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# The Biliary Bulletin

Volume 2, Issue 3

Winter 2000

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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.

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## From Rosemary

Dear Friends,

So good to hear that many more people are getting together. Lesley, Monica and Daisy in Queensland are meeting and keeping in touch and there are good stories too from South Australia. Keep up the good work ladies.

Maybe you would like to send your stories to Jocelyn, the BB editor? I am sure everyone would love to hear of your meetings.

My husband Bill and I had tea with Wilma, Gloria and husband Paull in Bendigo during the Easter break. I can assure you we did not stop talking the whole time, a wonderful day enjoyed by all.

Exciting news for us; our Biliary Bulletin and all future printing projects are now very kindly sponsored by Orphan Australia, who have very generously donated a laser printer and duplexer to our support group.

This will certainly make life much easier in the future when printing the BB as we have been using a very old, unreliable photocopier.

I would sincerely like to thank Rob Chiarolli and Orphan Australia for the wonderful donation and for their interest and support.

A huge thank you too to Jack Thompson, Hastings, Victoria for donating their unwanted computers to our group, and to my husband Bill for helping to make this possible.

We have been able to set up two computers so far, one in Bendigo and one in Pakenham. Thank you once again to John Holman for his continued hard work for our group.

I am waiting to hear from my local council who tell me that they will be in touch when they upgrade their computers.

The computers are being set up for people to keep in touch with each other by email and to access medical information. If you are interested please contact me for further information.

My thoughts and prayers are at this time especially with those people awaiting transplantation. I know from being in contact with Maria during her time on the transplant list, that the waiting seems endless. Try to keep positive and hang in there.

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If you would like to talk to others who have received their gift of life please contact me for telephone numbers. I hope the waiting is over soon and you will be on the road to a speedy recovery.

Keep on keeping positive everyone and remember to smile.

Best wishes,

Rosemary

## That's Not My Job

*Author unknown*

This is the story of four people named Everybody, Somebody, Anybody and Nobody.

There was an important job to be done and Everybody was sure that Somebody would do it. Anybody could have done it, but Nobody did it.

Somebody got angry about that, because it was Everybody's job.

Everybody thought Anybody could do it, but Nobody realised that Everybody wouldn't do it.

It ended up that Everybody blamed Somebody, when Nobody did what Anybody could have done.

*Sent in by Lois Taylor.*

### Speaking of Which...

We need someone to be a 'social secretary' Someone with time, energy and imagination. Interested? Please call us.

## Member Profile

*Lois (Flossie) Taylor*

In May 1997, a few days after my 45th birthday, I visited my GP as my skin/eyes were yellowish. (I actually “blew” the urine/jaundice test scale in her office!). She ordered blood tests, ultrasound and scan.

At a subsequent appointment four days later, she advised that test results showed that both my liver and spleen were enlarged/inflamed and lymph nodes in my stomach were abnormal. After phoning and discussing the results with a specialist, they both thought that I might have either lymphoma or chronic autoimmune hepatitis.

I was admitted to hospital where, upon examining me, the specialist said “but you’re so well!” He couldn’t believe that just a few hours before admission I had completed my daily exercise – a 12 kilometre walk.

After biopsy I was diagnosed with chronic active (autoimmune) hepatitis (CAH), however, the biopsy and blood test results didn’t gel for a straight CAH diagnosis, and had him perplexed. He told me I was “an oddity, a rarity”. Looking back now, I think he termed me this as he considered I was very lucky indeed to be alive and so well, despite my LFT’s being so abnormal.

I immediately commenced Prednisolone to halt jaundice and return liver and spleen to their normal size. Blood test after blood test, visit after visit to the specialist followed (I know you have all experienced these). But those couple of readings still didn’t gel. Meanwhile my liver and spleen returned to their normal size, and bilirubin levels and lymph nodes became normal.

Biopsy results had been forwarded to mainland Australia and overseas (everyone has their “15 minutes of fame”!) for more analysis. In October I commenced the immune suppressant Imuran, and reduced the Prednisolone dosage.

Finally in November, after a harrowing, nail biting six months, my specialist gave me the news that as well as having CAH, I also had PBC and that I was in a very grey area (I knew he wasn’t referring to the grey in my hair!). I momentarily didn’t care because finally, I knew why the other couple of readings didn’t gel!

He advised me in the future I might require a liver transplant! To say I was dumbfounded and flabbergasted is putting it mildly! He then explained PBC was a very rare disease, caused destruction of the bile ducts of the liver, there was no known cause or cure, and was most common in women aged 40 plus. However, tests could get better on Ursafalk.

So, in early December I started Ursafalk and after only 5 days had my routine blood test and the results were (as my specialist put it) “About 1000% better than they had been, and in such a short time!” I continue to take Imuran (reduced dosage) and Ursafalk and now I know I have “overlap” - a bit each of CAH/PBC. LFT’s are fine.

After reading stories of fellow support group members in the Biliary Bulletin I count myself very lucky not to have so far experienced the dreaded itch or tiredness.

All I have is some “dry eye”, not serious, and use artificial tears occasionally. CAH has been contained since 1998. I lead a very active, normal life. Aside from many unwanted kilos (partly a legacy of prednisolone, why won’t they simply disappear), I AM STILL HERE!

My husband, family in Queensland and friends here in Tassie have been a tower of strength to me and shown me much love and support.

I am so glad to be a part of the PBC support group and to have spoken to such lovely people. I enjoy reading other members’ profiles and all the other informative articles in the Biliary Bulletin. I photocopy these articles and make sure my specialist and GP receive them for their own knowledge and benefit.

Take care and keep safe, well and happy!

*Lois (Flossie) Taylor.*

## From the Editor

It is wonderful to be back after two months away, even though I enjoyed myself immensely.

I started my trip by attending the PBC Conference 2000 in Las Vegas, and then continued on to Canada for a wonderful holiday.

During my time away I met many PBC friends who were previously only known to me via the Internet, and it was really lovely to be able to put faces to names. I heard many PBC stories – all very similar and yet each one quite different from the one before.

When we are first diagnosed many of us wonder exactly what is in store for us down the track, and although our doctors, and the literature written about PBC can give a broad picture, no-one can really predict how it will go for us. Each person and each case is different.

All too often doctors will put a ‘time limit’ on us – tell us that we have 3 years, or 10 years before we need a transplant. Well, I am here to tell you that they are not always right!

I met people who were given 10 years, and double that has passed and they are still well! Diet, lifestyle, attitude and medication (especially urso) early in the course of PBC all seem to have a positive impact on its progression.

There are those whose PBC has progressed quite quickly and those who have arrived at transplant over a longer period of time, and it was wonderful to meet and talk with them. Some that I met were only a few weeks out after transplant and I was extremely impressed with how well they were. I met a husband and wife who had both had

liver surgery, he had donated 60% of his liver to her because no donor could be found in time.

This operation is quite frequently done in the US but until recently Live Donor Liver Transplant had not been done in Australia. I am pleased to tell you that it was successfully done recently for the first time.

It would obviously be very good for us if this operation became more commonplace here as the demand for organs outstrips the supply. We would be able to plan ahead and not have to wait until we were very seriously ill before taking this step.

The advances in the field of post transplant immunosuppressant therapy and the dedication of the doctors, make it possible to have an excellent quality of life after transplant, and this is enormously encouraging to those of us who will need this one day.

The PBCers Organisation in the USA, who conceived of and organised Conference 2000, grew from just one person in 1996 to a current membership of around 1200 members online. The group is a wonderful source of support and an exchange of information.

A couple of years ago about 125 members participated in a survey which was shared with the scientific taskforce of the American Liver Foundation and resulted in a major scientific survey which Dr. Eric Gershwin developed and administered to 250 PBCers and 250 of their siblings.

Dr. Gershwin submitted the results of that survey to the National Institute of Health in a grant proposal and he has now been granted \$US1.5 million over 5 years to perform the largest ever epidemiological study on PBC. It will look at hundreds of things from family history to reproductive risks, hormones, residency etc.

Along the way the PBCers Organisation has attracted sponsorship by Axcan Scandipharm Inc. the marketers of Urso250 in the USA, who sponsor the online Daily Digest and the annual PBC Conference. They also have a Doctors Panel made up of 14 doctors eminent in the field of PBC treatment and research.

This is a great example of how something mighty can grow from humble beginnings and should be an inspiration to all of us.

We also started very humbly when Rosemary Rimmer and Doreen Donaldson decided to form a support group and started to search for others with PBC. They found me and several others and in no time at all were writing off letters to local papers to get some media coverage.

Already we have about 150 members and people are finding us on the Internet and through their doctors.

Please tell your doctor about us, ask if (s)he has other patients with PBC who could be made aware of our group.

This newsletter is the first to be printed on our new Hewlett-Packard laser printer very generously donated by Orphan Australia. Our aim is to use it to help educate and inform as many people as we can about PBC.

Jocelyn

## Maria's Story

*Maria Muratore*

6 years ago I was diagnosed with PBC. I was frightened that I would not get to see my children grow up. I felt alone with something that I did not know about and felt that I was the only person with this unusual disease.

One morning my friend rang and told me that she had heard Rosemary and Doreen on 3AW talking about PBC and looking for others that had it to start a support group. I rang 3 AW and got Rosemary's number. The group grew and I met others with PBC. It was good to talk to others who knew what it was like and how it felt.

In 1997 I had a serious operation and 3 weeks later a massive haemorrhage. My liver tests were very high and my doctors were very concerned about my recovery, but I kept in good spirits and had faith in God. I did recover and my LFTs improved.

I went back to my everyday life but suddenly, I went downhill and my doctor suggested that it was time to see the transplant team at the Austin Hospital. I spent a week there for assessment and after that I was put on the transplant list and given a beeper.

During the wait I tried to work and keep up with everyday chores while all around me family and friends were worrying and trying to convince me to slowdown. Still I kept up my work and my church duties.

After a rapid deterioration I became very weak and spent a large part of each day in bed. The itching at night was very bad and kept me awake.

On Valentines Day I went to the Austin for blood tests and I was very, very weak. It was my friend's 50<sup>th</sup> birthday so I managed to eat a piece of birthday cake, joking that it might be the last piece of cake I had for a while if my beeper went off.

About 10pm that night the phone rang and Alice (the transplant co-ordinator) asked what I was doing. I knew straight away that she hadn't rung for a social chat! There was a liver for me.

My family were overjoyed and very confident, and we all rushed around packing etc. so I could get to the hospital.

The operation took only 8 hours and went like clockwork. The first thing that I asked for when I woke up was a cup of tea – but it was about 24 hours before it was allowed.

I have gone from strength to strength although there have been small teething problems along the way, and now I feel wonderful. I thank God in whom I placed my trust, and I thank the doctors and staff at the Austin Hospital.

I thank the donor family for giving me this wonderful gift of life from their loved one. I keep them in my prayers daily.

I also thank my friends from the PBC Support Group who sent cards and good wishes and a special thank you to Rosemary for all her support.

So here I am, alive and well and raring to go and enjoy my family and friends in God's beautiful world.

Maria

## Gift of Life for Lyn

Lyn Camp (Gold Coast) received her new liver on 23rd May. She is making excellent progress and is feeling wonderful. Lyn's positive attitude is an inspiration to us all. Wishing you continued good progress Lyn, all good wishes to you and Ron.

Rosemary

## Tapes from Conference 2000

Diet and Menus for PBCers *Norma J. Thiel, RD LD*

-a booklet of menus and meal plans accompanies this tape. Norma advocates a lower protein, fat, sodium and copper diet, and talks about sources of these things. She also speaks about vitamin and mineral supplementation.

Love Your Liver and Live Longer *Dr. Sandra Cabot*

Dr. Cabot believes that the liver is the protector of the immune system, and outlines diet and supplements to assist in improvement in liver function.

Combination Therapy in PBC *Marshall Kaplan MD*

Dr. Kaplan has a great number of patients with PBC and has been doing trials with drug therapies for many years.

He talks about how he came to use combination therapy, and gives history and details of some of his patients currently using combination therapy, to demonstrate how it can be useful, sometimes even in the later stages.

PBC, Where are we...? *M.Eric Gershwin MD*

Dr. Gershwin asks the question 'What causes PBC?' and lists some specific clues which he hopes might help in his research to answer that question. He asks PBCers to share with him their own theories on why they have PBC because he interested to hear them all. For those who were too shy to ask in public he gives his e-mail address so that we can write to him.

He tells us how the questionnaires which he sent out to about 500-600 PBCers and their siblings, provided many clues and indicated the need for a much larger study.

Funding for a very large 5 year study has subsequently been confirmed, and participants are in many countries.

Ursodiol Therapy for PBC

*Keith Lindor MD*

Dr. Lindor describes Ursodiol as a safe and effective therapy which slows the histologic progression of PBC and extends the time to transplantation.

He speaks about the various research projects on the benefits or otherwise, of urso in PBC.

Diagnosis of PBC

*Howard J. Worman MD*

This talk is about how a doctor brings all the pieces of information about the patient together to form a diagnosis of PBC. History, lab tests, biopsy etc. are all discussed as a means of diagnosis and predictors of the possible course of the disease. He describes what each of the enzymes in a Liver Function Test is indicative of, and the significance of rises in their levels.

Doctors Panel Questions and Answers

Dr. Sandra Cabot, Dr.M. Eric Gershwin, Dr. Marshall Kaplan, Dr. Keith Lindor, Dr. Howard J Worman, and Dr. Patrick Colin.

The audience members asked the members of the panel to answer various questions – the sorts of questions that you and I would like answered, eg.

Who will need a transplant? The best way to take urso?

What is there for the patient that cannot tolerate urso?

The most effective dose of urso?

The best way to take HRT? The use of marijuana for PBC symptoms? The four stages of PBC? And many others.

For further information about these tapes please contact Rosemary or Jocelyn.

The Biliary Bulletin is printed with the kind assistance of Orphan Australia



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