



PNH National Service Newsletter—2024/25

Welcome to the latest edition of the PNH National Service Newsletter for 2024/25. We hope you find this informative.

A gentle reminder to ensure your personal information is up-to-date. 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

Every two years, we ask patients to participate in our patient survey. In line with the NHS' aim to be digital, we will send the invitation via email. If you have not received an email from us, please use the following QR code or URL:

<https://www.surveymonkey.com/r/PWXF858>



Team Updates



Dr Abraham Varghese has changed roles and has now left the PNH Service. We wish him luck in his future endeavours.



Clinical Nurse Specialist Jess Molyneux is now on maternity leave until April 2026.



Dr Alex Pike has now completed her PhD and has started in post as a consultant with us in the PNH Service. Some patients may remember her as our Clinical Research Fellow.

Achievements

- IPIG Registry— we are pleased to announce that the IPIG (International PNH Interest Group) Registry opened in May 2024. It is now open in 5 countries, with just over 350 patients enrolled. It will continue to open in more countries, with a planned minimum recruitment of 2000 patients worldwide. Currently, the UK is the leading recruiter for the IPIG Registry.
- New approved treatments— as you can see on the other side of the newsletter, there has been a marked increase in available approved treatments for PNH. The PNH Service have been involved in the discussions for these new treatments with NICE and MHRA, and have been involved in all pivotal clinical trials. We are delighted that there are more treatments approved for patients with PNH.

Conferences and Webinars

The UK PNH Team represented the National Service at multiple conferences and webinars over the last year. Some of these include:

- European Hematology Association Conference in Madrid—June 2024
- Aplastic Anemia Trust Research Conference— October 2024
- European School of Haematology Conference in Paris—November 2024
- American Society of Haematology Conference in San Diego—December 2024
- IPIG Symposium in San Diego—December 2024
- Tablet Webinar (PNH Patient Support Group) — February 2025

Many of our clinicians also submitted trial abstracts and presented at the above conferences/webinars.



Keyrings

The National PNH Service have commissioned medical alert keyrings for patients with PNH (Paroxysmal Nocturnal Haemoglobinuria). The purpose of these keyrings is to help identify patients who have a diagnosis of PNH to other clinical teams involved in their care to ensure they receive safe and appropriate treatment.

There are two keyrings. One will be given to patients with a diagnosis of PNH (PNH clone over 50% and on anticoagulation). The second will be given to patients being treated with complement inhibitor therapy for PNH management. The keyrings have a QR code that takes the user directly to the emergency contact page of our website. This is supported by charitable funds raised by the patients with PNH and their families and friends alongside Leeds Hospital Charities. The decision to create the keyrings has come from patient feedback and the patient groups – PNH Support and PNH Scotland and the keyrings will be given to our patients when they attend clinic.



New Approved Treatments

We have had a hallmark year for new approved treatments, the details of which can be found at our website: www.pnhserviceuk.co.uk and discussed with our clinicians at your next appointment.

Treatments recently approved:

- Iptacopan (Factor B Inhibitor)
- Danicopan (Factor D Inhibitor)
- Crovalimab (C5 Inhibitor)

Clinical Trials

Thank you to each of the patients who have participated in a clinical trial with us.

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 2023/24.

2023-2024	Eng-land	Scot-land	Wales	N Ire-land	Other	Total
On Complement Inhibitor	186 (30.4%)	38 (65.5%)	18 (62.1%)	6 (40%)	1 (25%)	249 (34.7%)
On Trial Therapy	27 (4.4%)	1 (1.7%)	1 (3.4%)	1 (6.7%)	0 (0%)	30 (4.2%)
Not on Complement Inhibitor	397 (65.2%)	19 (32.8%)	10 (35.5%)	8 (53.3%)	3 (75%)	437 (61.1%)
Total	610	58	29	15	4	716

Contact Information:

PNH Service, Haematology
 Level 3, Bexley Wing
 Beckett Street
 Leeds, LS9 7TF 0113 2068625