



INFORMATION

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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) and other Inflammatory neuropathies

Dates to Remember:

Sunday, June 11 th	2.00pm	Guest Speaker:
Sunday, August 13 th	2.00pm	Annual General Meeting
Sunday, December, 3 rd	12 noon	Annual Christmas Luncheon
		Guest Speaker: Assoc. Prof. Andrew Kornberg

NOTES FROM MEETING HELD SUNDAY, 12TH MARCH, 2017.

Apologies: Peter Males, Rob Gardiner, Brian Boyd.

Margaret: Meeting dates are not quite what we normally have because the June and August meetings are closer together and today's meeting had to be today because we have to fit in with the library. We are here for the rest of the year.

Obtaining Guest Speakers is proving difficult especially as our meetings are held on Sundays. Andrew Kornberg will come to our Christmas meeting.

I have a very good CD on the workings of the Commonwealth Serum Laboratories and if you are interested we could show that. Would you be interested? I have seen it and it is very good.

A discussion took place about obtaining Guest Speakers with appropriate topics. Members as well as Committee are to seek speakers or CD's of interest. Let Margaret know who to contact.

Doug: Andrew Kornberg has been flying solo around Australia. His aim was to raise \$100,000 and as of today he has raised \$136,000 for movement disorders. He has stated that his two loves are flying and caring for children. At the moment he is in Geraldton. He is flying a single engine plane. Everyday he puts a Blog on the internet.

He has a very high profile job and he is doing all this but he still replies to all our emails.

John: In our last newsletter there was a link and I put it on the emails I send out and you can track him as he goes around.

Margaret: I have bought articles etc. for you all to look at or take home with you.

Doug: Since 1st October to end of December we have received subscription of \$275 and donations of \$825 which is representative of what happens. We also made \$1280 net after our Christmas Luncheon which was probably one of our all time highs. (Three generous donations of \$100 were included.) The dolls have raised \$535 and I have \$150 to bank and to **Gwen thank you very much for this fabulous job.** (Applause)

Our expenses were Internet costs, Library hire, Newsletter costs, postage and our donation of \$10,000 to Andrew in December which he appreciates very much.

I would like to record that The IN Group's first donation to Andrew at the Children's Hospital was done in December 1997. Since then and including our \$10,000 donation in December 2016, we have donated **in excess of \$142,000**. (Applause)

I thought it would be nice to put that on record for all our other members who are unable to attend our meetings to know this is going through. It is all thanks to our members from all around Australia and the couple from Overseas as well.

Finally, we still have \$2,845 in the bank so we are well on our way with our new financial year beginning July 1 and I have every confidence that we will reach again a \$10,000 minimum donation in the coming year. (Last year our receipt had a handwritten thank you).

Those present sat in a circle and we introduced ourselves as we chatted together.

Costas. I'm a bit hot because it takes me 2 hours to get here on public transport.

It is good to have a support group. It puts a different aspect on it. I went to a GP recently (who wasn't my normal GP) and I asked "Can I have a prescription" as I was tired and I said I have difficulty sleeping. Then he started, "You are giving me too much work. You will have to make a double appointment." That's how busy GPs are and **neurologist when you go there they are so busy**. You can imagine how difficult it would be for them to come to speak on a Sunday. Also, **some don't acknowledge that a support group is helpful**.

Comments made by those attending:

1. Some people don't come because they are apprehensive in case they see people worse than they are, which is sad.
2. You get to come and chat to the different people and you certainly get a different perspective and **encouragement to push on**.
3. It's called a support group for a reason. **You get support**.
4. A support group is not for everyone. A lady I was speaking with the other day had neuralgia and she had an operation behind the ear where they put in a pad between the nerves to ease her tremendous pain. **She was saying she had joined a support group because what she had done she had not heard of. That's the thing, you think you are the only person with the problem and then you go along and talk to others and you find things are not so bad.**
5. You can always find someone worse off than yourself.
6. **It is interesting finding out how they make themselves feel better. Maybe they do water aerobics or whatever, then it gives you an idea of things you can do.**
7. My biggest problem is getting into a pool!

My name is **Janice** and I got **GBS 18 months ago**. I had been away with my girlfriend and her husband **overseas for 6 weeks**; on and off buses, you know, doing all the things you do when you are away. I live in Melbourne and they live on the Gold Coast.

We came back to the Gold Coast and I was leaving the following week and this was on the 13th August and it was her birthday on the Sunday so I said, "I'll come back one day next week." The only thing was I had a really bad cough when I came back to Queensland. **I had been to a doctor in Ireland to make sure I could fly home okay and he said, "You have no infection. You just have this really bad cough but you are okay to go home."**

To cut a long story short. We came home about 2.30 in the morning and got into Brisbane airport and decided we would stay up all day and unpack and go to bed in the night-time. My friend said to me **"That damned cough of yours is no better."** We went to a doctor in the shopping centre near them and he said **"Get a blood test and make sure they take a swab of your throat but you haven't got any infection."** This was on the Friday. He said, "Come back on Monday and I'll have the results of the blood tests."

I was fine that day. The cough was not so bad. He had given me a codeine based medicine so **the cough got better**. I went to bed. **I had the best nights sleep**. Went to bed about half past 8/9 o'clock and didn't wake up. Woke up the next morning at 7.30am and it is hard to explain because I don't really know in my own mind, **but when I woke up and went to get out of bed I thought "Something feels funny**. I thought, Oh it's probably Jet lag or something. I had to walk through the bathroom and the toilet was there. I got to the toilet and **my legs went from under me**. I got myself up again, went to the toilet and then back to bed.

My girlfriend came in and I said, **"Something just doesn't feel right."** She said, **"I think because you have had that cough we better get an ambulance."** The ambulance bloke came and had a look at me and said, **"Something is not right but I don't know exactly. We will take you to the hospital."** I am not a snob so don't

take this the wrong way, but I said, "Don't take me to a public hospital I couldn't stand being there and trying to get diagnosed." So there is a **good private hospital just near so they took me there. Well I was diagnosed within 2 hours of having GBS. By the time they got me to the ward, (the chronic ward or something) all I could move was my head.**

There I stayed for 6 months. I had two lots of 'Intragam' and 10 doses of plasma exchange but I have had no 'Intragam' since.

I came back to Melbourne in February last year and **had 3 months in St. George's rehab. I am not under any neurologist. I am just under the rehab. Doctors. They just say it is exercise. My biggest problem was I couldn't walk and had to be hoisted everywhere. I couldn't do anything.**

Now I have been in my **home since April** and I have **Villa Maria do homecare** for me. I can **now walk unaided. My biggest problem is my hands.** That is as far as I can go with my hands. I now have to look as **to whether I will be able to drive again** and the car will have to be modified if that happens. I have just been back to see the rehab. Doctor last Friday so **now I have to follow up on the car bit. My brother says "You will be alright. You will drive again."** I think yeah that's alright for you to say.

Comment: Lucky you went to the hospital so quick or it could have been much worse.

Janice: Yes it was a doctor in emergency. I think he was an American. He said, "I think you have GBS". I didn't know what he was talking about. I didn't have any idea.

A lady used to come and visit me. The ladies in rehab suggested it one day. As you can imagine, the only people I had up there was my girlfriend, her husband and her family who were very, very good to me but all my family were down here. Not being married and I only have one brother left and he's 80, it's harder for him and he has a handicapped daughter. **I have my friend Mary who is here with me today.** So one of the nurses suggested "if we got **Di in because she had been in the hospital 3 years prior to that and she was just wonderful.**" **Di would come every week to visit me and she would bounce in the door and she has foot drop but she lives on her own and she would walk in the door and stand at the door and say "Well what's the news this week? What have you done this week?"** That was really great, so I can believe in support groups because that's the reason why we have come here today.

Comment: I am interested to know what therapy they are using for your hands.

Janice: Not very much at the moment. They are thinking. **The rehab Doctor is going to refer me to the Hand Clinic (probably at St. Vincent's) because that is my biggest bug bare.**

Comment: I notice you are keeping your hands nice and flat.

Janice: **You modify and you learn to do things;** like people would normally just pick up a pen. **Well, when I first went home I dropped every imaginable thing. I couldn't get a pinch grip.**

Comment: Are your fingers numb? Do you have pins and needles?

Janice: Ah, not really. It is a funny sensation actually. Yeah, **probably like a pins and needles and they are like it all the time.**

Comment: I have it. I have it in my fingers but sometimes it goes all the way to my palms. It is terrible picking things up.

Janice: Yeah, well mine is not so much down here. Because I have minimal use in them **I can't use a pick up stick and they suggested in rehab when I was first learning to walk again that I use a walking stick, but I can't grip a walking stick.**

Comment: I am blind in one eye so I can't tell distances.

Janice: So not knowing anything about Guillain-Barre` until about 18 months ago, coming here today is really good.

Gwen: Janice, I have a suggestion which may help you. I have a long stick with a magnet on the end. If you had two of them the magnets will pull each other together. You may be able to pick things up with that.

Janice: Yes, but **I still can't hold the stick.**

Gwen: Well you get things with a flat bit. You can't probably buy one ready-made but it is the sort of thing you can get someone to whip up for you. I have lots of home made gadgets that help me to do things but the magnets grabbing each other is a good idea.

Comment: You could probably have something with a Velcro band and do it that way.

Janice: Like I was saying to the **Doctor the other day** at the rehab when she asked me what I had been doing and I said, "Well I pruned all the roses. Yes if I can't pinch them then I get them like that and do it that way." She said, "You can come and do mine if you like." So you learn to modify.

Comment: Where there's a will there's a way.

Margaret: We had a member diagnosed in 1989 and it was years before they said what was really wrong with her but things have improved a lot. The local doctors now seem to know about it where years ago they didn't. Your diagnosis was just wonderful. I think with our late member they diagnosed her with motor neurones and when she didn't die they looked for another diagnosis. She was found to have CIDP. So being diagnosed early is encouraging.

Comment: Outer Eastern Rehab are wonderful what they can do. I couldn't walk. They showed me simple things to do and how to use my hands again. We could have thought of that ourselves but we didn't. They have different practises and were very caring people. I think the rehab people are wonderful what they do.

Margaret: I guess, like many things, to some people it is just a job where for others it is their calling in life to make sure they spend as much time as possible helping people.

David: I went into the Knox Hospital about 3-1/2 years ago in June that year. I went in with Double Pneumonia and a few days later I thought I was going home, but they couldn't get my blood pressure down and it was 212 and my heart beat was down to 45. It was all over the place and they said "We have to put a pacemaker in" and when I was there I said, "Oh look my fingers are all tingling and I have pins and needles in my toes."

When I came out of the operation I couldn't stand up. The specialist diagnosed me with Guillain-Barre`. I was in intensive care for 4 weeks and they didn't know which way I would go. I was trying to say goodbye to everybody. When I was trying to say goodbye to my grand-daughter something gave me the will to live because the pain was so intense, even though you are almost out to it. When I came out of that I went to the Ferntree Gully Hospital and was there 2 or 3 months and started rehab and learned to walk again. Having to be lifted up by crane and being in a wheelchair is fairly demoralising and you feel so helpless.

Question: David, at what point were you diagnosed?

After the flu. It was lucky I was in the hospital and they picked it pretty quickly.

Question: Did you have a pacemaker put in or not?

David: Yes, they put the pacemaker in and that probably saved me.

The pain has been terrible. I am on Lyrica and I take Panadol and another pain killer.

Janice: It is interesting that you say that, because **I didn't have any pain. I am on no medication whatsoever.** They put me on Lyrica then they took me off it.

David: It took me a long time to be able to put my shoes on as the pain was terrible and I am numb from the knees down and feel like I'm walking on stilts. The feet are so tender as the nerves are hypersensitive. I also have the tendons that go from the big toe back to the heel so tight they generate so much heat I can't put them under the sheet and have to take more pain killers to get to sleep. It is not what I want to do. They have no answer for it. If I am on my feet too long or do too much walking they swell up.

Margaret: Janice you had the cough and David you had the pneumonia, do you think it was that which brought on the GBS?

David: What I had explained to me is that it is a virus like the flu and it sits in your body and when you get right down it takes over and it affects your nerves and because your fingers and toes are the furthest away from your heart you feel it worse there.

David to Janice: Did you get a flu injection before you went overseas?

Janice: I have had the flu injection as I have it every year but they said “No it wasn’t the flu injection.”

Discussion took place about flu injections and swine flu. Some believe the flu injection was the reason they had GBS while others believe everyone reacts differently to vaccinations.

Margaret told how she collapsed after having the flu injection 3 years ago.

Member: My husband and I have just had our DNA done for Pharmaceutical reasons. What they did was collect our DNA from a mouth swab. Our Chemist supplied a list of drugs we are on and after they looked at our DNA and the affects it would have on the drugs we take, a lady came to our house with a list three pages long of what drugs we were taking and drugs that we might have to take later in life, like Warfarin for example. Neither of us has ever had Warfarin. Our DNA showed that my husband can have Warfarin but it would not be as good for me.

Previously the group were talking about pain killers. The list gave the pain killers name and then whether or not it would give us an adverse reaction or a good reaction.

From my DNA they found that the medication I take for reflux is not strong enough. I will now discuss this with my Gastroenterologist.

We were given a card which has a number on it and any doctor can go onto the site and put in our number and see whether the drug they are prescribing is the best one of its type for our DNA.

Margaret: I think there is something about going to the same GP which doesn’t happen so much these days. We go to a particular GP and so do our children and so do our niece and nephews and he will often say, well that’s not good because that’s in your family. Over the years it has been quite interesting. Doug and our eldest son have been found to react after fasting so now their cholesterol tests are done a different way.

Member: When I got out of hospital, I was in a wheelchair and I had to get all the forms to use aids and I went back to my nerve doctor and he just said, “Well you will never walk again. Your inner and outer nerves have both been damaged and will never be good again.” I went away feeling quite depressed and I decided, what does he know anyway and I got myself up and around and walking. I was a builder then, so I built a couple more units and climbed up the ladders. I went back to him and I made a point of getting up from the chair and walking into his office and all he could say was “Well you have got half way haven’t you.”

Comment: You proved him wrong and they don’t like that.

Member: The next time I went back he told me why I wouldn’t get better from that and he said “I can’t do anything more for you.”

It has been a big struggle with the pain and you wonder if it is worth it sometimes.

Janice: How long ago did you have it?

Member: Three and a half years.

Janice: Do you drive?

Member: Yes, I was determined to drive. I am lost without my car.

Janice: Did you have to go for a test?

Member: Yes, I do a test every year. VicRoads get in touch with you every year and you get a report from your doctor.

Janice: Did the occupational therapist give you a report?

Comment: Once the first time is done it is a form to be filled in by your doctor each year.

Joe: I have just been given three years until I have to report again.

Margaret: Doug has numb feet but that was because of a back problem.

Member: Yes when I was in intensive care that really tested me. Also being older it is harder to bounce back.

Gwen: I would like to share my driving history. **I am 84** and have multiple things wrong with me and **I still have my Heavy Vehicle Licence** as in the time I became a teacher we were required to be able to drive a school bus. I never did and I never intended to. Over the past 7 years **the licence has been extended to cover all over Australia** and I didn't have to do a thing about it. Recently I was only given a 3 year licence and I thought my other licence would cease but it didn't **but I can only drive a 10 Tonne truck now!** (Laughter.) I have no intension of doing that either.

My son tests me every birthday as he has had experience in that field. **When you hear the news it is an elderly driver if they are over 60 but when a young person does it the car did it**, the car ran off the road. I think that is unfair. I have never had an accident and I am very careful. My reflexes in spite of the CIDP are very good.

Margaret W: I would like to say something about Support Groups. My dad had GBS and he wasn't interested in coming here, not for quite a long time, and then he did find interest in it later on but **it was the family who benefited from information we received from this group and being able to be directed to other places. So, it is not always the individual that support groups help. For the family to know that just because their loved one is like this today, didn't actually mean that in 6 months time they will still be like that. Even though we couldn't see it, we knew there would be an end to it and he just had to work towards it. It helped us be more positive and to understand and we borrowed books from The IN Group library.**

Member: Your father was the one that impressed me because I thought if he got over it then I can too.

Margaret W: My dad would be pleased to know that. He regained all his feeling and he tried everything and massage made the difference and I was wondering if that would help your hands Janice.

Janice: I do have hand massage and she is very good. There is plenty of feeling there.

Margaret: I was pleased to hear Dr. Richard Stark say from a medical point of view they find that having a support group is excellent.

Comment: My doctor has 4 patients with GBS. I was his first and now he has another three.

Member: Talking about family, what my family went through when I was in Intensive Care wasn't good. My eldest son said, "My dad's not going to die, he's a fighter" with tears in his eyes and my wife sat there for hours every day wondering which way it was going to go.

Margaret W: Yes it is very stressful for everybody.

Member: They need support to get over it.

Margaret W: In a way the person with GBS has support as they are in the care of people in the beginning and getting organised about what they have to do. The family is still thinking and having access to information, especially antidote, is the best kind. When you are sitting down talking to someone else and how they have coped to me this support from the group really benefits the families.

Member: I couldn't even sign my name and my wife had to take over everything.

Margaret W: The IN Group has been good for us.

Gwen: I want to ask if anybody on 'Intragam' has had their dose reduced?

I am very unhappy. I have **changed neurologists** as I was going to the Alfred and it was just too far. I transferred to Knox and the new neurologist and I **started at the end of last year getting less** than I used to get and no-one seemed to know why. The nurses said "Well that's what's on it". I **tried to ring the Doctor to see what the reason was, but I couldn't get on to him** even though I had the correct phone number. I tried every possible time. **After 4 weeks I wrote to him. I got a reply to say that I could have got him on his pager. I didn't have his pager number** anyway. I wouldn't think to do that if I hadn't been told to do it.

He thought perhaps the 'Intragam' was stronger, he didn't know, and he hasn't found out. It was as if he didn't care anyway. He is very pleasant and I can't fault him in that way but I didn't get an answer I was happy with.

The next time the same thing happened, a lower dose. The third time he came to see me. His answer was that presumably my weight had gone down but he'd never weighed me. It is weird.

Member: Did it make you feel different?

Gwen: I thought I was, getting more tired, but it could be other things. But no muscle or strength tests were done and I didn't think it would be changed without the doctor knowing.

John: Change doctors. Ask your GP to find another neurologist with visiting rights at Knox.

Discussion took place about various doctors.

Afternoon Tea was then enjoyed with lots of one on one chats and even swapping of recipes.

NEWS FROM THE COMMITTEE

The IN Group is now on Meetup.com. This website caters for groups that have regular meetups and helps with their promotion and management. Please join our group by visiting https://www.meetup.com/IN_Group_AU from here you will receive notifications about our upcoming meetings and can RSVP online with a simple click.

Additionally, **the IN Group now has a Twitter.com account.** Twitter is an online news and social networking service, operating on short messages - known as tweets. If you have a twitter account please 'Follow' us at https://twitter.com/IN_Group_AU

The Committee would like to thank our new committee member Neil McCoy for his work and expertise in setting up these contact points. Thanks Neil.

Yearly subscriptions will be due on 1st July and will be able to be paid by cheque, money order or online banking. Details will be in our next Newsletter.

The National Blood Authority has a new program called BloodSTAR being rolled out across Australia for the authorisation of IVIg to patients. Victoria is now on the new system.

Also CSL is transitioning from Intragam P to Intragam 10. Intragam 10 is more concentrated so infusion amounts are reduced.

Quoted from BloodSTAR newsletter February 2017.

“As part of the upcoming transition from Intragam P to Intragam 10, the existing product management functionality has been revamped to cater for the introduction of Intragam 10 as well as other future product changes. Extensive testing has been undertaken to ensure minimal disruption to ongoing patient care upon transition. BloodSTAR will automatically transition patients to Intragam 10 according to transition dates.

From 1 March 2017, existing patients for whom an authorisation request is submitted in BloodSTAR will be allocated to receive Intragam 10”

Email Mailing List. If you would like to be included on The IN Group email mailing list please send an email to John Burke at the following address: John@BAL.net.au

If you use *hotmail* or have junk mail filtering software running you will have to include the above email address in your “safe list” otherwise *hotmail* or your junk mail software is very likely to delete our emails.

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Booklets- GBS	\$3	\$
CIDP	\$3	\$
After GBS	\$3	\$
The Road to Recovery A-Z	\$6	\$
- Boy, Is This Guy Sick	\$2	\$
Recipe Book -\$12 plus postage & handling	\$16	\$
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(Donations of \$2 or more are tax deductible)		_____
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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)
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