



<Address of Patient Identification Centre >

[Patient Name]
[Patient Address]

Dear [patient]

Our records show that you have a liver condition called **Primary Sclerosing Cholangitis** (PSC for short). This is the reason we see you in our clinic.

You may be aware that the cause of PSC is not known. 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 and serum from people with PSC to identify which genes contribute to disease. In doing so, this study will contribute to a better understanding of what causes PSC and how it may be treated.

The **UK PSC Study** needs the participation of around three thousand people with PSC. I wonder if you would like to participate. You can find out more, including answers to Frequently Asked questions, at our website www.uk-psc.com

If you join the study, you will be asked to provide the following:

- Two samples of blood (2 x 18mls, equivalent to 4 tubes). One will be used to extract DNA and one will be analysed for markers in the blood associated with PSC

You will also be asked to complete a questionnaire about your general health and a short questionnaire about your experience of itching with your PSC. The blood samples can be taken at your usual clinic appointments or by your GP. The study does *not* involve extra visits to the clinic.

If you are interested in participating in the study, please put the return slip (enclosed) into the pre-paid envelope provided. Alternatively you may contact the **UK PSC study team** (email ukpsc@uhb.nhs.uk; Tel: 0121 371 8101).

When the investigators have heard from you, they will send you a recruitment pack containing further information about the study, blood tubes (with instructions) and two questionnaires.

Please note that contacting the investigators does not mean you have agreed to take part in the study. You can make your final decision when you have received the recruitment pack.

Best wishes

< NAME OF THE CONSULTANT/INVESTIGATOR RESPONSIBLE
FOR THE PATIENT AT THE PIC >.



[Name of recruiting hospital]
[Address of recruiting hospital]

Return Slip for 'The UK PSC Study'

Yes, I am interested in participating in the UK PSC Study. Please send me a recruitment pack.

Yours sincerely

_____ (Signature)

Name..... (Print Name)

Address.....

.....

Tel (optional):

Email (optional):

Date of birth

NHSor CHI no.