



UKPIPS Community Newsletter

Issue 1 January 2023

Welcome:

This is our first Newsletter for some time, and we hope that you will find the news of interest. The team have been working to keep you informed via our Facebook, Website and LinkedIn pages through these difficult times. We have also been trying to understand how UKPIPS can support you and what you would like us to do, remembering that all the work is done by volunteers and that many also have health problems. We are so grateful to them for the work that they have been doing and our Medical Panel who also support us.

Save the Date – Community Event:

Whilst the Trustees were very disappointed to have to postpone the Community Meeting on 8th October 2022, due to the low numbers of attendees, this important Community Zoom Meeting has now been re-arranged for **Saturday 11th February 2023 from 10 am – 12.30.**

Please put this date in your diaries and the invites and a reminder have been sent out.

This will be an interesting and informative Meeting. Our keynote speaker is a well-known researcher and Consultant for Immune Diseases, leading some Covid Trials for such patients. You will also have the opportunity to ask questions of all the speakers including the Trustees.

We do hope as many of you as possible will attend, even if for a short time, as the Trustees also want to advise you all on the 2023 direction for UKPIPS.

NHS News:

Changes in NHS Commissioning

NHS England continues its structural changes away from Clinical Commissioning Groups and towards Integrated Care Systems (ICSs). This change is not likely to affect the Specialised Commissioning of Immunoglobulin until 2024, at the earliest, and it's not yet clear what impact, if any, this could have for patients. Whatever happens, NHSE will maintain responsibility for service specifications at a national level in terms of Immunology services.

Further information on Integrated Care Systems can be found here: [NHS England » What are integrated care systems?](#)



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UK Plasma

It has been two years since the ban on UK plasma was lifted and the NHS is still working to appoint a UK fractionator. Despite promised deadlines that have passed, we believe a preferred partner will now be chosen before the end of February 2023 and the mobilisation phase through to UK-based production will then start. The earliest we are likely to see UK plasma available to patients will be mid-2024. This update comes with a big shout out and THANK-YOU to all those UKPIPS community members who are involved with the NHS Blood & Transplant awareness campaign which has been extremely successful in increasing the plasma donor pool.

Immunoglobulin Commissioning Policy 2021

Following a big UKPIPS campaign in mid-2021, many community members responded to the consultation on the new commissioning policy. After some time in post-consultation discussion (behind the scenes) this has now been published. It can be viewed here:

[cpag-policy-for-therapeutic-immunoglobulin-2021-update.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/wp-content/uploads/2021/12/cpag-policy-for-therapeutic-immunoglobulin-2021-update.pdf)

Covid Treatments

The list of available treatments for those designated as “high risk of getting seriously ill from Covid Infection” (previously called Clinically Extremely Vulnerable) has been reducing through 2022, as the effectiveness has diminished. For most adults, antivirals such as Paxlovid, are the first line of treatment, with monoclonal antibody treatments only being used in exceptional circumstances where antivirals are not indicated (e.g. due to other medication interferences).

Sadly, children under twelve do not have any access to Covid medications and we just hope there are developments in this area in 2023.

Alongside other patient organisations, UKPIPS has been involved in the campaign for prophylactic treatments, so that immune-deficient patients can receive monoclonal antibody treatment as a preventative, rather than as a last resort once you have Covid. For us, this campaign has been running throughout 2022 and (despite the growing support) has simply not been recognised by DHSC, who have now passed the decision to NICE for a technology appraisal. We expect the result of the Evusheld appraisal in February. Sadly, this will be too late for the winter season and it is unlikely Evusheld will be much value in 2023 as new variants develop. We are awaiting news updates on prophylactic treatments in development.

Facebook Community Group

If you haven't joined us on Facebook yet, please follow our public page - search on Facebook for UK Primary Immunodeficiency Patient Support (UKPIPS)). We also run a closed members



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group which can be accessed through the public page - click on *More* and you'll see the *Groups* drop down. The closed group is listed as *UKPIPS* for our community members, their families, friends, and carers. There are a few security questions to answer so we can maintain the group securely for the UKPIPS community.

You may not be aware that we also hold weekly community Zoom meetings which you can find out about through our closed Facebook group.

Funding:

As you are aware, UKPIPS is a charity solely funded by kind donations and grants from a variety of sources. Unfortunately, the charity's income has reduced significantly during the pandemic and this has restricted the work that the charity can undertake to support its Members.

We are now contacting relevant pharmaceutical companies and, up to now, have three that may be able to support UKPIPS. However, we really need to triple our current annual income to allow us to expand our activities. While we are continuing to explore other avenues, we are hoping that some Members can provide monthly donations. For example, if half of the Members sent £5 a month to UKPIPS, that would provide around £15K of annual income which, together with the company donations, would allow the charity to significantly expand its activities to benefit all its Members.

If you, your carers or relatives are able to donate to the charity, please follow the link to the donation page on our website. Many thanks.

And Finally:

Erald Kuniqi has recently resigned as a Trustee, and we would like to thank him for his contribution to UKPIPS. Although he was a Trustee for a short time, he worked very enthusiastically on the survey of Members, helped with Medical Panel liaison and provided support for the work of the other Trustees and Management Team. We were very sorry to learn of his decision.

This means that once again we are looking for more Trustees to join the team. If you would like to know more about the role of a UKPIPS Trustee, please contact Carolyn Middleton at admin@ukpips.org.uk. We would love to hear from you.

Keep in Touch:

You can contact us at info@ukpips.org.uk, find us on Facebook and LinkedIn or visit our website www.ukpips.org.uk. Do tell us what you would like to read in future issues of our Newsletter.