

PNH National Service Newsletter—2025/26

Welcome to the latest edition of the PNH National Service Newsletter for 2025/26. 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.

Leeds Team:

Telephone: 0113 20 68625

Email: pnh.leeds@nhs.net

Kings Team:

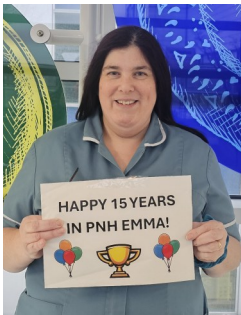
Telephone: 020 3299 8625

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Leeds Team Updates



Clinical Nurse Specialist **Briony Robinson** (nee Forrest) returned to the PNH team as CNS team leader.



Clinical Support Worker **Emma Scott** celebrated 15 years with the PNH

Medical Alert keyrings continue to be distributed to patients with a diagnosis of PNH (PNH clone >50% and on anticoagulation) and to those on complement inhibitor therapy for PNH management, kindly supported by charitable funds raised by friends and families of those with PNH alongside Leeds Hospital Charities.

Please let us know if you do not have a PNH keyring and would like one!

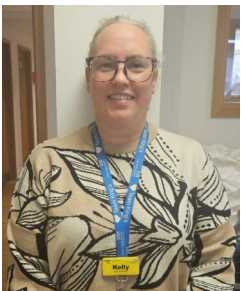


Achievements

- Research Fellow **Dr Matthew Holt** and Medical Student **Caitlin Roger** both received an Abstract Achievement Award for PNH at the annual American Society of Haematology conference in December 2025.
- Advanced Clinical Practitioner **Louise Arnold** raised £1,626 for The Aplastic Anaemia Trust from sponsors for her Great North Run! This marked 25 years of her working with patients with Aplastic Anaemia and PNH.
- Clinical Nurse Specialist **Joanna Large** spent a week running workshops for the haematology nurses in Baghdad. She covered topics such as infection control, chemotherapy management and how to manage intravenous lines.

See below for some photos of the team during their achievements!

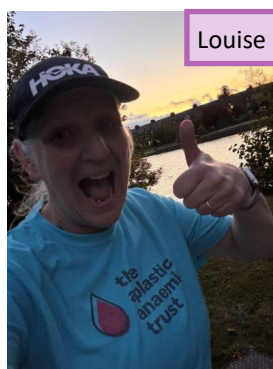
Kings Team Updates



Kelly Rowe joined the PNH team as service co-ordinator.



Dr Holt & Caitlin



Louise



Joanna with nurses in Baghdad

Conferences

The UK PNH Team represented the National Service at conferences and webinars over the last year.

Some of these include:

- **European Hematology Association** conference—June 2025
- **British Society of Haematology** conference — April 2025
- **American Society of Haematology** conference—December 2025
- **IPIG Symposium**—May 2025
- **10 year anniversary of PNH Patient Support**—October 2025

Our clinicians presented at the above conferences, and continue to provide education sessions on PNH for clinicians worldwide.

If you would like more information about this, please contact the service directly.

Clinical Trials

- **Apellis APL3007-PNH-102**—a single dose SiRNA (a subcutaneous injection) clinical trial for patients who have been on Ravulizumab therapy for at least 6 months—*currently open in Leeds only.*
- **Regeneron ALN-CFB-PNH-2468**—a clinical trial for a new therapy in PNH, for patients who have been on C5 inhibitor therapy (Eculizumab, Ravulizumab, Crovalimab) for at least 6 months. This is an additional therapy of a single dose SiRNA (a subcutaneous injection) —*currently open in Leeds and planned for London.*
- **Alexion ALXN2040-PNH-302**—an add-on oral therapy of Danicopan for Paediatric patients (from 12 to <18 years of age) who have been on Ravulizumab or Eculizumab for at least 12 weeks—*currently open in Leeds and London.*

NHSE Commissioners—Yearly Meeting

Every year we attend a meeting with NHSE where we present data for the previous financial year. Below is some of the data we shared with NHSE for 2024/25:

Combined number of patients within the service: 1,146

2024-2025 (Leeds PNH Team)	England	Scotland	Wales	N Ireland	Other	Total	2024-2025 (Kings PNH Team)	England	Total
On Complement Inhibitor	203 (33.7%)	42 (64.6%)	23 (67.7%)	6 (35.3%)	1 (25%)	275 (38.1%)	On Complement Inhibitor	164 (38.7%)	164 (38.7%)
On Trial Therapy	384 (63.8%)	22 (33.9%)	10 (29.4%)	11 (64.7%)	3 (75%)	430 (59.6%)	On Trial Therapy	253 (59.7%)	253 (59.7%)
Not on Complement Inhibitor	15 (2.5%)	1 (1.5%)	1 (2.9%)	0 (0%)	0 (0%)	17 (2.4%)	Not on Complement Inhibitor	7 (1.6%)	7 (1.6%)
Total	602	65	34	17	4	722	Total	424	424

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