
The Biliary Bulletin

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

Letter From Rosemary

Dear Friends

I hope that you are all well and keeping positive, I think that most of us here in Victoria are looking forward to the cooler months ahead after the constant heat we have had recently.

The most wonderful news since the last edition is that our dear friend Maria Muratore here in Victoria received her gift of life on the 15th February.

After some ups and downs I am happy to say that Maria is now home with her family and progressing well, thanks to the dedicated transplant team and staff at the Austin hospital.

Keep up the good work Maria, you have done so well and been so patient, we send you our love and best wishes for good health in the future.

The latest news from Orphan regarding PBS listing for Ursofalk is that the final submission was forwarded to the PBAC for consideration on Friday March 17th. Orphan expect some initial comment/advice by July - with any luck Ursofalk may be PBS listed around November this year.

To those people who have not already contacted their Federal Members, please help by contacting them now to ask them to add their pressure to the application.

For those members who might be interested in owning a computer, we are hoping to receive donations of unwanted computers to our group from various organisations. These will then be set up for use and given to interested members free of charge - a donation to our group would be most welcome.

If you are interested please contact me for further information. At this point I must thank John Holman for all the work he does for our group. John is the guy who does all the work on our web page (please take time to look) and I know many of us enjoy his computer corner in the Bulletin. Thank you John for your continued support.

I would also like to once again thank all the kind people who have made donations to our group by sending money, stamps and raffle prizes, all donations are greatly appreciated.

Our membership to date is 137. I have been contacted in the last two weeks by people who have seen our information in doctors' waiting rooms, or been given the information by their

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doctors which is good to hear. Also good to hear of the get-together by some members in South Australia, we hear from Sylvia that 6 of them met for coffee and chat, and are looking forward to doing this again. Keep it up ladies, maybe next time there will be more of you.

Keep positive and smiling everyone, good to be in touch with you all.

Best wishes,

Rosemary



Member Profile

Grace Chung

Hi, I'm Grace Chung from Kuala Lumpur in Malaysia. I am 57 years young, and had never heard of PBC until September 1999, when a tentative diagnosis was made after I presented with post-op jaundice and intractable itching, following knee replacement surgery. Early PBC was confirmed by liver biopsy in January, 2000.

Since September, I have been reading and learning as much as I can about PBC, mainly through the Net, and the knowledge gained has allayed a lot of anxieties. Getting in touch with Rosemary has been an emotional life-line, and being on line @egroups.com has helped me feel less isolated.

Ursofalk has worked well for me in that I no longer have the itching, and the skin darkening seems to be arrested. I do get tired - and it can be quite sudden and unexpected, whether I have been active, or just up from sleep - but I do not feel guilty now about 'feeling lazy', and try and rest as much as I can whenever these bouts occur.

I am married, with two adult children, a daughter aged 27 and a son, 22. My family does have emotional links to Australia in that my husband and I and our daughter graduated from Australian Universities. We keep in touch with our relatives and many friends in Melbourne and Queensland.

I have been involved with social and mental health Non-Government Organisations in Kuala Lumpur for many years, and continued after retirement. I am taking 'time out' for this year just to energise.

God bless,

Grace

Talk by Dr. MacKay

Brief summary of the talk given by Dr Ian Mackay at our meeting at Monash University 27 February 2000

Dr Mackay began by saying that little was known about PBC in the 1800's. It was in the 1950's that the disease began to be understood. In 1959 Dr. Mackay discovered AMA's, antimitochondrial antibodies. It is not known why AMA's are specific to PBC. The antibodies are present in every cell, in every tissue in the body but the disease is focused on the liver.

About 30% of all AMA positive patients do not appear to have PBC or anything wrong with their liver. In these cases a liver biopsy is not required, but these patients should be kept under observation for 5-10 years during which time liver function tests should be performed.

There is a widespread impression that the number of patients with PBC is increasing. Recently interest in PBC has increased

considerably, this may be attributed not only to advances in understanding the immune mechanisms of the disease but also to increasing recognition of apparent variation in its incidence and prevalence.

A study in the UK has shown an extraordinary increase in the prevalence of PBC with a smaller increase in incidence, the study has also shown that PBC was widely under-diagnosed especially in women over 40. The disease is becoming important in the community.

The most frequently seen chronic liver diseases in Australia are:

Cirrhosis (unspecified)

Alcohol related cirrhosis

Cirrhosis related to virus (Hepatitis B& C)

Haemochromatosis

PBC

Autoimmune hepatitis

Hepatocellular cancer

Rarer causes would be drug-related liver disease and biliary tract diseases of childhood.

PBC is beginning to leapfrog in the list ahead of Autoimmune hepatitis. Using the automatic diagnostic kit, prevalence in Australia is getting closer to the prevalence in North East England and Sweden.

Rosemary

From the Editor

I am very much looking forward to heading off to Las Vegas for the PBC 2000 Conference at the end of May. It will be great fun to meet all those other PBCers that I "talk" with all the time via e-mail, not to mention the fun to be had taking the shuttle bus from casino to casino!

I will be taking a basket of Australian Beauty products as a present from our group, which will be sold in the Silent Auction. I hope to be able to tell you how a silent auction works when I return 😊

While I am there I will attempt to report on the various topics discussed, and I will of course bring home tapes of the talks that I think some of you may be interested in.

As I will be going on to Canada for a while, the next Biliary Bulletin may be a little late. I know you will forgive me if it is.

Each day I search my mailbox in vain for contributions from our 130+ members, and each day I am disappointed. Please send something – this is a self-help group. Your personal experiences will certainly interest, and may help others.

Jocelyn.

Talk by Amanda Anderson

At our meeting at Monash Medical Centre on 27th February 2000, Amanda Anderson gave a talk entitled 'Eating your way through PBC'. Amanda is an accredited practising dietician.

Amanda advocated a healthy eating pattern consisting of a basic diet of:

- At least 5 serves a day from the bread and cereal group
- At least 4 serves of vegetables and fruits including one leafy green vegetable and one orange fruit/vegetable
- At least 3 serves of milk or milk products
- 1-2 serves of meat or meat alternatives
- 3-4 teaspoons of oils/butter/margarine
- 6-8 cups of fluid

A serve of a food containing vitamin C (eg. Broccoli, capsicum, orange) would help to absorb the iron of any iron rich food being eaten.

Amanda felt that with a balanced and healthy diet vitamin supplements weren't necessary, but conceded that liver disease could cause deficiencies in the fat soluble vitamins (A,D,E and K). She said that our gastroenterologists would advise us about this, and also the need for Calcium supplements.

(Editors note: Deficiency of these vitamins can lead to a range of problems including night blindness, osteomalacia, osteoporosis, and an increased tendency to bleed.)

Amanda pointed out that calcium is better absorbed from food and supplements are best taken at night as this is the time of peak absorption. The best type to take is elemental calcium.

Jocelyn

Notes on Osteoporosis

A report of a talk given by Dr. Michael Davie, a Consultant Physician on Bone Disease, UK

Osteoporosis occurs in many PBC cases because of the reduction in liver function, usually an obstruction in the outflow of bile. This reduces the body's ability to absorb both vitamin D and calcium, causing a drop in bone mineral density. Dr Davie has carried out exhaustive research, comparing the bone density of PBC sufferers to that of healthy subjects.

Normally, bone mineral density declines in middle age, beginning in the late 40s. In PBC however, the decline begins earlier "when PBC patients first come to me, most are way below recommended levels and according to World Health Organisation figures, already have osteoporosis".

Dr Davie's own research has shown that PBC patients have on average 50% less calcium and vitamin D than those without PBC. Thanks to the considerable research done by Dr. Davie and his colleagues, PBC sufferers can now take a pro-active approach and look at a variety of treatments that will not only alleviate bone disease but will stop its progression.

Dr Davie was adamant that early diagnosis was the key: "early diagnosis through blood and urine tests or X-Rays mean that we can begin treatment almost immediately, not only alleviating the symptoms but most importantly by stopping any further development".

There is now a variety of treatments available which can help to prevent the onset of osteoporosis. It is important to increase absorption of both vitamin D and calcium. This could most obviously be achieved through diet and supplements, taken both orally and intravenously. Increasing your exposure to sunlight was also recommended.

Most controversially, hormone replacement therapy has been used to treat osteoporosis in PBC patients and on the whole was recommended. Dr. Davie explained: "HRT has already proven effective for PBC. In most cases we use a much reduced oestrogen level to treat the osteoporosis with excellent results. In general, I think that HRT provides an excellent treatment with very few side effects and with no real change in the values of the liver function."

Dr. Davie went on to reaffirm his belief that bone disease in PBC can now be controlled effectively with a variety of treatments.

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The full conference, held at the Queen Elizabeth Hospital, Birmingham, 2/11/96, was videotaped. To borrow or buy a copy, please contact Rosemary.

Support URSO/PBS Listing

It would be great if as many people as possible would contact their Federal Member of Parliament to ask them to support the application to have Ursfolk listed on the PBS. To find out your Federal Member's name and postal address, ring the number below in your state .

ACT	02-6271-4419	NSW	02-9375-6333
VIC	03-9285-7171	QLD	07-3834-3400
SA	08-8237-6555	WA	08-9470-7299
TAS	03-6235-0500	NT	08-8981-1477

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Computer Corner

John Holman

Three common reasons for not getting a computer are: (1) they cost too much; (2) they require endless hardware and software upgrades; (3) fear of learning new things. We won't discuss (3), except as it relates to (1) i.e. the fear of wasting a lot of money.

Number (2) is an easy problem to get around. By installing only software that was current when the computer was new, and resolutely refusing to upgrade to the newest and latest of everything, problem (1) suddenly disappears. For example, 486-model computers are now available for next to nothing. The author picked up two from the side of the road recently, in perfect working order. A 486 computer with 8 megabytes of memory is just adequate for running a minimal installation of Windows 95.

It will be a little slow, and you will need to close down one program before starting up another (to free its limited memory for use by the second program) but if you get impatient, just count the change you got from \$2000 to pass the time ☺

Rosemary is scrounging some used computers from local councils and various agencies. You can spend about \$15 upwards, depending on what you want to do with it.

All computers supplied will be able to connect to the Internet and be *at least* suitable for email and general word-processing duties. Doubling the memory to 16MB makes quite a difference, and will cost about \$15. Some will require a \$20 upgrade to use a fast modem (which downloads Internet data over your telephone line). You can also put in more money for a larger or better-quality screen if you want to.

For email only, an ancient slow modem from the Trading Post will be fine, but for viewing pretty pictures you will need a new-ish one, from about \$65. There are fewer secondhand modems about, because people keep them for use as cheap fax machines. You will also need an account with an Internet Service Provider (ISP) in your local call area.

ISP's come in all price ranges too. A very cheap one will often have all their phone lines tied up, especially in the evenings – but might cost only \$100/year or \$2 per week. The opposite end of the price range would be one like Telstra Big Pond. You will be able to dial straight in without ever getting a 'busy' signal, but you might pay \$5 per hour. There are even free ones which bombard you with ads. Your choice.

If you want to join the online community, just decide how much you want to spend and give Rosemary a call. We will advise on a local provider, get you the best possible equipment for the money, and set it up to connect to the Net. Then it is up to you to learn how to use it – about a zillion others have managed so far.

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Support URSO/PBS Listing

Continued

Rosemary's letter – please copy if you like

"Dear Sir/Madam

I suffer from Primary Biliary Cirrhosis and have been prescribed the drug Ursofalk. I understand that an application to have Ursofalk made available through the Pharmaceutical Benefits Scheme is being submitted by Orphan Australia Pty. Ltd. and I am asking you to please lend your support to their application.

Primary Biliary Cirrhosis (PBC) is a chronic, progressive autoimmune disease which affects the liver and for which there is no known cause or cure (it is not alcohol related). Ursofalk slows down the progression of PBC in many people, thus delaying the time until transplant, and sometimes eliminating the need for this expensive procedure entirely.

Our lives would be helped considerably if Ursofalk were made available to us at a more affordable price through the PBS . To this end I urge you to support the application on behalf of all sufferers of Primary Biliary Cirrhosis in Australia.

Yours sincerely,

....."