
The Biliary Bulletin

Volume 1, Issue 2

March 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 & Doreen

Dear Friends,

How time has flown since the first edition of our newsletter, such a lot has been achieved in the past three months, we have located many more people through the magazines and with the help of some good doctors. We are finding now that small groups are forming in some States which is wonderful as this is what we hoped for but we do need more people to be involved by contacting others in their areas. Also it would be good if some of you could contact your local newspapers to do a story to give out our information.

Fundraising is another area where people could get involved to help our group, things like coffee mornings, making things you are good at to sell, garage sales, fashion shows, just a few ideas.

Good news is that some doctors are happy to be involved and are interested in what we are trying to do. We must take this opportunity to thank Dr Gideon Shaw and Dr Katrina Watson at St Vincents, who are giving out our information to their patients, also Professor Robert Batey at the John Hunter Hospital in NSW. Dr Shaw would like to hold a meeting at St Vincents to talk about drugs and PBC and is willing to write something for a future newsletter. I will follow this up in a few weeks time as he is going away.

We are in contact with Dr Eric Gershwin at the University of California who is working so hard to find the cause and the cure for PBC that he cannot sleep at night for worrying about it. Such a dedicated man sparing some of his valuable time to send us a message, he gives us hope that the cure will be found in the not too distant future.

We need more doctors like these to be involved, so do not be afraid to ask for their help:- they won't bite. Indeed Dr Shaw is getting used to being hassled and does not seem to mind at all.

We are continuing to write to many more newspapers as we know that there are more people who have PBC still to be found who are thinking that they are all alone, so let us all do as much as we can to locate them and offer our support.

Best wishes, keep well...

Rosemary and Doreen.

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Spreading the Word

Does your doctor know about us? She/he might have other PBC patients who would like some support. Next time you see your GP or Specialist, show her/him this newsletter and ask if it could be copied and shown to others with PBC. If more copies are required - just ask.

Thank You

Many people have sent in donations of books of stamps, phone cards and money. To all of you a huge Thank You. It certainly helps to keep the costs down. Doreen and Rosemary make many phone calls and send out a lot of mail which they pay for themselves, so Thank You to them too!

Membership

An annual membership fee would be a good way of raising funds to keep our support group going. We have decided to ask for \$5 per year. If you can afford more and would like to contribute more, please feel free to do so.

A Letter From Dr. Gershwin

Greetings from Davis California, and the laboratory of Dr. Eric Gershwin.

Here in Davis we have a very active program in PBC research involving about 15 people. We have scientists from several countries working in the Group including Japan, England, Australia and France. In fact our work began in 1985 when I was on a sabbatical leave, working at the Walter & Eliza Hall Institute in the Unit headed by Dr. Ian Mackay. Dr. Mackay and I remain active collaborators and have written much together on PBC. Our focus has been on the genetic basis of why some people get PBC and the dissection of their immune systems.

We are greatly interested in finding out the names and addresses of anyone with a family history of PBC, such as a father-daughter or two sisters or whatever. With their permission I would write to them and arrange for a blood sample to be drawn in their city and then mailed to me in Davis.

M. Eric Gershwin M.D.

*The Jack and Donald Chia Professor of Medicine
Chief, Division of Rheumatology, Allergy and Clinical Immunology*

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Research

Prof. Ian Mackay would like to hear from anyone willing to give blood and saliva samples to help his research into PBC. If you are willing, or for more information, call Rosemary.

See Your Name in Print

Please send any letters, items of interest, hints etc. to the editor :
Jocelyn Newman, 50 Narrawong Rd., Sth. Caulfield. Vic. 3162
Ph: 9578 5785 or e-mail joc@eastax.com

Getting Bigger

We now have 101 members around Australia. 58 in Victoria, 16 in Queensland, 12 in NSW, 6 in Tasmania, 5 in WA, 3 in SA and 1 in New Zealand. A number of the Tassie PBCers had a get together - read all about it next issue.

Welcome to all new members!

Video

Don't forget that we have a copy of a video sent by the UK PBC foundation covering PBC and Osteoporosis in PBC. Doreen can arrange a copy for you for the cost of the cassette and postage.

Ugghhh Questran! *A tip from Joan Sharp.*

Friends, it has come to my notice via the bulletin and chatting to PBC sufferers that quite a lot of people can't seem to take the Questran. I have been taking it for 9 years and have it dissolved in 1/2 water and 1/2 orange juice. It is a pleasure to drink, and quite honestly I PREFER orange juice with Questran to neat orange juice. Try it and see. Good Luck.

Identity Crisis

We seem to have survived our identity crisis. Most members who expressed an opinion didn't like the idea of joining up with the Friends of the Transplant Unit at the Austin Hospital. Most seemed to prefer the group to stay informal and self directed so we will.

Report of the Las Vegas Convention *Linda Brown*

As you can probably tell I feel a bit like a school kid giving a report about a field trip. It feels strange for me so please bear with me if it's not much good. Thanks.

Rob (my husband, who has stage 4 PBC) and I left our home at 11.30 am of January 11th, we flew to Sydney, where our international flight to Los Angeles left at 4.30 PM. We flew for 14 hours to L.A. where we waited 2 hours for our connecting flight to Las Vegas. We arrived at the Imperial Palace at what would have been 11.30 am the 12th, which means it took us 24 hours travel time to get to Las Vegas. We were exhausted. We had a day to recover, which was a relief.

Rob and I attended the introduction session on Friday afternoon. We both felt awkward, as we, of course, didn't know anyone. So we grabbed a cup of coffee and chose a table and sat down. We introduced ourselves and things just started to snowball after that. They were impressed with the fact we had travelled from Australia to be at the convention. Little did they know how important their support on the Internet had been to our family and to Rob's sanity during his illness. Rob would have done just about anything to be there to meet these people. We met Linie and Rob thanked her for starting the support group.

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Las Vegas Convention

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I'm sure most of you will have read the postings from others who attended the convention so I won't go into details. I just want to mention the highlights for us.

Dr. Miskovsky was a wonderful speaker and quite obviously dedicated to the fight against PBC, as were all the medical people who attended. I suppose this is logical as they took time out from their lives to attend. I was still very impressed with their dedication to the cause. Dr. Miskovsky talked about transplants, including the use of part livers from living donors. Very interesting!

The biggest inspiration for me was Ron and his wife Wendy. Ron had a transplant 16 months ago and he just looked wonderful. I suppose they impressed me so much because here was a husband and wife team I could relate to, because as you are probably all aware, not many men have PBC and Rob and I sometimes feel a little out there because of this rarity. Ron has made a complete recovery and is living life to the full again. There were others there who have had transplants. Judy had one five years ago and Diana had one nine years ago, both have never looked back.

Dr Kaplan spoke to us about remarkable success they were having in the early detection and treatment of PBC. He also spoke of the use of Methotrexate and Colchicine in conjunction with URSO in the treatment of late stage patients who were not responding to URSO treatment only. I would recommend everyone get a copy of his tape from the conference to give you an idea of how your doctors are performing in regards to your treatments.

Research scientist, Dr. Van de Water was very encouraging in relating to us the direction of her research into a possible cause and hopefully cure for PBC. Her research sounded fascinating to me. She has found PBC to be a duct disease, meaning that it attacks Bile Ducts, Tear Ducts and Saliva Ducts. Bile Ducts are affected the worst. She is trying to develop a saliva test to measure the illness, instead of blood tests. She asked the American transplant patients to send their damaged livers to her to help with her research. Very gross! Still if it helps everyone in that room was prepared to do this.

The unity of these people was truly remarkable. Their one goal was relief from this most unpleasant and debilitating disease.

Rob and I attended every session of the conference and met and spoke to as many people as we could. We were disappointed that we couldn't meet everyone but we were delighted with meeting the few that we did. Maybe we can afford to travel to the next convention in the year 2000 and possibly some other Aussie PBCers can too.

Marilyn Klainberg's tape from the conference would be very beneficial to newly diagnosed PBCers as it has ideas of what to do to help with associated problems.

If you have any questions Rob or I would be happy to answer them, if we can. We can be contacted at Rob's e-mail address. The address is rob_brown@rocketmail.com, or you can write to us at:

Linda and Rob Brown
25 Eisenhower Street
Stretton QLD 4116.

Tapes from the Las Vegas Convention

Thanks to Rob Brown we are able to provide those who are interested with tapes of some of the speakers at the Las Vegas PBC convention held recently. For full details of which are available and their cost please contact Rosemary or Jocelyn.

Member Profile *Gloria Lahn*

My name is Gloria, age 56 years, happily married for 34 years, with two lovely children and two gorgeous grandchildren. I am a RN, and until 14 months ago worked as Night Supervisor at a 60 bed Nursing Home. A role which was challenging, busy, happy, sad, and increasingly difficult to perform to optimum as I became increasingly beset with agonising bodily pain, poor sleeping patterns, concentration and memory problems, fatigue and alopecia. This last insult to my body was too much, as although my hair is definitely not my crowning glory I like it to stay as attached to me as I am to it!

So began a merry-go-round of health practitioners - the naturopath who said your liver is stressed - take these - give me \$140.00 [at least she was on the right track!]. The osteopath who said you have strained your shoulder, strained your back, strained your legs, you have golf elbow, tennis elbow, and queried 'have you been walking too much?' More large accounts. The Doctor who looked at me and saw a middle-aged lady, greying hair [I still had some!] with aches and pains, emotionally distressed, physically whacked who said 'Would you like some hormones?' Many large accounts for extended consultations later, I said to these people, I don't need hormones/massage/pills/patronising looks/labels, I need some answers, please do some blood tests, and so PBC was finally diagnosed, making sense of all the suffering, and vindicating me as a woman [as opposed to a menopausal wreck].

At the same time I saw a rheumatologist who diagnosed Fibromyalgia Syndrome, and further research has revealed PBC is often associated with other autoimmune diseases, FMS being one.

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Member Profile

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However, there was not much help forth coming from any health practitioner as to how best to cope with either disease, in this regard I have found the internet invaluable, with the PBC group offering much information and support constantly. More recently, due to the efforts of Rosemary and Doreen, our own Oz group is emerging and I have been fortunate enough to find one other person in my hometown with whom I can share the highs and lows of PBC. As well, a local FMS support group has formed, meeting monthly, sharing information, providing support, and raising community awareness.

Last November I fronted for the liver biopsy I had avoided for as long as possible, and discovered I am in stage 2. I saw Dr. Gideon Shaw in Melbourne who is arranging for me to commence Ursosalk, he assures me I will feel enormously better once begun. However, I find there is still a paucity of day to day information, such as dietary advice, although I follow a low fat, low sugar, high carbohydrate regime, [except over Christmas!]. I believe we should be ensuring an adequate protein intake, plus high water intake, purified preferably, as our livers don't need to be overloaded any more than they are. My exercise level is currently extremely poor, [excuse, too hot] but I encourage all of you not to copy this example, and get out there and be as fit as possible, it helps to beat the fatigue/sleep/pain cycle, and promotes well-being, important for our peace of mind. So far I have not had to deal with the dreaded itch, for which I am extremely grateful.

Through all of this I have mourned the passing of my working life, I am daily fatigued/pained enough to realise my past employment is too stressful to return to. I have mourned the loss of wellness, and faced the uncertainty of the future. I give daily thanks for a loving and supportive husband and family [and the return of my hair!!] and for friendship and support via the work of Jocelyn in producing this newsletter, and through internet groups.

On a positive note, I have completed a Grad. Dip. in Health Sciences [Gerontology] and will graduate in a ceremony at our local University this year, an event I look forward to with much anticipation. One thing I am sure of is that life is what you make it, Steve Monagetti's rule is fixed firmly in the front of my mind – 'there is a beginning, a middle, and another beginning'. I believe I have arrived at another beginning, and look forward, albeit with some anxiety, to what it will bring. I wish all of you well, and hope you also recognise and embrace new beginnings, and will also share your hopes fears and dreams with fellow PBCers.

Feel free to contact me at lahn@netcon.net.au I am always happy to chat!! *Gloria.*

Transplant

Dorothy Moss had a liver transplant 8 years ago and is very happy to talk to anyone about it. Dorothy lives at: 219 Yarra Street, Geelong South. Vic. 3220 Ph: 5229 3093

Write or call.

Mark these in Your Diary**Afternoon Tea**

On Sunday May 9th we are having a gathering at The United Kingdom Settlers Association rooms - upstairs at 146 West Toorak Road, South Yarra (between Punt Road and Nepean Hwy.) from 1.30 to 4.30. No particular agenda - just drop in and have a cup of tea or coffee with us.

Please Come For Lunch

On Saturday 27th March, a few of us are meeting for lunch at Global Vegetarian Restaurant, 499 North Road, Ormond at 12.30 p.m. Please just come and join us! If you would like more information ring Jocelyn - 9578 5785. The food is great and very cheap.

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