

## **PNH Service Patient Newsletter - June 2020**

### **Welcome to the new look PNH newsletter from the Leeds Team**

We would like to introduce a quarterly newsletter with service updates including trial information, performance and information about the service. We have included service performance from the last few months throughout COVID-19 and an invite to all patients to our virtual patient group meeting on 26th June. We hope this finds you safe in these challenging times. For information on the current pandemic advice please refer to the PNH Service website at [www.pnhleeds.co.uk](http://www.pnhleeds.co.uk) or if you still have questions please call us on 0113 29068625.

### **Changes To The Team**



In February 2020, Dr Morag Griffin accepted the role of Clinical Lead and will be joined in leadership and service development by Dr. Richard Kelly who is returning in August.



In January 2020 we were excited to be joined by Dr. Petra Muus from London and an outstanding career in PNH and Aplastic Anaemia caring for patients in the Netherlands.



The nursing team expanded to 4 Clinical Nurse Specialists to support patients with PNH and Aplastic Anaemia bringing Briony Forrest to the team at the end of 2019.



We have also had the opportunity to complete our admin team with new Business Manager Rachel Midwood, Jacqueline Linn has joined as the Service Data Manager



#### **FAREWELL AND GOOD LUCK**

We are sad to say goodbye to Kathryn Riley who has been with the service for over 6 years. She has a new role as lead nurse in the new CAR-T service within the department. We wish her all the best for this exciting venture and would like to thank her for all her hard work.

### **Telephone clinic appointments during COVID-19**

Thank you to all patients for your cooperation through the past couple of months with the ongoing changes which have occurred during the restrictions brought by Covid-19. We transferred 346 face to face clinic appointments to telephone appointments starting on the 17th March through to the 29th May.

This was a great challenge for all members of the PNH Team and involved a lot of hard work from the admin team. The swift changing of appointments ensured everyone was still contacted to engage in a clinic appointment. With most face to face appointments suspended until further notice there were only a few patients who attended hospital clinic appointments. We await further government advice in order increase our face to face clinic capacity and resumption of outreach clinics



## Clinical Trials

Clinical trials that were already open have continued where possible and there has been ongoing work in the background to keep the momentum of research when we are able to commence trial activity as we move forward. There will be more information to follow in coming months.

### Invitation to the PNH Patient Group Virtual Zoom Meeting

Friday 26th June at 2.30pm for a virtual zoom meeting for chat with the team.

The Zoom meet ID: 832 3495 7568

The Zoom password: 6p1B82

Please email any questions in advance or on the day to [pnh.leeds@nhs.net](mailto:pnh.leeds@nhs.net)

We cannot 'open the room' until 2.30 on Zoom so please bare with us.

### Video Clinics For The Future— Attend Anywhere

The PNH Team have been working towards the introduction of video clinics to give alternative options to patients.

As a national service, we want to improve the accessibility to the service.

There is a pilot video clinic on Tuesday 23rd June. We will start with 6 patients from what would have been our Birmingham Outreach clinic.

If you are interested in future video clinics, please let us know via

[leedsth-tr.pnhonline@nhs.net](mailto:leedsth-tr.pnhonline@nhs.net).

## Thank you

Take care during this time and stay safe. We would like for as many of you to join our Zoom patient group on Friday 26th June.

Please get in touch via email or telephone if required.

Finally, we would like to say a final thank you to everyone for their continued support of the National PNH Service from everyone in the service.

### Contact Information:

PNH Service, Haematology

Level 3, Bexley Wing

Beckett Street

Leeds, LS9 7TF

0113 2068625

[pnh.leeds@nhs.net](mailto:pnh.leeds@nhs.net)