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NHS Foundation Trust

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Study contact details: 0121 371 8101
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Date

[Patient name]
[Patient address]

Dear [patient]

Re: Your participation in the UK PSC Study

Thank you for your interest in the **UK PSC Study**. As you may know, the cause of Primary Sclerosing Cholangitis (PSC) is unclear. However, there is evidence that genetic factors are important - we just don't know which genes are involved. That's what this project is about: we want to analyse DNA from people with PSC to identify which genes contribute to disease and study markers in the blood which could be related to PSC. In doing so, this study will contribute to a better understanding of what causes PSC and how it may be treated.

This study needs the participation of around three thousand people with PSC. If you wish to play a part in helping, all you need to do is answer some simple questions, provide blood samples via your GP or hospital, and send them to us with your signed consent form. We will then extract DNA and serum from your samples and look for other blood-related PSC markers.

What's in the enclosed UK PSC Study Pack?

- Participant Information Sheet
- Consent Form
- Participant Questionnaire (covering your general health and treatment history)
- Itching (Pruritus) Questionnaire – 'Pruritus Questionnaire A ost': please complete this if you **have had a liver transplant**
- Itching (Pruritus) Questionnaire – 'Pruritus Questionnaire Bre': please complete this if **you have not had a liver transplant**;
- The UK PSC GP Information sheet – to give to your GP or PSC clinical team, when requesting that they take your blood samples
- 4 Sample Tubes and sample transport kit
- Pre-paid envelope

How to Participate

- 1) Read the **Participant Information Sheet**. Make sure you understand what the project involves for you. If you have any questions, you can contact the project team.
- 2) Read the **Informed Consent Form** carefully. Make sure you understand each statement. If you agree with the statement, write your initials in the corresponding box. If you do not agree with the statement, leave the box empty. Please note that, to join the study, you are required to write your initials against all statements apart from no.s 11 and 15, which can be left blank.
- 3) If, after you've read the information sheet and consent form, you would like to participate in the study, please sign the consent form in the space provided.
 - Please complete the **Participant questionnaire**. All of the information requested in the questionnaires is useful to us.
 - Please complete **one** of the Pruritus questionnaires: Pruritus Questionnaire A', if you have had a liver transplant; 'Pruritus Questionnaire B', if you **have not** had a liver transplant;
- 4) Please arrange to donate **two blood samples** (2 x 18mls, 4 tubes) during your next visit to the GP or hospital. *Do this by taking the enclosed blood tubes, sample transport kit and the 'UK PSC GP Information sheet' to your GP or hospital, and they will take your blood.*
- 5) Place your signed consent form, completed questionnaires and samples in the pre-paid envelope. Pop it in the post as soon as you can.

Once again, thank you for your support in helping us better understand the causes of PSC and childhood autoimmune liver disease. If you would like further information or have any questions, please do not hesitate to contact the study team (ukpsc@uhb.nhs.uk or tel: 0121 371 8101) or visit the UK PSC website at www.uk-psc.com.

Many thanks,



Dr Palak Trivedi
Chief Investigator