestones to achieve precision medicine and a personalized approach to haematopoietic stem cell transplantation for children and adolescents with immunodeficiency.

The trial has been developed in collaboration with the Newcastle Clinical Trial Unit, Population Health Sciences Institute, Newcastle Cancer Centre Pharmacology Group and Leiden University Medical Centre.

We are very grateful to Immunodeficiency UK and the Bubble Foundation for their active roles in patient and public involvement in designing this trial.

HSCT is the most widely available curative treatment for many children affected by severe combined immunodeficiency (SCID) and non-SCID inborn errors of immunity. Survival and outcome have significantly improved in recent years due to factors including earlier diagnosis, superior HLA (tissue) matching technology, an increased number of available donors, improved supportive care and treatment of infections and complications.

**Improving transplant success for people without a suitably matched donor**

Until very recently best results were obtained when an HLA-matched family or unrelated donor were used, but many patients do not have a suitably tissue-matched donor. An alternative is to use a mismatched related or unrelated donor and take out the donor's T cells prior to infusion. This is referred to as T cell depletion. Historically, the major challenges of using such mismatched donors were graft-versus-host disease (GvHD), transplant failure, and a high transplant-related mortality. Removing T-cells leaves the patient at risk of infection for at

least 4 months post HSCT when the engrafted donor stem cells start to produce new T-lymphocytes.

### **Targeted removal of cell types that cause problems in HSCT**

There are many different types of T-cells which play different roles in the immune system. Each type of T-cell is distinguishable by the markers it carries on its surface. Various methods are available to deplete certain T-cells based on these markers have been used over the years. A promising step forward has been the ability to selectively deplete the T cells that cause GVHD. These are known as CD3+ T-cell receptor  $\alpha\beta$ , or TCR  $\alpha\beta$ + cells for short. Removing these cells decreases the risk of GVHD but leaves behind other 'good, helpful' T-cells, such as T-cell receptor- $\gamma\delta$ + cells, which help to fight infection (and leukaemia) and enhance engraftment.

Using a similar approach certain B-cell types can be removed to help improve outcomes for patients. For example, removing CD19+ B-cells decreases the risk of Epstein-Barr virus-driven post-transplant problems.

Using the combined approach of this specific B-cell and T-cell depletion strategy has been shown to provide rapid and sustained engraftment, faster immune recovery, and a low incidence of GvHD. In 2018 Newcastle and GOSH published a report of 25 patients who had this type of procedure with an overall survival of 84%. More recently Dr Su Han Lum and colleagues in Newcastle showed that survival was equivalent for children under 5 years of age whether they had a matched family/unrelated or a mismatched TCR  $\alpha\beta$  depleted donor transplant.

However, children over the age of 5 years, had a significantly lower overall survival following a mismatched TCR $\alpha\beta$  depleted transplant compared to a matched family/unrelated donor transplant. Survival rates were lower due to viral infections and associated health complications indicating that an additional strategy was needed.

### **Giving back 'good' T-cells**

The team at Newcastle have been working on a strategy to tackle these poor survival rates using an additional depletion step. This involves removing what are known as naïve GVHD-producing T-lymphocytes, amounting to about 10% of the donor cell harvest. This process leaves behind a pool of donor cells containing important memory T-lymphocytes (labelled CD45RO+) which can fight infection and enhance engraftment. Early results of giving memory T-cells back the day after the HSCT are extremely promising even in children over the age of 5 years with viral infection.

**The Haplo+4kids project** will assess different doses of the memory T-cells to find the best one and include detailed analysis of the drug concentrations, in the patient's blood, of the different treatments that are needed for 'conditioning' the patient's immune system prior to transplant. In addition, there will be careful monitoring of how the cells of the immune system recover after HSCT. Results will be compared between groups of patients – those who receive these extra

cells to those who do not, and to outcomes of patients who have already undergone HSCT, including those people who received matched donor transplants.

The option of using mismatched donors who are often parents who are half-matched (haploidentical) to their child, means that every person who needs a transplant has a donor. This is revolutionising HSCT practice. The transplant can be arranged quickly and despite the laboratory costs of the cell depletions, may be more cost effective than using unrelated donors.



### The Haplo+4kids team

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## Immunodeficiency UK supports study into the impact of COVID-19

Immunodeficiency UK is proud to support the **IDIDPSYCH** study: Impact of a **D**agnosis of primary or secondary Immuno**D**eficiency on **PSYCH**ological health in the United Kingdom. This study was designed during COVID-19 with the aim of exploring how the pandemic has affected mental-health and quality of life for individuals with immunodeficiency over time, and to examine whether there are regional differences across the UK in terms of these health outcomes.

This study is coordinated by the Royal Free London Foundation Trust and hopes to recruit adult patients with either primary or secondary immune deficiency receiving care from NHS Immunology Trusts across the UK, with representation from all four home nations. The lead researchers are Dr Mari Campbell, Consultant Clinical Psychologist at the Royal Free Hospital and Dr

Philip Bright, Consultant Immunologist at Southmead Hospital in Bristol (pictured below).



Interested participants will be given access to an online link and prompted to complete 20 min of questionnaires about themselves approximately every 6 months (for a period of up to 2 years).

Recruitment will start in the next 3 months. If you are a patient, then your centre may be in touch to ask you if you would like to be involved.

Participation in this project will provide valuable insights to help healthcare professionals better understand the specific needs of patients with immune deficiency regarding their mental health and the impact of COVID-19 on this. By sharing your experience, you will contribute to improving care and support for individuals with immune deficiency.

Immunodeficiency UK has provided £1,560 in funding to pay for the licence for the online questionnaire facility and travel for a researcher to set-up the study and collect data at other sites in the UK where necessary.

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## Birmingham plasma donor centre reopens in new site with expansion to meet need for 5,500 more lifesaving donations



Susan, CEO of Immunodeficiency UK, was among many speakers invited to talk at the reopening ceremony of Birmingham's new, plasma donation centre

following a move, modernisation and expansion to bring in 5,500 more plasma donations a year.

The donor centre has moved to a new site several doors along to a new space on the ground floor. It now has a public 'shop window' facing on to busy New Street with the centre now bigger and brighter, with 12 plasma donation chairs instead of nine, increasing the amount of plasma that can be collected each day.

Plasma is made into lifesaving medicines which are used to treat more than 50 diseases. Over 7,000 people with primary and secondary immunodeficiency rely on having immunoglobulin (IG) therapy, which is made from plasma donations. Susan, in her speech, highlighted how important IG is to our community and the impact of the worldwide shortage of plasma during the COVID-19 pandemic which led to some patients receiving lower doses or having to wait longer between infusions. She hugely welcomed plasma collection in the UK, which would lead to greater security in IG supply, and less reliance on imported IG products.

There are only three plasma donation centres in England, including Birmingham, so it's very important that the NHS makes the town a hotspot for plasma donation. Over the last 12 months, the centre collected around 5,850 donations. But the new centre needs to collect around 11,350 donations over the next year to reach donation targets and boost NHS supplies.

The Birmingham plasma donor centre is in 61 New St, Birmingham B2 4DU.

If you live in the Birmingham area, please encourage friends, family and work colleagues to sign up. Donation takes about 35 minutes and the whole visit – including questionnaires and snacks - takes around an hour.

Find out more donating plasma at [How to donate plasma - NHS Blood Donation](#).

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## Free Wills Month



We're taking part in [Free Wills Month](#) this October to give our members the chance to have a simple will written or updated for free.

### **So, what is Free Wills Month?**

Free Wills Month takes place in March and October each year.

Immunodeficiency UK supporters can have a simple will written or updated for free.

If you choose to write your will using our service. We hope you'll consider leaving a gift in your will to Immunodeficiency UK, although this is entirely optional.

### **Benefits**

- Control who gets your estate
- Protect your family
- Leave money to charity
- Set out your funeral wishes
- Reduce inheritance tax
- Get true peace of mind
- ALL Wills solicitor checked

To get started head to [Free Wills](#).

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## Natassia and Matthew's fundraising story



Natassia and Matthew's son Brooklyn was diagnosed at 8 months old with X-Linked CD40 Ligand Deficiency (also known as Hyper IgM Syndrome). X-Linked Hyper IgM compromises the body's ability to produce antibodies to pathogens such as bacteria and viruses and those affected are therefore at significant risk for opportunistic and repeated infections.

Thanks to their amazing work they have to date raised over £5,100 to support our work.

Here Natassia shares why they decided to fundraise for Immunodeficiency UK and what activities they took part in to raise funds.

Brooklyn undergoes fortnightly immunoglobulin replacement therapy as well as taking prophylactic antibiotics, antifungal and antiviral medication. These keep him relatively stable but are not a cure – the only known cure is an allogeneic hematopoietic stem cell transplant. Brooklyn has a full unrelated match and is due to have a transplant this Autumn.

## Why we decided to fundraise

We wanted to raise funds for Immunodeficiency UK to help raise awareness for all of those living with a PID and the constant worry of illness and sickness that comes with it. There's so many articles and support pages provided by Immunodeficiency UK that were invaluable to us post diagnosis with understanding more about Brooklyn's condition.

## What we did to fundraise

A lot has been done to raise funds so far, with many family members and close friends pulling together, some of these include:

- 5km run for 50 days
- 5km charity walk
- X2 charity football matches
- CrossFit challenge
- Goggins challenge (run 4 miles, every 4 hours, for 48 hours)
- BBQ and bake sale.

Thanks so much Natassia and family.

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Best Wishes,  
Susan and Fay  
The Immunodeficiency UK Team

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