

THE LIVER LIFELINE

July 2003

Presidents Note:

Welcome to the July issue of the Liver Lifeline Newsletter. Firstly I'd like to thank the members of the Executive Committee for holding the Annual General Meeting in my absence whilst I was in hospital. At the same time I would like to congratulate them on their re-election. The Executive Committee members are as follows:

President: Mark Rosser
Vice President: Doreen Cheong
Treasurer: Jim McKinlay
Secretary: Jennifer Loupis

What a great year this has been;-

- The bank balance looks great
- Patient support is up
- We have a large donation to be made to research
- The stall is functioning and performing amazingly.

Thankyou all for your support throughout the past year. Let's all look forward to another year of growth and friendship.

See all of you that are able to make it at the next meeting.

-Mark Rosser President

Treasurer's Report.

Since the new committee took office the Group's financial position has steadily improved. We had funds available of \$18,665.00 as at the date of the report. However, we have a commitment to Liver

Research of \$4,000.00.

The stall and raffle should be congratulated on their results. The group as a whole, especially our President, Mark Rosser, has been very active in seeking out donations of \$12,295.00.

The Group has been active in patient support. Since January 2002 we have assisted five families in need to the extent of \$963.61. In September 2002 we also gave financial support of \$750.00 to three members to attend the Transplant Games in Surfers Paradise. We have continued to supply bottled water to the clinic at a cost of \$99.00 a month. A grant of \$1,000.00 was also made to assist our clinic nurses to attend a Liver Transplant Conference in America.

Jim Mckinlay - Treasurer

Liver Transplantation from a Carer's Perspective

(As presented at the last education day for patients awaiting transplant & their families.)

As I write this article, I am happy and relaxed. I am here to say that the last 2 ½ years (to last September) have been the most difficult, traumatic of my life and that of my immediate family.

Our journey through life has highs and lows for everyone and I have had my share, losing close family and friends and divorce to name a few, but this is different and hard to cope with, because it is so intense, ongoing, scary, unknown,



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emotional, life threatening, to name but a few of my feelings and that of other carers I have spoken to.

In my husband's case, he became so ill he was child like, couldn't make decisions, and could hardly function, so I took charge of everything, making all the decisions (some I made were good and some not so good). Looking after family and relationships, all household matters, everything physical, being responsible for doctors visits, liaising with the Medical Profession and hospital staff and in the process maintaining **some** form of normality and self preservation.

Indeed it becomes a huge balancing act, being supportive, positive, caring, staying quiet sometimes, feeling down, and appreciating how the patient is feeling and what they are going through. Some days giving them a little push (physically in a wheelchair maybe which I did one day with the brake on and a flat tyre). I've not been the same since, or pushing them in a positive direction, but at all times trying to maintain their self esteem and preservation.

I have always tried to be a positive person and believe if a door A closes, door B or C will open or that I can make that happen.

It is such a relief to actually get on to the transplant list and then comes the waiting period, but when our call came and my husband had his transplant it wasn't actually as bad as I had prepared myself for. Sure there were times that were difficult and spending a lot of time in hospital wards can be a very unpleasant experience, but there are people there for you, who understand exactly what you are going through and can help.

Then after transplant, when your loved one is recovering and becoming better and able to start doing things the balancing act continues because it is time to start letting go – encouraging little jobs done, again being very positive about progress, but pulling back, which can be a little difficult, because one has been used to being in control and this can cause conflict.

I would like to offer some helpful coping strategies,

1. At all times maintain self preservation, because you need to stay fit and healthy to cope.
2. Take time out, reward yourself - even when the patient is in hospital, if they are O.K., have a day off or an overnight stay with friends or family, or in my case my favourite shop.
3. Do something different on the way to the hospital, i.e. visit a friend or a favourite place.
4. Bring something to occupy yourself while visiting i.e. crosswords, craft etc. as the patients are often sleepy and you may be in a private room.
5. Leave the ward for awhile if things get too tough – have a cuppa or call a friend or family member or go for a walk.
6. Above all else – ask for help. I was stoical, thinking “I can handle this”, but there were times when I should have asked for help. People often offer help – say “**YES**, perhaps you could get me some supplies or make me a casserole.”
7. Understand that it can be hard for close family member, especially young people to deal with spending a lot of time visiting, so it's O.K. for them to leave when they need to.
8. Understand also that some people can't deal with long term illness, they may send a get well card and when the person doesn't get better quickly they are uncomfortable – try not to expend your energy on that.
9. Often the patients aren't themselves because of all the drugs they are taking – allow consideration for that.
10. Before – during and after transplantation take one day at a time and deal with things as they come.

In closing know that the magnificent Liver Transplant Team is always there for you and your loved one, never be afraid to call them if you are worried or have a query and we say a huge thankyou to them for everything they have done for us.

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Also my husband and I have found great comfort, friendships and even a lot of laughs by joining and participating in 'The Liver Support Group'. We are obviously very grateful for our 2nd chance of life, but by taking part in days like today and the activities of The Liver Support Group it is not just saying thankyou it is doing thankyou.



- Wendy Priestly

The RPA Footy Jersey Raffle 2003.

The Royal Prince Alfred Hospital is raffling a State of Origin Footy Jersey to raise funds to purchase a new Ultrasound for the RPA Liver Transplant Unit.

1st Prize: NSW State of Origin 2003 Football Jersey signed and framed.

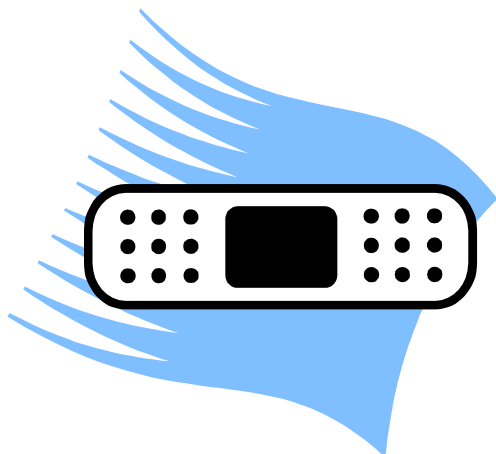
2nd Prize: Wallabies Football

3rd Prize: Wallabies Hat & Scarf.

Tickets are \$2.00 each and are available from:

Mark Rosser (Details below)
Enquires Office (Main Entrance RPA.)

The raffle will be drawn at 12.00pm, midday,
Thursday 11th September in the Jacaranda Café.



Some Infection Control Issues

MRSA: (Methicillin Resistant *Staphylococcus aureus*.)

What is MRSA?

MRSA stands for Methicillin Resistant *Staphylococcus aureus* (MRSA).

Staphylococcus aureus is a bacteria commonly found on the skin of healthy people. Occasionally, staphylococcus can get into the body and cause an infection. Infections from *Staphylococcus aureus* may be minor, such as boils and skin conditions or serious as blood infections.

Methicillin is an antibiotic that in the past was used to treat *Staphylococcus aureus* infections. Some staphylococcus bacteria have developed a resistance to Methicillin and can no longer be killed by this antibiotic. This resistant bacterium is called Methicillin resistant *Staphylococcus aureus* (MRSA)

How do I know if I have MRSA?

Several different Units tithing RPAH routinely take swabs to look for MRSA on patients. Sometimes MRSA can be on your body and not make you feel unwell or give you any signs or symptoms of infection. This is referred to as colonisation.

Infections with MRSA can occur at many different places around the body, for example in wounds, urine and blood. Most patients with MRSA are colonised with the bacteria and do not have an infection.

How is MRSA spread?

MRSA can be spread from patients already carrying the bacteria, through contact with unwashed hands or contact with dirty equipment. It is important that everyone maintains good hand washing practices.

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Can I spread MRSA to other people?

Patients in hospital are more at risk of infections because their body's defence mechanisms may be weakened by surgery, illness or drugs.



Hospital staff may wear gloves and gowns when they are going to touch you or your bedding and will wash their hands when finished.

All visitors should wash their hands before leaving the Ward or Unit.

What precautions should I take?

At RPAH patients with MRSA are isolated from other patients to prevent the spread of the bacteria. Sometimes several patients with MRSA will share a room.

Attention to personal hygiene is important and you will be required to shower or wash daily. Your nurse may provide you with a special soap.

You may leave the Ward or Unit if your condition allows, although it is important that you have a shower and your dressings are tended to first.

Because there are different types of infections in hospitals it is important that whilst you are in hospital, you do not visit other patients either in your Ward or other parts of the hospital.

What about my visitors?

There are no restrictions on your family and friends visiting you in hospital. However all visitors should wash their hands on entering and Leaving the Ward or Unit.

Please do not allow visitors to sit or lie on your bed.

They should visit other friends in RPAH before coming to see you.

What Happens when I go Home?

When you go home healthy family members are not at risk of getting MRSA. Good personal Hygiene and general household cleaning are sufficient to limit the spread of MRSA.

Contaminated pads or swabs can be put into the garbage bin.

All eating utensils and dishes can be washed as normal.

By following the simple points above, there is no need to restrict your activities or visitors.

MRAB: (Multi-resistant Acinetobacter)

What is Multi-resistant Acinetobacter?

Acinetobacter are species of bacteria that are found in almost all soils and surface water worldwide. Up to 25% of normal healthy people may carry the bacteria on their skin.

Acinetobacter has the ability to develop resistance to antibiotics and to survive on dry surfaces for long periods.

This has caused a problem in many hospitals worldwide.

How do I know if I have Multi-resistant Acinetobacter?

Multi-resistant Acinetobacter is usually discovered when routine swabs or specimens are tested in the laboratory.

Infections caused by Multi-resistant Acinetobacter can include blood stream infections, urinary catheter infections and pneumonia.

It may be present on your body and not make you feel unwell or give you any serious signs or symptoms of infection. This is referred to as colonisation.

How is Multi-resistant Acinetobacter spread?

Multi-resistant Acinetobacter can be spread from patients already carrying the bacteria, through contact with unwashed hands or contact with dirty

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equipment. It is important that everyone maintains good hand washing practices.

Can I spread Multi-resistant Acinetobacter to other people?

Patients in hospital are more at risk of infections because their body's defence mechanisms may be weakened by surgery, illness or drugs.



Hospital staff may wear gloves and gowns when they are going to touch you or your bedding and will wash their hands when finished.

All visitors should wash their hands before leaving the Ward or Unit.

What precautions should I take?

At RPAH patients with MRSA are isolated from other patients to prevent the spread of the bacteria. Sometimes several patients with MRSA will share a room.

Attention to personal hygiene is important and you will be required to shower or wash daily. Your nurse may provide you with a special soap.

You may leave the Ward or Unit if your condition allows, although it is important that you have a shower and your dressings are tended to first.

Because there are different types of infections in hospitals it is important that whilst you are in hospital, you do not visit other patients either in your Ward or other parts of the hospital.

What about my visitors?

There are no restrictions on your family and friends visiting you in hospital unless they are providing direct care, in which case they would be required to wear a gown, However all visitors should wash their hands on entering and leaving the Ward or Unit.

Please do not allow visitors to sit or lie on your bed.

They should visit other friends in RPAH before coming to see you.

What Happens when I go Home?

When you go home healthy family members are not at risk of getting Multi-resistant Acinetobacter. Good personal hygiene and general household cleaning are sufficient to limit the spread of Multi-resistant Acinetobacter.

Contaminated pads or swabs can be put into the garbage bin.

All eating utensils and dishes can be washed as normal.

In many patients Multi-resistant Acinetobacter disappears with time and by following the simple points above, there is no need to restrict your activities or visitors.

VRE: (Vancomycin Resistant Enterococcus)

What is VRE?

VRE stands for Vancomycin Resistant Enterococcus. It was first recognised in Europe in 1989 and first reported in Australia in 1994.

Enterococcus is a bacteria that can be found normally in the bowel. On rare occasions enterococcus bacteria can go to other parts of the body, such as the urinary tract, and cause infection. Vancomycin is an antibiotic that is used to treat infections caused by enterococcus, and some enterococcus bacteria developed a resistance to vancomycin and can no longer be killed by this antibiotic. This resistant bacterium is called Vancomycin Resistant Enterococcus (VRE).

How do I know if I have VRE?

Infections with VRE can occur at different places around the body, for example in wounds, urine and blood. Sometimes VRE can be found on your body and not make you feel unwell or give you any signs or symptoms of infection. This is referred to as colonisation.

Most patients with VRE are colonised with the bacteria and do not have an infection.

How is VRE spread?

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VRE can be spread from patients already carrying the bacteria, through contact with unwashed hands or contact with dirty equipment. It is important that everyone maintains good hand washing practices.

Can I spread VRE to other people?

Patients in hospital are more at risk of infections because their body's defence mechanisms may be weakened by surgery, illness or drugs.

Hospital staff will wear gloves and gowns when they are going to touch you or your bedding and will wash their hands when finished. All visitors should wash their hands before leaving the Ward or Unit.



What precautions should I take?

Patients with VRE are isolated from other patients to prevent the spread of bacteria. Sometimes if there are more than one patient with VRE they may share a room.

Attention to personal hygiene is important and you should wash your hands correctly using an antiseptic for at least ten seconds each time after you use the toilet.

You will have some restrictions but if your condition allows and after you have consulted your nurse you may be permitted to leave the Ward or Unit, although it is important that you have a shower and your dressings have been attended to first.

Because there are different types of infections in hospitals it is important that whilst in hospital, you do not visit other patients either in your ward or other parts of the hospital.

What about my visitors?

Your family and friends may be asked to wear a gown whilst visiting you in hospital. All visitors should wash their hands on entering and leaving the Ward or Unit.

Please do not allow visitors to sit or lie on your bed.

They should visit other friends in RPAH before coming to see you.

What happens when I go home?

When you go home healthy family members are not at risk of getting VRE. Good personal hygiene and general household cleaning are sufficient to limit the spread of VRE in the home environment. There is no need to restrict your activities or visitors.

If on discharge you require further medical or nursing care, then your care must wear gloves and wash their hands when they come into contact with your body fluids (urine, blood etc.).

Contaminated pads or swabs can be put into the garbage bin. All eating utensils and dishes can be washed as normal. All bed-linen should be washed as normal.

If you attend outpatients, or you are readmitted to hospital, please let the nurses know you have VRE so they can take steps to prevent the spread of the bacterium.

**Information supplied by:
Royal Prince Alfred Hospital
Infection Control Unit.**



Cooking Corner

Apple Cinnamon Pikelets

Ingredients:

1 cup self raising flour
2 tablespoons caster sugar
1 egg, lightly beaten
25g unsalted butter
2/3 cup milk
1 tablespoon sunflower or vegetable oil
For the Cinnamon Apples:
50g unsalted butter
¼ cup caster sugar
1 teaspoon cinnamon
1 tablespoons lemon juice
2 apples sliced into 5mm pieces.

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Method

1. Sift flour and caster sugar into bowl and mix. Combine the egg, melted butter and milk Whisk into the flour mixture.
2. Heat a frying pan and add ½ the oil to cover base of pan Add tablespoons of the mixture into the pan and cook until bubbles appear Turn over and cook for another 30secs Remove from pan and keep warm.
3. For the cinnamon apples, melt the butter in the same pan Add the sugar, cinnamon and lemon juice Stir until well combined Add the apples and simmer for about 5 mins.
4. Serve pikelets with the apple slices on top and drizzle with the juices from the pan Serve with ice cream, cream or yoghurt.

The Liver
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Lemonade Scones

Ingredients:

- 4 cups self raising flour
- 1 x 375ml can lemonade (diet if you are watching your sugar)
- 1 x 300ml carton cream (lite cream if you are watching the fat content.)
- Pinch Salt
- (Mixed fruit may be added if you wish)

Method

1. Sift flour twice into bowl
2. Add lemonade and cream
3. Mix gently with a wooden spoon till dough forms
4. Knead lightly
5. Place on floured board and role out to 2cm thickness
6. Cut to desired shape (a 4cm circle works well)
6. Bake in a hot oven 220C for 15-20 minutes or until golden brown

The John Smith Experience

1987 was the turning point for my family and me. I was feeling fine but had to visit the doctor for a routine procedure, I needed the wax cleaned out of my ears. Whilst there he did a blood pressure check and he thought I might have a heart problem. So I was sent me off to see a specialist the very next day.

After many checks and blood tests I was told there was nothing wrong with the heart. But I did have a problem I had Hepatitis B, which had developed into cirrhosis. So I asked the question what is the treatment and is it curable? Nothing can be done was the answer, if the liver starts to bleed we can fix that and if you develop cancer we can treat that also. But there is no cure for Hepatitis B.

So doctor what is the prognosis? A maximum of ten years to live, (you ask the questions be prepared for the answers), as a family we were devastated.

I had not felt unwell although I had been very tired, but I put that down to sometimes after working eight hours and driving for two more I was called back to work for emergency breakdowns. Often this would mean just getting home to have to turn around and maybe work all night and the next day. This could happen anytime night or day seven days a week. After I was diagnosed I had to stop all of these call-backs and I just did the normal eight hours shift.

I continued to see the specialist every three months so he could monitor my condition. Then in 1989 I saw another specialist when my regular doctor was not in attendance. It turned out this specialist had worked at R.P.A. on the transplant team. He asked me if I had considered a liver transplant. We had never heard of this procedure and we were a bit surprised it had not been offered before. This doctor made an appointment there and then and we willingly went along to meet Professor McCaughan.

Are first meeting with Professor McCaughan went very well and he indicated that a transplant could be done when the time was right. My wife and I left the hospital that day laughing and cuddling and if I had had the energy I would have jumped with joy.

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There was light at the end of the tunnel, there was hope!

On the 27th June 1991 I received a call from Graham Kidd asking if I still wanted the transplant, I sure did. Be here in two hours John to get prepared for the operation.

After calls to the families in the U.K. and my daughter in the Blue Mountains to tell her we would see her at the R.P.A. we set off. My son driving and my wife taking care of me in the back seat. The preparation took a fair amount of time but my family took my mind off all the poking, prodding and shaving. They were telling jokes; laughing in fact it was like a party in the room. There were no second thoughts, this was the chance I had been waiting for and I really felt positive about the procedure. Then the call came they were ready for me down in theatre. My family all wished me well as I entered the airlock of the theatre, and said we will see you later, but there was never a goodbye.

My next recollection was waking up in intensive care with my wife and daughter at the bedside. My wife saying it is all done and you have come through it all. She tells me that she could not believe the grip I had when she held my hand for the first time after the operation compared with how it had been before.

As soon as all the tubes were removed from me and I was taking off the respirator I was moved into the transplant unit. This was about four days after my transplant.

Next morning I was greeted by two smiling sisters asking if I would like to take a shower, that was an offer I couldn't refuse. They got me out of bed and into the shower sat me in a chair turned on the water and said they would be back in a few minutes. So I got busy, got myself standing up and was really enjoying using the hand held shower to spray the warm water all over me. Just then the door of the shower opened and I turn to see who it was and of course with the shower head in my hand sprayed

water all over the sisters. Needless to say there was no more offer of assistance re the shower.

Things went along very well for me after my transplant, my sister, brother and his wife came out from England and arrived about five days after my operation. This was a boost for me but I feel it was more worry for my poor wife who had the job of looking after them. All the same she never complained to me about anything and was at hand when I needed her.

All my test were going well and there was no sign of the Hepatitis B, then about two weeks after the operation I suffered some rejection. The doctors were quick to tell me this was normal and had the problem under control smartly. I was determined to make the most of my opportunity of getting a transplant and would exercise everyday walking up and down the ward and on the trying out the exercise bike.

I was discharged after a month and I was delighted at that, as I had expected to be in hospital for up to three months. Of course there was the usual three visits a week then two per week and then weekly. During this time at home I continued to exercise walking everywhere I went, I seemed to have so much energy I couldn't believe it. It was now November some five months after my operation, I was getting stronger and I really felt very well. So much so that when some friends asked me if I fancied a part-time job one day a week starting in the New Year, doing some work on a computer and answering the telephone I thought I might give it a go.

Then in mid November I started to get flu like systems and my blood tests started going out of whack. The Professor didn't like what he was seeing and I didn't like what I was feeling. After awhile and things were not getting any better it was thought I should have a biopsy. So late in December I went into hospital for the day to have this performed. I was at this time still feeling well but I had the dread of the Hepatitis B hanging over me.



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My family and I spent Christmas together and we had a real good time, it was my best festive season for some years. My wife and I had been invited to a New Years Eve party at some of our Scottish friend's home, and we were looking forward to having a great night there. These friends always had terrific parties with lots of sing a longs and merriment.

That New Years eve about 4:0pm in the afternoon the telephone rang and it was the Professor with the result of the biopsy. Not good news John I'm sorry said Geoff, the Hepatitis is back with a vengeance. He wished my family and I all the very best for the New Year and I returned the same to him and his family. I put the telephone down, I told my wife. She walked up to me and put her arms around me and we just cried. I don't know how long we embraced but when we broke away we decided we couldn't go out that night. I decided to start the job I had been offered, as I said I was still feeling O.K. I found this helped me take my mind off things, and one day quickly became two days a week.

I was still going to the hospital on a weekly basis and I used to keep abreast of my results getting a copy from the nurse each week. My wife and I would discuss them with Geoff and we could see things were getting worse. Then one day I asked if it would be at all possible to get a second transplant. Knowing that it was most unlikely seeing it was the Hepatitis B that was causing the trouble. The Professor sat back in his chair and told me all the reasons why I should not get a second one, and then said but don't discount it. We must consider that back in 1992 there were no anti viral drugs to fight Hepatitis B, and the medical profession knew that a second transplant had very little chance of success. In-between January and June of 1992 my condition deteriorated quite rapidly and I was admitted into hospital in mid June. I was desperately ill and there seemed an endless number of doctors and nurses attending to me. Unbeknown to me I had been going though an assessment again to see if I have able to get though another transplant. Then Professor



McCaughan, his registrar and nurse came to my beside one day in July while my wife was there and said John we are going to give it another try. You talk about **OH WHAT A FEELING**. You have never seen two happier people than my wife and I, we thanked Geoff and he quickly left. The registrar and sister remained to tell us that the Professor had been searching for possible treatments for Hepatitis B all over world and had found a company that wanted to trial a new drug. It was not a condition of getting a second transplant but would I like to go on the trial. Having been told the slim chances I had of success without help it was a very easy decision to say yes.

Shortly after midnight on the 8th August 1992 the registrar and the night sister woke me up. The registrar said John do you still want the transplant. I thought at first he was just playing a joke on me, as he knew that it was my birthday, so I asked him if he was pulling my leg. He burst out laughing and said no John it is on if you want it, go back to sleep and we will come and get you later. Of course I wanted it and there was no way I was going to be able to go back to sleep.

They then took me to a private room and started to prepare me for the operation. I asked them not to call my wife who was staying in the nurse's home in the Queen Mary building until later. As they had told me the operation was not going to be until 8am in the morning and I thought it would be better if she was able to rest. My family where going to have a long enough day as it was waiting for me coming out of the theatre.

Shortly before 5am they came I said I would be going to theatre in an hour, you had better wake my wife and call my son and daughter then I said. They quickly got my wife and two security men went to Glebe to pickup my son. A telephone call was made to my daughter in the Blue Mountains and arrangements made with the police to ensure that her and her boyfriend had a safe run through to the hospital. All the family were there when it was time to go down to theatre, this time at the airlock the family and staff all sang **HAPPY BIRTHDAY**, this was a very emotional moment.

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Once again I find myself in the transplant unit after a short stay in I.C.U. Having already been through it before I knew what to expect procedure wise. Unfortunately what I did not expect was the return of the Hepatitis B so quickly. A biopsy showed in the first few days after the transplant that the Hepatitis had returned. This was of great concern and I was immediately put on an intravenous drug to fight it. This was not the trial drug we had talked about which was not available as yet. This intravenous drug seemed to do the trick as it was holding the virus at bay.

Six weeks after my transplant I was discharged from hospital after a severe bout of rejection and some other problems. But nothing that the doctors could not handle, they were on top of everything. I was shown how to administer the intravenous drug through a porta-cath I had fitted in my chest.

I continued to use the intravenous drug for some six months and it held the Hepatitis at bay. After six months there were Hepatitis markers starting to show in my blood tests. At this time I was given the trial drug to take and it was immediately successful in knocking out markers. This was of great encouragement to me as well as the hospital. I was taking six tablets a day of this drug and I had to have regular blood tests for the drug company's benefit, which I was quite happy to do as this medication seemed to be working very well for me. After awhile the drug started to cause me some problems and they had to reduce the dose from the six tablets to four. This in turned created the problem with the return of the Hepatitis B. Although Geoff thought that if we could contain the level of the Hepatitis it could be O.K. Later on as my results began to improve the Professor put me back onto the six tablets to try and knock out the Hepatitis B. This proved very successful as it quickly reduced the DNA level of the Hepatitis B to not detected.

I continued on this treatment up until 2001 and then I was put onto one of the new anti viral drugs, which has proven to be even more successful for



me. It has knocked out all markers of the Hepatitis B and I am now producing my own antibodies to fight the virus. Apart from my Hepatitis concerns I have had other problems such as bile duct blockages and a hip replacement but the medical staff were always able to deal with them.

At this point in time all of my tests are very good and I enjoy a good quality of life. My wife Audrey and I go dancing three times a week, we walk on a regular basis and I do the gardening. We have been back to the U.K. on a couple of occasions to see our families and this has been a bonus as at one time I thought I might never see them again.

At this point I would like to say thank you to my hospital family The Transplant Team for what they have and still are doing for me. My wife Audrey, Martin, Diane and Gregg who were all outstanding and very understanding. My relatives and friends who have all supported us so well throughout this time. Also I must not forget the company which supplied me with the trial drug that did such a great job for me. Incidentally that drug was only successful on two patients in the world, so how lucky was I?

In ending I would just like to say I have always remained positive of the outcome and I have always felt that it was up to me if the transplants were to be successful. The medical staff and the nurses do a wonderful job but it works better when the individual puts in the most effort. Then and only then will you see the best results for yourself (that's what I think anyway)?

The Liver Support Group Monthly Stall.

As usual the stall is producing amazing results. Thankyou to all the people who have contributed to the success of the stall, whether it is through donations of articles, knitting/crocheting or cakes. A special thankyou to Carl & Wendy Priestly, Anne Roman, John & Audrey Smith, Bob & Betty Barker and Janet Mann for the continued manning of the stall.

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Remembrance Services

Following my attendance, for the second time, at the special service of remembrance and reflection at St Andrew's Cathedral for all those who have been touched by organ and tissue donation and transplantation, I thought I would share this beautiful and moving experience with you.

This is an annual event which is held around May and, while a religious service, it is non-denominational. The Cathedral was full of families and friends who wanted to remember and reflect on an event that had changed loved ones' lives forever.

On arrival, each person was invited to wear a cream ribbon if their 'special' person was a donor while transplant recipients and their families wore a green ribbon. Amongst the congregation were medical, nursing and administrative staffs involved with transplant as well as staff and organisers from the Lifelink-Organ Donation Network NSW/ACT. A String Quartet played as the congregation filled the Cathedral. As we arrived, we were all given a gold star upon which we could write a personal message if we wished. Later in the service, the congregation were invited to move forward and place their dedicated star around the base of several trees at the front of the altar, around the commemorative tableau. This tableau was a symbolic token of remembrance to all those who have donated, received or made transplantation possible. The creation of this commemorative tableau started at the beginning of the service when ten transplant recipients placed ten green stars around a large gold central star. The significance of this act was to represent symbolically that one donor can help as many as ten recipients.

Last year, we were all given a flower each to place at the altar and the long row of massed flowers in their myriad of colours was very beautiful indeed. The procession by the congregation to make their contribution to the commemorative tableau is an



especially moving part of the service. Personally, this part of the service enabled me to give expression to the many emotions welling up within me.

The congregation was welcomed by the Assistant Minister of St Andrew's. He led us in prayer, including giving thanks for the gift of life and the selflessness of those special people who in their lifetime expressed a desire to help others through transplantation at the time of their death. Other participants, including a donor family member and a transplant recipient, gave readings, while an acapella group provided musical interludes and a choir filled the Cathedral with beautiful choral works and gospel singing during the service. While there were specific people who participated in the service, the whole congregation felt included and involved throughout. The service concluded with a Blessing and then the congregation was invited to light refreshments.

While I frequently think of and give thanks to the donor of my liver and their family, attending this service appears to me to be another opportunity to give tangible expression of my gratitude.

Doreen Cheong
(Liver Transplant Recipient September 2001)

Central Area Health Service & LifeLink

I have received the following invitation from The Central Sydney Area Health Service & LifeLink.

Dear Mark,
Kindly include this invitation in your next Newsletter. Also, please inform your members that they are **under no obligation** to sign up as volunteers when they attend the workshop. Some may just come want to come along for the information.

Many Thanks
Myra

For more information contact:

Mark Rosser - President

The Liver Support Group

4 Hickory St Woonona NSW 2517

Ph/Fax: 02 4285 9901 Mobile: 0418 231 824 EMAIL:rosserm@bigpond.com

Volunteers Wanted

For the Central Sydney Area Health –
LifeLink

Donation and Transplant Support Network

Who can join?

Anyone who wants to help promote
Organ/tissue donation & transplantation.

By joining the support network, you could help
educate others about this vital
Community Service. As a network member you
could be involved in public speaking, media
campaigns or as volunteers for events and other
activities.

Come and join us at a

Email & Web Sites.

A lot of members have requested that we include
the websites listed in the last issue. Please note that
the information found in these web sites are from
around the world and may differ to the procedures
and systems in Australia.

Gastro & Liver Clinic General Email Address:
gastroandliver@email.cs.nsw.gov.au

General Liver Disease Information:

RPA Web Site
www.cs.nsw.gov.au/Gastro/Livertransplant

American association for the study of Liver Disease
<http://www.hepar-sfgh.ucsf.edu>

American Liver foundation:
<http://www.liverfoundation.org>

Current Papers in Liver Disease
<http://cpmcnet.columbia.edu/dept/gi/references.html>

Volunteers' Workshop

3rd September 2003, Wednesday
9.30am to 12.00 noon

Special Functions Room, Queen Mary
Building, Royal Prince Alfred Hospital,
Camperdown

(Morning tea & refreshments will be served)

RSVP: August, 15th 2003

- Mark: 02 4285 9901

Membership – The Liver Support Group

Welcome to all the new members to the Group, it's
great to see that we are still growing as a group. The
membership for the group is \$5.00 annually, (per
family) payable as of 1st of January each year. Please
forward the completed membership forms to Mark
Rosser (details below)

Liver Pathology

<http://www.pds.med.umich.edu/usersgreenson/>

Metabolic Liver Diseases

<http://www3.ncbi.nlm.nih.gov/Omin/>

HepNet

<http://www.cdc.gov/ncidod/diseases/hepatitis/index.htm>

Liver Support Group Meeting

The next Liver support Group meeting will be:

Date: Sunday 24th August 2003
Time: 11.30am
Venue: Rydges Hotel
Missenden Rd
Camperdown NSW 2050
Menu: Chef's Selection Of 3 Salads
Roast Chicken
Vegetarian Lasagne
Fresh Fruit Platter
Coffee & Tea
Cost: \$22.50 per head

RS.V.P. Tuesday 18th August 2003

For more information contact:

Mark Rosser - President

The Liver Support Group

4 Hickory St Woonona NSW 2517

Ph/Fax: 02 4285 9901 Mobile: 0418 231 824 EMAIL:rosserm@bigpond.com

Please forward cheques, made payable to The Liver Support Group to:

Mark Rosser
4 Hickory St
Woonona NSW 2517
Mobile: 0418 231 824

Transplant Games.

On behalf of The Liver Support Group, I would like to wish all of the participants of French and British the games all the very best.



For more information contact:

Mark Rosser - President

The Liver Support Group

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Membership Application Form

Name: _____

Address: _____

City/Town: _____ **State** _____ **P/code** _____

Phone: (Hm) _____

(Wk) _____

Email: _____

Transplant Date: _____

NEWSLETTER

To enable us to produce a newsletter that is of both use and interest, please take a few moments to jot down some notes or questions that you may have;-
