



PNH National Service Newsletter—2023/24

Welcome to the latest edition of the PNH National Service Newsletter for 2023/24.

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

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Welcome To The Team



We welcomed Isla Storey to the team as our newest Clinical Nurse Specialist. Isla joined us in December 2023 from one of our Haematology wards here at St James.



We welcomed Bryan Callao to the team as our newest Senior Clinical Support Worker. Bryan joined us in December 2023.



We welcomed Emily Charlton back to the team following maternity leave. Emily joined our Clinical Trials team in 2023 as a Research nurse.

Unfortunately, we said goodbye to Kirsty Musij and Briony Forrest. Kirsty left us to further her career within the community and Briony left to expand her skills and knowledge in Haematology malignancies.

Achievements



Louise Arnold completed her Masters and qualified as an Advanced Clinical Practitioner.

Congratulations to Louise.

American Society of Hematology Conference 2023

The UK PNH Team represented the National Service at the International American Society of Hematology conference in San Diego in December, presenting a Medscape educational session, clinical trial abstracts and symposia. Several potential clinical trial options were also discussed with more information to follow.

As always, we thank the patients for furthering the PNH field by entering clinical trials.

Further information and clinical trial abstracts can be provided on request.



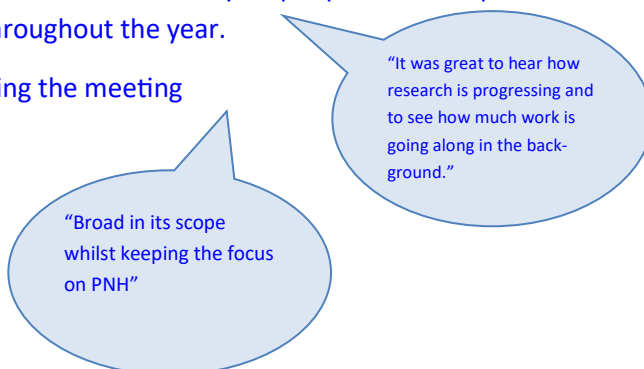
Patient Group Meeting—Rare Disease Day 2024

The PNH National Service, with PNH Support, welcomed the opportunity to mark Rare Disease Day 2024 with an update on PNH in an online meeting. Rare Disease Day is recognised worldwide with many events including receptions in Parliament, people wearing colourful things and undertaking fundraising or campaigns such as ‘Light up’ by Eurodis (Rare Disease Europe).

In the UK there are 3.5 million people living with a rare condition and, by bringing attention to PNH on Rare Disease Day, we can support education to the public, healthcare professionals, and policymakers about the challenges faced by individuals living with rare diseases. This can lead to increased research funding, improved access to treatment options and better support for patients and their families.

The speakers covered different areas from the service; Louise Arnold ACP introducing the importance of rare disease and the focus on support, research, awareness, education, treatment, and solidarity of working together. Dr Griffin gave an update of the service and current research of therapy discussing the submission to NICE for new therapies including a tablet treatment to manage PNH symptoms. Dr Holt, Clinical Research Fellow, is undertaking a PhD in furthering understanding of breakthrough haemolysis in PNH which can occur when a patient with PNH is treated with a complement inhibitor. Lastly, Dr Kelly introduced the new PNH registry managed by clinical staff under the International PNH Interest Group (IPIG). The meeting was well attended with nearly 50 people and with positive feedback. The aim will be to follow this with further patient events throughout the year.

Many thanks to PNH Support for hosting the meeting



Join other PNH patients and family members face-to-face at an informal meeting over coffee.

Where: Hayward Gallery Cafe located on the 1st floor of the Hayward Gallery building – <https://www.southbankcentre.co.uk/.../hayward-gallery-cafe>

Time: 11am
Date: Saturday 13 April 2024

All welcome

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 clinician at your clinic appointment.

<u>Trial</u>	<u>Open or upcoming</u>
Regeneron 2021	Open

NHSE Commissioners

Yearly Meeting

Every year we attend a meeting with NHSE where we present data for the previous year. Below is some of the data we shared with NHSE for 2022/23.

2022-2023	Eng-land	Scot-land	Wales	N Ire-land	Other	Total
On Complement Inhibitor	175 (30.8%)	36 (65.5%)	17 (63%)	7 (58.3%)	1 (0.25%)	236 (35.4%)
On Trial Therapy	31 (5.5%)	3 (5.5%)	2 (7.4%)	1 (8.3%)	0 (0%)	37 (5.6%)
Not on Complement Inhibitor	362 (63.7%)	16 (29.1%)	8 (29.6%)	4 (33.3%)	3 (0.75%)	393 (59%)
Total	568	55	27	12	4	666

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