

# The Biliary Bulletin

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Summer 2001

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

First I must thank all those people who sent such lovely cards to me at Christmas time, and I would like to wish everyone a very healthy and happy year 2001.

Especially in my thoughts are those awaiting transplantation. I hope you all receive your very special gift soon so that you can all look forward to better health and a brighter future.

Life has certainly been made easier now that we are able to get our prescriptions for Ursosalk from our GP's and are able to access it through our local pharmacies. Being able to have 5 repeats on our prescriptions is even better than expected.

Our end of year get together at Debbie's on 9th December was a great success, thanks to Debbie and David for a lovely afternoon and for all the work they put into it.

I am looking forward to seeing many of you at the meeting at St Vincent's on March 18th, if you will be attending please let me know as soon as possible.

To those people who have received membership renewal reminders with their newsletters, can I please ask that you post your renewal subscriptions to me with the membership forms. Please do not ask to pay at the meeting as this makes things a little more difficult for us.

Remember always to keep on keeping positive.

Best wishes, Rosemary

## Meeting at St Vincent's

A meeting will be held at :

The Mary Aikenhead Conference Centre, Conference Room 3, O'Doherty Room, St Vincent's Hospital, Victoria Parade, Melbourne on Sunday March 18th 2001.

Time 2pm-5pm. Please be seated by 1-50pm.

Guest speakers:

Dr. Katrina Watson (St Vincents)

Dr. Ian Kronborg (Western Hospital)

Cost \$7.50pp including tea/coffee and biscuits.

Please reply to Rosemary as soon as possible.

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## Obituary

It is with sadness that I tell you of the passing of Pamela Sladden.

After fighting so hard due to many complications Pamela lost her battle in December in the Austin Hospital.

Pamela Anne Sladden, wife of Robert, loving mother of Brett and Jasmine, daughter of Peter (dec) and Bessie, loved sister of Peter and Paul passed away on the 16th December 2000.

I attended Pam's funeral on behalf of our support group and extended our deepest sympathy to her family with a beautiful spray of flowers. The following words were included in the service and Pam's family thought that this is how she would like to be remembered by her friends:

### ONE AT REST

Think of me as one at rest, for me you should not weep  
I have no pain no troubled thoughts for I am just asleep  
The living thinking me that was is now forever still  
And life goes on without me as time forever will  
If your heart is heavy now because I've gone away  
Dwell not long upon it friend, for none of us can stay  
Those of you who liked me, I sincerely thank you all  
And those of you who loved me, I thank you most of all  
The answer to life's riddle in life I never knew  
I go with hope that now I will, and even so will you  
Oh foolish, foolish me that was, I who was so small  
To have wondered, even worried at the mystery of it all  
And in my fleeting lifespan as time went rushing by  
I found some time to hesitate, to laugh, to love, to cry  
Matters it now if time began, if time will ever cease?  
I was here, I used it all, and now I am at peace

Rosemary

## Member Profile

*Dani Brown*

Reading the stories about other PBC sufferers, it's been interesting to see how long diagnosis took for some people, and how a lot of sufferers said that they were relieved to find out what was happening. In contrast, my diagnosis of PBC was totally unexpected.

I'd been suffering some increasingly regular bouts of depression for about nine months or so, in 1999 and the first couple of months of 2000. I thought I was going crazy! I'd also had this weird itching in my feet and hands, but didn't think a lot of it, as it wasn't too bad for a long while, and I had been feeling increasingly tired during the afternoons and early evenings.

I got my GP to give me a broad-spectrum blood test to see if there was anything going on I needed to know about, although we both thought my fatigue was due to stress at work. Surprise, surprise, there were abnormal results for my thyroid and liver. I was diagnosed with hypothyroidism pretty much immediately. I went on to thyroxin and have increased my dosage over the last 7 months or so, and it has totally controlled the periods of depression that were scaring me so much.

It took me a while to get in to see a specialist, but by mid-May my specialist had confirmed that I had PBC. It was totally out of the blue. I had always been very healthy, never got colds or the flu, never really had much wrong with me. Then to find out I had an incurable liver disease, well, it took some getting used to.

Having had a few months to think about it and gather information, I'm feeling a bit more accepting now, and am starting to take positive steps to change my lifestyle. After the first three months or so of being on the Urso, my liver wasn't responding too well, so I had to double my dosage.

After that, though, I saw a lovely woman who is a naturopath, and she has changed my diet and eating patterns, so the itching is virtually non-existent now, and the fatigue is getting better.

My blood test results are significantly better as well. I feel good having taken action, rather than just sitting around waiting for the medication to kick in.

I still have the occasional moment when I get a bit angry and depressed about the whole thing, but at those times, I call my Mum or my boyfriend! All my family and friends have been enormously supportive and understanding.

Getting in touch with the support group has been a lifeline. The emails and the bulletins (great website, by the way!) have been very important sources of information, which has made me feel a bit more in control. I love it when my specialist gets surprised by how much I know!

All the members of the support group, and their friends and families, deserve a medal!

Regards

Dani

## Anti-Oxidants in Primary Biliary Cirrhosis

*Dr. David Jones, Freeman Hospital, Newcastle upon Tyne, England.*

Most treatments studied to date, in PBC, have been used with the aim of slowing the progression of the disease.

Clearly, slowing progression in this way is very important and trials of new drugs with the same aim will go on in the future.

The question of whether or not these drugs designed to slow disease progression improved the symptoms of PBC (in particular itch and fatigue) was often not studied.

In recent years, the importance of treating the symptoms of the disease, as well as progression, has come to be appreciated.

The symptom which is most difficult to treat in PBC, is fatigue.

Following observations reported to us by two patients with PBC, who had found that their symptoms had improved when they took anti-oxidant vitamins (compounds which are normally present in the body and which help the liver to "de-toxify" harmful agents such as free radicals produced by the liver when it goes about its normal function), we set out to study whether or not vitamins of this type may be helpful in treating the symptoms of PBC.

A group of PBC patients was split into two subgroups, one of which took the anti oxidant vitamin preparation Bioantox (one tablet 4 times a day for three months), whilst the other took a combination of Bioantox and Co-enzyme Q10 (100mg daily for three months).

The severity of the symptoms of PBC was measured in both groups before and after treatment using detailed symptom impact scoring systems.

The patients taking just Bioantox showed no improvement in their symptoms.

In contrast, the majority of patients taking Bioantox and Q10 showed improvement in both fatigue and itch.

No harmful effects were seen.

In order to appreciate the true benefit of anti-oxidants in PBC, further larger trials are required (we have almost finished a much larger and longer trial).

At present, it is reasonable to say that these apparently harmless agents may help with the symptoms of PBC.

Any patient thinking of taking them should, however, check with their doctor before doing so.

(Reproduced from *The Bear Facts-December 2000*, with their kind permission.)

Dr. Jones was writing about the Case Report which was published in:

The Journal of Gastroenterology and Hepatology (1999) 14, 1034-1040

## My Transplant

*Tilly Hale*

It is now eighteen months since my operation, I would like to tell you about my transplant.

After nine weeks on the 'bleeper' my call came on Sunday, 25th July 1999, at 3.50 p.m. I felt as if it couldn't be happening but it was 'the real thing' and so I made my way to ward 12 to be met by the Ward Sister. The doctor came to do some last minute blood and heart checks, I had a chest X-ray, talked to an anaesthetist and then it was a case of waiting for the operation.

Next morning at 6 a.m., after a shower and a hairwash, and dressed in a hospital gown and white stockings, I was taken to the operating theatre on a trolley, accompanied by a porter and a nurse. The anaesthetists were waiting for me and told me they would start me off and then take me into theatre proper – that was the last I knew of my operation as I went out like the proverbial light. Some people say they see the transplant team – not me, if I spoke to them I don't remember, and can only hope I was polite.

I woke around 3.30 p.m. complete with ventilator and at 5.30 it was removed and I felt wonderful! I started telling everyone that my mouth was dry – I couldn't make myself understood (what language was I speaking) so wrote the word 'dry' on some part of me and pointed to my mouth and muttered/grunted/made some noises. I was told I couldn't have a drink for 24 hours but I was given some sponge lollies to dip in sterilised water which I could suck and these helped a lot.

By this time I was talking to my visitors, to the doctors, to the intensive care nurses, to the pain nurse, to anyone who would listen. I still felt tremendous and during the night I only had about 40 minutes sleep in any one session and talked the rest of the time. An intensive care nurse was with me throughout, constantly checking the machines and the various lines going into me.

Next morning I continued to feel well and at 3 p.m. I moved to the High Dependency Unit. I was looked after by a team of nurses who were so kind – no matter how often my drain leaked they patiently changed my sheets and gown; I was attached to numerous machines, had lines going in all over the place, all sorts of monitors, vent flows, neck lines, and the pain control button; they explained everything to me and made me part of my care. It was fascinating.

I was put into a sitting position in the bed and was taught the 'one, two, three' beloved of casualty to move from lying to sitting. Next day I was sitting up in a chair, quite indecently clad in a hospital gown which revealed more than it hid (fortunately I didn't know this at the time) and could have sips of water but no meals as I was being fed by an intravenous drip. Thanks to a catheter I didn't need to use a bedpan.

Over the next few days the various lines came out one by one which meant I could move around more, and by the Friday I was eating soups and light puddings. Saturday I was having normal meals – these must have been a little too much as I developed quite a 'trapped wind' problem. I also began to hallucinate. I can remember this quite clearly and did find it frightening but the staff were marvelous and thanks to them it ended up being very funny. Apparently lots of us hallucinate but not everyone remembers and not everyone is frightened.

Sunday morning (six days after the operation) – I had my first shower and had my hair washed. This was done with a nurse to help – in fact she really did it all and I hung onto a handle. Modesty went out with the bath water so to speak, but oh how lovely to feel so clean. This was a big effort and I felt very weak afterwards and was glad to get back into bed.

I eventually transferred into the main bay. Usually patients go from High Dependency to a cubicle but the ward was busy and there were none free so it was into a six bed bay. This can be a nervous time. It was for me, as I had been in isolation and now felt very aware of being with other people and their visitors and the thought of cross infection was very real. When visitors came to see me I tended to drape my sheet over my face and peer out at them. I wanted everyone in rubber gloves and wearing masks. However, this paranoia did pass and it was just me being neurotic.

I did have a period of rejection at about seven days but this was corrected by treatment with steroids. We talk about rejection, we expect it, but it is still a shock when you hear the words applied to you. However the majority of us have what is known as 'five day rejection' (5 days after the operation) and it is easily treated. I was very fortunate and that was my only rejection – some people have a couple of episodes, but it does get treated and it does respond.

After the operation I continued to have tests, scans, biopsies, X-rays, and the daily blood taking, temperature and blood pressure checks etc. There were doctors' ward rounds morning and evening and a huge weekly round when all the doctors, surgeons, physicians, turned up. The doctors took the time to explain procedures and offered lots of encouragement.

The nurses were wonderful, listened to worries, and always tried to find time to spend with everyone, which isn't easy on a busy ward. I was encouraged to get out of bed, sit in the chair, and walk around. The physiotherapist called regularly to take me for walks to the gym for supervised exercise. I was allowed to go to the restaurant in a wheelchair which gave me a change of scene and this is encouraged by staff as it gives you confidence to face the outside world.

Finally the next big day arrived – I was sent home. I went home after two and a half weeks, some people go earlier,

some take much longer. It doesn't matter – we go home when the doctors think we are ready – and after all there is little point in going before that.

For anyone coming up to transplant, or anyone told that this is a possibility, please do remember, lots of us are walking around with new livers – we have been given a second chance. Everyone in the medical team, the doctors, nurses, co-ordinators, social workers, physiotherapists, want to help us, they want a success story. Yes, there are risks, but there are risks with any hospital procedure and these are explained thoroughly beforehand.

At one year and one day post transplant I took part in the British Transplant Games. I won a gold medal in the cycling event – I won because I was the only over 55 taking part, but it was a 5km ride and it was hard work. I got a silver in the 100m breast stroke (for coming second or last!) but I won a bronze in the 50m when I was one of 6 in my age group, so you will realise that I did really win that medal.

No competitor could feel prouder than I did, but I also felt very humble. I did it for me, and for my donor – thanks to her decision to be an organ donor, and the kindness of her family in keeping her wishes I was able to take part in the TX Games. Life is good, I am very fortunate.

Tilly Hale (Newcastle upon Tyne, England)

## Thank You

*Jocelyn*

A big thank you to everyone who was involved in making our end of year get together such a success. I certainly enjoyed talking to so many old friends and making new ones. Thank you Debbie for opening your home to us all, and to you and David for being such gracious hosts.

Thank you too, to all who donated prizes for our raffle: June Cummings who crocheted a stunning rug, Wynston Cummings for the bottles of wine, Derrick Swann for the cameo necklace, Debbie Brent for the Body Shop Hamper and the Sara Lee Company who generously gave us a selection of products from their very diverse range.

## Calcium Supplements

NEW YORK, Dec 27 (Reuters Health) -- Not all calcium supplements are created equal, according to three new studies by researchers at the University of Texas Southwestern Medical Center at Dallas.

The amount of calcium absorbed from calcium citrate supplements is consistently higher than the amount absorbed from calcium carbonate supplements, the research shows.

This difference is important because women who take calcium supplements that are poorly absorbed are not as well protected against calcium-related bone loss and possible osteoporosis, Dr. Khashayar Sakhaee and

colleagues note in the December issue of the American Journal of Therapeutics. "It is well recognized that calcium supplements taken at the proper time can help prevent bone loss in elderly patients," Sakhaee said .

Sakhaee and colleagues pooled data from 15 previously published studies in which men and women took either calcium citrate or calcium carbonate supplements. "Calcium citrate is better absorbed than calcium carbonate by about 25%, whether it is taken on an empty stomach or given with meals," they conclude.

Similarly, in the November issue of the Journal of Clinical Pharmacology, Dr. Howard Heller and colleagues report that postmenopausal women who took a calcium citrate supplement had 2.5-fold better absorption of calcium compared with those who took calcium carbonate.

In the third study, Sakhaee and others found that postmenopausal women who took a calcium citrate supplement for 2 years had greater preservation of bone density in the spine than women who took an inactive placebo.

The amount of protection against bone loss was not as dramatic as that provided by either hormone replacement or specific drug therapy for osteoporosis, the investigators acknowledge. Still, they say, the protective effect from calcium citrate was "more prominent" than in other studies of calcium supplementation for postmenopausal women.

In conjunction with a pharmaceutical company, researchers at the Texas medical center were the developers of Citrical, the calcium citrate supplement that was used in the second and third studies.

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Journal of Clinical Pharmacology 1999;39:1-4.

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