

# 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)  
Postal Address: 26 Belmont Road, Glen Waverley, 3150.

## **MEETING DATES FOR 2010**

Please note change of date for our first meeting. This is our “daylight saving – night meeting” now to be held on:

**TUESDAY, 23<sup>RD</sup> FEBRUARY, AT 7.30PM**  
**BALWYN LIBRARY MEETING ROOM, WHITEHORSE ROAD, BALWYN**  
**GUEST SPEAKER – DEBORAH LOWE, BOWEN MASSAGE THERAPIST**

Dates now **confirmed** for further meetings on:

<b>Sunday May 16<sup>th</sup></b>	<b>1.00 p.m.</b>
<b>Sunday August 15th. (AGM)</b>	<b>1.00.p.m.</b>
<b>Sunday November 21st. Christmas Luncheon</b>	<b>12.00 noon</b>

## **CHRISTMAS LUNCHEON, 2009.**

President, Margaret Lawrence, opened the meeting, welcoming our guest speaker, Associate Professor Andrew Kornberg and Ken Clarke, who had come to do the Auction.

She read the apologies, including those from our Patron, Dr. Richard Stark, Jenny Murray from the NZ support group and Stephen Bowditch from CSL.

She told how “Gwen and Peter McInnes, Doug and I went to their Christmas gathering in a private home. They had a lovely luncheon and mini auction as well. They raised \$115 approximately for The ‘IN’ Group. Many thanks to the wonderful members at Geelong!”

## **Talk by Andrew Kornberg.**

Again **thank you to The ‘IN’ Group for supporting me and the research we do** at the Royal Children’s and St. Vincent’s hospitals over many years.

I am not going to stand up here today and say, “I’ve got a cure for CIDP or a cure for Guillain-Barre` Syndrome”, but I guess everyone in the room needs to know there are really good treatments for both those two groups of conditions plus many others.

There is a lot of research going on and it is so important that research is part of looking after people. Everyone thinks that research is like guinea pigs, etc., but I talk about an important thing such as childhood leukaemia. In 1963 there was a 5% cure rate, so 95% of children died in 1963 from leukaemia. In the 70’s the cure rate was about 5%., in the 80’s about 40%, in the 90’s 70%. Now it is around 90 or so percent depending on what type of leukaemia you have. What was the difference?

The difference was that everyone and every child were actively involved in research. There were treatments being used and they were part of research projects and it has taken a long time from 1963 to 2009 to get those sort of cure rates, but little steps at a time actually make a big difference in the long term.

Even now when there is no cure, most people with GBS and CIDP live entirely independent lives simply because there are really good treatments available.

One of the things that happened over the last year or so was the availability of IVIG. Everyone knows that at one stage IVIG was in short supply. With The 'IN' Group pushing CSL and government to fight hard, as well as doctors, particularly who were involved, what we were able to do was to get government to formulate, (with the help of doctors), what treatments IVIG should be used in. We also lobbied the government, that if we were going to be using IVIG, we are using it at adequate doses.

**So nowadays I have not heard of anyone who doesn't get an adequate dose of IVIG.** It may be the case in some places, but in reality the supply has become more stable and those patients are actually able to get it.

In addition there have been some new medications being made available. At St. Vincent's hospital there is a medicine we are beginning to use in multi focal motor neuropathy where IVIG is the main treatment, but there are other treatments. Not everyone responds to IVIG but in those individuals we are able to give this very expensive drug that changes people's lives. How has that come about? It has come about because of research. Clinical research. Trying different things.

But the bottom line is, we have got to know what causes these conditions and once we know what causes them, , then we are able to actually make specific treatments or get drug companies to supply the specific treatment.

People have heard of Multiple Sclerosis. Once upon a time MS was thought of as one condition but over the last year or so in fact, we now know by testing, and antibody testing, they are separated. Because they have been separated out we know now patients with this particular type get this sort of treatment and this particular type get this sort of treatment.

Now with MS we are not far away from a treatment once a month instead of daily injections or every other day injections. There is now an oral tablet being started in trials and some of those medicines may actually be applicable to patients with CIDP.

In the last year we have begun to unravel how these conditions are caused and what we need to do and there are **lots of drugs now becoming available for us to actually use. It is not just steroids, not IVIG, not just plasma exchange, but a million things.**

Let's go back to Guillain-Barre` Syndrome. GBS tends to affect young healthy people. It can affect older individuals too. It is a one off event. Now we are beginning to understand we have to provide treatment early on. Doctors are now switching in and understanding that this person may have Guillain-Barre` Syndrome and then treatments

are administered early, which protects the nerves and longer term people do better. It is not just the treatment but getting the treatment early.

CIDP is a little bit harder. It is not as common and not as dramatic, but once again what is happening, people coming into the hospitals are being treated right at the start at adequate doses which will make a difference. In the next little while some of the medicines that have come out in MS and other sorts of treatments will also come out.

One of the other things that happened in the last year since I spoke at the Christmas Luncheon was, **understanding what are the triggers**. We know that in individuals it is something about that individual. There is a genetic reason. It is not one gene but people are susceptible to having these conditions. Then they come into contact with some sort of trigger and that brings on the disease. In MS again, ( I just did a talk on childhood MS in Hong Kong), but in MS what has actually happened is we have begun to isolate different environmental triggers, whether it be certain viruses, vitamin D deficiencies, sunlight exposure, on top of the genetics, and that's what we are also going to find in time in CIDP.

There is some tantalizing evidence but we are not as far advanced as we are in MS. Learning about something in MS, we start to bring that into other conditions.

I guess in the last year we are beginning to understand how these diseases are caused. We are beginning to understand the triggers of these diseases, and what sort of other treatments can become available, and probably the most important thing is now we have adequate supply of medications. The hospitals are even paying for some of the more expensive medications when other things don't work. So we have gone a long way in the last year and **it has been very, very exciting for us at the Children's, St. Vincent's, that we are actually able to do that and we are now also nurturing collaboration with lots of people all around the world**. Not just one place, we are collaborating.

**Over the years The 'IN' Group has supported our research and not only that, have supported some of the younger people who are very interested in nerve and muscle. Two years ago some of the money that was raised helped us to employ a "fellow" who was actually doing research into nerve conditions. That person has gone to Canada, has written about ten papers. Trail blazing work, and now she's coming back next year. She is going to be part of the next generation of people who are active and interested and passionate about nerve and muscle.**

**I think you need to know that your work throughout the year actually does make a difference to everyone. It makes a difference to you here and it will make a difference to the next generation so it will be just like leukaemia, 1963 to one day a cure.**

**Thank you very much for your support.**

### **Question Time**

**Question: Swine Flu Injection.** There was a tick sheet that said that if you had had GBS don't get the flu injection. I rang my neurologist and asked about it and he said "the jury is still out. Make up your own mind" so I decided not to have it. What is the story?

Answer: **The Swine Flu is a very interesting case.** You don't really want to get Swine Flu. In (I think 1968) there was an epidemic in the USA of Guillain-Barre` Syndrome. It was related to the vaccine given in that year which contained Swine Flu. Subsequently there has never been an epidemic of GBS above the normal rate for swine flu vaccination or any other vaccination. I think that year tainted what people should or shouldn't do.

**Question: If you have CIDP and you have the Swine Flu Vaccination, is your risk of a relapse higher?**

Answer: **The short answer is it may be a little higher.** It may be that everyone in Australia had a risk of say 1 in 100,000. The risk of someone who has GBS or CIDP or MS may be 1 in 90,000. It still means that the risk is low. **But the risk of having Swine Flu is much higher. If you got Swine Flu you would be very sick, and what I tell my patients is in fact to have the flu injection.**

I am on a committee for the government looking at Swine Flu complications. At the moment (it was started about two months ago) we have not yet met. That means that it is not going to be this high frequency occurrence.

I am not your doctor and you should decide. How I look at it is that, having a problem from it is lower than having swine flu. That's probably the way you need to look at it.

**Question: Anaesthetic.** I have **CIDP** and recently had anaesthetic and I went down hill for probably about 2 to 3 months. I am just starting to come back up. **Does anaesthetic affect it?**

Answer: **People who have any nerve or muscle problem can run into problems with anything that puts you to sleep and makes you weaker.** It may be the normal recovery process that everyone gets but it may be a little longer because you don't have the capacity to get back to normal. It probably knocks you around a little more, but it's not the anaesthetic. Once the anaesthetic is out of your system it is gone. It doesn't hang around long. It probably has to do with your fitness, your recovery, how much reserve you have rather than the anaesthetic. But it's good you are getting better. You will get back there.

**Question: Encephalitis. Is it related to Guillain-Barre`?**

Answer: That's a hard question. Encephalitis means inflammation of the brain, but **there** are variants of GBS where you can have an encephalitic component. There is conditions called **Millar-Fisher Syndrome, which is not encephalitis**, but there is a thing called Bickerstaff Encephalitis. Bickerstaff Encephalitis is at one end of Millar-Fisher/ GBS. You can have that as part of, but to normal doctors Encephalitis is inflammation of the brain from a virus.

**Question: CIDP. Is it common for it to attack nerve roots and if it is, should we with CIDP have an MRI at some stage to determine whether the nerve roots are being damaged or does that manifest itself in the severity? I am told it is peripheral but I have read where it can attack nerve roots as well.**

Answer: The Central Nervous System is from the brain to the spinal cord. **The peripheral nervous system is actually from the nerve roots to the muscle. Having involvement of the nerve roots is still peripheral but it is more central.** It just means it is closer to the spinal cord. **There are in Guillain-Barre` Syndrome for example and in CIDP you have the same issue, some people who have most of their inflammation just as the nerve roots come out of the spinal cord. They may have back pain or a variety of things. They may have a discomfort, bladder problems or other things, and that's because those nerves have been mainly involved.**

We see that particularly in children. The nerve roots tend to be more involved than the peripheral nerve, but it is all still the same disease.

Now why is the nerve root more susceptible? It is because the blood/nerve barrier is a little bit deficient as the nerve goes out of the spinal cord. Whether to do an MRI? MRI's are hard to come by. Most of the time your doctor should be able to pick from the tests that you have had. An MRI just shows you what you know. What is the treatment? Exactly the same, therefore if it is not going to change anything, don't do it.

**Question: Exercise. I have a friend who tells me I should do exercise and that's going to help strengthen my muscles, but I've found although I did start to do exercise, I get so tired afterwards, it knocks me out. I really don't know the answer. I can't find a way to explain to them that it's not helping me. I would like to do exercise but I don't want to do it if it is going to make things worse and I know if I don't do any exercise I won't be able to walk at all, so I am left without any answer from doctors or anyone.**

Answer: If I was given a dollar for every time someone asks me that question I could fund the research for the next 20 years. I guess I will give you two things.

There was a **very important paper published in one of the neurology journals this year** talking about exercise in Neuro-muscular diseases. Neuro-muscular is nerve and muscle conditions. Doctors have always been on about you shouldn't do exercise as it might hurt your muscles and you do get fatigued and everything else. This study **clearly showed that people who did some exercise with Neuro-muscular disease did better. There is no question, you need to do exercise. The question is how much.** You know how everyone says when you go to the gym., no pain no gain. I have switched that around. **For my Neuro -muscular patients, pain is no gain.**

**So if you are overly tired after the exercise or it is hurting - you are doing too much.** Just the same as you go to the gym and your son or your daughter goes to the gym, the first time. They feel really good and they overdo it and they tear a muscle. You know what happens? They don't go to the gym any more.

**You have to set goals, but they have to be goals at an achievable level.** If you find walking round the block wherever you live you are feeling so fatigued and tired the next day, you have done too much. Walk to the post box 100 metres down the road and walk back. You are having some exercise. If the next day you are not feeling too bad, you can do it again.

After a few weeks you will slowly and slowly be able to walk further and you will be able to get round the block. But you have to set your goals over months, not days. The other thing I say to people with muscular disease, **if you don't use it you lose it.**

**Some people live with pain every day of their lives but you have to control the pain. You have to live a normal life and don't let the pain control your life. That's easy for me to say, but there are people here who live with pain every day but they learn to live with it.**

**There are others here who have no pain, but they have FATIGUE. But if the next day they have pain because they have done exercise or they are more fatigued, they need to come back a little bit.**

**Question: I have pain just walking so how can I do it?**

Answer: You have to see whether walking more than you usually manage causes more pain or fatigue. If it does, you have overdone it. A single day or two days of overdoing it doesn't matter, but if you are overdoing it more often, you are stressing nerves that are a little bit sick and if you stress nerves which are a little sick you may tip them over to be sicker and they will degenerate. Slowly but surely. **The 'IN' Group slogan is SLOW BUT SURE, and that's very important.**

**In Guillain-Barre` Syndrome most people recover. Do you know what they all have? FATIGUE! It is the biggest symptom and problem they have for many years. No question. Big studies have said that 10 years since, they are strong and everything else, but they still get tired. They can't do what they could before Guillain-Barre` Syndrome.**

Slowly but surely, active programs, doing a little exercise and weight training, all those things are good, but in the confines of it not hurting and not overdoing it. That is something only the individual can tell, not the doctor.

**Question. You mentioned that CIDP and MS have a genetic component?**

Answer: **MS and CIDP are conditions where your own immune system is fighting yourself. MS, up in your brain, CIDP in the nerve.** There are very rare reports of people having both, but not common. I have seen one child with it and there is probably a report of 20 adults in the whole wide world who have had both. They are two separate conditions, but because they are both affecting white matter **is there some similarity?** No-one has actually clarified that.

So say someone has insulin dependent diabetes in the family. The other family members are a little higher chance of having an auto immune condition, because genes and auto immunity is not one gene but is a multitude of genes. If you have on two sides of the family insulin dependent diabetes, thyroid on another, then there is a little higher chance of those genes coming together, and then the trigger may bring it out.

**Question: Asthmatic?**

Answer: Asthma is not necessarily an auto immune disease, but if you had asthma you have a higher chance of eczema or hay-fever because that's the particular gene that's going to be affected.

**For auto-immune diseases like CIDP, MS, those are the conditions where you have a higher chance if there is another family member.** Eg. In MS – if there is no family history there is a chance in the wide population (because it is different in different populations) of 1 in 750. If there is a family member, like a cousin or something, it is 1 in 100. If you have identical twins and one twin has it, what do you think is the risk for the other identical twin? 30 percent.

Therefore it is not just the genes; it is the environment at that particular time, plus having some susceptibility for this to happen. That's why none of these conditions are anyone's fault. It just happened.

**Question. Have you ever looked at children with GBS or CIDP as to whether they are more prone following the condition to being more susceptible to high temperatures, colds, etc.?**

Answer: **No.** In fact kids with Guillain-Barre` Syndrome could have had multiple viruses in the past and never triggered and then they get one particular virus at that particular time is the trigger. So there are things we have to unravel and understand but there is no question if you are susceptible to it, the same trigger that everyone else has got will bring it out and its not just one gene. It's not like if you have had GBS then therefore your child was more likely to get it. It is a little bit higher but it is so low it's not worth worrying about.

**Question. What about Bells Palsy?**

Answer: **Bells Palsy is not really, genetic,** but there are families that have recurrent Bells Palsy but they have an underlying problem in their nerves and **we know the gene** for that but normally it is not an inherited thing.

**Question: GBS – to get the nerve to regenerate or repair, is there a correlation between heat or cold? Shoes or no shoes? What is the best way to make your feet more comfortable?**

Answer: I think it is trial and error. Nerves regenerate at 1mm per day.

**Update on Stem Cells.**

My view is Stem Cells will have a huge impact on nerve and brain, but not in 2009. Melbourne has two major stem cell research areas and there is no question that these are the things of the future.

We have now used stem cells in mice with muscular dystrophy. Stem cells have been used in conditions which affect the spinal cord, usually in mice, injecting it, etc. etc. People have used it in the Netherlands. You will find them and they will say you can come to China, you can come to the Netherlands, you can come to Germany. This is the cost. To be honest I don't know what they do. They say they are stem cells. They inject something. It costs you a lot of money. There is no guarantee.

So what I would say is that your doctor will tell you when stem cells are applicable, because that will become available for everyone.

Do I believe Stem Cells have a place? Yes, 100 percent; but not in 2009.

**Question. Are there trials in Australia for this class of condition; MS, CIDP, GBS?**

Answer: **In stem cells, not yet**, because even the German groups are not doing research. What they are doing is saying we will provide the treatment. We will fix it. When someone says they will cure it and you haven't heard about it on the front page of The Age, then you have to worry about it.

In Melbourne there is a lot of research going on in all those conditions. Stem cells -- no, because it is not part of a big collaborative study but that will come. We are **now doing some genetic treatments at the Royal Children's Hospital in a muscle condition**, part of a world wide group, so it does come and all our centres are involved in those sorts of studies.

**I guess the short answer is, it is going to have a huge impact, but not yet.**

Melva - One of our members had Stem Cells. He had multiple conditions. His health was extremely compromised before they gave him his Stem Cells. He sends update emails. He is now able to walk around his block with a frame. He has achieved so much but he has done it in little pieces.

Andrew's Reply: I remember I was in New Orleans when I saw my first GBS patient. I am a paediatric neurologist and then I did adult neurology. This guy was on a ventilator for a year. A whole year! If we gave him stem cells sometime you would have thought he would get better, but two years later he was walking, doing those sorts of things anyway, so sometimes depending on when you give treatment, it may not be that treatment. That's really what I would have to say.

It's like migraine. Kids who are given a tablet and their migraine goes away. But migraine goes up and down so it depends when you give the tablet to say whether it is actually working. I think the problem is one case could be true and that would be fantastic, but one case is not the answer.

**Treatment of Depression, sits alongside having chronic illnesses.**

**I think the worst thing doctors don't do is – they don't look at a holistic approach to the person.** It's mind, body, brain. A lot of people with chronic illnesses may have an



element of depression or grief. Grieving about the changes in their lives and these should be talked about and tackled very strongly.

There are a lot of individuals, particularly after Guillain-Barre` Syndrome who have some depression; say a 20 year old that has GBS, is on a ventilator, is walking now with braces, previously an avid sports person, you would expect some reactive depression. So you need to be looking for those people. You need to be treating that, whether by counselling versus medicines or whatever. Depression is quite common with it and that has to be tackled.

**Question: What is the story with stress and people with CIDP? What is the effect of stress on their bodies?**

Answer: Again, if I had a dollar for that question. Stress can play a part in everything. Stress is an emotion but **it** does have physiological changes. People will have different changes in their hormone levels, other things like that. And those things may affect nerves, muscles and how you actually respond. There may be a physiological effect. But you have to look at your illness and see if stress is actually a contributing factor or not. People who on a day to day basis have stress sometimes doesn't do so well either. So you have to **learn how to control your stress to relieve stress**, for stress is a part of our lives. One of the things I do **with my patients is I teach them bio feedback**. Has anyone told you about bio feedback?

**Self hypnosis. That is bio feedback. It is using some feed back that you can hear or see to actually do something to yourself and that tends to relax you and then reduces hormones.** One of the things I get some of my kids and adults to do is wear a heart rate monitor. When they get stress their pulse is 100 and something and what they do they look at it and will that heart rate to go down to 80 or 70 and they can control that. Doing that by willing and concentrating to do those sorts of things, **the stress actually dissipates and goes away.**

Or putting yourself in a different place because ultimately you are having an illness where you are not doing the things you want to be doing. You want to do this and you can't. All those things are going to initiate stress so how you cope with it is probably more important.

**Stress can cause Bell Palsy; it can cause an exacerbation in MS; it can cause epileptic seizures in children with stress but is it that or part of a lot of things?** I can't tell you if that is the case, but what you have to work on is mechanisms to cope with that - to take that away from the equation. The heart rate monitor has worked for many of our kids and adults I look after.

I know that **I had some surgery about a year ago. I got hit by a truck on my bike and I didn't want to have an anaesthetic** because I had a full day of work the next day and what I did was **I actually did exactly what I teach my patients and their families. I listened to the beat of the monitor**, (the oximeter), and I willed my heart rate to go down and they kept looking under the screen to see if I was alright, because **my heart rate was so low**, and in fact **I didn't feel anything because that was what I was concentrating on.**

**Question: Are you saying you had no anaesthetic?**

Answer: No. I had local anaesthetic; **local, no sedative** and I can tell you they were banging on bones and everything else and grinding and I could hear it and feel it but all I did was concentrate on that machine. **It is do-able but it means it takes practice.**

**Question: I read somewhere that one way of inducing calmness is to concentrate intensely on what you are doing. Is that the same thing you are talking about?**

Answer: **You focus on one thing and that takes away all the other things.** It is like when I am at home and at the dinner table and my wife's talking to me and I'm concentrating on the newspaper. (This is not being recorded and being sent to my wife I hope!)

**Secretary, Peter McInnes.**

Andrew, I think we will terminate questions here as you have been marvellous. The clarity in which you presented the information to us today has been certainly appreciated by everybody and the interest in what you had to say is the result of the questions.

You know of course that most of the people in this room have a direct personal interest in your research and those of us who do not, certainly have a concern for some reason. We are extremely grateful that someone like you is involved in a research project like this and we would certainly like to in our modest way, offer our support.

For that reason I am going to present you with two things. The first is an envelope which contains **a cheque for \$12,000** and the other Sir is to support you. I have no idea what this bag contains but if my suspicion is correct I recommend that you drink it whilst sitting down.

**Andrew's Response: This is a most generous gesture and I know how hard everyone works during the year to help provide the money. This is mind-blowing stuff. I know from other fund raising things I do, how hard it is for people to put in the time, and behalf of my research group, the fellows, the people who actually are going to use this money to make a difference, I just say a big "thank you" for everything and I can only hope that we can come to some huge breakthrough at some stage and help you even more. Thank you very much.**

Melva replied: **The cheque is from our members. The committee is overwhelmed by their continued generosity. We only have approximately 250 members world wide, yet they come up with this donation practically every year.**

(Unfortunately Andrew's mother had been admitted to the Alfred Hospital that day, but before leaving he said "**Just know that any time you would like me to be here I will be here.**")

**WE SINCERELY HOPE THAT ALL IS WELL WITH HIS MOTHER AND THANK HIM SO MUCH FOR HIS RESEARCH AND THE TIME HE TAKES FOR THE 'IN' GROUP.**

**Dutch Auction**

A special “Thank You” to committee member **Peter Males** who stepped in at the last moment to do the Auction. He did an excellent job. Thanks again Peter. We raised: \$642.

**Email Addresses**

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

**Paid Up Membership**

Thank you to all those who paid their Annual Subscriptions on time and for your generous donations. For new enquiries and those who require it, our form for purchases, etc., is below.

<b><u>THE ‘IN’ GROUP</u></b>	
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	
<b>Subscriptions due on the 1<sup>st</sup> July of each year.</b>	
1 <sup>st</sup> July 2009 – 30 <sup>th</sup> June, 2010.	
I am happy to help The ‘IN’ Group by my membership.	
Initial Joining Fee	\$10 \$
<b>Annual Subscription</b>	<b>\$ 15.00</b>
Other Items	
Booklets- <b>The Road to Recovery A-Z</b> \$6	\$
- <b>Boy, Is This Guy Sick</b> \$2	\$
- <b>CIDP</b>	\$2ea \$
- <b>GBS</b>	\$2ea \$
<b>Slippers – Woolly Foot Warmers.</b> (\$25 each includes Postage)	
Please circle size and colour required.	
Colours: Pink/Grey/Cream	Small Ladies 5 to 6
	Medium “ 7 to 8
	Large “ 9 to 10
	Mens 7 to 8
	XLarge “ 9 to 10
Donation to support medical research	\$
(Donations of \$2 or more are tax deductible)	_____
(Tick if receipt required ..... )	
<b>Total Payable:</b>	<b>\$_____</b>
Enclosed is a cheque/money order (payable to The IN Group)	
<b>Membership Details</b>	
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	

### **Geelong Cluster Meeting**

The next meeting will be held at Margaret & John Widdicombe's home on 20<sup>th</sup> February at 2pm. Please RSVP to either Dee Cooper 5244 3382 or Margaret Widdicombe 5244 5311. Come along and meet supportive people, socializing and making a difference.

### **WEB SITE**

Have you visited our new website? We can be found at [www.ingroup.org.au](http://www.ingroup.org.au).

Each month several enquiries are made through the website by people newly diagnosed or with a variety of neuropathy conditions.

Over recent weeks we have had 3 gentlemen via the internet; the first recovering from GBS in Queensland, another newly diagnosed with peripheral neuropathy awaiting an appointment with a neurologist and the third caring for his wife who has CIDP.

This week a lady phoned from Wangaratta asking for help for her father who has CIDP. One of our members agreed to phone and give support. Our unsung helpers. Thanks to those who help us in this way.

**DON'T FORGET OUR FIRST MEETING FOR THE YEAR IS A NIGHT MEETING**

A small plate for a light supper would be appreciated.