

INFORMATION

STICK WITH IT SLOW BUT SURE

NEWSLETTER OF THE IN GROUP: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC.
Supporting sufferers from acute Guillain-Barre Syndrome(GBS) & Chronic Inflammatory Demyelinating Polyneuropathy(CIDP)
26 Belmont Road, Glen Waverley, 3150. Victoria, Australia. www.ingroup.org.au email: info@ingroup.org.au.

**NEXT MEETING - SUNDAY, 19TH MAY, 2013
AT THE BALWYN LIBRARY MEETING ROOM
WHITEHORSE ROAD, BALWYN AT 1.30 PM**

**GUEST SPEAKER – LINA CAPOVILLA
CLINICAL NUTRITIONIST**

A small plate for afternoon tea would be appreciated.

Notes from the February meeting.

Margaret. Welcome everyone. It is great to see so many here today. Unfortunately Lina Capovilla who was to be a speaker today had to go to a Study Course. Dates made early in one year, can unfortunately clash with commitments in the New Year.

Apologies: Barbara and Tom Rivett. Assoc. Prof. Andrew Kornberg (who also had to be in Sydney at a Conference today where he is speaking) apologised but said “**I am happy to come to your High Tea on June 30th.**” I have replied to him and have said “Thank you.” We look forward to seeing him as it is very good of him to give up his Sunday.

For new members; **Andrew** is one of our **Patrons** and **is doing research into Guillain-Barre` Syndrome and Chronic Inflammatory Demyelinating Peripheral Neuropathy** and he has a researcher working with him and the money **we raise helps to fund this research.**

Treasurer’s Report.

For the quarter ending 31st December, we have received donations of \$1025 and \$435 in memberships. Outgoing of \$114 for the newsletter and we have booked the library for the next 6 months \$144. Our bank balance is now \$10,569. We have not given a donation at this stage but we will have a minimum of \$8000 and perhaps more depending on what flows in before then. We raised net \$1052 from our Christmas Luncheon.

Margaret: Now I would like to welcome our new members today. We will go around the group and each one can introduce themselves.

Doug. I have neither GBS nor CIDP and I’m the **Treasurer.** **Margaret-** perhaps we will say that we are in the group because a very great friend of ours had CIDP and she lived in the country. She heard about our founder, the late **James Gerrand** starting the group and she said, “How about coming to the meeting” and so I went to the meetings, ended up on the Committee and she said to me “Oh, you’ll probably take over and I said, Absolutely Not. Vilma passed away 8 years ago from complications from something else she had and I can

hear her saying “I told you so”. Her husband comes to stay every Christmas. He tries to come to the mid year function but he comes to the Christmas Luncheon/Dutch Auction and is the auctioneer.

Peter Mc. As far as I know the only couple involved in this group who are not directly affected by either GBS or CIDP are Margaret and Doug.

John. DR. I have had **CIDP** for 10 years. I started staggering around and nearly falling over. I am in my early 80’s now but it took over 2 years to find what was wrong with me. I was at the Peter James Centre for about a year where I did therapy walking over little steps and all those things, but none made any difference until eventually someone thought to send me to a neurologist. As soon the neurologist saw me walking in he said “You have CIDP” and I said, “What’s that?” He booked me into St. Vincent’s Private on ‘**Intragam**’ and I’ve been having 6 bottles every 4 weeks for the last 7 years and I think it has held it at a certain stage. I don’t think I’m getting any better and I don’t think I’m getting any worse. From what I can tell it can take some time to get a diagnosis as some doctors don’t know about it.

I have a cousin and his son is a doctor and his daughter (some of you know very well) **Anna**, got **CIDP** when she was 12 and she’s now about 20 and is involved with the Melbourne Symphony Orchestra and has played at concerts to raise money for CIDP and GBS.

My name is **Mary** and my troubles started more than 30 years ago and telling the doctor my problems and being told, “Well forget about that, have you got any other problems you want fixed?” That was the way it went until very recently. It didn’t have a name and perhaps they thought I was making it up, I don’t know. Various suggestions were made from friends and others and then a name was given to it as **Peripheral Neuropathy** and each time I go to a new practitioner I ask “Can you tell me more about it?” Now I’m happy to say I’ve had some extensive tests and maybe they will be able to give me something for it. I thought I’d write a story about my feet at one stage, but it hasn’t reached the end of the story yet.

I’m **Gwen** and I have been diagnosed for about 15 years now. I had a back problem which had the same symptoms so for 5 years we thought it was that, but eventually **CIDP** was diagnosed. **Richard Stark** is my neurologist and also our **Patron** and he has been very good. I have been on ‘**Intragam**’ for 13 or 14 years. I’m pretty good but I have a lot of other problems not related to it but I have a strong constitution. I have been in hospital for surgery 17 times in the last 60 years but each time I’ve been in hospital nobody seems to know anything about **CIDP** and you are a woman talking to a doctor and they don’t know about it. Now **I have a dossier** that I take everywhere I go **describing CIDP**, telling all the other funny things that go with it, like **restless leg syndrome – there is help for that – talk to your neurologist.**

Some years ago I was a guinea pig in the Alfred for Richard Stark with Industrial Doctors; qualified doctors working in industry who maybe didn’t know about neurological things like CIDP, but put the symptoms down to industrial accidents or fumes that you might breathe and affect your nerves or that you are diabetic or alcoholic. **Not one of the 30 doctors picked I had CIDP or even mentioned it.**

My name is **Peter Mc** and I am the **Secretary** of The IN Group and Gwen’s driver. That’s it.

I'm **Peter M.** and I'm a member of the **committee** and I have **CIDP** and have had it about 8 years. I get treated by Valerie Tay who I believe is one of the best neurologists around, as far as I'm concerned anyway. **I try not to let this complaint get me down.** I still go on trips and I do things and I still play the drums and even though I have to lacquer band the sticks to my hands, I won't let it beat me. Valerie says to me "Don't let it get you down as you are my most up beat patient". I go in **monthly** and I have stayed on an even path. **I had a nerve conduction test last month and I have more use in the nerves** but Valerie said you will not notice a difference and I don't.

I'm **Brian** and I'm on the **committee** too. I have had **CIDP** for probably 15 years and I thought it was arthritis, but the local doctor was switched on and he said to go to a **neurologist who picked it up immediately.** I was very lucky as many of the neurologists I've come across don't have a clue. My neurologist has retired and I now see Valerie Tay and she treats the whole body, not just the CIDP and she has found a lot of other things and CIDP is the least of my problems. Chronic arthritis is probably the worst. I go to St. Vincent's hospital **every 4 weeks** for '**Intragam**' and I specify '**Intragam**' as I don't want the other ones. My condition is no worse and no better.

John. I don't really qualify as I am just the driver for my dear wife.

I'm **Genevieve** and he is much more than a chauffer. It took quite a while to find out and then Dr. Gilligan (who has sadly died) had just begun my treatment. I then went to Dr. Stark and so I have been well looked after and I go to the **Alfred every 6 weeks** with my chauffer who waits around for hours. The worst part was trying to find out what you had. **It is nice to come here and hear the people with much the same thing, as all the friends are a bit doubtful that I'm making it up.**

I'm **Barbara** and I was diagnosed with **CIDP** 20 years ago this month. The first feeling I had was that my legs wouldn't cross the road. I was going down a slope and **it was the scariest thing ever.** When I saw my Rheumatologist, (I already had rheumatoid arthritis) he said, "I know you well enough to know you are not imagining it so I'll send you to a neurologist. I saw John King in the Epworth, who is now at the Royal Melbourne, and he put me into hospital. I had **a nerve biopsy** and they found I definitely had a problem and I went into the Royal Melbourne, had 5 days of '**Intragam**' and then came home and I have been on '**Prednisolone**' and '**Methotrexate**' tablets ever since because that copes with the rheumatoid and seems to have some affect on the CIDP. I'm having great difficulty getting around because I also have an artificial knee and hip and the rheumatoid is not getting better but I'm still here and I have had **a great deal of support from this group.** They are lovely.

My name is **Dorothy** and I had **GBS** 21 years ago. I am one of the original members of this group. I was overseas at the time and I got home and was too weak to open the door and I just collapsed in front of the garage and someone found me on the footpath and then I was taken to **Fairfield** which was **the most wonderful hospital.** I spent **2-1/2 months on life support** and 4-1/2 months in hospital. I came home really unable to do anything and I had a year of physiotherapy constantly and I'm still alive. That's about all.

My name is **Sonia** and in January **I got gastro and after that my feet started going numb and I had a lot of tingling in my legs with just weird sensations and numbing in my face. I went to the hospital and they said "We don't know, but you look fine to us and it's probably not MS".** It took a while to see a neurologist and he said that it's not too bad. I

couldn't remember the name of it so I went on the internet to Google it and I couldn't find any information and I read some of the really scary cases. I wanted to know more about it **and to find someone else to talk about** it as no-one really understands. They say there's nothing wrong with you. I've always had problems, but I just want to speak to someone who has this condition which is so rare. I haven't been formally diagnosed and **I have an MRI on Tuesday and hope to find out what's going on. The neurologist hasn't ruled out MS either.**

My name is **Margaret W** and I am the **Public Officer** for this group. 10 years ago my **Dad** (who is now 95) contracted **GBS**. He was complaining about not feeling very good, (the seat was hard, and things like that) when at my niece's wedding reception. We accused him of dancing too much with the bridesmaids, and I felt sorry afterwards when I found out what it was. As a family **we found it difficult to get a medical practitioner who knew what it was** about and through the auspices of another niece who is a radiographer, we got a referral very quickly to Owen, a neurologist at Cabrini. **As soon as dad came in, he said "You've got GBS" and we thought "how does he know this?" Dad was immediately put into hospital and he was there for a week.** He had residual weakness from his legs and from his elbows down, but his brain was great and his trunk, so he didn't have any breathing problems. He was in extensive rehab for 5-6 weeks. **We joined this group specifically for him to be able to talk to people who have similar conditions. We found it to be very, very helpful. When we have guest speakers, we have always found them very helpful. We have really appreciated what this group has done for him and us as a family.**

My name is **Barbara W.** and I'm very fortunate that I don't have the complaint. My husband does, and I come along as the afternoon teas are great. Chatting with people is great and it's a fantastic group, so that's why I'm here.

Len W. is my name and I'm a **committee** member. I was diagnosed about 7 years ago. I was a **distance professional runner** and **I ran in the "Gift" meetings** in the mile and 2 miles and in the 3,200 metres and in the winter in the **Cross Country and Marathons**. 8 years ago when I was training and it would get dark, I'd be running along a path and I'd go over this side and then over the other side, and I thought, hell, **I've got a brain tumour or something**. Also I was having odd attacks, every 3 or 4 months, with enormous pains, jabbing, and they reckoned I had gout because I enjoy a beer, so I was taking Zyloprim and then I saw a **doctor who put a tuning fork on my toe and I couldn't feel it**. He referred me to a Professor of Neurology (oh and when I was running my wife **Barbara** who is a runner too was actually beating me sometimes) who questioned me about my drinking. He told me I was drinking too much, so I gave it up for the 3 months until I saw him again and he took blood tests. Anyhow the tests came back and as he read them I could see his eyes going and he said **"You have an auto immune complaint that showed up in your blood. It is a fairly definitive way of saying you have it; it is either Motor Neurone, CIDP or a few other things. I had a nerve conduction test and that was pretty bad and so he put me into hospital and I had 'Intragam' and then Prednisolone after that and it stopped.**

I was feeling pretty good and I thought I was pretty right but **my nerve biopsy results came back and it was totally perforated as my immune system had destroyed the myelin sheath**. So that's how it was very **conclusive that I had CIDP**. I haven't had any treatment since then, but I see him every 6 months. I go up and down and have like **a terrible flu every so often** (I just got over it for a whole week) so I am maybe going to see another

Neurologist and pursue it. **I think I had it 4 years prior to being diagnosed, but being so fit it offset it a bit.**

I'm **John B.** and I have had **CIDP** for about 18 years now and I'm being treated at Monash every 4 weeks and have been for the past 14 years, but **the good news is over the last 2 years they have actually reduced the 'Intragam' I've been having and I haven't suffered any decline in performance. We are going to see how far we can push it by reducing the 'Intragam' slowly, over perhaps the next 12 months. There is a bit of light at the end of the tunnel, so I might be able to get off treatment. Good news eh?**

Margaret. John is also **Vice-President** and my offsider. Thank you.

I'm **Cheryl** and I'm just a chauffer.

I'm **Bruce** and I haven't been properly diagnosed yet. I see Dr. Valerie Tay and I saw her last year and before that I saw Dr. Hayden and he did a nerve test and he was totally puzzled so he referred me to Valerie and she did some blood tests and put me into hospital a couple of weeks ago for a week to have **'Intragam'** and I haven't noticed any change. **My problem is my balance. I was falling over and my hands were shaking.** Someone at work said "Why are your hands shaking?" I hadn't noticed it before; it could have been happening for years but it slowly got worse. I work as a gardener and walk as if I'm drunk. That's my story.

My name is **Kath** and I was diagnosed with **GBS** in August 2011. I was working at the time as a data operator and it was a Saturday morning and I was at work and I rang Rob at about 11 o'clock and said "You had better come and pick me up". I was bouncing off the walls. **I went to the kitchen to get a coffee and thought something's wrong** and on the Sunday I **couldn't get out of bed – my legs wouldn't work.** Rob took me to a local doctor who said it **might have been a mild stroke initially or GBS. Okay a mild stroke I understand, but GBS what's that?**

He sent me for a CT scan. Nothing showed up on the CT scan, nothing showed up on my heart test. They suggested I be referred to a neurologist. We live in the Western Suburbs so they referred me to a neurologist at the Footscray Hospital. I am still waiting for a call from them by the way. On the Monday, Rob rang our own GP and he said bring her in and **I could barely walk from the chairs in his surgery** and he said "**Just take her to St. Vincent's.**" I spent the day in there and at 11 o'clock that night, **one of their wonderful doctors,** after all the tests I'd had, **diagnosed it as GBS,** admitted me and the next day I was on **'Intragam'.** I had the 5 days and on the 6th day I said I wanted to go home. I still couldn't walk but I wanted to go home and they gave me a huge walking frame. I had home physio for a month then out-patients physio for 3 months and in October last year I had another course of **'Octigam'** this time. My doctor is also Valerie Tay, I found her through sending an email to Andrew Kornberg saying "Help Me!" and he was just wonderful. **I am on a plateau.** I told Valerie I don't want another course of the **ivig as it knocks me around** and I don't honestly feel any benefit from it.

I'm just trying to do as much as I can do. I can't work at the moment because I was a data entry operator and **I have issues with my hands.** I have started a **Facebook Page for GBS sufferers Guillain Barre Syndrome – Australia.** I managed to get an interview with our local paper last week, because I'm sure you are fully aware it is **Rare Diseases Day** at the end of this month so I rang and told them "**I have a rare disease**" and they came out and did

a story and I think that's being published this week which is great. I have also **written to our local MP to make him aware of rare diseases, so we can get some more awareness out in the public, because not enough people know about it.**

Hi, I'm **Rob** and I'm Kath's support group.

I am **Melva**, and I'm on the **committee**. I type the newsletters and support people who ring and so does Margaret. I also answer emails, as does Margaret and Doug. Because I send out the newsletters, I have the names of all the people so if somebody gets in touch with me from a certain place, I can put them in touch with the nearest member. I feel like I'm a conduit and that's my job and I'm here because **my husband Joe has CIDP.**

I'm **Joe** and I have had **CIDP** for about 25 years. Initially I took '**Imuran**' for about a year and then my neurologist Dr. Rollinson put me on '**Intragam**' every 3 months for 3 days in hospital. **After 9 years it seemed to stabilize** and so about 13 years ago I decided to stop having 'Intragam' and I found the sky didn't fall down. I have **gradually improved** and learned to live without it and I'm quite capable of doing things and things are looking good **without any treatment at all. So, there is hope. I think my myelin is slowly growing back.**

My name is **Russell** and about 2-1/2 years ago I became **very weak in my right leg** and I lost a significant amount of weight. **I had a couple of falls** and eventually I was referred to a neurologist at Epworth and we did a lot of tests looking for anything from a tumour to diabetes to whatever. **My leg and feet became quite numb and I suffered drop foot on both feet. Eventually he did a biopsy on the nerve and a muscle tissue biopsy and it came back and he diagnosed it as peripheral neuropathy. The underlying cause as a result of the biopsy was Vasculitis, which is a blood disorder and auto-immune disease** and I've been treated with **Prednisolone** and **Methotrexate**. With a lot of physio and hydrotherapy I seem to be quite good. I've chucked away the stick and the AFO on this foot and only have the one now. I'm feeling quite good and I've put on the weight again and it is going quite well.

My name is **Frank** and I'm a recovering **GBS**. This is my partner. For the last few months **she has been my angel** too. In August last year, I was working night shift and I had this horrible pain in the middle of my back which travelled down into my back. I thought "that's a bit strange" and I went home that day then back to work the next night and **my feet started to go completely numb and I started to walk around with big heavy steps**. So about 2am in the morning I rang the **Nurse on Line** and described the symptoms and she said, "**Go to hospital**". I guess they say that to everybody but **I did**. I went at 6am and I was admitted at the **Austin Emergency** and **I was in there a week. They did every test known to man and discharged me and told me that I had some sort of attack and they didn't know what it was.**

So I went home, heavily drugged, and about **a day later I started to lose vision in this eye**. Multiple vision; **I could see 6 of everything** and this one was getting a bit **foggy**. I had **tingling in my arms and by this stage I could hardly walk**. I tried to walk and smashed into the coffee table and so **off to the Austin I go again**. This time they put me in and drugged me up again and finally did **a lumbar puncture** to test the spinal fluid and **diagnosed GBS.**

I had '**Intragam**' the 5 lots and **by this time I couldn't move**, I was wheelchair bound, so over to the **Royal Talbot Rehab** where I spent 5 weeks. **Fantastic place**. Really, really, loved it. They were good to me with **a lot of physio, a lot of gym work, a lot of pool work** which I have been doing every since. So at present I've thrown away the wheelchair, I've thrown away the walker, I've thrown away the crutches, I've thrown away the sticks and **I can walk okay now**. I still drag this foot and I've still got the **foot pains**. You all know what it's like – **the pins and needles** and it kills me. I'm on the **maximum dose of 'Lyrica'** that you can have which seems to knock about 40% of the pain. I'm back at work part time and I fully intend to get back to what I was doing before this happened. That's my story.

By the way, my daughter is a chronic internet researcher and when we were told I had GBS she was into it. She started in America and worked her way all the way back to **John B.** who **came to see me at the Royal Talbot. She got onto Graeme Wright who played for Collingwood, he had GBS, and he came out to Royal Talbot and saw me and between what John and Graeme told me, was what I wanted to hear;** the truth about the outlook, which no-one had told me. **That was great to hear and I'm really glad that we hooked onto you guys.** That's it.

I'm **Costas**. I have **CIDP** and I probably had it more than 3 years before I was diagnosed. I used to complain about **tingling in my hands and tiredness** but I convinced myself it was carpal tunnel. It wasn't and then I had all the tests and now I have '**Intragam**' every 2 weeks. I tried to go 3 weeks but now I'm back on two weeks. We are all different.

I'm **Pat**, Geoff's wife and his case manager. I do all the paperwork, the appointments and everything. He's been in hospital for small **procedures which are CIDP related**, but what I'd like to say is that **on the hospital admission form in red pen** (you should see the form when I'm finished with it) **I write HAS CIDP and I spell out what CIDP stands for and also with an asteric CANNOT STAND UP UNSUPPORTED, NEEDS SEAT IN SHOWER and by the time he goes to hospital they are well informed on what CIDP is.**

Geoff. I suppose it took 3-4 years. I play a bit of sport and I had **pain in the shoulders and I had a series of falls**. The crunch was, I had just put down the perfect bowl and **then fell flat on my face**. Enough was enough. I went back to my man who put in my knees as I thought it may be these starting to wear as they were 15 years old. He sent me for x-rays. He patted himself on the back as they were as good as the day he put them in. He said "I think you had better go **see a neurologist**". I saw Richard Stark, then went into the Alfred and had the 5 day course of '**Intragam**' with monthly ivig but I'd run out of puff so now I go **three weekly**. It is 18 months now since I was diagnosed. **I do have fatigue** and I just nod off and this is happening quite a bit.

A year ago, I had a prostate operation. Since then I have been incontinent. I had this checked out with an urologist then went through a series of tests, but **because of CIDP I have lost the control of the nerves in the bladder**. Professor Stark was the first doctor who put it down to the nerve endings. I have just had a permanent catheter put in which actually allows me for the first time in 12 months to have a good sleep, instead of having to wake up every 2 hours. **It can also affect the muscles in the bowel** but is still **related to CIDP**.

Margaret. Thank you everyone for giving us all the little snippets of information because I think it helps everyone to hear how others deal with their problems.

I have just got three questions. I thought maybe if you are interested these could go in the newsletter for other people who are not able to come to the meetings.

Question 1. Do you have suggestions for help other than from the medical side, such as if you do water aerobics; play some type of sport, etc.

Brian. Yes I started bike riding 7 years ago and my neurologist said he had never seen such well developed muscles for someone with CIDP. I said maybe it's the bike riding and he agreed.

Peter. It is excellent to do water exercises and I do it twice a week which builds your muscles up. I find doing water exercises you keep your weight off. I have lost about 6 or 7 kilos over the year.

For people with **balance problems** they could wear **Brooks Beast shoes**. If you look at the sole they are straight all the way down and they stop your ankles from going to the side. I find these excellent for balance. \$250 but if you go on the internet and go to www.eastpay.com (they are in Wisconsin) you can buy them for about \$113 plus \$39 postage. I ordered them on a Sunday and a bloke came to the door on the Thursday. Or there is shoebuy.com which is out of Boston.

Margaret: Many years ago when Vilma was buying her **special schools, on her private cover, she could get a rebate** for them. **I don't know if it is still the case.** All these things are helpful to people who have to have special shoes.

Gwen: I have been going to **water exercises** – I won't call it aerobics, they are total exercise at the Monash Pool. I am 80 and I have a lot of things wrong but I am fit. This regime follows what the Arthritis Association does in the pool **and it exercises everything and you don't do enough to get sick of it and you can stop and do it at your own pace.**

Doug: Just getting back to Peter's Brooks shoes. There is a **factory outlet in Cheltenham near Southland and you can buy all Brooks shoes there ranging from \$80 up to \$130. It is called New Balance.**

Peter: Buy Brooks Beasts – don't buy others. My chiropractor recommended to me to wear Brooks Beasts because I have bad ankles from playing football.

Margaret W. My dad had a year of physio **following his GBS** and went from someone who couldn't do anything back to almost normal but he still had weakness in his feet and continues with **the physio and massage of his feet as he says they were like boards and the physio and massage keeps them supple.**

Question 2. As you know, if anyone needs a hospital visit we arrange this, but I was wondering if anyone just wanted to talk to somebody in their home, then we could visit.

Frank. I think that's an excellent idea. During the course of ongoing therapy I am having, I have come across **other GBS patients** at the Royal Talbot. They quiz me, **they ask every question under the sun, so that service provides information they don't get elsewhere.**

We could put this in the newsletter. If there is anyone who would like a visit we could see if there was anyone nearby who could go to see them.

Peter: I think it is **good for your wellbeing**. You have got a complaint and you feel bad, you are sitting around wallowing thinking “is this ever going to go”. **If someone comes along** and says, “Don’t give up,” **it gives you a lift**. If you want to do something, just go and do it. Don’t just sit there and let it beat you. I hate going down the pool twice a week, but I have to do it. **The greatest thing is to get up and go outside**. I still do my lawns but you have to learn not to overdo it. Do the front one day, the back another and the nature strip another. **Don’t overtax your body**.

Question 3. Are there any other services you wish us to provide?

Kath: May I just ask, is there a registry of GBS or CIDP patients available? How do you know when there is a patient in a hospital?

Margaret: We have to rely on someone letting us know. It is usually a relative.

Kath: I was in St.Vincent’s and just saw the neurologist of the day until Andrew Kornberg put me on to Valerie. She said, “You were in St. Vincent’s? Did I see you?” I said “No” and she said “Why not?”

Brian: What floor were you on? **Kath:** 9th floor. **Brian:** Usually GBS and CIDP patients I think go to the 6th floor.

Brian: There are **4 of us who go for treatment at the same time** and we visit each other and **we compare notes and that’s quite supporting**. I also tell others about the group when I’m having my treatment.

Doug: I think that is affective, the word of mouth; you people meeting others having the same treatments and spreading the word. I’d like to see it up in headlines on the front page of The Sun, but you can’t do that.

Peter: I think with Father Bob McGuire having it now we might get a higher profile and also Ian Stewart the footballer.

Kath: I emailed the Royal Melbourne Hospital offering to help Ian’s family with support. The hospital wrote back saying they couldn’t give patient details. I told them, no, I’m giving you my details and they can contact me if they would like some support. That is one of the reasons I started the Facebook page **Guillain Barre Syndrome – Australia**. I found the lack of support out there was terrible and **no one knew anything about GBS**. So **any of you who are internet savvy, get on there and say Hello**.

Brian: **I have come across two neurologists who knew nothing whatsoever about CIDP and they had told patients with CIDP that there is nothing they can do and that’s quite wrong**.

Melva: There are also some specialists who tell patients not to go to a support group because you may see someone worse than yourself and that could distress you, instead of what really happens in a support group; **you get support; you learn information** and we are all very

happy folk. There was a lady Margaret and I were offering support to for months, but she was too frightened to come to a meeting for that reason. It was very sad.

Gwen: I have recently had surgery for a twisted bowel and I was not given any of my medications for CIDP no matter how much I talked (Peter: And she did talk – I noticed).

Peter: My walking went back a bit after I had an operation and I wondered **if anaesthetic could affect people with CIDP?**

Kath: I am **having an operation next month and the anaesthesiologist phoned me this week to discuss my GBS.**

Frank: Interesting that you should say that because I had bowel surgery about 2 months before this happened, although I was told it was unrelated.

Peter: Nobody knows what causes this problem.

Melva: One of the things that people put on our survey form is they have recently had an operation. **Stress, an operation, a spinal injury, immunization, gastro or the flu are given as possible causes, not necessarily in that order.**

If you wish, please return the following form to: The IN Group, 26 Belmont Road, Glen Waverley, 3150.

Information Form:

Name:

ADDRESS:

.....

1. I would like someone to talk to me in my home. tick

2. I have found helpful for me.

3. Service we could provide

.....

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Newsletter of THE 'IN' GROUP: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC

Supporting those with acute Guillain-Barre` Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

Postal Address for Newsletter only: 44 Mavis Avenue, Beaconsfield, 3807. Telephone 03 9707 3278.