

The Biliary Bulletin

Volume 1, Issue 1

October 1998

A Letter from Rosemary & Doreen

We would like to welcome everyone to the first edition of our newsletter, we hope that this will be a good way for all of us to be involved in our group by sending in our thoughts, letters, information and ideas to make this newsletter a success.

As co-founders of this fast growing support group our focus is to bring together people with PBC who feel so alone and isolated because of this illness.

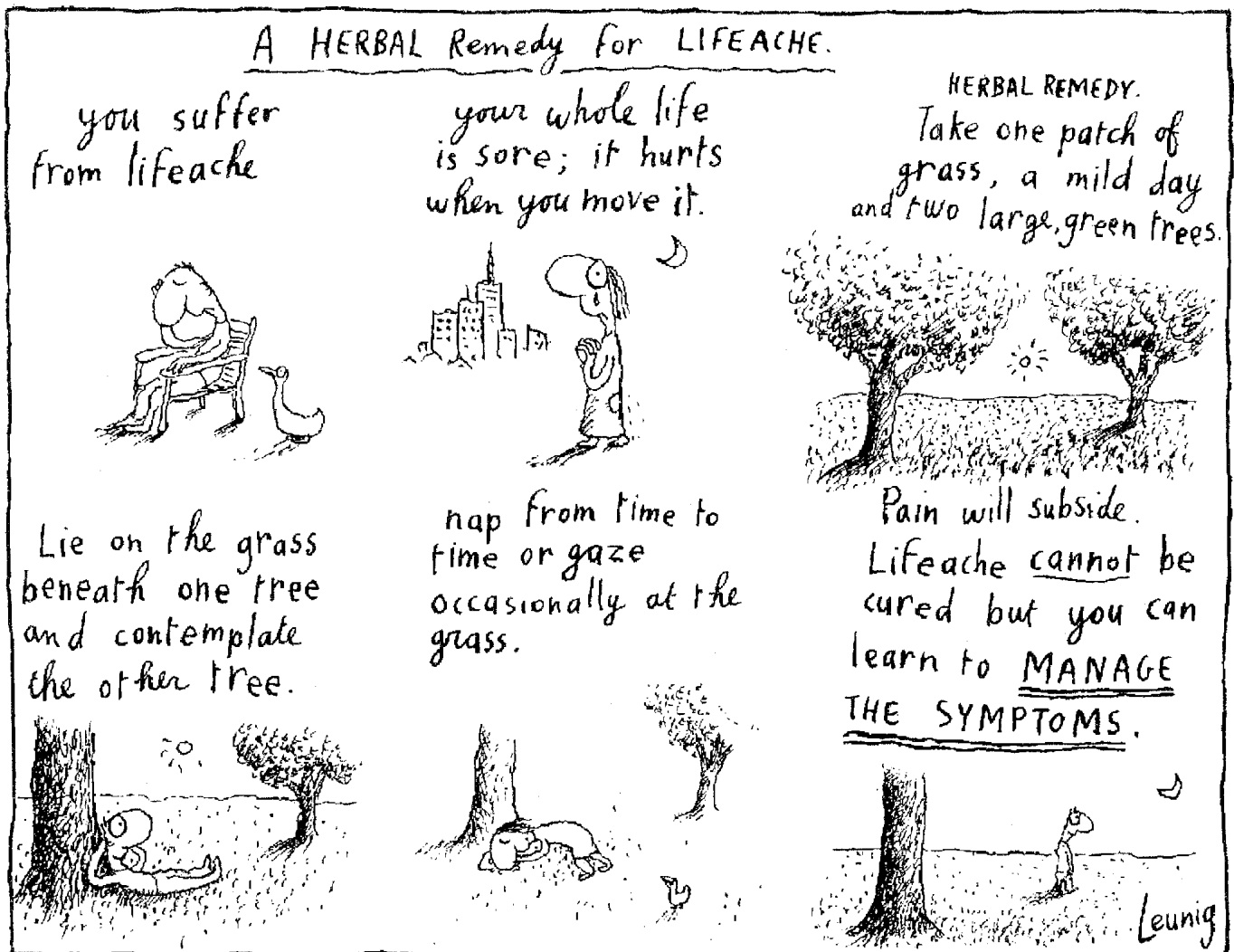
One of the most rewarding things for both of us is the relief in the persons voice when we make contact, everyone is so happy that we have started the group, now the job for all of us is to make the rest of Australia aware of PBC.

We would like to wish all of you and your families a peaceful and happy Christmas and New Year.

Rosemary Rimmer and Doreen Donaldson

INSIDE THIS ISSUE

1	A Letter from Rosemary & Doreen
2	A Word from the Editor
2	Sending Good Wishes
2	Funds Raised
2	Contact List
2	Social Talk
2	Video
3	Spreading the Word
3	International PBC Awareness Day
3	1999
3	Computer Corner
4	Member Profile - Nola Neilsen
4	Identity Crisis



A Word from the Editor

Welcome everyone to the first edition of The Biliary Bulletin. I hope we will be able to print 4 issues a year – this depends a lot on how much news there is.

We are all interested to hear stories from other PBCers. Please share them with us. What have you found that makes you feel better (or worse!), how do you and your family cope? This newsletter will be as good as you make it. Please use it as a forum for sharing your thoughts, feelings and ideas.

The more people that I meet with PBC, the more I hear positive stories, and the more I realise that we have much to be thankful for. When I was first diagnosed 7 years ago I was very frightened that I would not get to see my children grow up and become parents themselves, but now I see that PBC is not a death sentence – there are options.

There are some members of our group who have had transplants, I hope they will be able to give us some insight into what may lay ahead for some of us. There are others who have lived for some time with PBC and are fairly likely never to need a transplant, it would be great to hear from them too, we all need encouragement and hope for the future!

Please write and tell me what you thought of our first newsletter and with it, send some material for the next one. With my very best wishes to you all,

Jocelyn Newman
50 Narrawong Road,
South Caulfield. VIC 3162
joc@eastax.com
(03)9578 5785

Sending Good Wishes

To any of our members who aren't feeling very well at the moment, we send hugs, positive thoughts and good wishes. Remember that it can sometimes make you feel better to talk to someone who knows just how you feel.

Contact List

We now have about 40+ group members and the group is growing all the time. If you would like a list of the other members and their telephone numbers please contact Rosemary or Doreen. (Stamped, self addressed envelopes would help to keep the postage costs down)

Funds Raised

We are trying to raise money to purchase a photocopier. (Does anyone know of a cheap second-hand copier for sale?)

At the Hang Ups fashion parade last week – organised and hosted by Rosemary and her daughter Louise, we made about \$140 in commissions. The clothes were great and the models so professional that it was easy to spend money. Some lovely door prizes and raffle prizes were donated – allowing further profits of about \$130.

Some of our specially printed Christmas cards were sold, but there are still some left at \$10 for 12.

A big thank you must go to everyone who helped to make these fund raisers such a success. If you would like to host a fund raiser or have an idea for one, please contact Rosemary or Doreen.

Social Talk

It is great to get together to raise funds or discuss the business of the group, but do you ever feel like just getting together to chat with the other members? Do you like the idea of having an evening out, eating together and getting to know each other?

Debbie Brent is going to find a restaurant and organise a booking but needs an idea of how many to book for.

Please e-mail her at: bsherriff@pcr.com.au Tell her the suburb you live in and a contact phone number or ring Rosemary and tell her.

Video

Doreen has a copy of a video sent by the UK PBC foundation which is very interesting and informative. Dr. James Neuberger, chairman of the PBC Foundation Medical Advisory Board, and Consultant Physician at the Queen Elizabeth Hospital, Birmingham, speaks in a language we can all understand and covers the subject of PBC very thoroughly. One of his colleagues speaks about osteoporosis in PBC – what to do and what not to do.

Doreen can arrange for a copy of the video to be made and sent to you for the cost of the cassette and postage.

Spreading the Word

In an effort to raise public awareness about PBC, and let other PBCers out there know that a support group exists for them, we have sent letters and told our stories to many local newspapers. If you would like to help with this you could write to your local paper and tell them about us, or tell them your story.

International PBC Awareness Day

The UK group are having a National PBC Day on May 30th 1999 and would like to make it an International Day. Rosemary and Doreen like the idea of meeting in the City Square and perhaps getting a celebrity involved. Other members' ideas would be appreciated. A picnic in the park might be nice afterwards.

1999

Sometime early in the new year, after the holiday season, we are hoping to have a meeting at Cabrini Hospital in East Malvern. Alice Gleeson, a co-ordinator of the Austin Hospital Transplant Unit, has kindly offered to come and talk to us about liver transplant – a subject which I am sure many of us are very curious about. As soon as this has been finalised the date will be advised.



Doreen is planning on having a garage sale to raise funds for the group on the 2nd Saturday in February, at 18 Throsby Court, Endeavour Hills, so start clearing out those cupboards. If you have some goods to donate please contact her, or just come along and snap up a bargain.

Computer Corner

Those of you who don't use the Internet should be aware that you are missing out on a huge amount of interesting information, including the ability to keep up with the latest news and research on PBC and related diseases. A Net account also enables you to keep in daily contact with others both in Australia and overseas via email, and if you like, to Chat (by keyboard typing) with other PBCers around the world.

You don't need the latest and greatest whizzbang equipment - browsing the World Wide Web and sending electronic mail is a trivial task for a computer, and the cheapest machines on sale are more than adequate for the purpose.

If you don't mind things a bit slower, obsolete 486 computers are available for around \$250 at computer recyclers in any Capital city. (Note that 'slow' and 'obsolete' are relative terms; a few years ago, these were the latest technology. They were fine then and are fine now.)

Internet accounts are available in the Capital cities from a few cents per hour upwards.

The main difference is the number of phone lines the provider has – with the cheaper ones you get a LOT of 'busy' signals when trying to connect, though they aren't bad during the day when most people are at work. Unfortunately, people in the country don't have so many providers to choose from.

If you can't afford or really don't like the idea of owning a computer, you can usually access the Net at your local public library free of charge. Free email accounts are available, for example from www.hotmail.com which you can access with the Web Browser at the library. Your electronic mail will be stored at Hotmail for you until you choose to read it. You can read and answer it while online, but if you want a printed copy there is usually a small charge.

A good place to start is the Australian PBC Friendship Support Group Home Page, www.ozemail.com.au/~eastax/pbc which will lead you to lots of useful information.

(By the way, that squiggle in the address is necessary – it is the tilde sign, to the left of the numbers on the keyboard.) Happy surfing!

John Holman

Next Issue: Computer Tips

Member Profile – Nola Neilsen

Hello new friends. My name is Nola and I'm 48, happily married to Noel and have 1 daughter and 3 sons, (one of whom is living at home), and 2 grandsons. We live at Blackwater in Central Queensland where Noel works for BHP Coal. My PBC was diagnosed in 1997.

For a long time I was extremely fatigued and feeling joint pain. I presumed I had rheumatoid arthritis as both of my sisters did. I was sero-negative. A list of symptoms had me going to my GP. He refused to simplify it with a diagnosis of "chronic fatigue syndrome" and kept looking. (Thank you Raj) My gastro did my first biopsy in January this year and proved stage 1 PBC - a very early diagnosis. My most frustrating symptoms so far have been the fatigue and the itch. Questran helps the itch - pity it's so hard to swallow. As for the fatigue I've learned to work when I'm able and rest when I can't.

I have recently had some abdominal pain - on the left which also concerned me as I have a history of kidney illness (I've had a partial nephrectomy). This led to an ultrasound then a CT scan which showed some spleen involvement. Still don't know why I had pain in left abdo. The LFTs done at that time showed increases. My gastro wants me to start Urso. I go back to him next week with my answer. Having read the web pages and seen the reports from other pbcers I've decided to have it. Thanks to the group I now know to ask at the public hospital. My only other alternative was private purchase with a hope of consideration of ex gratia payment from our health fund. So already you've helped without knowing me.

Cheerio for now, **Nola**

Identity Crisis

It has been suggested that we might like to throw in our lot with the Friends of the Transplant Unit group at the Austin Hospital. We would like to stimulate some discussion about whether this is a good thing or not, and whether our members would like this to happen. There are arguments for and against, benefits and disadvantages.

At our meeting on November 19th, we are hoping to hear Gae Di Blasi present some of these to us, after which we may have more idea of what is involved.

This newsletter has been kindly sponsored by

Trumble Szanto Lawyers
10 Cecil Place,
Prahran, Vic 3181.
Tel: 9529 6222



**TRUMBLE
SZANTO
LAWYERS**

Co-founders of the PBC Friendship Support Group:

Rosemary Rimmer

30 Sidney Parkinson Avenue, Endeavour Hills, Vic 3802.
Tel: 9700 2981

Doreen Donaldson

18 Throsby Court, Endeavour Hills, Vic 3802.
Tel: 9706 2404

Editing and page layout assistance:

Vibron Pty Ltd
366 Glen Eira Road, Caulfield, Vic 3162
Tel/fax: 9523 6464 Mobile: 0413 743 560.