
PSC NEWS

April 1995

Issue No 1

Welcome to the inaugural issue of PSC NEWS. Let me start by saying that one key purpose of the group is to find help in each other and to this end, I hope you will help me to fill the pages of this newsletter! Starting up a support group is all new to me, and I welcome your input, be it in news, views, ideas, experiences, help in organising local groups, or anything else. If you have any information or experience which you feel would benefit other members please do not hesitate to let me know!

Deborah Martin, organiser

LIVER UNITS

Several of you have asked where the specialist units are that deal with PSC. The following are the key liver units with specialist knowledge: several of these are carrying out research as well as treatment.

John Radcliffe Hospital, Oxford
Royal Free Hospital, London
King's College Hospital, London
Queen Elizabeth Hospital, Birmingham
Royal Liverpool University Hospital
Manchester Royal Infirmary
St. James's University Hospital, Leeds
Freeman Hospital, Newcastle-upon-Tyne
Gartnavel General Hospital, Glasgow
Royal Infirmary, Edinburgh
Southampton General Hospital

It is evident from the questionnaires, that a number of you have been diagnosed and continue to be treated at your local hospital where the number of PSC patients may be minimal. It is not known precisely how many PSC patients there are countrywide, though it is probably counted in the hundreds and not thousands. With these patients spread right across the country, it is not surprising that a local hospital may not have had much, if any, experience, with PSC.

Numbers vary even within the bigger liver units. In order to get an idea of the number of patients currently in treatment, I have asked the main liver units to let me know how many patients they have. Unfortunately, only three replied. Southampton General Hospital has 10-15 patients, John Radcliffe Hospital in Oxford has 50-60 patients, and the Royal Liverpool University Hospital has roughly 30-40 patients.



**Happy 25th Birthday PSC
Support!**

**This is the first ever newsletter, hand
typed and published in April 1995**

MEDICAL NEWS

The cause of PSC remains unknown. It is most commonly associated with inflammatory bowel disease, usually ulcerative colitis. It may be due either directly or indirectly to an inflammatory process in the bowel wall or to an infection. The body's immune defence mechanisms may also play a part.

In PSC the bile ducts inside and outside the liver progressively become smaller and distorted as a result of inflammation and scarring. As a consequence, bile that is normally carried from the liver into the gut accumulates in the liver. This obstruction to the flow of the bile can result in liver damage.

At Southampton General Hospital, they are studying the progression of the fibrosis or scarring of the tissue. They consider that part of the problem is that the scar tissue is not broken down in the normal way in PSC patients.

At King's College Hospital, London, they have been looking at the relationship between PSC, ulcerative colitis and cholangiocarcinoma (cancer of the bile duct). While a link between these is known to exist, why there is such a relationship is unknown. At King's they have been investigating the presence of a mutation of a gene called the p53 gene to determine what relationship this may have to the diseases and if there is any potential use of this gene for treatment or diagnostic purposes.

At the John Radcliffe Hospital, Oxford, trials of the drug ursodeoxycholic acid are being conducted to determine their benefit in treatment of PSC. They are also looking at the cause of anti-neutrophil antibodies in PSC patients and to determine if these would have a diagnostic value.

Doctors notes

For anyone who feels that his or her doctor may not be as clear or as open as he or she would like, you have the right under the Access to Health Records Act 1990 to look at your notes. While wading through medical jargon can be difficult, it need not be impossible. If you find that the handwriting or terminology is indecipherable, you can ask the doctor for this to be explained.

Subscription fees

In order to cover postage, stationery costs etc, it is necessary to ask for a subscription fee of £6 per annum. This will cover the production and mailing of the newsletter, which will hopefully come out 3 times a year and also other mailings regarding meetings, or updates.

Publicity

Thanks to the NACC who let their members know about the setting of PSC Support, approximately 20 people have already joined as members and enquiries have come from a further 10 or so.

We need to find as many ways to contact other PSC patients as possible. There are posters which are available for hospital notice boards. If you haven't seen one at your clinic, and would like one to put up, please let me know.

Also, if you have details of any registers of support agencies where you believe we could benefit by being listed, pass it on.

From you to you....

You are all probably wanting to know more about your fellow members of PSC Support. At the moment, members age from 15 to 78 years of age and from recent diagnosis to 15 year old histories! Some have few or no symptomatic problems and one has had liver transplant already. Many of you have commented on the lack of information that is available from doctors. This can have as much to do with its rarity as to the fact that even among specialists in this illness there are a lot of unanswered questions as to what causes the disease and how to treat it.

Here are some of the comments gleaned from your letters and questionnaires:

"I have never heard of anyone having it and it's good to know I'm not alone."

"I could never get any information on cholangitis and nobody knew of anybody who suffers with the illness so I could never talk to anybody and 'compare notes' so to speak....It would be great to have an objective viewpoint from fellow sufferers as I myself have tried to study the effects of diet, yoga, acupuncture, homeopathy and other things on my illnesses...."

"In 1988, I was diagnosed as having PSC. This has had a much more profound effect on my life than having UC (ulcerative colitis) as last March my husband and I had our approval to be adoptees withdrawn due to the unpredictable nature of this disease."

"Whilst I found the PSC Information Guide very useful, it depressed me for some 3 or 4 days afterwards."

"I did find it quite difficult to get information and was surprised at the consultant's negative attitude at the time of diagnosis. He simply told us, 'Unfortunately, John, you've developed a progressive liver condition which has no treatment or cure. However we'll keep an eye on you.' That was it. I thought it rather blunt to say the least." (Mother of 17 year old patient)

"As far as sclerosing cholangitis is concerned, I have even come across a couple of doctors who have never heard of it!"

"I am frightened by my uncertain future and that whilst on one hand I want to know more, on the other hand, I'm scared to find out anything that will make me feel any more worried and down than I already am."

To keep this as your page, I would like to hear more of your personal experiences which can be shared with the other members.