

# INFORMATION

## STICK WITH IT SLOW BUT SURE

NEWSLETTER OF THE IN GROUP: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC.  
Supporting sufferers from acute Guillain-Barre Syndrome(GBS) & Chronic Inflammatory Demyelinating Polyneuropathy(CIDP)

**Next Meeting**  
**18<sup>th</sup> MAY, 2008 at 1.00pm**  
**Balwyn Library Meeting Room**  
**Whitehorse Road, Balwyn.**

**Our Guest Speaker will be Dr. Russell Gibbs on Anxiety and Depression**  
A small plate would be appreciated

Annual General Meeting 1.00 pm  
Christmas Luncheon 12.00 pm

Sunday 17th August  
Sunday 7th December

## NOTES FROM THE FEBRUARY MEETING.

A short meeting was held prior to the guest speaker, with apologies read, and Minutes accepted. Treasurer, Doug. Lawrence, reported on general finance and also advised we have received \$1300 awarded to Self-Help Groups from the Department of Human Services. Thank you Doug for all the work you do on these submissions.

We received a letter from CSL advising of the appointment of a new General Manager, for Bioplasma Pacific, Dr. Jeff Davies. It is great that CSL keep us informed.

As we all sat in a circle we introduced ourselves. We had some new members who we were very pleased to meet.

We answered questions put to the group by members. Steven Cohen told how he was invited to the St. Vincent Pain Management Clinic for ten days. If anyone is interested he would be happy to tell about it. He found it very, very useful with the pain, for coping with others, and to help with sleep. He said, "One of the things I found is **it is a lot better to look at all the things you can do**, not the things you can't do." We will endeavour to have a guest from St. Vincent's Pain Management Clinic speak at one of our meetings. Stephen can be contacted on (03) 9570 7385.

## GUEST SPEAKER

**Leanne Deltoso, is a member of The 'IN' Group and is aiming to be selected as a member of the Australian Wheelchair Olympic Team for the Beijing Paralympics.** Here is an abridged version of her talk. (Thanks to Barbara Rivett for the use of her Dictaphone as our machine did not record successfully.)

Leanne began: I was diagnosed at 19 with CIDP and I'm 27 now. I came to these groups which are very good. I have had every test, and tried many things but now receive 'Intragam' regularly. I realised there were lots of things I couldn't do but also realised there are still lots of things I can do. I travelled overseas carrying a 26kg. suitcase. I did it regardless of what everyone thought.

The doctors have had to reassess my diagnosis because my brother (also at aged 19) started having the same symptoms. Our older brother is okay. My Neurologist realised something may be causing it through our genetics. Mum and Dad want answers.

I keep going forward which is hard, but you only have one life.

I always played sports. Sport was my life, so I went along to see what I could do and was told "You are a Basketballer. You can play Wheelchair basketball". I had never been in a wheelchair. I worked so hard not to be in a wheelchair. It took a long time but I told myself, "I can do it".

I went along to the Knox centre and tried it. I would tip over. I would push and go the wrong way. It was very difficult to learn but regardless of your disability, everyone is equal on the court. I started playing at Knox and then was asked by a representative of the Victorian team to train with them.

I had to find out how much training my body could take; how much training I should do in the wheelchair and how much walking I needed to do to keep my legs strong and to help my balance. I was not good as I was not co-ordinated, but I could shoot for goals and read the court. The Head Coach would say I was doing okay. Then I was asked to go to train with the Australian Team so I went along. The other girls were so much better and were way up there and I was way down there. They trained me and I eventually joined the Australian Team.

I train for hours each day. My condition has not improved but it hasn't got worse. It has been a really hard year in the Australian team working towards the selections for Beijing. I don't know if I will make the team but I strive to do my best.

My story is different from anyone else in the team as I am not wheelchair bound which is a massive learning curve. My hands are weak, so when I'm playing I get really tired. It means I can't go out with friends. There are hurdles you have to overcome to do what you want to do. You have to think what you've gone through, get through the next day and then see where you can go. It's the journey that's important.

Are there any questions?

### **Has it ever been suggested that too much exercise could cause damage?**

I don't think my nerves are inflamed but when I do too much I have to rest for a few days. I have to work out how much is right for me. I do believe that if you don't use it you lose it.

### **Wheelchair sport is not exactly gentle. Is what you're involved in, "rough"?**

No, it's about skill to avoid hitting each other.

### **How is a team constructed?**

The players on a team are all given points to signify their level of disability. The team has to make up 16 points. Someone with Spina Bifida can use their hands and are therefore classified as 1 point. I can use my body so therefore I am given a level of 4.5 points. The team goes on the skill of the players and their points. Therefore if you have two players who are at the same skill level, the one with the lesser point score would probably be selected for the team, so they could select more players.

Wheelchair basketball can be played by able bodied people as a sport. You can make up a team of your friends and family and it is lots of fun. It is harder to play if you are able to walk as you want to get out of the chair. It's a strange feeling and one you have to master.

Wheelchair bound athletes can train every day but I need to walk too and strengthen my arms and legs.

Co-ordination is lost when your numb. My feet started to get numb. I can't stand up on my toes. I wear these ski boots and I wear braces on my ankles and legs. If I put shoes on without my braces, my ankles would break. They are so weak. I am in these braces permanently.

### **What are the Steps for selection for the Australian Olympic Team?**

We have over summer been scattered all over the place. The girls from Victoria have gone to America to train. We had a camp in January for selections. It was difficult for me because I work (for Netball Victoria) and you have to fund everything yourself. Beijing selections are in May with a trip to Japan in April.

I have only been playing for a year and a half and have played for both my State and my Country. It's an experience not many people can achieve so I'm going to do anything and everything I can until May and if I don't get to go to Beijing I WILL BE SHATTERED.

**We wish Leanne every success and she has the support of all The IN Group in her quest. Good luck Leanne!**

### **GUEST SPEAKER FOR MAY MEETING – Dr Russell Gibbs**

(Dr. Gibbs has Immune Deficiency and receives 'Intragam'.)

Here is a sample of what you can expect at our next meeting. The following came from the end of his last visit and is very useful. Try it!

#### **Relaxation - Sitting down exercises.**

Put your hands down by your side. Breathe in slowly whilst raising your arms over your head. Exhale slowly bringing down your arms slowly. Make a noise when you breathe out ...ooooooooohhhh. That empties your lungs and gets rid of tension in the system. Shut your eyes and do it again. As you breathe out you can feel your neck and shoulders relax and tension go from your body. Do three more.

Interestingly some people were coughing, that is because, when we breathe we don't always expand the bottom of our lungs and with this exercise it means you are using the bottom of your lungs where all the rubbish collects. Breathe in again. (We continued with 3 more until we were all nearly asleep.)

The next thing I'll tell you is, if you have a disagreement with somebody it's a very good exercise to do this, just sitting with your hands on your knees, breathe in and as you breathe out feel your shoulders relax - and again – in/out. I do this at work between cases and it is very good as sometimes I have difficult patients who blame me for not getting better. I have been doing this for about 25 years and it's been very good.

When you think "He's a pain in the neck and I'm going to tell him what I think", what I do is say to myself, "Is it worth saying? Will it do any good? Will it achieve my objective?" and the answer is always NO, so I relax and go onto the next thing.

John Burke, (one of our committee members) relayed the following: “One of the first times I met Russell we were sitting waiting to have our infusions. When the nurse took Russell’s blood pressure it was up through the roof. He told the nurse to go away and come back in 10-20 mins. We all sat there watching him as he went off into his relaxation technique. When she came back and took his blood pressure it was better than mine. Whatever he does – works”.

### Anxiety

Anxiety is produced by a natural hormone which is Adrenalin which is the fright/flight/fight hormone. If you are faced with something that is apprehensive, like I was, having this woman stick things into the back of my hand and she was going to tip buckets of stuff into my veins and I wondered if I would get a reaction from it and all that, my blood pressure was up. I produced the adrenalin that put my blood pressure up, my heart rate up, made my skin blanche, etc., all caused by this hormone. You can, by learning the simple breathing relaxation technique, (you have to learn it you can’t just use it when you get frightened. You have to spend 20 minutes, 2 or 3 times a day for a fortnight to learn it properly) turn it on and it will defuse the situation and you won’t feel drained because someone has upset you.

Also do it at night. I have a sick wife and I’m often up at night with her and sometimes I’m worried about her and can’t go to sleep so I do the relaxation breathing. I do one breath and I count the breaths. Very rarely do I get to 10 as I’m usually asleep before that happens.

This is one of the important things about managing anxiety.

When we are looking at these illnesses there are two causes. Firstly the causes are external to us. We may live next door to a young family who play a lot of loud music or we may have trouble with our mother, our sister, our children and our children’s children and so on. Then there are internal forces. How we have been brought up. I come across a lot of people who have been brought up in abusive situations, either physically and/or verbally with father or grandfather who was a drunk and stuff like that and those are the internal things that affect us.

In terms of treatment it doesn’t always mean that you have to have pills. There are behavioural treatments for depression and anxiety. The world seems to live on ‘Cerapax’ and ‘Valium’ but these are not essential. You can teach people to do relaxation, to do with stress management, to do with problem solving and to do a thing we call CBT which is working out why they think the way they do. All of you would know somebody and wonder why they think in that way.

People with anxiety need to learn how they could be in control of it, because when things go wrong at 3 o’clock in the morning, however nice your Doctor might be, he’s not going to come and visit you, he’s going to send you off to the nearest hospital where 6 hours later you may be seen by a Doctor who qualified last week.

**We will learn more on the 18<sup>th</sup> May. Come along and bring family and friends. You may be able to help someone who suffers from these debilitating problems.**

### **DID YOU KNOW?**

If you have food in the refrigerator, clothes on your back, a roof over you head and a place to sleep, you are richer than 75% of the people in the world. If you have money in the bank, in your wallet, and spare change in a dish somewhere, you are among the top 8% of the world’s wealthy people

## CSL VISIT

Members of The 'IN' Group boarded a bus near the Balwyn Library and headed across town to visit CSL's plant at Broadmeadows.

It was a very informative day.

Thank you to the wonderful staff, including Dr. Jeff Davies, Stephen Bowditch, Darryl Maher, Vita Micucci, Dr. Liz Campbell, Christine Chambers and Alex Stankovic. Thank you to Dr. Andrew Kornburg who also attended allowing some of our members the opportunity of a one to one chat.

Following the tour we were treated to a lovely afternoon tea before being counted and reboarded back on the bus to Balwyn. We even sang "Happy Birthday" to one of our members on the return trip.

All who attended enjoyed the day. It was lovely to see some of our young members able to join us.

**Our sincere thanks go to CSL for showing us over the plant and explaining how 'Intragam' is produced from the generous donations of blood by our wonderful Australian donors.**

We are indeed lucky to live in this wonderful country where work of this type is done and even luckier that the products are then made available to those who need it.

From left to right. Back Row: John Burke, (C) Doug Lawrence,(Treas.) Kerrie, Barbara Rivett, (Sec.) Joe Behr, Melva Behr, (C) –Other side of sign - Peter Males (C) and Fred Hooten.  
Front Row: Brian Boyd, (C) Margaret Lawrence,(Pres.), Tom Rivett, Dorothy Brennan, Anna Melville and Kirsty Melville. (C) = committee members.

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Postal Address: 66 Eva Street, Clayton, 3168. Telephone: 9543 2825

The 'IN' Group News.

Members, Jan and Bernie, have written from England advising that Bernie has now had two infusions during their stay. Jan and Bernie are our "hospital/rehab.visitors" but are at present caring for Jan's elderly father.

We have had a quiet couple of months for referrals in Victoria and hope the coming Winter will be quiet also.

Whether or not to have flu injections is always a decision which needs to be made by you and your physician. If you decide to go ahead and have the 'flu shot, I believe they are now available.

We would be interested to have any news from our members. Please drop a line to: Melva Behr, Newsletter Co-ordinator, 44 Mavis Avenue, Beaconsfield, 3807 or phone 03 9707 3278.

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Booklets -The Road to Recovery A-Z	\$6
-Boy, Is This Guy Sick	\$2
-CIDP	\$2
-GBS	\$3

Donation to support medical research \$ \_\_\_\_\_  
(donations of \$2 or more are tax deductible)

I do/do not require a receipt.

**Total Payable:** \$ \_\_\_\_\_

Enclosed is a cheque/money order (payable to The IN Group)

## Membership Details

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_ Postcode \_\_\_\_\_

Telephone: (Home) \_\_\_\_\_ (Work) \_\_\_\_\_

Email Address: \_\_\_\_\_

Signed: \_\_\_\_\_ Date \_\_\_\_\_

Thank you. Please forward this form along with your payment to The Treasurer, The IN Group, 26 Belmont Rd., GLEN WAVERLEY, 3150.

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