



Dr Palak Trivedi
The UK PSC Study

Research Centre:
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Our reference: [UKPSC ID]

[Patient first name] [Patient last name]
[Patient address 1], [Patient address 2]
[Patient city] [Patient post-code]

Dear [patient]

Thank you for your participation in the **UK PSC Study**. We are contacting you now to ask for your support once again, by updating your consent for the study. This will help us to further develop this important Primary Sclerosing Cholangitis (PSC) and childhood autoimmune liver disease study.

The main purpose of the **UK PSC Study** is to identify genetic factors involved in causing PSC and childhood autoimmune liver disease. So far, our success has brought us a global reputation for high quality research. You can find out more at www.uk-psc.com. In particular we have a Frequently Asked Questions section which goes into more detail about the study, if you feel the information provided here is not enough.

Using DNA samples donated by more than 2000 participants, we have performed a series of large-scale genetic studies that have identified a number of important new genes that appear to be associated with why patients develop PSC. These studies have improved our understanding of PSC and highlighted potential new treatments to investigate.

However, we need to continue to deepen our understanding of PSC and childhood autoimmune liver disease if we are to develop effective treatments and ultimately a cure.

We have recently extended the scope of the UK PSC Study to:

- study both adults with PSC AND children with autoimmune liver disease, to truly capture these diseases over all age ranges;
- study markers associated with PSC in the blood samples in the UK-PSC serum Biobank;
- perform genome sequencing of UK PSC DNA samples;
- share UK-PSC samples with other researchers working on PSC, so that research can progress more rapidly;
- keep participants in the project informed about other PSC and childhood autoimmune liver disease-related research taking place in the UK, enabling them to make informed decisions about joining.

How you can help

We are now asking for your help to build on our work by seeking your permission to:

- collect information about your health into the future, so that we can see how PSC affects you over the course of time;
- contact you requesting that you donate an additional blood sample and update your PSC patient questionnaire (no more frequently than once a year);
- share your DNA and serum samples, genetic and/or health-related information about you with other researchers. *(Please note that information shared with other researchers will be anonymised)*
- contact you from time to time with information about other PSC-related studies taking place in the UK, so that you can decide for yourself whether you might like to participate;
- inform your liver doctor if we sequence your genome and find a genetic abnormality that is known to cause a particular disease.

Please update your consent using the enclosed form, to enable us to work towards effective treatments for this disease.

What now?

1. Please read the enclosed Participant Information Sheet (PIS) and Informed Consent Form carefully. They have been updated to reflect the expanded scope and aims of the UK PSC study
2. Complete the enclosed UK PSC Participant Questionnaire and UK PSC Pruritus questionnaire (Please complete version A if you **have** had a liver transplant, and version B if you **have not had** a liver transplant)
3. If you have any questions about these documents or the study in general, we would be happy to discuss the study with you. Please do not hesitate to contact <insert name> , UK PSC Project Manager (ukpsc@uhb.nhs.uk; tel: 0121 371 8101) or your PSC clinical care team, by phone, email or in person, to discuss any aspect of the study.
4. If you are happy to update your consent for the study, please initial, sign and date the Informed Consent Form and send it, with the completed questionnaires, to our Cambridge office in the pre-paid envelope.

You will also find further information on the study on the UK-PSC website at www.uk-psc.com.

Thank you once again for your support. Together, we can make a difference.

Yours sincerely



Dr Palak Trivedi
Chief Investigator – UK PSC Study