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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

COME AND ENJOY OUR CHRISTMAS LUNCHEON AND DUTCH AUCTION SUNDAY, 3RD DECEMBER AT 12 NOON AT THE ASHBURTON LIBRARY, 154 HIGH STREET, ASHBURTON. ALL WELCOME. $20PP
RSVP: MARGARET 9802 5319 OR MELVA 9707 3278 BY 28/11/17
This is a fun day with good food and company. A wrapped gift would be appreciated for the auction. (An indication of approximate value would help the Auctioneer.)
We hope Assoc. Prof. Andrew Kornberg can join us and update on GBS/CIDP.

Minutes of the Annual General Meeting Held August, 2017.

President : Welcome everybody. It is great to see you all.

Apology: John Smith

Minutes of last year's AGM ratified.

President's Report: Margaret Lawrence

This past year for The IN Group has been very rewarding. We have had marvellous donations from our Members towards research. The Committee are a band of caring and grateful people who have once again stepped up to continue the work for another year.

Our special friend and colleague Peter McInnes who also was our Secretary for many years is unable to continue due to ill health. We say a big "Thank You" for all his Service.

John Burke has accepted the role and will continue as Secretary.

We had the pleasure this year of following Assoc. Prof. Andrew Kornberg on his solo flight to raise money for the Royal Children's Hospital. As you know Andrew is our Patron and part of the research program we support.

We will remain at the Ashburton Library for the time being as building works are still going on in Balwyn. When we came here they said 6 months. (Laughter)

This year we have struggled to get speakers but our members have enjoyed catching up for a chat. We thank Valerie Simpson very much indeed for her inspiring talk last meeting and look forward to Neil, an In Group member, speaking today about his health.

We also last meeting welcomed Ken Daniels a member and supporter of the New Zealand GBS Group. We receive their Newsletter. It is always very interesting to see and hear the ideas of another group.

Our Newsletter is an interesting and informative quarterly issue put together by Melva and Joe Behr. Thank you to them for all the work involved. We receive many notes of praise.

I finish off with a big "Thanks You" to everyone for their support and assistance. A great group of friends.

Treasurer's Report: Doug Lawrence.

Income for the year totalled $7,765 being from subscriptions $1,115, Donations $4,300 and general fund raising of $2,350. Our expenses totalled $2,027 and a donation of $10,000 was once again given to the Royal Children's Hospital via Assoc. Prof. Andrew Kornberg to be used in research relating to GBS and CIDP. Funds carried forward from 2016/17 now total $4,069 giving us a healthy start for this year.

As subs. are due from the 1st July our largest cash flow is in the first quarter of each financial year. Unfortunately, **I need to report that of our total membership approximately 50% failed to pay their subscriptions last year.** I would like to make special mention of four things.

1. **The first is the generous donations we receive with the subs. from our members each year and 2016/17 was no exception.**

The first get together of persons with GBS and CIDP occurred in the 1980's. The In Group was subsequently incorporated as a not for profit charity on the 18th May, 1992 and since then and up to the 30th June, 2017 a total of $140,000 has been donated for research by The IN Group.

The IN Group is also endorsed as a Tax Concession Charity. Therefore all donations are tax deductible. Those wishing to take advantage of this, do not forget to advise that you would like a receipt for any donations.

The IN Group also received approval to use the Registered Charity Tick from the Australian Charities Not For Profit Commission.

2. I would like to **acknowledge the assistance of CSL for their financial support in meeting our Website costs.**
3. I would also like to make special mention of our **Committee Member Gwen McInnes who with her special ladies contributed $816 from their craft sales. So to Gwen and the ladies a big "THANK YOU".**

4. Finally, to our hard working Committee, who not only work to give us a most enjoyable Christmas Luncheon, but also donated the majority of the food thus helping us raise a total of $1,280 on the day.

Thank you.

The Committee are: Margaret Lawrence, President. John Burke, Vice-President/Secretary.
Doug Lawrence, Treasurer. Melva Behr, Newsletter. General Committee Members: Joe Behr, Brian Boyd, Peter Males, Gwen McInnes, Neil McCoy, Barbara Rivett and Len Waters. We have had an exciting time as Ken Daniels has joined the Committee. (Applause)

Margaret: I would just like to say something about Neil who joined the Committee last year. His background is in IT and he has done a great deal of work in promoting us in a very modern way on the computers.

Some of you have probably seen **Meetup** so Neil is doing a lot of work there for us which is tremendous.

Annual General Meeting Closed 12.47pm

Talk by Neil at our August Meeting.

I am involved in Twitter and Meetup which are online social sites that can help to promote the group.

How many are aware of our Website – The IN Group Website? http://www.ingroup.org.au. Good.
The Meetup group is now on the Homepage. (Home Page brought up on screen.) Where we say "Forthcoming Events" that shows where we are today. Where this helps the Group is there are lots of Meetup groups around Melbourne who can utilize this service to promote their movement. People who are interested in certain topics can search, so Google connect to this website here. Meetup is a service. The other benefit to the Group is people can RSVP which can help organisers of the Christmas Luncheon and things like that to get an idea of how many may turn up.

We can also keep a log of our past events. Here is a photo of our last meeting where Valerie talked, also Ken as well. We have a photo there and it helps people know that we are around and we catch up and what the feel of the group is.

This also links to our Website and also links to twitter on line service. Twitter is a bit different to Meetup. Meetup is for organising things where as twitter is a different way of disseminating information.

Traditionally The In Group has a very good history of Newsletters. They are big chunks of information. Twitter is the other extreme. Very small snippets and you can have a quick skim. So this is our In Group Website and you can see there it says 19 hours occurred. I made a mention of our Meetup to come along. Hope to see you there.

On top of that we link to other organisations that are using the twitter service, so you can see that we have the Red Cross Blood Bank and we interact with their postings. They may say that this person has donated blood 500 times. With our group it is medical related sites like Inflammatory Neuropathy. CSL; we follow them. In our feed we acknowledge research that they have done. I just had a read of that article. It is quite interesting. You can go through like that and you can link to other support groups around the World. Here is one for GAIN which is the UK support group. Have a look around. You can't break anything and you might find some useful information.

Question from the floor: Do you need to have your own Twitter account?
Neil: No Twitter is really good asyou can just do a quick search. It is all open information. Twitter allows you to read the information.

Question: No subscriptions. Neil: No. No costs.

Neil: Our first Tweet was from Andrew Kornberg when he opened his charity flight. We were able to re-tweet it and share it around to people who follow us on twitter.

Facebook is something which would be good for us as well with the commentary side of things. You just need a Facebook account to start that up. I don't have one.

Meetup and Twitter are two things and I invite you to try them out.

Question: If you are at home and you want to get into Twitter do you have to put that introduction with the Twitter and The IN Group you have up on screen at the moment?

- Yes: Our Twitter page is (people are encouraged to bookmark it or "Follow" us if they have an account) - https://twitter.com/IN_Group_AU

Another way you can get to it is if you did a Google for Twitter you would get to this page. Then type in In Group Vic then wait for it to come up. The reason you use the Vic is it reduces the search a bit.

Question: I find if I go into a site like this I get bombarded with adverts. Is there risk of that?

Neil: Yes Twitter can spam but it will be about things you are interested in and you won't get unwanted things. I have a Twitter myself and I also manage this page here and I basically get zero. You choose how you want to be notified so I will get an email from Twitter saying they have a new follower, which means someone has found our content interesting and likewise our group follow others. You wouldn't get unsolicited things. It is possible but it is not like email.

- With Meetup as well, they won't spam you with anything. If you join our Meetup landing page (people are encouraged to click the "Join us" link and "RSVP") https://www.meetup.com/IN_Group_AU/

they will let you know when our meetings are happening. Meetup might send a message once a month just to say there is this other support group which may be of interest to you.

With Twitter, posting of content, you need someone to manage it and that is what I do once a fortnight. I will link to relevant other Tweets, so each one of these seen here on the board are tweets. I link to anything GBS or CIDP related.

Question: That one just there, could you play that article there now? The one about "How different IVIg brands can affect your CIDP healing". Now if I want to watch the rest of that how do I do it?

Neil: Click on "How different IVIg brand can affect your CIDP healing". That's now opening up their website. That is CIDP Neuropathy Support and that is American based in California.

Another thing with Twitter if you go to our site you just see what we Tweet, but if you create your own account and then you are followed, for all the people who are following (there are 19 people) if I go into my homepage I will get all the latest updates. I was just showing what our Tweets were there. I will see the new post from the Red Cross Blood Bank and these other support groups. When you have some time you just go to your homepage and you get an update of information.

Question: With the little arrow going down, if you click on that, you can control what you want to see and what you don't want. Can you unsubscribe?

Neil: You can actually control as to what you want to see.

This is the actual logged in version. I follow Neuropathy Action. I can go here and mute or I could unsubscribe or go to unfollowing.

Question: If we signed up to the Meetup one, how do we do it?
Neil: I do encourage it. There is no cost to it to be a participant. Probably the simplest way is to click on one of the upcoming things and there is an RSVP there. This will ask you to sign up. I click the RSVP. Join up is the one to do. If you have a Facebook account you can log in with that.

Yes, go to the site. Click on To Join Us, then RSVP. We actually had someone join the group, Ray.

Doug: All the Committee should be on it. John: All the members should be too. It gives you reminders.

- Our Meetup landing page is (people are encouraged to click the "Join us" link and "RSVP") - https://www.meetup.com/IN_Group_AU/
- Our Twitter page is (people are encouraged to bookmark it or "Follow" us if they have an account) - https://twitter.com/IN_Group_AU

I have also prepared a talk on my journey with CIDP.

INTRODUCTION

Hi my name is Neil, I'm going to share with you my journey with CIDP.

I was 35 when I was initially diagnosed with Guillain-Barre` Syndrome, or simply GBS

I was relatively fit and healthy, a husband, a father of an almost 2yr old son and working full time

For those that don't like spoilers, cover you ears now because I'm happy to say that the CIDP at last check-up was considered in remission and I'm for the most part all those things I said before with the major exceptions being the almost 2yr old son is almost 4 years of age and I'm also the proud father of a baby girl.

But, let's get into what happened in the two years in-between.

Symptoms and Diagnosis

One Thursday morning about 2 years ago I woke up with a bit of numbness and tingling in my fingers "no big deal" I thought, I've just slept on them and the sensation will go in a few minutes. About an hour later while walking to the train station my hands still felt the same, I thought "perhaps I strained a nerve while doing exercises earlier in the week, I'll just take things easy".

The next day Friday, was pretty much the same except while walking home I became suspicious of some tingling in my feet "gee must have really strained a nerve!"

Being what I understand as typically "male", I went through Saturday and Sunday not mentioning any of this to anyone and waited till the Monday morning to tell my wife that I was feeling a bit funny and made an appointment to see my GP.

By this time it's now the 5th day since the initial tingling in the fingers and I'm now starting to feel generally fatigued and uncomfortable which is starting to also cause restless nights sleeps.

I got an afternoon appointment with my GP where they made me wave my arms this way and that, stretch my neck in all directions and do some squats. It's probably worth mentioning I was still able to do squats using both legs but not like I knew I should have been able.

The GP straight away suspected GBS, made contact with a Neurologist and organised an appointment for me for 6pm that same day.

Needless to say when I was at the Neurologist I did some similar movement tests but also had my reflexes tested, which to my surprise were all gone.

I was told it may not get any worse from here but the Neuro preferred I go to Emergency now so they could get some other test out the way and start a treatment which was 5 days of an infusion.

I said I wanted to hold off for the moment and bring my wife up to speed to which he said "if at any point you cant stand-up from a squat, you must go straight to emergency"

I went home, spoke to my family and packed a bag for the 5 days I was going to be in hospital.

The next day I stumbled on the stairs at home and had my father drive me to the Emergency of the hospital the Neurologist consulted at. As you could imagine it was an interesting moment turning up to Emergency with a packed bag and no obvious sign of injury but when I handed over the $300 or so this particular hospital charged for their ED, the counter person realised I wasn't trying to prank them.

Hospital

Over the next 24 hours I had: a couple of blood tests, a spinal tap, an MRI and a CT Scan. By the end of those 24 hours I was checked into a ward and received the first of my 3 daily bottles of 'Octagam' - a brand of IVIg infusion many here would be familiar with. The three bottles over 5 days would deliver me a total 150g of Immunoglobulin.

I thought "sweet, 5 days, I'll be done by Sunday and back at work for Monday"...or so I thought.

By the time it was Saturday I was moved to ICU. The tingling sensations didn't go past my elbows or knees, but my arms and legs continued to loose strength. In the day prior to being moved I'd had two falls simply because I didn't recognise how weak I had gotten.

I also lost basically all of the movement in my face, in that photo I'm smiling as much as possible. I could still communicate, though it lacked some of the sounds that required control of my lips.

I believe it was this progression all the way to the shorter nerves of my face that was the main reason for me being transferred to the ICU. The doctors wanted my vitals monitored to ensure my breathing and heart didn't deteriorate too far.

On a more humble note, at about the time I was moved to ICU it also became apparent my bowels were also affected, the problem being my body wasn't able to move things along. I was given a combination of some super fibre tablets and laxatives and even then these needed to be continually increased just to let me go once, or if I was lucky, twice a week.

I think back to all this and for some reasons, not completely known, I seemed to be able to take most of this in my stride. I think when you have enough people worrying about you, you focus more on reassuring them, so I think I was too distracted just trying to be my usual self to keep them sane. I think another relevant point is, while from the outside people might thing "oh dear, that's serious" when you're in a hospital, you realise just how serious things really can get and perhaps, on the whole, I had it fairly good.

But, again around the time I was moved to ICU, now nine days from the first signs of tingling that the news I really struggled with came. Due to my swallowing strength and swallowing reflexing being affected I was only allowed thickened liquids and mashed food. My only solace to this devastating news was watching a show called "Rick Steins India"- A gastronomical work of art.

I worked out, or convinced myself and to a degree the Speech Pathologist who decides how you can eat and drink, that I wasn't at risk of choking as long as I was paying full attention to what I was doing. I managed to get a concession on unthickened water provided I only took small sips. Furthermore, with all the time I had on my hands, I was also able to find out that while the hospital would only serve me mush they wouldn't prevent food being brought in for me. Naturally none of my family wanted to bring unsanctioned food in... no one that is except for an unnamed family member who has a lovely Penfold's Grange hidden away somewhere. That was the promise I gave for some very over-cooked and almost mushy, but not mush, rice and lentils...it was worth every spoonful.

Getting back to the IVIg, it was about 5 days after the first lot of IVIg finished that I started to show signs of returning movement and strength. I was moved out of ICU, but the excitement was short lived where after about 3 days I started to loose what movement and strength I had gained and continued to deteriorate further, so a second 5 day lot of IVIg was administered.

At my weakest, when in bed, the act of manipulating my arm across my body, to say reach the nurse buzzer, was a massive effort. Having too thick a blanket on top would tip the balance against me, on top of that then pressing the button on the buzzer, which I couldn't feel, required both hands.

To top it all off I also developed double vision where I wouldn't be able to see things beyond a certain distance, at my worst this was anything beyond about an arms length.

Each day I'd try to spend some time perched up in a chair, even if just for 45 minutes. It was important to get as much vertical time as I could to avoid fluid settling in the lungs. It sounds counter-intuitive but apparently our lungs work best at clearing stuff out when vertical.

Regular lung functions test were performed to measure what's called Vital Capacity. Vital Capacity is essentially measuring what is the maximum amount of air can you breathe out. For the most part I didn't ever feel uncomfortable with my breathing but my Vital Capacity did dip to about half of normal.

Rehab.

I finally, after 37 days in hospital, made it to Rehab....that is for 2 nights, then got transferred back to hospital for now my 3rd five day course of IVIg. A week later I was able to return to rehab.

To many peoples surprise, including myself, 12 days after returning to rehab I walked out of the hydro pool, holding the rails but non the less, walked out and in to my wheel-chair. This marked one of many happy rehab milestones.

But, yes another one, in the days following my strength start deteriorating yet again, and one week later I was back to hospital. That's when the diagnosis was changed from GBS to CIDP. Along with the change of diagnosis I was then booked in fortnightly IVIg for 70g of Immunoglobulin and also prescribed a medium daily does of Prednisolone, a common prescription anti-inflammatory.

I won't go into all the details of my time at rehab except to share a few of my current opinions. With something like GBS or CIDP where the nature and duration of recovery seems quite variable, the information we got suggested Public over Private, and I understand this choice needs to be done from the start. An example of why was private rehab and private insurers like these 1 or 2 week packages, where after the package period finishes you're then footing most of the bill as an out-patient. I guess where possible, try and do your homework. As a guide, I required around 6 weeks all up of rehab at the Royal Talbot Rehab in Kew.

Speaking of the Royal Talbot, it's a great facility with many types of therapies available, such as
- Physiotherapy
- Hydrotherapy
- Occupational Therapy
- Speech Therapy - so even though I was able to talk, I had a few session just to identify and improve on, some of the areas that were lagging
- and gym

On top of this there were optional "wellbeing" type sessions available. Two I participated in were,
- art therapy
- and music therapy, where I got some guitar lessons - great for getting my IT fingers back. On the topic of my IT fingers, our ward also had a computer with the internet and I'd spend about 15 minutes most days doing a free online touch typing course. The metrics this provided was also a good contributing indicator to if I was starting to deteriorate again.

Finally about the Royal Talbot, the therapist, nurses and the rest of the staff are amazing people.

Challenges/Frustrations

Loss of independence is an obvious one. I found it challenging being so dependent on everyone, I think one thing it definitely taught me was to communicate better.

"Am I getting better or worse...or no where?!?" During that first week in hospital I had no idea if I was getting better or worse. There were Neuro observations where I would squeeze hands or try moving a limb but these were very coarse and naturally subjective forms of measurement. I learnt to be very conscious of the little things I could no longer do as well or at all, but inversely I'd always be trying new things, like could I bring a spoon up to my mouth, press the trigger on my can of deodorant, etc.

Secondary risks. There were the usual problems with being bed ridden: bed sores, DVT/clots, ankle drop; but these are well managed by the hospitals through: pressure stockings, daily anti-clotting injection, body checks and rolling you onto alternating sides, etc.

There were two though where I felt I really needed to be on top it. The first one being falls. Only I really knew how strong or weak I was and given it turned out to be a continually fluctuating thing, I learnt to speak up if at any point I didn't feel like I was able to do something I may have done, say with a nurse, the day before.

The other big risk item for me was choking during those really weak stages, it was easy for something to go down the wrong way, and my ability to cough well was reduced. On top of that if I did get myself into a situation my ability to call for a nurse due to my limited strength and co-ordination only added to the risk.

My last one is on something I call "Imposter Feelings". My first experience of this was the very first time I headed to the hospital. Nothing was broken or bleeding, it was simply my word that I was much weaker than usual. Likewise when I was moved to ICU, sure I was bed ridden but at a guess I'd say half the other beds were being used by people that either had a machine breathing for them, feeding them, or both.

Then in my final days at rehab, I was allowed to walk around the ward without a walking frame. Basically, if you're not dressed in staff clothes and you're walking around, you must be a visitor and on a couple occasions a nurse would stare at me a bit and then smile and say "oh Neil it's you". Knowing the effort my wife went to ensure I had the best chance of getting in to the Royal Talbot and the thrill I had after finding out it was my turn on the waiting list all those weeks back I really felt like I was now preventing someone else from having their turn.

Now

The fortnightly IVIg was gradually decreased in dosage and frequency where at around May this year, when I was getting 35g of immunoglobulin every 6 weeks, my Neuro and I decided to stop it. I caught up with the Neuro about 12 weeks afterwards where I was informed any traces of the last IVIG would be out of my system and given I hadn't had any signs of symptoms for over a year, the CIDP was effectively in remission.

I'm back to playing soccer most weeks like I used to and try and get a couple or so swims in each month. I'd love to do a lot more exercise but family commitments and working full time has meant it's again a juggling act.

As for any residual problems I can only call out some minor ones. I can at times have moments of physical fatigue, sometimes lasting a day but a lie down for even 15 minutes can get me back on my feet. As I work at a desk this hasn't been so much a problem during my work week.

I get tingling quite easily if there's pressure on the wrong spot, for example the way I sit or rest my arms can bring on tingling but adjusting myself will have it go away within a minute or two.

One somewhat funny one I've become aware is if I carry a mug back to my desk and I'm not paying attention I find I can start pouring it on myself as my hand unconsciously rotates as I walk. Now that I'm aware of it I just glance down ever few seconds to see if my wrist is drifting. For the moment I've put this down to zipping around the office much more confidently than I have in the past.

Acknowledgements

That's the end of what I've got for today but it really is a massive abbreviation of my memories of the past two years, especially those first 3 months.

I feel it only right to at least make a quick mention of all the many people who helped along the way

All my family - the many clothes drop-offs, massages, and sorting so much out, oh and the glass of Grange waiting for me at some point in the future.

My friends, work mates and employer REA Group for their visits, support and understanding.

My thanks to Scott Earl who visited me while I was in hospital and numerous people in the IN Group who played a big part in keeping my wife sane.

All the numerous medical professionals.

And finally, all the unnamed blood donors.

If it wasn't for all those people, I may not have been able to stand up here in front of you. Thank you.

Editor's Note: Over recent years our membership has reduced following the passing of our founder James Gerrand and other older members.

It is with deep sorrow that we acknowledge the passing of our esteemed member and Secretary, Peter McInnes and our thoughts are with Gwen and the family.

OUR THANKS TO THOSE WHO HAVE PAID THEIR SUBSCRIPTION FOR THE 1917/18 YEAR.

REMINDER RE ANNUAL SUBSCRIPTION

Please forward this form along with your payment to:
The 'IN' Group, 26 Belmont Rd., GLEN WAVERLEY 3150
MEMBERSHIP DETAILS (please Print)

Name:	
Address:	
Suburb:	Subscription: $15
Postcode:	Donation:
Mobile:	Total:
email	Receipt: Yes/No
To receive your Newsletter by email sent an email to John@bal.net.au	

Alternatively you may wish to pay on line using the following information.

BSB / Account: **063142 / 10006285**
Account Name: **The IN Group**
Make sure you include Your Name in "Description/Reference". Thank you.

INFORMATION

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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