

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 results that may be significant to your health or that of your family, generated by research using your samples.

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**.

The PNH Research Tissue Bank

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