Welcome to the October Immunodeficiency UK newsletter!

Hello Immunodeficiency UK member,

Welcome to the October newsletter. We hope you find the information useful to you.

Read on for our monthly news round up and, don't forget to visit us on Facebook to get updates throughout the month.

Grifol has provided a grant for the creation of the newsletter with no input into content.

STRAVINSKY study – a chance to get up to date!

STRAVINSKY stands for ‘Stratification of Clinically Vulnerable People for COVID-19 Risk Using Antibody Testing’. It is a 2-year study which aims to establish if antibody testing can identify who remains at greatest risk of severe COVID-19 infection after vaccinations.

The British Society for Immunology are holding another free webinar for the public to update on STRAVINSKY's progress at 18:00-19:00GMT on Thursday 31 October 2024. Click here to find out more and register

If you missed April’s webinar you can watch it at https://www.immunology.org/partnerships/stravinsky.

MHRA approves Leniolisib as a treatment for APDS

Good news! In September, the Medicines and Healthcare products Regulatory Agency (MHRA) approved leniolisib to treat the rare primary immunodeficiency activated phosphoinositide 3-kinase delta syndrome (APDS).

In clinical trials, patients taking leniolisib saw a reduction in lymph node size and a correction of the underlying immune defect. A lay summary of the trial’s findings can be found here. The drug is now going through a National Institute for Health and Care Excellence (NICE) appraisal. This will review the clinical evidence and its cost effectiveness to reach a decision as to whether the drug will become routinely available in the NHS.

Immunodeficiency UK has made a submission to NICE supporting access. This follows on from our collaboration with NICE to carry out a survey to understand the impact of APDS on those affected and their carers. The results of the survey can be found on our website at ID-UK-report-Impact-of-APDS-on-patients-andtheir-carers.pdf (immunodeficiencyuk.org).

Read Arabella's and Jasper's stories of living with APDS.

UK plasma products expected in early 2025

Thirty-two thousand units of frozen UK Plasma have been sent to the fractionator Octapharma, in Germany, to begin the process of being turned into the lifesaving plasma medicines, albumin and immunoglobulin, for the UK for the first time in 25 years. The first UK patients will receive these medicines in early 2025. Further shipments of 30,000 units of frozen UK plasma every week are planned. This will lessen the UK’s need for importing plasma-derived medicines from abroad and allow the UK to build a level of self-sufficiency of immunoglobulin to avoid shortages.

Read More:

Statement on the UK Plasma for Medicines Programme
NHS Blood and Transplant Update

🌡 Winter Wellness Update: Your Guide to Seasonal Vaccinations

As winter approaches, please ensure you get protected against seasonal illnesses. You can find information on the winter vaccination programme, including important updates on:

- COVID-19 boosters
- Flu vaccinations for children, patients, family members
- RSV vaccine eligibility

Visit our Get Winter Ready page for the full guide. Stay well this winter! 🌨

Thank you for your generosity on International Day of Charity

On behalf of everyone at Immunodeficiency UK, we want to express our heartfelt gratitude for your incredible support during this year's International Day of Charity.

Your donations will make a significant impact in supporting those with immunodeficiency. Your generosity doesn't just contribute to a cause; it changes lives. Every pound donated brings us closer to our vision of a world where people with immunodeficiencies can live their lives to the fullest.

Thank you for being a vital part of our community. Together, we are making a difference.

Spread holiday cheer with festive fundraising!

As the festive season approaches, we're excited to share some merry and bright fundraising ideas to support our cause. Your efforts make a real difference in the lives of those affected by immunodeficiency. Here are some jolly ways you can help:

1. Virtual Christmas Carol Concert
Organise an online carolling event. Invite friends and family to join in and ask for donations to attend or participate.

2. Festive Jumper Day
Host a festive jumper day at your workplace or school. Participants donate to wear their most outrageous Christmas sweaters.

3. Holiday Bake Sale
Whip up some seasonal treats and sell them in your workplace. Think mince pies, gingerbread, and festive cupcakes!

4. Christmas Crafts
Showcase and sell handmade holiday decorations, gifts, and cards to friends and family or in your workplace. Perfect for our crafty supporters!

5. Virtual Christmas Quiz Night
Host an online festive quiz. Charge an entry fee and offer holiday-themed prizes for the winners.

6. Gift Wrapping Service
Offer a gift-wrapping service in your local community for donations.

7. 'Deck the Halls' Competition
Organise a Christmas decoration contest in your neighbourhood. Participants donate to enter, and the community votes for their favourites.

Remember, your fundraising efforts directly support our mission to improve the lives of those with immunodeficiency. Every pound raised brings hope and help to those who need it most.

Thank you for your continued support, and happy fundraising!

Brooklyn's journey with CD40 ligand deficiency

At just a few months old, Brooklyn was diagnosed with CD40 ligand deficiency, a rare primary immunodeficiency. His parents Natassia and Matthew, share their family's challenging journey from diagnosis to successful treatment.

Brooklyn underwent a life-saving stem cell transplant at 15 months old at the Great North Children's Hospital in Newcastle. Despite initial complications, Brooklyn showed remarkable resilience. Now, almost a year post-transplant, he's thriving and enjoying activities that were once off-limits.

They offer valuable advice for other parents facing similar diagnoses, emphasising the importance of connecting with support networks and staying informed.

Thank you to Natassia and Matthew for sharing Brooklyn's journey with us.

Read Brooklyn's full story here

Opportunity to take part in market research

Acumen Fieldwork are looking to speak to people diagnosed with a primary immunodeficiency (PID) to take part in a study to support the development of an infusion set product. Involvement criteria:

- People diagnosed with a PID
- Who currently receive treatment, or are due to start immunoglobulin treatment via subcutaneous injections (SCIG)

To take part you need to complete the pre-screening eligibility questions at https://survey.researchopinions.co.uk/index.php/532887?lang=en

Alternatively, you can email harriet.connell@acumenfieldwork.com directly or telephone Acumen's offices on 0161 242 5215 and ask to speak to Harriet. After reviewing the pre-screening responses, suitable candidates for the study will be contacted by the Acumen team to take part in a one-hour face-to-face individual interview, which will place in either central London or central Manchester.

As a thank you for contributing to the interview session participants would receive £120 paid via bank transfer, and up to £100 towards travel reimbursements.

At the interview stage the research team will ask participants background questions, people's experience living with PID and administering subcutaneous treatments, explore any issues experienced with SCIG treatment and what solutions people might want to be developed. Participants will also be asked to evaluate some physical solutions and provide feedback (e.g., easy, difficult, or confusing to use), opinions, and experiences.

All pre-screening data will be stored on Acumen Fieldwork's system throughout the project duration and will be securely deleted within 3 months following the project completion, in line with our data retention policy.

Best wishes,
Susan and Fay
The Immunodeficiency UK Team