

INFORMATION

GETTING BETTER SLOWLY

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
ANNUAL GENERAL MEETING AT
BALWYN LIBRARY MEETING ROOM, WHITEHORSE ROAD, BALWYN
2.00 PM ON SUNDAY, 17TH AUGUST, 2014.

Guest speaker –Scott Earle on “How I beat GBS 10 percent at a time.”
Author of The Wave of Guillain-Barre` Syndrome.

A small plate would be appreciated for afternoon tea.

Nomination forms for the election of Committee Members are in this newsletter. All positions are vacant. All members are eligible. Please return the seconded forms to 26 Belmont Road, Glen Waverley, 3150 prior to the 17th August. Please note that if there is something you wish to raise at the Annual General Meeting, 21 days notice is required. Thank you.

Dates to Remember

Sunday, 29th June, 2.30pm Afternoon Tea at Lawrence Home
\$20pp RSVP 9802 5319 by 25th June for catering purposes.
Sunday, 17th August 2.00 pm A.G.M.
Sunday, 16th November – Christmas Luncheon 12.30pm. \$20pp

Welcome - Margaret Lawrence

Hello to everyone. There are quite a few new faces here today. Welcome to you all.

Treasurer's Report – Doug Lawrence

For this quarter we received \$1849 net being a grant plus donations minus newsletter and postage costs. Thank you to our generous members and a special mention to CSL who support us by paying our website costs. We run a website with details and newsletters and CSL have just paid another payment so to CSL on behalf of us all we say thank you very much.

We are in a good position to make another donation to research through Andrew Kornberg at the Royal Children's hospital and he may attend our Afternoon Tea and if not we will forward it to him as we know he is very appreciative of the help we give. We have donated over the years somewhere in the vicinity of 100,000 from our members. We get very few annual subscriptions which do not include something in the way of donation. We are trying to help find out more about GBS and CIDP. On behalf of the Committee “thank you again to our amazing members” as it is a tremendous result.

Margaret - I would like to invite you all to the mid-year function which this year is an afternoon tea at our home. It is one of our major fundraisers where you will enjoy a lovely afternoon tea plus the warm hospitality of our members and their friends. RSVP to 9802 5319 for catering purposes. We hope to see you there. For those who are new, Gwen our speaker today does so much for the group with her handcrafts, making bead necklaces, knitting, etc.

Talk by Gwen McInnes on products which make it easier for those with a disability.

Firstly, a lot of people have **four wheel walkers** but I like this one which has **only two wheels**. I don't really need it but it gives me confidence. My husband and I go to the shopping centres for the walk and the thing about this small walker is you can fold it up and put it in the boot with one hand. It is **very maneuverable**. Member: Where did you buy it? Gwen: I think it was in Ringwood but I do have **catalogues** where you would probably find them. Some of you will have them "**Magnamail**", "**Aids Today**" and "**Solutions**" and **several others**. They are not all for people who need help. Copies are here for you to look at.

Question: What do you think of the four wheeled ones? Gwen: I haven't used one. I really don't need one. **The fact that I have CIDP means I am unsteady walking on an uneven surface and this keeps me stable but we only walk at the shopping centres. Some of the disabled carparks don't have trolleys nearby so this gets me there safely. When I get inside and get a trolley I can just put this in and we are off. Because it folds so nicely there is plenty of room for groceries, etc.**

Member: Four wheeled ones are pretty easy. I hurt my ankle and wondered how I would get around so I used the four wheeled one and the good thing is it has a seat. My ankle had a moonboot on it and I was able to push myself around with the good foot.

Member: I looked around before I bought my four wheeled walker and there was about \$100 difference so it is worth shopping around before your buy.

Gwen: I was going to say about these magazines I get. Your first call is somewhere local. **Your pharmacy will sometimes get things in for you and also Cash Converters sometimes has a range of secondhand items.**

This is a dressing stick. I don't use it for dressing, I use it to put my coat hanger onto the rack. I got it through a pharmacy who ordered it in. If you have to pay postage that could be \$10 or so. Always check your local possibilities first.

Sometimes you can use something that works well. **You know the swivel seats you can get for in cars, they are very good, but a plastic bag works very well too and it costs you nothing.**

Just put the plastic bag on the seat and you can swivel. Try it, it is great fun.

I won't tell you about all of these things. I hope you will come and ask me questions.

There is a book here and I have cut out all the relevant pictures of things that are a help. Have a look at those. Some I have and some I haven't. The first one is my **folding walking stick. This fits into my handbag. Just flick it and there it is. We keep one in the boot of our car.** I don't use it all the time but it is handy to have when you need it.

We will start **in the bedroom**. Getting dressed can be a problem. Something you can get for instance is **the sock-putter-on-er**. Have you ever had trouble reaching down to your toes? The sock goes on here, it hooks on here and you put your foot in and pull it up. **Stockings too.** They are easy. There are **different sizes**. Member: The blue one is the biggest size.

In the bathroom, lots of things are a nuisance. **Put your soap in an old stocking** and put a loop in the stocking and then it doesn't drop on the floor. That works well. This is a **foot scrubber** which attaches on the floor of the shower.

I couldn't resist this. I had a skin condition and this was a **very cheap body wash. It has honey and milk in it and sometimes I get one with chamomile too. All very good for your skin.** I use it, love it and was able to stop rubbing myself all over with cream every time I had a shower. This was from like a \$2 shop but you can get it in the supermarket. When you age your skin tends to get dry and thin and this is a good moisturizer. Just put it on in the shower and rinse it off. Member: **QV cream** is good too.

Gwen: I took my GP a bottle and she liked it too and she said honey is good for you and Cleopatra used to bathe in honey and milk. Sorry we don't have an Asp.

You have all got a **long shoe horn** I'm sure and you can get them **that bend** around. They are very handy not only for shoes but I can scratch my back with it and things you don't do in public.

You have had your shower and you have your clothing on and you come **into the kitchen** and that is where things really get troublesome. You have to get your breakfast. I am very keen on saving power. You can get these **egg poachers from the \$2 shop**. **They take a minute and a half. This is for cooking a Hard Boiled Egg – also in the microwave. It means you don't have to boil water.**

Long tongs of course for everything. **You can reach up high, down low, under things and it is small compared to a pick-up-stick**. The end of the pick-up stick sometimes won't go under something where you haven't quite got a grasp of it, this is a **good alternative**. I didn't bring my pick-up stick.

This is a **porridge or milk microwave container**. I don't know if you have porridge but I make porridge most mornings. It comes up and froths over no matter how big a container I use. This has holes in here and **when the contents bubble up they come over the top and then disappear again and so you don't have your microwave dirty** as porridge and milk are hard to wash off.

If you have an **arthritic condition in your hands** this is a beauty. It is a **knife with a big handle**. **There are knives and forks with handles that are thick but you can also buy this plastic stuff and wrap it around and you can do it on all sorts of things. This is the best thing I have found to open jars. This is using the palm of your hand over the top and turn it. (This was plastic fabric with holes – sometimes used to keep rugs steady on polished board floors.)**

Help yourselves to one of them. Member: We have them **on a tray for when you are carrying things. They don't slip.**

These are two kinds of **Scissors**. You don't have to open them **they open themselves**. You don't have to do two actions as it **springs open ready to do the next cut**. This **one has a light which you put on the line and it keeps you straight**.

This is a **can opener**. **You sit it on top of your can, press the button, after a moment off it goes and cuts the top off your can, no strain whatsoever on your hands.** They are great. Again you can get various prices in the magazines but I paid about \$20 for these.

When I started thinking about this I had just joined a group in the **Knox Community** and the Occupation Therapist said she would come out and I'd show her these things and she said we have a group where we teach these things and the way to get around things and you might like to come and show what you have and see what I have. Now I went along and I had an interesting letter back thanking me for showing the things and if you enjoyed the program please assist us by recommending it to your family and friends. They say **you do not have to be in the Knox municipality** and they will assist you with transport if you need it. I will leave the information for you to have a look at.

My favourite thing in the kitchen is this **small grill**. It has a grill, and you can heat up your bread roll.

Member: What do you use it for? Gwen: **Grilling anything. I use this or my flat bed sandwich toaster. Instead of having to warm up my big griller and then clean it, I use the little griller for steak, chops, sandwiches, eggs, bacon, tomatoes. I also use a small toaster oven. It heats up more quickly than your oven. Costs a lot less to heat. Member: What is it like to clean? Much like the other one. I spray a little olive oil. What I have recently tried is putting a bit of baking paper down and I grill on that and I didn't think it would work but it does. You are not even dirtying it.**

The idea of this course was to make you think about ways you could do things easier and more economical.

Here is the **cutlery** with the stuff on them **to make the handles big**. Here is a **bracelet putter-oner**.

Recipes – I hope you are all wanting to buy The IN Group cook book. It has my sort of recipes – quick and easy. Have a look at it. You might be interested.

Ironing – I don't iron. 53 years ago we went on long service leave with 3 small boys and I thought I'm not spending 3 months ironing. At that stage the drip dry things came in and I thought I'll have everything that doesn't need ironing and it was so successful I haven't ironed since. No-one is allowed to buy anything that requires a lot of ironing. I don't mind doing something special but I never iron Pete's shirts and he always looks tidy. I hang them out from the washing machine and when they are dry I put them straight into the wardrobe.

Some people are in danger of tripping on the iron's cord. If you can find one, there are cordless irons. They are great. Nothing is hanging down so no danger. As we get older the main thing is to avoid falling. Lots of things make you fall so think ahead. At this course they said, Make your bed with fitted bottom sheets" and one of the ladies said, "But they are so hard to fold and to iron". I nearly fainted.

In your bedroom you may find your bed is a bit low. They have things that look like flower pots and you place them under your bed and they raise the bed about 8 inches. We have them and they have made such a difference.

In your car, you have seen the gadget that fits into a socket in your door and helps you get in and out of your car, (on your plastic bag) and it also has a **cutter for if you are unfortunate enough to be in an accident you can cut your seat belt with it and there is a **hammer** where you can break your window.**

If you have any questions I will be happy to answer them and I'd be happy for you to come up and have a look at things, ask about them. You can also get things around your house like **the chairs that lift you up and tip you out**. You can get **tables that go across your bed** and **a rail to help you get out**. There is also a **rail to hold your blankets up off your feet**. I have trouble that way. There is a **little ladder to help you pull yourself up** in the bed.

Member: There is a mobility shop just 50 metres from here and it is open today.

Member: I think you would have to be mandrake to solve this problem, but I have a wonderful wife – it is doing up buttons. Gwen: Yes here is **a button doer upper** too. Here is one. You put it through the button hole, over the button and then pull it through.

I find it **very useful having a packet of moist wipes**. I use them so much and **I'm amazed at how many stains they can get off things**. I was out recently and one of the guests spilt something down his white shirt and I got out the baby wipes and it looked as if you would never get rid of it and I wiped it and it cleaned remarkably. I carry some with me and it is **amazing how often I use them**.

Member: My daughter has two little boys and they put their hands over everything and she comes behind with the wipes and all the marks disappear from walls etc.

Member: I have **difficulty drying myself and a chap came up with the idea of a toweling dressing gown**. Member: Using a **hairdryer** is good especially for drying toes. Member: **Spraying your toes with methylated spirits dries toes** too. Member: **I'd like a sponge on a back scratcher** and I'd use your honey and milk moisturizer. Member: I've made a disabled ladder with smaller spaces between as I can't lift myself up more than 200 mm. I've got an extra rung in between as they are usually 300 mm. Gwen: You shouldn't be climbing ladders. Member: I knew I'd cop it. Member's wife: He has only been using it for 28 years with CIDP.

Gwen: You can hire a **chair lifter which goes on a hard surface chair**. There are lots more so check them out.

Member: A friend of mine is a theatre sister and she said **more than 90% of the elderly people who go to theatre have fallen getting dressed. You must be extraordinarily careful when you are getting dressed. Have a habit of bending on your bed or near a bed. We are probably more careful as we are looking all the time so we don't trip over.**

Margaret. For the new members here today, we have a container over there with books you can borrow. Just write your name down so if there is anything you would like to borrow please do.

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.

ANNOUNCEMENT OF DRUG TRIAL FOR CIDP PATIENTS

Oral replacement for IVIg (ie Intragam / Octagam / Kiovig)

Patients need to be otherwise healthy, have CIDP which is still clearly responding to IVIg and are prepared to trial stopping the IVIg and replacing it with an oral drug (Fingolomod) to see if that can fully replace the benefit of the IVIg. This would clearly have greater convenience, but the responsiveness and effectiveness over time needs to be tested. If the CIDP breaks through the oral drug treatment, previous IVIg treatment would be resumed. More detailed instructions could be discussed with any interested subjects.

Any patients interested in the trial should contact A/Professor Tim Day at the Royal Melbourne Hospital on Timothy.Day@mh.org.au If you are interstate or overseas contact your Neurologist to see if there is a trial near you.

Study purpose and conduct

Patients are invited to participate in a clinical research study to evaluate how effective and safe the drug FTY720/Fingolimod is when used to treat people who have chronic inflammatory demyelinating polyradiculoneuropathy (CIDP).

Fingolimod is an oral once-a-day medication that has been approved in over 40 countries for the treatment of relapsing multiple sclerosis (MS) but has not been approved for the treatment of patients with CIDP. (In Australia Fingolimod (Gilenya ®) is approved by the Therapeutic Goods Administration for the treatment of MS). Fingolimod is not available for doctors to prescribe for CIDP therefore it is considered an “investigational” drug.

Fingolimod acts on certain types of white blood cells (lymphocytes) responsible for immune reactions. It makes some of these cells move away from areas of inflammation (tissue injury) and redirects them towards lymph nodes and other places in the body where they rest. These cells are believed to play an important role in the inflammation process associated with MS and CIDP. It has been shown in CIDP animal studies that Fingolimod completely suppresses paraparesis (partial paralysis of the legs) and reduces the severity and duration of the disease. Fingolimod has not yet been studied in humans with CIDP. Most of the information on Fingolimod has been obtained in patients with MS, which may or may not apply to patients with CIDP.

This is a clinical research study sponsored by the pharmaceutical company named Novartis. The main purpose of this study is to determine if Fingolimod is effective in treating CIDP and if it is safe for patients with CIDP. Information from this study may be used to support the registration of Fingolimod as a treatment for CIDP if it proves to be effective.

Subjects who participate in this study will be randomly assigned (like flipping a coin) to receive 1 of 2 treatments:

- Fingolimod 0.5 mg (1 capsule a day)
- placebo (1 capsule a day that is identical in appearance to the Fingolimod capsule but contains no active drug).

The treatment assignments will be equally distributed among all participants, so that half of the patients will be assigned to receive Fingolimod and half to receive placebo. You have an “equal” or 50% chance of being treated with either Fingolimod or placebo. Neither you nor your study doctor will know which treatment you are receiving (that is, your treatment assignment will be masked or blinded). However, your study doctor can find out what you are taking if there is an emergency. Otherwise, you will not be able to know which treatment you were receiving until the study is completed and the data have been analysed.

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.

Can you help?

We received the following Email.

I am seeking any cited articles or original research relating CIDP to a surgical procedure.
Michael.stark@live.com.au

Stem Cells for CIDP Patients

Question to the GBS/CIDP Foundation in the US:

Over the last couple of days I have had two people asking about Stem Cells as treatment. Do CIDP patients receive treatment with Stem Cells in the USA?

Reply :

In the US Stem Cells for treatment of CIDP is considered experimental. A patient would have to have the means to pay for the whole procedure before being considered. They must also have tried every other treatment under the sun and not had a good response to treatment for consideration. Stem Cell is much like cancer treatments in that your immune system is totally compromised before giving treatment.

There is a doctor in the Midwest that is doing the procedure but, since it is in the early stages and he is using the treatment on different diseases not just CIDP I do not know his success rate for CIDP. A few of our patients have gone through the procedure and have said while a daunting procedure they felt better after they left. Walking after treatment when they came in a wheelchair type of things. Some have been able to return to work (desk job). Again, this is so new that the long term effects have not been fully realized as yet.

Welcome to New Members

What a wonderful meeting we had where we welcomed new members Michael, Christine, Nathan, Steve and Rhonda. We hope you enjoy the support and friendship The IN Group provides. It was lovely meeting you all. Welcome also to new member Nicki.

Contacts: We have had contact with quite a few patients over recent months. One, a gentleman from Q'land said “My legs were feeling weak so I phoned my GP daughter in WA who advised me to go to the nearest hospital. They sent me home with Panadol. Later when worse I phoned my daughter again. She said “Go back and tell them I think you have GBS”. He did and the Doctor said, “No-one gets that but it would be good if you had private health insurance as the private hospital has a good neurologist.” He did have cover, was treated quickly and effectively and is now home but distressed by what he experienced at the public hospital.

ANNUAL GENERAL MEETING
The Inflammatory Neuropathy Support Group of Victoria, Incorporated
Balwyn Library Meeting Room, 366 Whitehorse Road, Balwyn at 2pm on 17/8/14.

Agenda

1. Confirmation of Minutes of 2013 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.

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

Nomination form for Committee

Position:

Nominee:

Nominated by:

Seconded by:

Accepted by:

Date:

To be returned to: The Secretary,
The IN Group, 26 Belmont Rd., GLEN WAVERLEY 3150 by 5th August, 2014.

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.

FORM FOR NEW MEMBERS, CHANGE OF ADDRESS, & 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 No: A0025170R

Subscriptions due on the 1st July of each year.
1st July 2014 – 30th June, 2015.

I am happy to help The 'IN' Group by my membership.

Initial Joining Fee	\$10	\$
Annual Subscription		\$ 15.00
Other Items		
Booklets- The Road to Recovery A-Z	\$6	\$
- Boy, Is This Guy Sick	\$2	\$
- CIDP	\$2	\$
- GBS	\$2	\$
 Recipe Book plus postage	 \$14	 \$
 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

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Supporting sufferers from acute Guillain-Barre Syndrome(GBS) , Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

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