



## PNH National Service Newsletter—2022/23

Welcome to the latest edition of the PNH National Service Newsletter for 2022/23.

Our newsletter will now come in a yearly installment and going forward, we would like to send the newsletter via email. If you have not already provided us with an email address, please let us know via email or telephone as below.

Telephone: 0113 20 68625

Email: leeds.pnh@nhs.net

### Welcome To The Team



We welcomed Dr Abraham Varghese to the team in August 2022. Some patients may remember him from a few years ago when he worked within the team. Dr Varghese has a wealth of experience within PNH and Aplastic Anaemia.



Nora Youngs joined the clinical nurse specialists team in December 2022. Many of you may know her already as she has moved across from the PNH Research Team where she worked for many years.



Jess Molyneux joined the team as a Clinical Nurse Specialist in July 2022. She joined us from the Oncology Day Unit in Preston where she worked as a chemotherapy nurse.

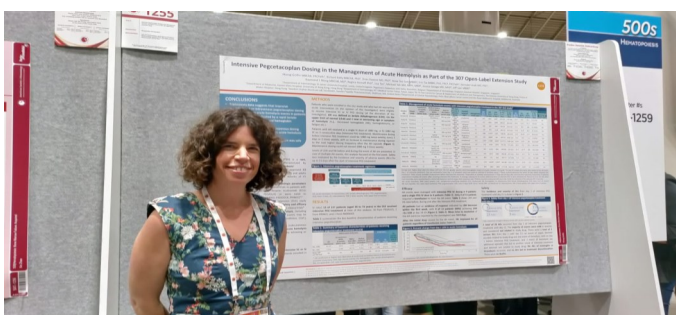


Kirsty Musij joined us in August 2022 as a Senior Clinical Support Worker. Kirsty joined us from A&E. Many of you will meet her at outreach clinics or speak on the phone.

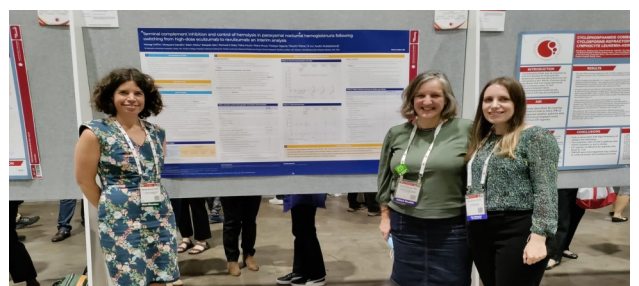
### ASH (American Society of Haematology) Meeting 2022

Several members of the team were privileged to travel to the American Society of Haematology meeting this year in New Orleans, for educational learning. We were also delighted to attend Professor Hillmen's inaugural Ernst Bueller lecture on Complement covering his life's work in PNH.

We presented work on several clinical trials, including Pozelimab and Cemdisiran, Ravulizumab high dose cross over study, Pegcetacoplan, and a service update from over 20 years of our PNH experience. Some photos of the posters below:



Intensive Pegcetacoplan dosing in the management of acute haemolysis as part of the 307 Open-Label Extension Study



Terminal complement inhibition and control of haemolysis in Paroxysmal Nocturnal Haemoglobinuria following switching from high dose Eculizumab to Ravulizumab: an interim analysis.



### Clinical Trials

We currently have a number of clinic trials in pipeline and some that are open to recruitment. You can speak about trials with a consultant at

<u>Trial</u>	<u>Open or upcoming</u>
Regeneron 1947—Aplastic Anaemia Trial	Open for patients with relapsed refractory Aplastic anaemia
Regeneron 2021 (cemdisiran and pozelimab) Pending	Naïve trial for patients with PNH not currently on treatment who are eligible for treatment
Omeros 01 : Pending	For patients with extravascular haemolysis
Novartis (Itacopan): Pending	For patients with extravascular haemolysis

We would like to invite our patients and their relatives to our next PNH Patient Focus Meeting hosted by The National PNH Service.

It will take place on 18th March 2023.

Location:

The Bridge Community Church

Rider Street

LS9 7BQ

If you would like to attend, please let us know by emailing the service at [pnh.leeds@nhs.net](mailto:pnh.leeds@nhs.net)

We have included the poster for the event with this newsletter.

### New PNH Website

Our new website went live in July 2022.

<https://pnhserviceuk.co.uk>

The new website was funded by Leeds Hospitals Charity with donations made by our patients and relatives.

Thank you for your donations.



### Patient Survey 2023

It is time for our next bi-yearly Patient Survey. We plan to use Survey Monkey (an electronic survey platform) again this year as it was successful in 2021.

We require an email address in order to send you the link for the survey.

If we hold your email address on file, we may contact you to ask for your permission to send the survey. Alternatively, please contact us on the telephone number or email address below with your email address.

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