

# The Biliary Bulletin

Volume 2, Issue 4

Spring 2000

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.

## From Rosemary

Dear Friends,

The good news is that UrsOfalk will be available through the Pharmaceutical Benefits Scheme from 1/11/2000. This will make life much easier for many people, especially in country areas, and also means that the medication will be available to those who could not afford it before. Our thanks to the many support group members who took the time to write to their Federal Members, an excellent effort.

We need your help to educate Australia about PBC. Enclosed with your Biliary Bulletin you will find copies of our educational brochure. Please help by putting these in places such as doctors' rooms, hospitals, pharmacies, libraries, health centres. If you would like more copies please let us know, we will be happy to send them out.

There will be a meeting at St Vincent's Hospital Melbourne on 18th March 2001. One of our guest speakers will be Dr Katrina Watson, the second guest will be announced shortly. The meeting will be held in the Mary Aikenhead Conference Centre, O'Doherty Room (room 3) 2pm-5pm. The last meeting at this venue was excellent, so if you wish to attend the meeting please contact me for further details.

Our thanks to all who have renewed their memberships and to the many very generous people who have added donations to their subscriptions. Can I just ask that when you receive your membership renewal reminders that you send them in as near to the due date as possible, as it costs time and money to keep sending out reminders?

We have heard recently from Janice in WA that some of our members there met for coffee, they are hoping that this will become a regular habit. It would be so good to have someone in each state to organise these kind of meetings. I am sure there are many good organisers among you, why not give it a try? You do not have to organise big occasions, just small get-togethers on a regular basis would be wonderful.

Christmas is nearly upon us again, the year has passed so quickly, I am looking forward to seeing many Victorian members at the end of year get together on 9th December. It will be a very special Christmas for me as some of my family are coming out from England, lots of catching up and laughter ahead I know. It will be just wonderful.

I would like to wish everyone a very happy and healthy Christmas, keep on keeping positive.

Rosemary

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## PBS Listing of UrsOfalk *Rob Chiarolli*

UrsOfalk (ursodeoxycholic acid) will be made available through the Pharmaceutical Benefits Scheme from November 1st, 2000, Authority required (100 capsules + 2 repeats), for the treatment of Primary Biliary Cirrhosis. This provides up to 3 months therapy before another prescription is needed.

Doctors will have to phone the Health Insurance Commission (HIC) for an approval number and can then write a prescription.

From November 1st, UrsOfalk will be available through any community pharmacy which should make it more convenient - particularly for rural patients. We expect that some pharmacies may not stock UrsOfalk initially, but all will be able to get the product within 24 hours from their wholesalers. After a few weeks we imagine that they would establish a regular buying pattern and a pack of UrsOfalk will always be available. We have ordered additional stock and do not expect any supply problems whatsoever.

We expect that PBC will gain a higher profile among the medical profession, and result in its earlier diagnosis and treatment with adequate dose.

Orphan Australia has a range of materials for doctors who may need additional information on the treatment of PBC with UrsOfalk. They can be directed to us at:

48 Kangan Drive, Berwick, VIC, 3806.

Ph: (03) 97695744 Fax: (03) 97695944

e-mail: [info@orphan.com.au](mailto:info@orphan.com.au) website [www.orphan.com.au](http://www.orphan.com.au)

## Member Profile

*Maxina McCann*

Would you believe it I have a big mouth, so big that you could just about drive a Mac truck through it. When I said that I would write a profile of myself for the Biliary Bulletin I thought "is that coming from my mouth?" It was!

So be it, I agreed to write something and here it is. My full name is Maxina Billie McCann and I was born in Central Queensland in a small town call Biloela on 17th of October, 1943. My parents were farming at that time in the Callide Valley. I am the middle child with an older sister and younger brother.

I can recall that my early years were fairly happy and full of excitement and wonder as my parents frequently moved from place to place. At one stage they were cooks in a railway settlement, and at another my dad grew tobacco on his Soldiers Settlement farm at Clare Dale near Ayr.

When I was about 10 mum and dad parted and we went with our mother to Sydney, where she had originally come from. This period of my life was scary, coming as I did from a small country area to a big city. However, I went through school and left at 15 to commence my working career. At 17 I started nursing, a typical career for girls at that time, left nursing when I married at 18 and had my first child at 19.

At this time in my life I was perfectly healthy, despite getting Psoriasis - the first of my immune system diseases. In 1970 I had my Gall Bladder removed.

I had always had the urge to study and try to make something of my life...being married and having children didn't fully satisfy me. I went back to high school in 1985 after successfully completing two Leaving Certificate subjects by correspondence, and obtained my Matriculation Certificate. This enabled me to go on to University to study Social Work.

As is sometimes the case, plans do not go as you want and I left South Australia and went to be with my family in Sydney. At that time I had three children and no husband.

Being the self sufficient person that I am, being alone with my children did not faze me and I set out to provide for my children the best I could.

I found a job in a Women's Refuge and worked there for four years. In the meantime, I obtained welfare qualifications which stood me in good stead when I applied for and obtained a position with the Department of Community Services as a District Officer.

I stayed with this job for 14 years and was medically retired in 1997, when my Primary Biliary Cirrhosis (PBC) affected my ability to do the job as I thought it should be done.

I am a person who does not do things by halves. Its either all or nothing for me. In 1988 I moved along with my new husband, young son and parents to a small farm in the

Hunter Valley. City life had got too frantic for me and a stint in the country with the cows and chickens appealed to me. Not so my husband who craved for city life.

Whilst working full time I completed an Associate Diploma in Supervision at TAFE, and completed a Bachelor of Arts in Welfare Work through Charles Sturt University. I was then elected to Port Stephens Council as a Counsellor. It was at this time that I began to notice that my stamina was failing me and strange symptoms were occurring.

I recall an incident one day when I could barely make it to my desk after being out with clients. This incident, and the utter fatigue that I was experiencing sent me from doctor to doctor who could not find anything wrong with me. On one occasion I was hospitalised and diagnosed with Glandular Fever, and another time spent time in hospital with blood clots on my lungs. Despite a close association with the medical profession during this time and abnormal liver results no definitive diagnosis was made apart from Chronic Fatigue Syndrome.

Eventually a biopsy was performed and I was diagnosed with PBC stage 2/3. It was good to put a name to my condition and not to feel that "it was all in my mind". I looked good and it was hard to convince people that I was feeling bad - it was, for want of a better analogy like being a "battery without a charge". Even now when I go back to my old work place they tell me how good I look.

At that time I was suffering with aches and pains over my entire body, stiffness, lack of concentration, poor memory, low motivation, dry eyes, and I felt like I was trying to think through cotton wool. I was extremely fatigued and could only walk for short distances without becoming short of breath and distressed. I really felt that life as I knew it was at an end.

All I knew about PBC was that it could not be cured and very little could be done to ward off the symptoms. The liver specialist put me on Methotrexate, a drug that is also used for Psoriasis.

I was worried mainly about my intellectual functioning as I reasoned that I could do things that didn't require much physical energy, so I embarked on another external course of study at Charles Sturt University, the Bachelor of Social Work. Had I known the amount of effort this required I would have crawled away in the other direction.

At this point I would like to caution people about attributing every symptom to PBC. I was doing a Practicum of 3 months for my Social Work Degree and getting progressively more exhausted. I put it down to the study pressures and home commitment but was rudely brought to my senses when a routine blood test revealed that my iron stores were almost depleted. After hospitalisation, blood transfusions and tests it was revealed that I had Colon Cancer. I was fortunate that my cancer was found early and an operation solved that problem.

The only other difference at that time was my craving for pop corn and mushrooms.

These cravings had been so bad I went from shop to shop for the mushrooms as I couldn't adequately explain how one person could eat so many mushrooms. I used to sit in the car outside of the shop peel them and eat the lot and go back for more. I now know how a drug addict feels when they are trying to get a fix. When my iron levels increased, my craving for mushrooms and pop corn ceased.

Well that brings me to the present time. I have finished my Social Work Degree. I work two days a week as an Adolescent and Family Counsellor at our local Neighbourhood Centre and enjoy being productive. I have been on Urso with the Methotrexate for the last four months and my liver function tests are normal. I still feel fatigued and problems remain with my memory and concentration but I have learned to cope with this.

Making contact with the PBC support group has taught me so much about the disease and how to live with it. I am trying to get a support group started in NSW as I believe that it is essential for people to have the ear of those who know about it. I even believe that informed PBCers probably know more than most doctors do about PBC. Most of the doctors, nurses and allied health professionals that I've talked to have little knowledge about the disease.

I would like to thank Jocelyn for asking me to do this profile... a bit lengthy but as I said "I don't do things by halves".

Cheers.

Maxina McCann, Raymond Terrace NSW.

## End of Year Get Together

We would love to see as many of you as possible – please come to our end of year get together to be held at Debbie Brent's house on Saturday December 9th at 12.30 pm.

Her address is: Unit 3, 2 Griffiths Street, South Caulfield., Telephone: 9571 3735

A sausage sizzle will be provided by Debbie, just BYO drinks and if your name is in the first half of the alphabet – a small salad to share. If it is in the second half – a sweet to share would be nice.

There will be a treasure hunt for the children and a raffle with wonderful prizes including a crochet rug made by June Cummings, some wine donated by her husband Wynston, a Body Shop hamper, a hamper from Sarah Lee – courtesy of Debbie., and a cameo necklace donated by Derrick Swann.

The weather will be perfect – a lovely way to meet other PBCers and have a pleasant afternoon.

Please phone Debbie or Rosemary in the week before and let them know you are coming for catering purposes.

## Thank You

Thank you to all the wonderful people who have sent in donations of money and stamps, especially to the person who sent \$100.00 – you know who you are! We are very fortunate to be in a position to be able to cover the expenses associated with running the group – thanks to all.

## A Letter

Grace Chung

"And ...Speak to us of Friendship"

It was a bright sunny afternoon when four very special ladies, accompanied by two gentlemen and a young lady, met a stranger from Malaysia, under the clock at Flinders Street Station.

The lunch at the Blue Train, in South Bank was filled with laughter, sharing of some of our concerns about living with PBC, and the hopes and aspirations for the Support Group; brainstorming about the logo and motto, and preparations for Christmas.

I felt very welcomed by their spontaneous acceptance and was reminded of Kahlil Gibran's poem on Friendship\*. I have taken the liberty to quote in part what echoes in me, to describe that afternoon

*"...And let there be no purpose in friendship save the deepening of the spirit  
And in the sweetness of friendship let there be laughter and the sharing of pleasures  
For in the dew of little things the heart finds its morning and is refreshed."*

Thank you Rosemary, Jocelyn, June, Debbie, Bill, David and Melanie for taking the time out of your busy schedules and responsibilities. You inspire me by your positive attitude and encouragement in the face of a reality that sometimes can be overwhelming.

I'd like to share, with respect, the following incident.

A while ago, a friend told a mutual friend who had come to Malaysia for a visit, that I had PBC and that the condition was very rare and affected 5 in 100,000 persons.

Our mutual friend turned to me and in an awestruck tone said, "I feel very privileged...I have never met anyone before who was 5 : 100,000".

Keep positive and happy!

Grace Chung

Kuala Lumpur, Malaysia.

*\*Kahlil Gibran was a Lebanese poet, philosopher, and artist (1883-1931), whose family emigrated to the USA when he was a child, but he returned to his homeland to complete his education. He has been called 'the Shelley of the East', and this excerpt was taken from his famous work, 'THE PROPHET'*

## Q and A

Dr. Andrew Mason

Andrew Mason, M.D.

Medical Director of Liver Transplantation Ochsner Clinic.

Assistant Professor of Medicine, Tulane University Medical Center.

Assistant Professor of Microbiology, Immunology, and Parasitology, Louisiana State University Medical Center. New Orleans, LA

1.) Any ideas what causes Primary Biliary Cirrhosis? Since 95% diagnosed are women would it be safe to say the cause is hormonal? Do you know of any current PBC studies being done other than Dr. Gershwin's at UC Davis?

Answer

We have been working on the idea that an infection causes PBC. Researchers in my laboratory have been cloning and characterizing a novel human virus that may be associated with PBC. In collaboration with Dr. James Neuberger in Birmingham, UK, we have found that normal biliary epithelial cells can be transformed to appear like PBC diseased cells in the laboratory by mixing them with the presumed infectious agent from PBC patients. We hope to publish more details about the relationship between the virus and PBC soon.

There are obviously many other differences between the sexes apart from hormones, but we believe that they may play a pivotal role in PBC. For instance, we think that our virus may be stimulated by female hormones but we have not formally proven this yet.

2.) In your opinion is it safe to take adult vitamins when diagnosed with PBC or any other autoimmune liver disease? Instead of taking adult vitamins would it better for PBCers to take children's vitamins?

Answer

I usually recommend that patients with autoimmune liver disease and biliary disorders take regular multivitamins with the recommended dosage of any brand. Patients with biliary disease and those taking oral corticosteroid treatments are prone to bone disease. Therefore, patients should ensure that the multivitamin tablet has vitamin D in it and take additional calcium supplements 1 to 1.5g per day.

3.) Can you recommend or suggest other treatments for PBC besides Actigall & Urso medications?

Answer

This is the only recommended treatment for PBC at present but several groups are trying alternative immune based and other therapies. We have conducted a pilot study using anti-viral treatment for PBC patients and found that the treatment was well tolerated. Although no one had a complete biochemical response, several patients with early

disease had marked improvements in their liver biopsies after a year's treatment. We will soon be commencing a second pilot study to assess efficacy and safety of a more potent anti-viral regimen for PBC patients.

4.) Do you know of any alternative methods used to help improve the liver and PBC such as Milk Thistle?

Answer

I usually tell patients that there are no good studies to indicate prescription of alternative medicines. Milk Thistle appears to be well tolerated but of unknown benefit. I am not aware of any other good alternative treatments but I always recommend a daily multivitamin with vitamin D as well as calcium supplements.

5.) What causes the decrease of vitamin D in a person with PBC? Shouldn't this be easily corrected by taking vitamin D orally?

Answer

Vitamin D is a fat soluble vitamin that can be inadequately absorbed in patients with biliary disease. This can be easily corrected by taking 400 IU vitamin D, which is the usual dose in a standard multivitamin tablet.

*By kind permission from PBCers Daily Digest 16th August, 2000*

## Christmas Cards

There are some Christmas cards left over from last year. They are printed with a small message about PBC. Please contact Rosemary if you would like any.

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