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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**

**THE NEXT MEETING WILL BE OUR ANNUAL GENERAL MEETING  
TO BE HELD ON SUNDAY, 18<sup>TH</sup> AUGUST, FROM 2-4PM  
AT THE ASHBURTON LIBRARY,  
154 HIGH STREET, ASHBURTON. ALL WELCOME.  
Guest Speakers will talk about sight health and hearing.  
A small plate to share would be appreciated. Thank you.**

### **Dates to Remember**

Sunday, December 8th      Annual Christmas Luncheon & Dutch Auction      12 noon to 4pm

**Queen's Birthday Honours.** Congratulations to our Patron Assoc. Prof. Richard Stark who received an AM for significant service to neurological medicine.

### **Notes from Meeting Held Sunday, 23<sup>rd</sup> June, 2019**

Our President, Margaret Lawrence, opened the meeting.

Apologies: Margaret Wilson, Val Blakey and Doug Lawrence my husband. He has had a knee replacement and came home yesterday. The knee is good, the operation went well, but the medication was hopeless. He was not good at all and not only did it make him spaced out, but it affected his kidneys and his sugar levels. They were taking tests all the time. He has had a bit of an ordinary time so that's why he's not here but as far as the leg goes, it is going really well. This is his little financial report.

The financial figures for the quarter ending the 31<sup>st</sup> of March are:

<u>Receipts:</u>	Donations:	\$1,035	Subscriptions	\$30
<u>Expenses:</u>	Newsletter	\$191	Postage	\$100

Equity stands at \$9,458 so we are looking good as far as our donation goes this Christmas.

Just to let you know, at the next meeting the speakers are going to be from my local Specsavers. They are not going to come representing Specsavers, because it just so happened I was speaking to the Manager and he told me he had been working on the phones for the Children's Hospital. I said, "that was good of him" and he said "No I do things like that all the time". Then I told him about The 'IN' Group and he said "Would you like someone to come and speak on the eyes, because **the eyes have a lot of bearing on your health and your hearing.** So, there is a lady coming to speak on hearing and I think a man to speak on the eyes and he is going to come as well, but it is not a sell from Specsavers it's what they do to help the community. I thought that could be quite interesting for everyone.

**John Burke is going to give you a run down on something we are going to send into the Government. We will finalize our submission at our next Committee Meeting. So, I'll hand over to John who will give you an idea on what is happening.**

**John: There is a government advisory committee that most of us were quite happy not knowing about. It is The Medical Services Advisory Committee. Never heard of it have you? They are conducting a study and economic evaluation into the use of IVIg in CIDP. We are going to make a short submission into this Advisory Committee on behalf of members. It is also open to members to make their own submissions as well. As Margaret said, it is open for public comment until October. I have sent the information around to the email mailing list along with details to make submissions.**

The full details of the background to the economic evaluation is on the web. It is rather hard reading. I have sent out a three or four page summary with the email and that is pinned to the front of this document. I will leave it on the afternoon tea table for those who want to have a look at it. If anyone has any questions on it (not that I know a great deal about it) I'll answer questions.

**The focus of our submission is basically we will push the point that we don't believe it should be an economic decision. We believe it should be a clinical decision on the use of IVIg.** We still have to hone in on the actual wording of our submission. One of the points is my own experience and whether we actually go with that will be up to the Committee. I put forward where, on the advice of my Doctor, we tried plasmapheresis instead of 'Intragam'. It didn't work. It put me flat on my back in hospital for three weeks with massive doses of 'Intragam'. That can be costly. It took me twelve months to physically get back to where I was before I went off the 'Intragam'. That had effects on me, my family life, my wife and my kids. How do you cost that? That is the question I propose we actually ask the Advisory Committee. You can't really put a cost on it but it is something that has to be taken into account.

If anyone wants to speed read this they can. It is all on the web. Submissions to: [hta@health.gov.au](mailto:hta@health.gov.au)

Margaret: At our next committee meeting in July we will refine our reply.

We have Scott Earle here to speak to us and we also welcome Ann-Maree and his parents Mick and Marg.

### **Talk by Scott Earle.**

This is the second time I have been able to come down and share your afternoon. Just a show of hands if anyone was at the first time at the Balwyn Library.

What I wanted today is not just me talking but a collaborative chat where you are free to ask me any questions about my experience as I step you through what happened to me in 2011. Each case is very different. Is there anyone in the room who did have GBS? A couple. What about CIDP? A few more. Whilst significantly different there are still a lot of similarities between the two. I can only speak on behalf of GBS sufferers and what my experience was, so anything that worked for me through my journey was specific to GBS, but again being quite related, a lot of this will make sense to those CIDP sufferers as well.

It was 2011 and I was 36 years old. At that time, I was pretty fit and healthy and taking on a lot of challenges of life. I was trying to renovate a house and had just five months before that become a father. I also had a business. I took on a lot of different stresses all at once. At the age of 36 I was trying to juggle probably too many things.

**What presented to me was initially flu like symptoms. I felt like I had a fairly severe flu. I was put into bed and laid up in bed for a couple of days, went to the Doctor and the very first time I went to the Doctor he said "Look, you have got a bit of a virus. Go home and go to bed. You will be fine." Two days later, so four days into what was the flu, I was a lot weaker and I still wasn't getting any better so I went back again. I saw the same doctor and I was a little bit weaker. I was starting to lose a little bit of stability and he said "I think it is probably a flu. Go home." Twice I presented with flu like symptoms. Twice I was sent home.**

It was only on the third occasion, I myself felt it was more serious. I had driven there, but as I walked in I stumbled and fell at the front door of the doctors. A lady had seen this happen and walked me inside. At that time, we knew it was more serious. It was a Saturday morning. It was the 14<sup>th</sup> of May, 2011. Mum came down and picked me up and took me straight to Cabrini Hospital. We just figured that having a couple of diagnosis that weren't giving us much information and the fact I wasn't getting any better, it may be something that needed to be taken more seriously.

Thankfully, that morning **at about 8.30am when I went into Emergency, there was a doctor on named Jack Wodack. Jack was a neurologist at Cabrini and he sat me down and did a couple of simple tests and within 5 minutes had me diagnosed. Thankfully, having a lot of background with GBS, he sat down with mum and me and said "There is some good news and some bad news." You have a neurological syndrome which can be quite severe and you are going to be here in hospital with us anywhere between 3 and 18 months. Now at that time I thought I just had a flu. It was a bit of a shock. He went on to say "You have Guillain-Barre` Syndrome" which he wrote on a piece of paper for us. Mum and I picked up our phone and typed it into Google and pretty quickly realized it could be quite severe.**

It's Saturday morning. You have just been told you are going to be in hospital for months. They sent me straight to the Ward **and over the course of the next two to four weeks I regressed very slowly.** It wasn't a quick drop off. It was sort of a very slow gradual thing where my body just started to lose function to the point where in a week or two they had to use a lifting machine to get me out of bed. Dad would come in and bathe me and help me getting in and out of bed and it was a very gradual period where I was getting worse. During that time, I was having **courses of IVIg but not getting any improvement.** I would be stabilizing and then drop off and then stabilizing. When I had been in hospital for about four weeks, had dropped a significant amount of weight, was losing function in my arms and legs, had numb feet and numb toes, we still felt I might have been in the clear. Mum had checked a couple of rehab hospitals and I felt that I had gone through the worst of it. Obviously at that period **they were very quick to keep an eye on everything that was going on with my breathing and my lungs. The key was to hope that the GBS wouldn't affect the nerves around my heart and my lungs and that I could stay out of being incubated and having to go into ICU.**

We sort of had a bit of good news and Mum and Dad were checking out rehab hospitals and we knew where I was going to go. We were just waiting until a bed became available. At the same time, every hour or two, **I was doing tests checking that my lungs were okay.** It was a Sunday night, Dad was there and all of a sudden, I was blowing into this particular machine and if my normal reading had been 30, this was 5. I tried again **and if my normal reading was 30, it was 6.** We called the nurse. The nurse called ICU (Intensive Care Unit) and **within 10 minutes I was in ICU with breathing tubes down my throat** and then that's when things went from bad to worse. Unfortunately, it had got to a point where it affected my lungs and my breathing. **The decision was made to put me in ICU for more appropriate care and they also made the decision to place me into an induced coma. They felt they needed me to do that to give my body the chance to respond. Then they took the next step of putting me on the incubator, on life support and giving me a Tracheostomy.**

For anybody who has an understanding of GBS that is as severe as it gets. For the period of five days after that I was in an induced coma on life support. Of course, I don't have any memory of that and I woke up and I still remember waking up in absolute shock. The only memory I had previous to that was being wheeled out of the Ward on the Sunday with Dad down into ICU and then no memory of the next week.

I woke up almost completely paralysed to the point where obviously with breathing tubes in my throat I was unable to communicate. Can't talk and that was when it really hit home about the severity of my battle with GBS, where unfortunately it had got to the point where I had a very severe case.

**For the next 33 days I was in ICU on life support** and through that period my body had shut down completely to where I was **completely paralysed.** It got to the point also where the muscles in my eyes weren't able to blink to be able to lubricate my eyeballs, so they had to stitch my eye shut. **At the very worst of it I had dropped 25 kilos, was completely paralysed, one eye stitched shut, life support, compression stockings, lying in ICU and the only thing I could do was I still had my hearing. I could still listen to everything that was going on around me and became super aware of what was happening.** Naturally when all your other senses are taken away that is the one that becomes more heightened and I sat there listening to all the prognosis from the physios, from all the doctors and understood the enormity of where I was at. **That was almost rock bottom.**

This is probably the hardest part for Mum and Dad to hear more than anyone else, but there was a stage where one particular evening **the doctors had called Dad, I think, and said, "Scott is having problems with his heart."** The muscles around my heart had been affected and my heart had failed once and they had to bring me back when all the alarms went off in ICU. I believe they said to Dad that over the course of the next half of an hour to an hour it had happened 5 or 6 times. That was the direst position to be in. Mum and Dad jumped into the car and went to Cabrini not knowing what they were going to be faced with as just before they left I was in a severe state and being revived every five minutes or so. I believe the story goes, as recalled by nurses, the very end was the sixth or seventh time they started my heart they had their eyes on the clock and once it got to the 30 second stage that was a celebration and when it got to a minute they were sitting there waiting for it to fail again, then it was two minutes then 3 minutes and here I am today.

That was the worst of it more so for Mum and Dad than me. I had no idea what was happening at that point, then gradually things started to improve. They were weaning me off the life support and rather than the machine doing all the breathing, I began starting to build some strength in my lungs and I started to get better. I regained some feeling in this hand and I remember the physio came in and said, **"All we want you to concentrate on for the next few days is to touch your first finger to your thumb."** (Audience member: Were you still having IVIg? Scott: Yes. I had 17 courses altogether. They would usually give me them in lots of 5 and after the third block of 5 there didn't seem to be much improvement so then I had another two and then they gave me a course of plasmapheresis as well. I don't know if that helped or not. It was after that I started to see some improvement. That's another story. I'll tell it now.

The machine they needed to use was at another hospital and they had to get the machine sent over and they didn't have an ambulance available so they sent a taxi to pick up the machine. The machine got picked up and they brought it back and said, "Well alright, we will have a go at this," but it had the wrong filter. They had to send the taxi back to get the right filter. Then they were putting it all together and they broke the filter and so they had to send the taxi back for another filter. It was a comedy of errors but two days later I had the treatment after a taxi running back and forward to the Austin Hospital to get filters so I could get my treatment.

**The physiotherapist had asked me to touch my first finger to my thumb. That took me 3 days. It was just a matter of gradually, very slowly, being able to bend the finger to touch the thumb. Once I had done that finger I turned to him and said, "Look what I've got to!" He said "Great. Now do the next one." The enormity of just doing that, (showed his finger touching his thumb) had taken all my power and my will. Then I had to turn around and focus to do the next one but it only took 2 days. The next finger, 1 day and gradually I started to improve. After 33 days with most of it, but not all of it, being completely paralysed and gradually getting some strength back, we got the news I would be coming off the ventilator. I was looking forward to that because it was hard not to talk for 33 days and I had some questions I needed answered. I had a lot of, I don't think anger, but I just wanted to communicate again. After 33 days the tracky was removed and Dad was there and I think my first words were "It's good to be back." Then I didn't shut up for 3 days.**

**ICU, that period where you get the most incredible care anyone could ever ask for, 24/7 care, is the reason I am standing here today.** It is because of the wonderful nurses and doctors at Cabrini who give you that critical care at that time. From there it was another week or so on the Ward in Cabrini trying to get some feeling back. One of the most frustrating for me and I know for Mum was sitting in North Ward, on a Sunday afternoon. The doctor had walked in and I hadn't seen her very often and at that time **I had been in hospital for 8 weeks and seen lots of doctors, nurses and physios and the amount of people who come through, but this young doctor stood at the bottom of my bed and said, "Don't worry Scott. Paraplegics can still have a good life."** Yes, those were her words. Paraplegics can still have a good life. Now at that stage I couldn't feel my legs. I had no feeling whatsoever. I couldn't move a muscle. I had some feeling in my arms and obviously I had come through a pretty severe period, but to hear that and look at my Mum whose face had gone white, the way it was delivered I suspect maybe she hadn't been told not to deliver the information to me, but she didn't do it in the right manner. Right away I thought, **NO! IT IS NOT GOING TO BE ME!!** I didn't believe it. I didn't consider it, no matter what the doctor said. I was going to get better. **This finger is getting better. There is a little bit of feeling here. It will happen.**

**At 10 weeks** maybe a bit longer, **I got a bed at Caulfield Rehab.** Now Caulfield was the old soldier's hospital, been around since way back when. The reason we chose it was that the Government had just put a whole lot of money into it for new facilities. **The physiotherapy facilities with the swimming pool were first class.** The Ward itself was very old and run down. The food was terrible. You were sharing with three other people, but as

a family we decided it was more important I had the care that I needed. I was in the best place to give me the recovery and I could deal with a crappy Ward and everything else.

**Once I got to Caulfield that is where the hard work began.** Up to that point I had been surrounded by doctors and nurses and specialists and high touch care but in rehab that care is scaled back and the emphasis is on you trying to get back to learning things. There was **a lot of speech pathology, physiotherapy, hydrotherapy and every day was like being at school.** You would have 4 or 5 classes and at that stage I would have Mum and Dad and my daughter coming in and I would go off to a physio class and then come back and then be whisked off to another class. That was again a time where there was a very gradual improvement. **That period was also a time where I really had a lot of pain, which was nerve pain, around the legs.** Just a simple task of them trying to lift me in and out of bed was something I never would look forward to because of the pain. No amount of Morphine or painkillers, or Endone or Oxycontin could change that. **It was just part of every day. The pain getting in and out of bed.**

**All up it was three months, but I never lost focus. I never believed I wouldn't walk out of there one day.** For the first 3 maybe 4 weeks there was still no movement in my legs. I still couldn't wriggle my toes. I couldn't move anything below my hips, but I never thought I would not be able to walk out of there. Then one day, in a room not dissimilar to this, **my physiotherapist put me on a bike,** strapped my toes into a motorised bike and she said, **"We are going to program 500 metres and I want you to concentrate on trying to push the pedals."** As soon as she pushed the button I remember sitting there in the wheelchair and my legs are moving as obviously they have been strapped into the pedals and I was trying to use them to pedal. At the end of the 500 metres my feet had stopped and she brought up a reading on the screen and **the readout said that of the 500 metres I had contributed 17 metres. My entire being and focus was going into trying to push these pedals and that was enough for me. 17 metres. They work. There is something going on there.**

The very next day I said **"Get me back on that bike. I want to try that again."** The next day I contributed **25 metres.** Then gradually that was my measurement that **I felt my legs were working and the muscles were coming back.** I still couldn't move them. I still couldn't feel them or wriggle my toes. That was **all I needed to give me the hope that they were going to come back.**

Throughout that time, it became clear that there were hundreds of nurses, specialists, visitors, family and friends, the support network of literally hundreds of people day in and day out who come to care for you, visiting you, sending good wishes in cards, visiting Mum and Dad and family was a ginormous effort, just to keep me putting one foot in front of the other each day.

**Gradually, throughout rehab, I was putting on weight and Dad being a handyman decided it would be a good idea to make some hand weights. I had these little strap-on weights that I put on my hands and while in bed I would sit up and move my hands and keep the muscles active. The other thing was I had a problem in my fingers. Dad walked in one day with a couple of sheets of ply board and some bands and he stuck my hands in. I was sitting there in bed with my hands on these two bits of ply board as he made up a little contraption to make my fingers straight again.**

**Rehab. was a tough time.** All through that time the thing that kept me going was the **positive mindset,** my daughter coming in everyday with my Mum and Dad, my sister and a lot of family support. At this time my daughter was 7 or 8 months old. Thankfully, she will never remember that period. Gradually we got into **pulling myself up and using my upper body to get onto the parallel bars** and I started to get movement in my feet. Like with my hands when I was in Cabrini, I started with just wriggling one toe, then my foot and **gradually the nerves had regrown** and the feeling had come back into my legs. Those rehab sessions, which were also the hydrotherapy sessions, were literally stepping stones to getting onto the bars, then gradually onto the crutches. **Four months after setting foot into Caulfield I walked out. When I say walked, I was on crutches. It was a very slow walk but I walked out as I had envisioned I was going to, which was something to me that was never in doubt.**

**Once I was out of rehab. then it was literally still years to improve.** I went back to living with Mum and Dad for the next couple of months, getting my strength and still going to rehab. 3 times a week as an outpatient. **Right through that period I still had the positive mindset; making sure I showed up every day to do my session and I guess not giving in.** Beyond being out of hospital for 12 to 18 months I continued to try to improve through different therapies. **I tried all sorts of different therapies to try to increase the feeling in my feet, my mobility and general wellbeing. I did reflexology, chiropractors, saw some personal trainers trying to gain more strength; Chinese herbalists, Chinese medicine – I tried everything. I have landed at**

**a position now where 8 or 9 years down the track where I have a good understanding of what has got me back to where I am today, where I have very little residual issues.** I have some numbness of the feet now and then. It tends to be a little more during Winter than any other time of the year so now it is starting to kick in again, but otherwise **I would say I have recovered 98-99%.**

**I look back and remember where I have come from to where I am today. Was I lucky? Maybe. Was it a hell of a lot of hard work, not only by me but obviously my family and friends, doctors, nurses, specialists, support groups such as this. the GBS Charities? There is a Guillain Barre Syndrome Foundation of Australia based in Sydney, ([www.guillainbarresyndrome.org](http://www.guillainbarresyndrome.org)) a fairly new charity which is also providing a lot of support. This is what has led me to be able to say I am a GBS Survivor.**

From the doctors at Cabrini saying “This is the worst case we have ever seen of anybody who has survived”, to coming out the other end and getting to this point, has been a bit of a journey.

Any questions?

Member: Do you take CQ10?

Scott: I have heard of it, but I don't.

Member: I have some residual effects. I also had GBS very similar, but not as severe.

Do you have problems with fatigue when walking and things of this kind?

Scott: No. Not as much now. **The fatigue I manage like I manage my day. I go to bed early. I try to get 10 hours of good sleep each night and that is the way I try to manage the fatigue.**

Probably in the early years of recovery I definitely did. Certainly, in the first one or two years fatigue was a big issue, but now it is something I am very mindful of and I know that if I have a few late nights or exercise a bit too much, I will get a few reminders and the reminders are my feet. As soon as I start getting nerve pain in my feet and I start getting that sensation, then that is a trigger that something is out of balance. Is it I am not sleeping enough? Am I not eating enough and I use that as a trigger. Now fatigue is not such a big thing.

Member: **Talking about rehab. and being focused did you have something that helped you at the start?**

Scott: **Yes, there were two things. I was reading a book. An old football coach of mine had given me a book by Chris McCormack who was an Iron Man who did the Hawaiian Iron Man and won it four times. Iron men are those crazy guys who go out and spend 10 hours doing a swim and a run and a bike ride in Hawaii in 40 degree temperatures and they defy what the body should do. They defy it through the power of the mind. By training and showing up every day and ticking the box. So, for me it was about everyday ticking the box. I would look at my schedule, today it is physio, today it is this and that and to get to the end of the day and tick the boxes and just tick the boxes on that one day. Don't worry about what is coming the next couple of days. I had a motto which was Win Every Day. To win was to be able to tick the boxes. There were days when I didn't want to, when I didn't want to get out of bed and do the rehab. Just by showing up and being there you get it done. It is amazing how those little gains, day on day on day actually can be huge gains down the track. Yes, it was breaking it down into maybe a half day box, but just ticking the box.**

Coming back to the book. Chris McCormack wasn't a blessed athlete. He wasn't the fittest guy, but he went on to win three World Championships just by having the mental focus and the mental strength. He believed that when he was 35 kilometres into the ride after the swim, when his body would start to scream at him and he felt he could not take anymore, was when **he would take himself to the next level and his mental state would get him there.** The analogy there is, he was choosing himself, pushing through pain barriers to make sure he could achieve what he wanted to achieve.

I was not there by choice, but I had a choice, if I wanted to give in or not. We all do every day. **But it was just that mindset to when you wake up to show up.**

Yes, this book made me a bit crazy. **When I was in hospital and the doctor said “Life was going to be okay as a paraplegic”, I think I turned to Mum or Dad and said, “I am going**

**to do a triathlon.** They did, of course, look at me and say, “Hey, one thing at a time.” Sitting there in bed and we don’t know what is going to happen, **but it was one of those things I committed to.** I think if you connect to something mentally, that’s half the battle. Once you have committed to it, you are going to show up.

Ann-Marie and I had a yoga session this morning. Just before we walked out, just near the end, Kelvin the teacher said, “It’s 5 degrees out there. Most people are still home in bed and you guys have just made the decision to come in and you have turned up. That’s half the battle. **Once you show up, great things can happen.**

**Just a little reminder. It doesn’t matter where you are in life or what you are going through, illness or recovery wise, by showing up it is half the fight.**

Member:  
Scott:

**A personal question. Your bowels? How did they go? Did you have a lot of trouble? It’s a great question. When I first got to rehab. because I had spent the best part of six weeks horizontal, one of the first things they were doing was they would strap me to a bed and with this particular machine, they would sit there with a button and the idea was to gradually get me to be vertical again because your bowel and your organs have been used to lying down for eight weeks. If you were to go straight up again, everything would just not work. The very first time in rehab was three days of being strapped to a bed and very gradually they would raise me up. Day one, I probably got to there (showed with hand the angle) and my bowels let loose. I told them and they said, “That’s normal.” On day two maybe I got up a little further and I had no control. Day three and sure enough day 4 and then on day 5 it just didn’t happen, so it took a few days for gravity to affect them from above rather than below.**

I had a catheter for the whole time basically, so that was a bit uncomfortable and then after that there was a daily drink. It was an issue with the medication and everything and even after rehab I had this daily drink.. I had it for months afterwards, to help my bowels, but once I got through that six months period, again adjusting my diet where I figured out what I should have been eating, it sorted itself out.

Member:  
Scott:

I had trouble putting pegs onto a board. I didn’t have the strength to do it. That was day one of my class. There was a piece of string and I was told there are pegs on the table. Just pop them up on the string. At this stage I had the left hand back so I was able to do it, but it took the right hand a while. I picked the peg up and there were no muscles through the shoulders or my back as they had wasted away. I just couldn’t do it with my right arm and hand. Again, that was another very gradual thing until I gained my strength.

Another Member: I still can’t do it.

Scott: Is it the pain that stops you?

Member: No. I just don’t have the muscle to do it.

Scott: My toes, when I lie in bed at night, my toes will drop. I had foot drop quite severely and for a while through rehab I wore UFO’s. They were part of everyday life for some time. Even in bed. Even now my toes will just gradually go down.

Being part of the GBS Foundation for the past few years there is no common story. Everyone has their own story. Everyone’s recovery is different. I feel lucky to have come out with a great recovery and others are not so lucky.

**Jade Parsons was the founder of the Guillain-Barre` Foundation Australia based in Sydney but it is a national charity. Jade and plenty of other people in Sydney give all their time to helping people out there raise a lot of money and there is also a lot of funding available for people who want to try different treatments or try different recovery methods. I put it to you all, anybody who wants to be put in touch with the Foundation and with Jade, all the money, every cent, from that charity goes back into helping families. I know Jade has paid mortgages for families that haven’t been able to make end meet. They have got people specialists, treatments, rehabs., hydrotherapy, anything that is within the confines that will help the recovery, they are really open to.**

**Please feel free to reach out to me or leave some details because I can certainly facilitate that with Jade. Even if there it is something, like your hands for example, a therapy that might work or something you haven't tried, that is where the Foundation can make it happen for you. Even a 2% or 5% improvement is going to help your quality of life. Please use the Foundation. If Jade was here now she would be spreading the same message. There is a big support network and more importantly funding to help. No request is too big or small. Her and the girls and a bunch of guys as well, they have raised significant amounts of money through a fundraiser they do every year and lots of corporate help as well. That is something to keep in mind.**

- Member:** At the moment I am working with a neuro-physio and he gives me a tough exercise program and I know that CIDP's motto is Slow but Steady. I just wondered if anyone has had experience with how much exercise you can do or how to tell when to take the pressure off.
- Scott:** I think fatigue is such a personal thing. Only you would know, on a given day, what your energy levels are as if you had done a session the day or two before, that may have impacted you and made you tired in certain muscles. Because of the difference between GBS and CIDP, I certainly can't speak of the experience you are going through, but I know, from my experience, it was slow. Listen to your body.
- Member:** I would like to give an answer to that. I find that if I push myself past when I feel tired I am much worse. Stop as soon as you feel you have just about reached your limit. A lot of well meaning people say "Oh, but if you can keep going you will be better." I haven't found that and I have CIDP.
- Member:** I think the answer is you can't do yourself any harm, it is just a fatigue thing, and if you push yourself too hard you get fatigue, so it is not an advantage. **If you work yourself too hard you will get fatigue which is not going to do yourself any good. You have to work it out for yourself where that fatigue level kicks in. (CIDP)**
- Member:** Sometimes fatigue, especially with GBS, comes along for no reason at all. It is not exercise related.

**Neil:** I would like to thank you for giving up part of your Sunday to come share with us your story but also the work you do ongoing. I know you do hospital visits. I was a recipient of them. As a sign of our appreciation please accept this small gift. Applause.

- Member:** Just one last question. You said you slept for 10 hours. Do you still do that?
- Scott:** Yes. Last night 12. I don't sleep for all that time but it just rests your body. I am still trying things. Yesterday I did an intermittent fast. My last meal yesterday was at 3pm and I didn't eat today until 11.30am. There is research into intermittent fasting and how that can give your immune system a boost. There are lots of things you can be trying apart from rehab and physiology to help the immune system and the body recover. I am a huge advocate of Yoga. Yoga is great for your central nervous system in terms of calming your central nervous system and trying that as an exercise form. Hydrotherapy. Any exercise in water not having the body weight to have to contend with. Diet is a big one. Through Winter I will make up a big batch of chicken bone broth. The health benefits of bone broth and every day have a cup of bone broth every morning before I start my day to try and keep myself healthy. The rest is mental wellbeing. You can never have too many holidays. You can never have too much time with your loved ones.

- Member:** We have just come back from Spain and I had IVIg over there in a hospital which was pretty amazing, so you can organise things abroad if you really want to.
- Scott:** You only get one crack at life. Some of us have been dealt a hand that we would prefer not to have got but it doesn't mean you have to stop doing anything. It certainly might restrict you, you might need to amend your plans, you might have to do more creative ways of enjoying the country getaway somewhere in the sun, but you have to continue doing things.

**Disclaimer:** Information presented in "INformation" the Newsletter of the Inflammatory Neuropathy Support Group of Victoria Inc., is intended for information only and should not be considered as advising or diagnosing or treatment of Guillain-Barre` Syndrome, CIDP or any other medical condition. Views expressed in articles are those of the authors and do not necessarily reflect the opinions or Policy of The IN Group




**ANNUAL SUBSCRIPTION DUE 1<sup>ST</sup> JULY, 2019.**

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 <a href="mailto:John@bal.net.au">John@bal.net.au</a>			

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

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

## 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)

Newsletter Postal Address: 44 Mavis Ave., Beaconsfield, 3807. Telephone: 9707 3278

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**INFORMATION**

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ANNUAL GENERAL MEETING  
The Inflammatory Neuropathy Support Group of Victoria, Incorporated  
To be held at the Ashburton Library Meeting Room, High Street, Ashburton, at 2pm on  
18/8/2019.

Agenda

1. Confirmation of Minutes of 2018 AGM.
2. Reports from President and Treasurer
3. Election of Officers and Members of Committee.
4. Any special business of which 21 days notice has been given.

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Positions to be filled are: President, Vice-President, Secretary, Treasurer,  
Public Officer, Membership/Newsletter Co-ordinator, General Committee Member/s

**Nomination form for Committee**

Nominee: ..... Nominated by: .....

Seconded by: ..... Accepted by: .....

Date: .....

To be returned to: The Secretary,  
The IN Group, 26 Belmont Rd., GLEN WAVERLEY 3150 by 11<sup>th</sup> August, 2015.

Signature of Nominee: ..... Date: .....

**Please be advised that 21 days notice has to be given on any matter to be raised at the Annual General Meeting.**