
The Biliary Bulletin

Volume 1, Issue 3

June 1999

Primary Biliary Cirrhosis (PBC) is a rare autoimmune disease which affects the liver and for which there is no known cause or cure. This newsletter exists to communicate news and information to members of the Australian PBC Friendship Support Group and other sufferers of PBC.

A Letter from Rosemary

Dear Friends

First I would like to thank Jocelyn for our excellent newsletter, I am sure you will all agree that she is doing a wonderful job. It takes a lot of hard work and time, which is very much appreciated, thank you Jocelyn.

I would also like to thank all the people who have returned their membership forms, subscriptions, and very kind donations. About half of the people we have contacted have not returned them yet. It would be really good if all those who would like to become members could return the forms and subscriptions as soon as possible please, to help support the group and keep it going.

Since the last newsletter more people have joined us mainly from Newcastle NSW, SA, WA, and Victoria. We now have contact with over one hundred and thirty people Australia wide who have PBC and the best news is that people in most States are now contacting each other. I hope that in the future each State can hold their own meetings and get the doctors involved.

Information about our group will be going into some future newsletters of the GESA (Gastroenterological Society of Australia) whose membership is 1000 strong so I hope that this will help to locate many more people. I have also made the Australian Liver Association aware of our existence (thank you once again Dr Katrina Watson).

As you know we keep in touch with the PBC Foundation in England. In a recent letter from Collette Thain (Chairman) she tells me that the experts believe that the way it is looking at the moment is that we all seem to have a genetic fingerprint. Although we do not have any mutant genes the experts believe that we have taken on board some kind of common everyday virus and that virus has turned on us internally, but it is a common everyday virus and we have a disposition. There are many answers to be had but it is thought that in the next two to five years we will know a lot more. Collette sends her best wishes to everyone.

An area of much concern is the availability of Ursosalk (ursodeoxycholic acid). Some people are being told there is a

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International PBC Day lunch

On Sunday May 30th about 25 of us met at Pristkars to have lunch and celebrate International PBC day together. Margaret McClunie made and decorated a rather special cake for the occasion, which was both beautiful and delicious. The food was good and it was very pleasant to be able to chat with new and old friends. Needless to say we didn't run up a large bill at the bar!

Letter from Doreen

Summary of the March meeting at
The Austin & Repatriation Medical Centre
Victoria -14th March, 1999

Speakers were Dr Peter Angus a member of the liver transplant team & Alice Gleeson the liver transplant co-ordinator, both of the Austin hospital.

Dr Angus formatted a list of questions & answers about PBC, which included some of the questions patients ask him.

What is PBC?

It is an autoimmune disease that attacks the bile ducts in the liver. Dr Angus described it as an unusual disease and very uncommon in Australia. Most people are diagnosed with PBC by routine blood tests for other ailments.

Dr Angus spoke of a survey he was involved with in 1992 on

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Member Profile *Ian Swindells*

I am a 45 year old male who was diagnosed with PBC (stage 1) in March 1998. I am married to Marie and we have two daughters Renee (13) and Monique (11). We live in Whangarei, 160 kms north of Auckland, where I teach electronics at the local Polytechnic. I have a special interest in computers in education.

Diagnosis was reasonably straightforward for me as I had a brother with Lupus who passed away two years ago. Once elevated liver functions were confirmed, my specialist discussed with me the likelihood of PBC.

Whilst my specialist was very good, initial feelings on being told you have something like PBC, were similar to shock. I immediately got on the Internet where I found a stack of information and support groups. The next three months of daily email contact with others with PBC was pivotal with my coming to terms with my illness.

I was dismayed that the NZ government didn't subsidise UDCA for PBC treatment. This meant I paid \$340 / month for Actigall. Because we supposedly have a partially funded health system in NZ my health insurer didn't cover this expense. Since then I have embarked on a program of complaining and letter writing at a political level and from 31/3/99 Actigall goes on the subsidised list in NZ.

I am currently really well. I play squash, enjoy fishing and gardening and my family.

The Itch

Itching was the first symptom of PBC that I had. I tried to ignore it for a year - it can't be anything serious, just an itch after all, I said to myself. I tried antihistamines, which did nothing except helped me sleep through some nights. I tried creams, lotions, soap substitutes etc. nothing worked. Still I didn't go to the doctor. Eventually though a liver function test led to diagnosis and for the first time in ages I was able to get some relief and start to live normally again.

I think I was pretty close to losing my sanity at that time - those of you who itch will be familiar with the intensity of it, the existence of deep places never thought about before, like way down past the eardrum. And how do you scratch an eyeball? Many is the night that I went to bed with a bristle hair brush to try and minimise the damage from my fingernails. Sitting up at two in the morning with my feet in a bucket of iced water to get some relief was another frequent happening.

Questran was my miracle. Tastes awful I know, it has an unspeakable texture, it does awful things to the digestive system too - but it stops the itch! Urso never really helped

dampen my itching, so when I had reached the top dose of Questran my doctor prescribed Rifampicin - an antibiotic that reduces the intensity of the itch, but no one seems to know quite why or how. I have found a cream that works temporarily (great for those nights when you wake with itchy feet or hands, rub it on and you have ten to fifteen minutes before it starts again, to get back to sleep). The cream is Nature's Remedy, available in the First Aid section at Safeway.

Do you have the itch? How do you cope? What works for you?

Please e-mail or write and tell us all.

Jocelyn.

Good Wishes

Rob Brown (QLD) recently had a liver transplant. Wishing you a speedy and trouble free recovery Rob and good wishes to you and all your family.

A Letter from Rosemary *continued from page 1*

waiting list of two years. After many letters to Dr Michael Wooldridge he has replied but has not been of any help at all. I contacted the office of Simon Crean and have received a letter sent to them by Senator Grant Tambling in response to representations made on our behalf putting us in touch with the Australian sponsor of Ursolfalk, Orphan. I spoke to the company, who tell me that Ursolfalk is being registered for use but of course this does not mean it will be on the PBS list, although they are making an application to the government for PBS approval which unfortunately can take 9-12 months.

I also contacted the office of Jenny Macklin, Federal Shadow Health Minister who have contacted me by telephone and letter to say that they consider the matter to be serious and will see if they can assist us in any way. I also contacted John Thwaites in Victoria today.

I have to say it is indeed wonderful to be in touch with everyone. We have come to know many very kind and generous people. I would like to thank Margaret McClunie who has a heart of gold - she very kindly offered to make the cake for our International PBC Day lunch at Pristikars, Park Royal. Thank you dear friend.

We are looking at how we can help to promote organ donation. The Transplant Promotion Council in Victoria suggested we take part in manning displays in shopping centres. If anyone is interested in helping please contact us after the next meeting.

I send everyone all my very best wishes. Remember we are all here to help each other! Keep positive and smiling.

Rosemary

Thank You

A very big thank you to our two sponsors without whom this newsletter would not be such a success.

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We are very grateful.

A Letter from Doreen *continued from page 1*

the prevalence of PBC in Victoria. The group of doctors involved in the study wrote to all hospital specialist physicians with an interest in hepatology and found 84 people with PBC.

Dr Angus also said that you have to try and live a normal life and not let PBC take over as you may live for 10, 20, 30, 40, 50 years, (his words,) before you have serious symptoms indicating you have PBC.

Treatment.

Dr Angus said it was very important to be on the medication Ursodeoxycholic Acid as soon as you are diagnosed with PBC. The doctors did not know who would advance to end stage of PBC, it is important to take the medication because it does slow down the damage to the liver. You could stay in the early stage and never advance to end stage and transplantation.

Fatigue, Itching and Jaundice.

The other points spoken of were fatigue, itching and jaundice, which are the main symptoms of PBC. Also mentioned was the importance of being referred for a liver transplant early enough for the doctors to keep an eye on you when you do get to end stage PBC so that they can decide when you need to go on the transplant list.

Alice Gleeson

Alice spoke mainly on promoting organ donation. As we all know we need to promote organ donation as some of us may need the gift of life in the future, and to bring awareness to the public that they need to talk about organ donation with families so that their wishes are known. Alice also showed a number of slides of a liver transplant operation, liver transplant teams, and liver transplant patients whilst they were in and out of hospital.

Alice said in the past, when patients were referred to be assessed for a liver transplant, they did not know much about PBC or the procedures of a liver transplant. Now, thanks to the support group they will be better educated about PBC and about staying healthy so if you do need a liver transplant you will be better prepared.

After meeting Dr Peter Angus and Alice Gleeson, if I were to be referred for a liver transplant, I would feel that I could not be in better hands and you will all feel the same way when you meet them. We are all here for every one so don't hesitate to contact anyone of us if you need someone to talk to.

Keep positive.

Doreen

Liver cells made from bone marrow

May 13, 1999

Source: Lori Valigra UPI Science News

WASHINGTON – University of Pittsburgh researchers have derived fully functional liver cells from adult bone marrow, creating hope that liver transplants some day might be avoided.

The scientists said this is the first report that stem cells from adult bone marrow can provide a lineage for cells that make up solid organs like the liver.

The study results, published in Friday's issue of Science, indicate that cells derived from bone marrow might eventually repair or replace injured or diseased livers, reducing the need for liver transplants.

The research, conducted in rats, also counters the current theory that fetal cells are required to generate the differentiated cells of adult organs.

"This is a critical paper that bridges a gap in our understanding of how the liver repairs itself under certain physiological conditions," said Byron Petersen, lead investigator on the study and research associate in pathology at the University of Pittsburgh's School of Medicine.

He added, "A lot of people feel this will end the controversy in Congress about fetal tissue research. We now have a way to create whole organs with adult cells."

Congress and the president have been debating the ethical aspects of using fetal tissue for scientific research. Until now, many researchers thought fetal tissue was the only type that could create whole organ cells.

Dr. Joe Grisham, professor of pathology at the University of North Carolina in Chapel Hill, N.C. and an expert on tissue, agreed with Peterson.

"The research certainly demonstrates bone marrow stem cells have the potency for differentiation that we previously didn't realize," Grisham said. "The breadth of differentiation approaches that of fetal stem cells. It may help relieve that debate."

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Grisham added that the discovery offers a great deal of hope that these sorts of cells could be used as a source for a wide variety of cells in the body. A previous study by another research team, he said, found that stem cells could be differentiated into striated muscle cells.

Earlier scientific reports showed that bone marrow cells give rise to two major types of tissue cells: mesenchymal cells that develop into bone and muscle, and endothelial cells that form the lining of blood vessels. This report is the first showing that bone marrow cells can give rise to a third type of tissue cell, epithelial cells, which can develop into solid organs.

Liver cells show a strong ability to regrow. Healthy liver cells, or hepatocytes, regenerate an injured liver. But if the division of hepatocytes is hampered or stopped, a type of cell called an oval cell appears. Oval cells proliferate in the most severe stages of kidney disease or injury, helping to repair the damaged organ.

Petersen said his experiments with bone marrow transplants on animals showed that cells derived from bone marrow eventually become fully functional liver cells, probably through intermediate oval cells.

Petersen emphasizes that the research is still at least five years to 10 years away from being tested in humans. So far, only 1 percent of the liver cells were repopulated in rats, and that needs to get to 60 percent to 70 percent before human studies are done.

The next step, he said, is finding the bone marrow stem cells giving rise to the oval cells or the signal that the liver broadcasts to bring such oval cells to the area of a liver injury.

The researchers are looking at new drugs that can recruit the oval cells to an injured liver as well as surgical methods to remove damaged cells to give the remaining cells a better chance to repopulate.

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... before we think about surgical removal
we'll try putting you on camomile tea for
a few weeks and see what happens.



Leung