

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 AUGUST AT 1.30 PM

ANNUAL GENERAL MEETING

Guest Speaker – Neurologist, Associate Professor Richard Stark

BALWYN LIBRARY MEETING ROOM, WHITEHORSE ROAD, BALWYN, VICTORIA

A small plate would be appreciated.

November 18th. 12.30pm. Christmas Luncheon

February, 2013 1.30pm. Occupational Therapist, Caulfield Hospital – Name to be advised.

Special Event - MID YEAR LUNCHEON ON SUNDAY, 15TH JULY AT 12.30PM

RSVP Margaret on 9802 5319 or Melva on 9707 3278 by 10th July. \$15 pp.

Come along and enjoy great company, great food and have great fun.

Notes from May Meeting

I would like to say a big welcome to everyone and it is especially great to have some new people here today, so a warm welcome to you all.

Apologies:

John DeRavin

Both Barbara Clifford and Irma Hannah are not very well and we send them our best wishes.

Financial Report:

A quiet quarter as we are only 6 weeks from the start of our new financial year. Last quarter we received subscriptions of \$175, donations of \$710. We had one donation of \$500 from a certain person who is a member of the Group and that was tremendous and there was \$60 from general sales and craft. As you know we gave \$10,000 donation to Assoc. Prof. Andrew Kornberg during this financial year. Expenditure last quarter was \$98 for newsletter, and \$375 for a new printer. Cash in the bank of \$2578. We are reasonably on track We have applied to the Department of Health for the Self Help Grant.

Emails: We receive quite a few emails through the website. All are replied to. One of these has come from Vicki Malcolm the wife of Peter Malcolm who most of you here would know. Peter has CIDP and this email refers to WILL YOU TELL YOUR STORY and reads: “I support the **Every Australian Counts Campaign for a National Disability Insurance Scheme**. I have told my story to make sure every Australian counts and the NDIS becomes a reality this year. Australians with disabilities, their families and carers deserve a fair go. Will you support me by telling your story?”

I have copies of that email on the table here for anyone who would like to participate. You go to <http://www.everyaustraliancounts.com.au>.

The other one is a survey with the objective: **Harnessing the power of the patient movement more effectively. A global index of patients’ advocacy that compares the effectiveness of the patient movement in different countries** and it came to us from the Inflammatory Neuropathy Group of New South Wales. Email: info@patient-view.com

Margaret: Today I thought we will start with our new members who would like to tell their story and maybe get some input from people who are already part of the group, but prior to that Gwen has something to tell us. Gwen is our handcraft lady who makes us a lot of money with all sorts of bits and pieces so it is very good to have Gwen helping so much.

Gwen: There are some things on the table you might like today.

I want to say two things really. **I recently had cancer and I would like any woman who wants to talk to me to do so. It was ovarian cancer. I’m fine, but if you would like to talk to me, I would like to talk to you. I was lucky because it was very early and I know what you should look for – that’s the first thing.**

I have this book here called “Food Remedies” and it tells you what is in food, like which vitamins and what is good for us and I found it very interesting reading, so if you would like to have a look at that too.

The second thing is - In the process of having chemotherapy recently I had a “port” put in. I had never heard of one and the great thing about it is after 10 years of not being able to find a vein for my infusions, I now have a port which is a permanent installation, just under the skin, so all they have to do is go in, so if you are interested, I will tell you about that too.

Linda: I had GBS in late 2010 with a **very rare form of GBS**, so they didn’t pick it up straight away as they couldn’t figure it out for about 5 months. I basically was in a lot of pain; back pain, leg pain and getting slower and slower and couldn’t walk and then eventually had to go into hospital and didn’t come out for a month and was eventually diagnosed with a rare variant of GBS.

I have had rehab. since then and went back to work about 12 days after I was discharged in a wheelchair. I wheeled myself into work which was probably not a sensible thing to do in hindsight.

In terms of treatment for GBS? I didn't have much treatment. I think you can have 'Intragam' and stuff like that, but because they didn't know I had GBS, I didn't have any treatment. I haven't had a lot of treatment. I now am on a cocktail of drugs. Subsequently **I have also developed a lot of other "conditions"** I suppose you could say, **related to auto immune deficiency** since I have had the GBS. That is very interesting I guess.

Margaret: Do you feel much better for taking all the drugs?

Linda: Ah, **I have to take the drugs.** If I couldn't get one dose of my drugs, I know three or four hours later I'd be in pain, so I have to take them. They make a huge difference as I am in immediate pain. **I have terrible nerve pain in my legs and arms.**

Brian: How is the recovery?

Linda: **Recovery has been very slow and it is very variable.** Like today I am having a very good day, but tonight I might have to walk with a stick. My left foot drags. **Tonight I might be really, really, disabled, incredibly disabled** and hardly able to walk across the room.

Brian: That must be very depressing?

Linda: I think **only recently I am adapting** to that. It does take a while to adjust to your life changing, because my life has changed a lot. I can't do a lot of things I used to do. **I used to be very active** and ride my bike a lot and do very physical things and I can't do those things anymore, **so that's the real things that I miss.**

Brian: It may come back.

Linda: It may come back, **but it is nearly two years now and I have regained quite a lot** but I'm not sure. I just have **this level of fatigue.** I have managed to gain quite a lot but I am also **getting a lot of other conditions develop, auto immune conditions.** For example: food allergies. I have had enormous amounts of irritable bowel syndrome so I can't eat a lot of foods. I can't eat wheat – a lot of things. This has all developed since I had the GBS. I have other pain syndromes which are related. One thing will improve and I get hit with some other disease it would seem, so that's difficult.

I have treatment with a neurologist and various different specialists. Next month I will go and see a general physician just to try and get an overview of my condition.

Russell: My name is Russell and I don't have either GBS or CIDP. **I have peripheral neuropathy which is an issue with the peripheral nerves, in this case mainly in the legs and feet.**

It started about 18 months ago when I lost a considerable amount of weight (11 kgs) unexplained and **I noticed my thigh area was numb and aching** and I went to my GP and he referred me to a neurologist who works out of Epworth Hospital. He did conduction studies and physical things and he wasn't sure what it could be other than a tumour, a trauma of some sort, pressure on the nerves, that sort of thing. He whipped me into Epworth and spent a week or so doing tests, the whole shabang like MRI's, x-rays, lumbar punctures, bloods, but never really came out with anything and it was just before Christmas so I got out for Christmas.

At that stage **I was getting weak in this leg.** In the new year it got worse and for some reason this **foot became drop foot** (which you probably know) and he decided to redo all the tests which they did. Again nothing came out of it. They **tested glucose intolerance** as that can be an issue, and **then this foot became drop foot and it was numb and sore, so they did a biopsy of the nerve and muscle and it came back as vasculitis, which is inflammation of the blood vessels, in this case affecting the peripheral nerves, non systemic.** He put me on Prednisolone IV, 1000 per day for 3 days, and I did a fair bit of physio. In all my stays at Epworth **I have done some form of physio as well as hydrotherapy.** I have been an outpatient for quite some months and it flares a bit but hasn't got worse really, but it hasn't got better so I have been weaning off Prednisolone and went on 'Imuran' but I couldn't stomach it so I am off that and now on Methotrexate which I can handle pretty good.

That is where I'm at. CIDP is the closest I have found to my neuropathy. I am doing hydrotherapy once a week. My physio ran out so I am now doing my own.

Geoff: Where do I start? I love my lawn bowls and **I started losing my balance** on the green. **I had a couple of falls** and got back on my feet and got on with it. I have **two knee replacements and they're 15 years old and I thought what's going on? Are they wearing out or am I wearing out.** So I headed back to the man who put in the knees. He looked at all the x-rays and checked them out, patted himself on the back and said what a good boy was he, so that ruled that one out. I had a few more falls and **in passing the doctor said maybe I should see a neurologist.**

Learn to march. That was the best advice he gave me. When you march you shorten the stride and it improves your balance as balance was the problem for me.

It took a few months and we got to see Mr. Stark and **I was diagnosed with CIDP.** It basically took 7 months until we got to that stage, but I'm looking back to even further because these things tend to creep up on a person without them realizing. Going back maybe 3 or 4 years ago I was having trouble with my arm. You go to a physio and they try and put something right and I honestly feel that was the start. **It is something that creeps up on you.**

Now we are at a stage with the Alfred with infusions every 3 weeks. I do get to do hydro and physio a couple of times a week which has helped me. I am on a very heavy dose of 'Lyrica,' 300, twice a day. It is doing its job but sometimes you feel it isn't. You just have to grin and bear that. At present I am feeling - What else can a man do but get on with it?"

I don't go to work as often now. I used to put in 10-12 hours a day and I'm down to 3 hours, but **you do feel fatigued.** You cannot do what you were able to do, it's impossible, as much as you'd like to and as for my goal of getting back onto the bowls green, I don't know, I really don't know. It's a goal to work towards but perhaps a social game where you don't fall flat on your face.

Pat: When Geoff was diagnosed last August with CIDP, I came home and went on the internet to find out some information and I actually got onto the NSW website before I got onto you and the information booklet put out by NSW is, (I found as a layman not knowing what or where to go or what to do), absolutely excellent. It is in layman's language. It

explains it very simply; in fact I printed off several copies and have given them to our adult children to understand what Geoff is going through.

Geoff's father was a doctor. He didn't know what CIDP was. Geoff and I go to different GP's. Neither of our GP's knew what CIDP was. I went to my Dr and said "Geoff's got a chronic illness and it is called CIDP". She said. "What is it?" I sat there and went through what I had found on the internet (and by the way I found the previous newsletters to be valuable, excellent, I self educated myself through them) and I sat with my GP and explained what CIDP was and I said, "This is ridiculous. I'm the patient you're the doctor but I'm telling you what it is". Even the GP's don't seem to know what it is. There should be more education for the GP's.

Gwen: We understand how rare it is, because we have it. It is a mystery to most GP's. Actually I was guinea pig for Richard Stark at the Alfred for 2 years for trained doctors working in industry to come in and see if they could find what was wrong with me. A lot of the symptoms are the result of accidents or industrial fumes or something with neuropathy. Over the two years **everyone thought it was either diabetes or alcoholism**, but not one of them came up with CIDP. I found that very interesting. **These were practising doctors.**

Brian: **I have come across two patients whose neurologists have told them there is nothing they can do for them and that they just have to accept it. That's shocking. If this happens to you, get a second opinion. There are neurologists who are interested in CIDP patients.**

Doug: We have had numerous members who have come through here with GBS who have all got better and they don't come anymore. We at this group are not here to advertise doctors or neurologists, but sometimes it can be handy to know other neurologists than the one you are using, one that is familiar with the complaints you are all suffering. With other things in life we don't hesitate to get a second opinion. We can't promote doctors or neurologists we can't promote treatments because we're not trained in it, but we can talk to each other about what is happening individually, and that is why **we sit around here every so often and transfer information from each person that may be some use to someone else in the room.**

Maria: **Our little boy has CIDP and when he was 3-1/2 we were in palliative care as we were visiting my grandma with cancer and he kept saying his legs were hurting.** I had been looking on the internet at growing pains as he had been complaining a lot and looking back he used to fall over when we were in shopping centres and I'd look at his shoe laces and he'd have Velcro straps and I couldn't understand what was going on.

We took him to **the Austin and he was seen by a paediatrician.** I got there at 11pm at night and I didn't get to see him until 7am the next morning. All I said was my son has sore legs and can't walk very well, and he has got weakness. They did the bloods and the bloods came out okay. **The paediatrician referred us to The Children's.**

We left my grandma's funeral for **an emergency MRI** because by her funeral he was all over the place like he was drunk. People were watching him in the church **saying why isn't he walking well?**

The **MRI people said he could have either GBS or CIDP**. He was quite tight with his breathing, so The Children's had him on the 8th floor in the Critical Care Ward under observation for his breathing and he was doing okay.

They gave him IVIG and said he has GBS. **He took the IVIG really well and he had physio but within 3 weeks he had a relapse, with balance issues, and went back to square one**. They said it could still be GBS so they did '**Intragam**' again, and within that month again he relapsed. Up until 6 months ago he was relapsing every single month. **He would get better with the IVIG which was like a miracle**. I can't explain it.

Because he is so little, he wants to play, and he wanted to go to the playground, and he'd watch the kids going down the slide and want to do it but he just couldn't do it. I didn't know how to help him because I didn't know what was wrong and to this day he doesn't like to talk about it. **He calls them "spiders"** and it is very hard to talk about it.

It's a family thing as one minute we are okay and the next we are off to the hospital for a few weeks and we don't know what's happening in our lives. We need to meet others who have it. It is heart breaking as a mother to see your child like this and that's why we joined today.

Peter: Maria and Leo. I think you told me that your son is having 'Intragam' at the Children's hospital. Now you heard Doug mention in his report about the \$10,000 donation given from fund raising from this group. It happens most years and that money goes to Associate Professor Andrew Kornberg at the Children's Hospital who is **conducting research into the possible causes of GBS and CIDP**. **As new members we would like to say there is hope. There is light at the end of the tunnel with people like Andrew working on it.**

Maria: Sometimes I felt there was no hope. He has now been on Prednisolone and hasn't relapsed but he is on monthly 'Intragam' as well, and they have measured him and he still has some weakness, **but at the moment he is quite stable**. He hasn't got any worse. We are remaining positive. **We needed to find a support group like this** because the children are all on the one level and you see children with brain tumours, etc. and they have their support groups and counsellors on the wards, **but for CIDP there is nothing**.

Children use their fingers to write. Until today **dressing has been** an issue. **Balancing** on one leg. He still can't skip. We work on those things at the Children's and at home. He hasn't done hydrotherapy and **I would like to know what they do in hydrotherapy**.

Also **about the "spiders" what is he feeling that it could be similar to? Is it like sitting on you leg for too long?**

Costas: It is a wooden feeling.

Joe: but also a constant tingling.

Maria: He says, "**This foot has 20 spiders but this foot has more and it changes**". The neurologist was weaning him off the Prednisolone quite quickly and he went all over the place so now they are weaning him off more slowly. They say to us, we are not God, we don't have a magic ball, we can't tell you when your child will be better; **because it is neurological, every day can be different** and that is hard for everyone.

Costas: **Even as an adult it is hard to cope with.** I was diagnosed three years ago with CIDP and a lot of things Geoff said I concur with and you can't do the things you used to do, but it has taken 3 years just to get out of the forest and **try to accept things and manage things.**

Maria: As a parent, if your child has a temperature you run to the Panadol. **I wanted to help him and I couldn't. That was my biggest struggle. But it is not about me, it's about him.** He says, "Why does Thomas run faster than me?" I have to try to explain.

Melva: You were asking about hydrotherapy. Hydrotherapy seems to be very good for people with CIDP. We had a spa at our previous house and Joe would lay with his legs along the bubbles. Just the bubbles were enough and he improved out of sight.

Maria: We have been thinking of getting a spa and **another thing he loves to do is bend his toes back. He always likes to stretch his toes and fingers.**

Joe: **It is good for him to stretch his fingers and toes. I could feel my fingers and toes contracting and consciously, whenever I sit, I stretch my fingers out flat on my knees. It works. My fingers are not bent but my toes are; I can't move them, they are curled up. I should have done something in the early days.**

Maria: I used to ask him what was he doing and he would stop straightening his fingers as if he was doing something wrong. **: It is good to join a group like this.** He loves his bath. You say it is good for him to exercise in warm water, but not too long.

Maria: He is starting school next year.

Melva: He may not be able to do sport for as long as the others. He needs exercise but not too much. You will probably need some expert advice and then advise the school.

Maria: We Google a lot and we've been told that 80% of children do get better, but with CIDP **we have been told there are three ways he can go** and one way is **relapsing** all the time; he could **have it for 3 years and then get better**; the other is **to live with it his whole life** and they can't tell us which way he will go.

Melva: Do you think there was something that might have been the trigger?

Maria: He had tonsillitis. He was actually due to have surgery on his tonsils in February last year. His tonsils were swollen and he was swallowing, and the doctor prescribed antibiotics. He would get better and then within about a week he would get the tonsillitis again. He also had a respiratory infection with a very bad cough before he was diagnosed with GBS.

Leo: I think it might have been the infection.

Member: Idiopathic means – they don't know the cause.

All those present then shared information over a lovely afternoon tea. Our thanks to all who "bring a plate" for our meetings.

E-mail Mailing List If you would like to be included on the IN Group email mailing list please send an email to John Burke at the following email address jburke@contracts.com.au. If you use *hotmail* or have junk mail filtering software running you will have to include the above email address in your "safe list" otherwise *hotmail* or your junk mail software is very likely to delete our emails.

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.

AGENDA

ANNUAL GENERAL MEETING

The Inflammatory Neuropathy Support Group of Victoria, Incorporated
To be held at the Balwyn Library Meeting Room, 366 Whitehorse Road, Balwyn on

Sunday, 19th August, 2012 at 1.30 p.m.

Confirmation of Minutes of 2012 AGM.

Reports from President and Treasurer

Election of Officers and Members of Committee.

Any special business of which 21 days notice has been given.

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

PRINT POST APPROVED
PP 335708/00020
(ABN) 77 954 503 188

SURFACE POSTAGE PAID
MAIL AUSTRALIA

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

If undelivered, please return to sender.

THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA, INC.
NOMINATION FORM

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

Nomination Form - Committee

Position:

Nominee:

Nominated by:

Seconded by:

Accepted by:

Date:

Signature of Nominee: Date:

ANNUAL SUBSCRIPTION
THE 'IN' GROUP

The Inflammatory Neuropathy Support Group of Victoria Inc.
Supporting sufferers from acute Guillain-Barre` Syndrome (GBS and Chronic Inflammatory
Demyelinating Polyneuropathy (CIDP) Registered Charity No: A0025170R

1st July 2012 – 30th June, 2013.

Annual Subscription \$ 15.00

Other Items

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

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

(Tick if receipt required

Total Payable: \$ _____

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

Membership Details

Name: _____

Address: _____

_____ Postcode _____

Telephone: (Home) _____ Work) _____ Email Address: _____

Signed: _____ Date: _____

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