PNH National Service
LEEDS

UNIVERSITY OF LEEDS

NHS
The Leeds Teaching Hospitals
NHS Trust

The PNH Research Tissue Bank

OPT-IN TO RECEIVE SIGNIFICANT HEALTH-RELATED RESEARCH FINDINGS

Please read this information carefully to find out about how to opt-in to receive significant health-related findings. These are unexpected findings from research using your samples that suggest a serious health condition, or a risk of a serious health condition, which may be important to your healthcare or that of your family.

If you wish to discuss your decision to opt-in to receive significant health-related research findings, please contact the PNH Team. You may also wish to discuss this with your family.

If you do decide to opt-in, please complete the form overleaf with your details and signature.

You should complete this form if

- You ticked the 'no' box on the PNH Research Tissue Bank consent form, indicating that potentially significant health-related findings produced by research using your donated samples should not be communicated to you *via* the PNH Team

  and

- You now wish to receive these and have them discussed with the PNH Team

- We will begin acting on your wishes as soon as we have received and processed your Opt-In form.
- Any significant health-related findings that may have been found using your stored tissues in the PNH Research Tissue Bank will be reported to the PNH Team to discuss with you.
- Any significant health-related findings that are discovered in future research using your stored tissues will be communicated to the PNH Team to discuss with you.
- General results of research using your donated samples will not be reported to you individually – only those that may be of importance to your treatment or diagnosis.
- Your original consent to join the PNH Research Tissue Bank remains otherwise unaffected by this opt-in.
- You can choose to opt-out again at any time.
- You can still choose to withdraw from the PNH Research Tissue Bank at any point, without providing a reason

Contact us

If you wish to speak to anyone about the PNH Research Tissue Bank, please contact the PNH Team on **0113 206 8625 or email pnh.leeds@nhs.net**.

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OPT-IN FORM FOR SIGNIFICANT HEALTH-RELATED FINDINGS

If you wish to opt-in to receive significant health-related findings/have them communicated to the PNH Team, please initial the boxes, complete your details and sign your name at the bottom of the form

Please initial

1	I have read and understood the Opt-In information version 1 dated 08/08/2016 for the PNH Research Tissue Bank.	
2	I give my permission for any future or previously discovered health-related research findings from research using my donated samples that may be significant to my health, or that of my family, to be communicated to me *via* the PNH Team.	

Your full name (BLOCK CAPITALS)

Date of Birth

Signature

Date

When completed please return to:

The PNH Team
Haematology
Level 3, Bexley Wing
St James' University Hospital
Beckett Street
Leeds, LS9 7TF