

# 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](http://WWW.ingroup.org.au) email: [info@ingroup.org.au](mailto:info@ingroup.org.au).

**NEXT MEETING, SUNDAY, 20<sup>TH</sup> MAY AT 1.30 PM**

**BALWYN LIBRARY MEETING ROOM, WHITEHORSE ROAD, BALWYN, VICTORIA**

**A small plate would be appreciated.**

## Upcoming meetings

- August 19th. AGM            1.30pm. Guest Speaker, Neurologist, Dr. Richard Stark**
- November 18th.            12.30pm. Christmas Luncheon**
- February, 2013            1.30pm. Occupational Therapist, Caulfield Hospital – Name to be advised.**

## Notes from February Meeting

**Brisbane Cluster Group** – Helen & Barry Henzell email: [bmhome@bigpond.com.au](mailto:bmhome@bigpond.com.au)

**Geelong Cluster Group** – Not having formal meetings at the moment. Contact for assistance in the Geelong Area only - Jim Coates on [jimsade@bigpond.net.au](mailto:jimsade@bigpond.net.au)

## Talk by Scott Edwards, Neurological Physiotherapist.

Thanks for having me here. It is a real pleasure to be here. I think your group is terrific. I was speaking to Doug and Margaret and earlier to Melva and the way you band together people with such rare conditions is quite admirable and looking on the website and seeing your newsletters over the years, going back about 12 years, is really helpful as well.

I am a physiotherapist and I work in Melbourne and I have worked in neurological rehabilitation. I imagine most of the people in the audience would have had GBS or CIDP. Can I have a show of hands if you have or have had these conditions? The nice thing about The 'IN' Group is the way it brings in other conditions as well. Over the last two years I have been working with the Neurological Rehabilitation Group in Mt. Waverley and Windsor where I have actually seen more CIDP than GBS. I have seen a variety of conditions including body myositis where the patients don't actually have a neurological condition as such, but it is an inflammatory disorder of the muscles and the medical treatments that are available to them at the moment are quite similar in terms of 'Intragam' treatments, with varying degrees of success.

Does anyone have **Multi-Focal Motor Disorder** here? Does anyone have **peripheral neuropathy**? We have a broad range of people here and hopefully the information I give today is relevant in terms of what physiotherapy can offer.

It has been 10 years since the last time a physiotherapist has (I think it was Mark Hinson) talked to The 'IN' Group and he worked at the Austin Repatriation Centre and talked more from an acute point of view, as in the acute hospital system, where he was working at the time. **I have worked in the hospital systems as well, but I prefer to give more of a community focus, which might be helpful as you are living in the community dealing with the consequences of the conditions you have and the problems that you are still experiencing.**

The first question I ask myself when I'm looking to do a talk like this is **"What research there is about physiotherapy?"** Physiotherapists like to base what we do on scientific research. Unfortunately, with neurological rehabilitation, research is trying to get enough numbers to find meaningful results and with GBS and CIDP it is sometimes hard to get enough numbers to get meaningful results. There is a little bit out there but most of it is poor quality and you can't draw really accurate conclusions from it. There was a recent study done in 2010. It is called a Cochrane Review. Has anyone heard of Cochrane Reviews? Essentially what they are is **one of the highest levels of research that can be done in terms of Scientific Research and Medical Science Research. They do a systematic review. They look across all the different studies that have been done around the world and they draw out those studies and pull them together and analyse how good they are and try and draw conclusions from them.** This Cochrane Review did a study on GBS and physiotherapy and unfortunately they only identified a few studies that were of any reasonable quality. Basically, **they let us know that a lot more has to be done**, particularly in terms of longer down the track. It said that there is enough evidence from the research that physiotherapy can help when you are in hospital, but there is not a lot of research that helps later down the track. This doesn't necessarily mean that just because there is not enough research, that it is not the case. What physiotherapy draws from the research at the moment around GBS and CIDP and other inflammatory neuropathies, is the role of natural recovery, and physios play a role in helping to maintain the level of ability, or work with the body to try and get it better.

We use techniques that we know work for other neurological conditions and we try and translate them to the specifics that we know about people with inflammatory neuropathies. We know quite a bit about what people present with later down the track. There is a really good study from the United Kingdom 2 years ago and they did a questionnaire. (Doug was saying that when you join The 'IN' Group you do a questionnaire. That is really helpful to pass on to therapists so they get a clearer idea of what's working and what the main problems are.) But, this particular study from the UK talked about what some of the major problems were, long term, with inflammatory neuropathies. **90% of the 884 who did the questionnaire said they had seen a physiotherapist.** I imagine that most people in the room have seen a physio at some point. Can we have a show of hands for that? **Particularly with GBS** if you are going into hospital and you quite quickly deteriorate, **you need physiotherapy**, but along the way most people get advice from a physiotherapist at some point.

Fatigue is identified as a really big issue and **60-70% of the 844 placed fatigue in their top three problems** still. **Is anyone still coping with fatigue? Is it a bit of an issue? Yes, I notice it is a really big issue. It is often under treated and under recognised particularly amongst health professionals. Pain was also much higher reported than people were expecting from the study. Does anyone suffer from pain as a result of their condition? Not quite as many as fatigue but still quite a high number of people.**

Some of the ongoing problems that this questionnaire brought up was people when they are out of the hospital system and back home still complained about decreased abilities, decreased strength, decreased quality of life – not being able to get out and do the things that they wanted to do, or were doing better before, and then those last two, fatigue, being a bigger issue than people probably recognised, and pain.

Physiotherapists can help with these conditions and neurological physiotherapists in particular are well equipped to deal with trying to help with some of these problems. My role today is hopefully to try and explain how we can offer assistance or advice. I guess the trouble with talking about a group as broad in range and scope as inflammatory neuropathies, is that some information is going to be relevant and some is not going to be relevant, **but the nice thing is hopefully there is a bit of relevance there for everybody somewhere along the way.**

Physiotherapists, particularly those that work in rehabilitation are very good at turning neurological recovery into improvements that actually matter to the person involved. Being able to get yourself back to whatever you wanted to do; going back to work; going down to the shops; getting yourself around; getting yourself running again in the case of GBS where you are particularly fit. With all those things physiotherapists can help. We like to work with the neurological system to do that.

I'm sure everyone here is aware of **neuro-plasticity**. It is a **relatively new term** being used a lot more these days as we understand more and more about the body and we can look more in depth into studies that look at the physiology of what is happening in the nerves and the function of nerves. What we know now is that nerves are very plastic in that they can change a lot. Plasticity is a term associated with changing the neurological system. The neurological system is very good at finding new neurological pathways in the body. If some are damaged and not working as efficiently because of inflammation, we can try and tap into ways of doing things in slightly different ways, The body is much more neuro-plastic than we ever thought it was previously.

What I thought I would touch on is, what your experience is likely to be with physiotherapy across the board, of having whatever condition, or waiting for a diagnoses. All those things that unfortunately happen when you have the rare conditions that you have.

The first thing is to go back to what Mark Hinson was talking about 10 years ago with the acute physiotherapy. It's not like everyone here has been to the acute ward because of their condition, but has anyone been there because of it? **Does anyone here have GBS and did you ever go into the acute section of the hospital?**

A member said **"No. I went into a general ward because they had no idea what I had."**

That is such a common thing. It is so annoying. I can't imagine what it would be like going through something like that. **Did you need any breathing support?**

**"No because I had a rare variant of a rare disease so I didn't, but I did have some breathing problems later on, so I did need ventilation when in rehab."**

Another members said, **"I had two and a half months on life support and 4 months in hospital."**

It must have been really intense. **At that time you find that physiotherapists are more involved in giving respiratory care. Sometimes they are using particular types of breathing equipment and if you have the more common form of GBS for example and you do deteriorate quite quickly and you lose the ability of your breathing muscles, you may need a physiotherapist involved at that point. Otherwise you are quite sick, you are medically unwell, and a physiotherapist would help with other things like stretches, positioning, splinting and maybe starting some gentle strengthening exercises to get you going.**

Another way a **physiotherapist is involved is post-acute**; after you are medically deemed well enough to move onto rehabilitation or into an inpatient ward. It might be if you have CIDP, you have been **an inpatient in a rehab. hospital because of a relapse**, (if you have that particular variant) or for **a burst of rehabilitation** because you were struggling a bit at home.

**Has anyone been a rehab. inpatient in a hospital? Yes a few people have been. Barbara: At Cedar Court. Scott: I used to work at Cedar Court. How long were you in there? Barbara: 4 weeks I think. The swimming in the water was the best part. Scott: Absolutely. Swimming is such an important part of physiotherapy with inflammatory neuropathies at any stage. In the rehab. centres, that is likely to be when you start a gym program, particularly at Cedar Court, now called Epworth Camberwell I believe. You are probably doing two sessions a day, 30 minutes a day of exercises. You get going with exercise physiologists who run gym programs and pool programs. You are starting to more intensively strengthen and start to do functional activities, to try and improve what you are able to manage at home.**

That is all hospital based therapy. **The crux of what I want to talk to you today is about the community side of physio. and identify 7 major roles of physio.**

1. Later as you are **in the community** and you are living at home, you may be living quite rurally. A **physio can help** in these areas. Any sort of physiotherapy that you do with someone when you are in the community and you have an inflammatory neuropathy, it really should be in the context of **what you want to achieve** and what **your particular set of circumstances are**, rather than what your goals are. The **physiotherapist should recognize that and help you through it.**
2. The second thing is **cardiovascular exercise**. Does everyone know what cardiovascular exercise is? **Essentially it is heart and lung fitness.** It is feeling fit.
3. **Fatigue management.** We talked about **fatigue being often under treated** and I think it is important to recognise it.
4. **Encouraging self management.** I know one gentleman lives in Bendigo and it is quite easy to access health care there but **in more rural areas it might be hard to get to a physiotherapist regularly. Finding ways to encourage to self manage a problems and stay as well as you can are really important.**
5. **Strengthen** in everyday ways.
6. **Hydrotherapy**
7. **The role of equipment.**

The **first thing I identified** as a really major role that people like myself and others that work in the community who work with you guys is, **to make exercises really contextual. Everyone with CIDP or GBS or peripheral neuropathies, even if they don't know what they have, they have certain things they want to get better and it is really important to focus on them.** It might be that it is best for the physiotherapist to see you in your home and a lot of **physiotherapists do come to people's homes**, because there is nothing like **seeing someone in their home environment to see the real shortcomings in what people can do, whether it is going up a flight of stairs; all those sorts of things.**

The second is **cardiovascular exercise**. It is something that **can fall by the wayside** a little bit for people with inflammatory neuropathies. There is such an emphasis on the medical management, **trying to improve the neurological function of your nerves**, to try and strengthen and get through daily tasks, that **you forget about the overall fitness of your body**. Most people when they think of **cardiovascular fitness** and trying to get exercise **they think of very aggressive fast sports like running or on an exercise bike** and that sort of thing, **but really all we are trying to do is get a sustained period of time when you are doing some form of exercise that you are capable of doing**. In the pool is a very good way. **If you have trouble with your legs you can do it on an arm bike**. There are **arm bikes that you can get but in the swimming pool** is a particularly good strategy. **You can do riding in the corner if you are going in the pool**.

Do many people **go in the pool as a regular therapeutic treatment**? Quite a few people do. It can help to keep you fit. **Keeping fit will help manage fatigue and it will also give you more energy to do the things you want to do during the day**.

There is obviously **a risk of doing too much**. That is an issue as **if you do too much fitness work you are likely to suffer from that and not get the gains**.

If you were going to **start cardiovascular exercise you would start with 2 or 3 minutes and hopefully doing it a few times a week**, but the idea is you are trying to get your heart rate relatively high so you are working quite hard on your body to try and get this type of fitness. You are **trying to work at 60 – 85% of your maximum heart rate**, which is really quite high – getting up into the hundreds with your heart rate, probably **potentially around the 120-130 mark for a little bit**. By doing that you are **making your heart and lungs fitter and that gives you more energy for doing other things**. Gradually you would work up to say **20 minutes, 4 or 5 times a week as an ideal**.

**Fatigue**. Another thing with fatigue, (we don't know this for sure) but **we assume in some respects fatigue may lead to a slower natural recovery**. It could also **lead to a deterioration** so if you are trying to maintain a certain level of ability or a certain level of functioning, **if you are constantly exhausting your body, it is not going to be helpful in maintaining your level of ability and certainly not promoting any further recovery**.

If you are receiving 'Intragam' or any of the trial medications like Prof. Andrew Kornberg at your last meeting was talking about 'Fampridine' an exciting drug that could potentially increase nerve conduction, and you are constantly exhausting your body and at the end of the day you just can't possibly do any more, then you need to look at that. A physiotherapist can guide you.

Has anyone seen an occupational therapist before? **Occupational therapists are terrific**. They are really helpful people and they also can be involved in the community setting. You can see them as an **outpatient at a hospital or at a community rehabilitation centre**. They are really helpful in **helping to manage fatigue**.

Strategies include trying to conserve energy; having **structured workdays**; having **deliberate rest times and not doing exercises on every day of the week**. Essentially the main idea behind making sure you are not too fatigued is **if you are feeling tired at the end of the day, that's okay, but if you are still feeling tired the next day afterwards and really exhausted you are possibly doing too much and you are possibly over exhausting your body**.

Not everyone can see a physiotherapist all that regularly and really people with your conditions, (those present at today's meeting) are very capable of dealing with the problem on their own. I can see all who have come in today are trying to find out the latest information by talking to each other at this support group. At this point the **physiotherapist in the community takes on more of a guidance role**, a consultative role, about **trying to get the balance right between exercise, the right exercises, and what you can do**.

Other people come into play.

**Does anyone see a personal trainer or go and see a massage therapist or a chiropractor? Member: I have one come to me. Is that a massage therapist? Yes. Scott: They can be very helpful with pain and lots of the people with pain benefit from massage. Member: It hurts a bit at the time but afterwards it is much better.**

**Scott: Does anyone see an osteopath? Member: Yes, I go to a chiropractor and I also go to Yoga.**

**Scott: Yoga can be absolutely terrific if you can get yourself into that; so much flexibility; a holistic way to move. It is terrific for most of your body. Member: I might not be able to walk well some days but I can still do Yoga.**

**Member: I found an occupational therapist and they gave me all the exercises to do and now I go twice a week to the pool; a warm water pool. Scott: What they teach you sticks doesn't it? Member: I feel really good the next day. After a couple of days I go down again so I go back to the pool and then I'm up again. Scott: It sounds like you have got the balance right.**

**Essentially this is what my point is. It is about what this gentleman is doing. Managing his own condition and if he needs some advice he can go back to the occupational therapist. If you feel these dips and peaks are too much in your week and there is too much dip in between, maybe you can find strategies to help with this.**

**Member: They do put you through a lot of things. They teach you how to get your balance right and how to use an exercise bike in the pool. It is an hour, but you get a different structure of things, like on the bar, etc.**

**Scott: Your program sounds really well balanced.**

I notice with many people in this room **it is about maintaining a certain level of function** rather than getting cured but hopefully the cure is around the corner. It is about getting as good as you can or **even improving the best as you can from what you are dealing with at the moment**.

I think this is really interesting and **neurological physiotherapists in particular, are quite skilled at this**. It harkens back to what I was mentioning before about what we know more and more about, **the concept of neuro-plasticity and how the body can remember things it used to do. Sometimes people call that muscle memory**.

You can imagine that when you go skiing for the first time in a couple of years, (water skiing or snow skiing) and initially you are very sore and tired until **your body remembers what it used to feel like and you go back into it quite quickly, even though it might have been 10 years since you have done it. You quickly remember what that feeling is like. What we know about strengthening muscles and neurological recovery, the way the nerve pathways fire is probably even more important than how strong the muscle**

is, so neurological physiotherapists are quite good at creating strengthening exercise programs that really target trying to get back doing things you want to do in the most efficient way possible. We work with the neurological system to do that.

In other words, if we are trying to improve going up stairs and you come in saying you are struggling to go up stairs, then a neurological physiotherapist might take the approach of practicing some things like knee control when standing against the wall. What that does, is put you in a position similar to that needed to be in when you are going up stairs, so the body can somehow remember that feeling. Then you can work on particular skills that you require to do that task. It is hard to explain really. Is it confusing anyone?

Often they combine two different things. People can get really long exercise programs where they have to do lots of bed exercises or just bending your arms up lifting weights. That's helpful in itself and some people really benefit from that, but if you feel like you are doing too much and you are focused on a particular goal, like walking, going upstairs or going in the bathroom, or going back to running or playing sport again, physiotherapists can help you to find the right sort of exercises that combine balance with a bit of strengthening, in the same functional position you need to be in to do the goal you want to achieve. The evidence suggests from other areas and other neurological conditions, what we know of the physiology of nerves, can be really helpful and effective.

**Water Therapy.** I think it was Bill Stephens two years ago who talked to the group and he was a pool aerobics instructor. I saw it on your excellent website. His talk, which was really interesting, was about **the benefits of water exercises** and quite a few people have been doing water exercises. I think it is great, particularly for pain management, as the freedom of movement you get that perhaps you don't get on land, can help you do quite a bit of strengthening and also help you get a cardiovascular workout as well. This makes you fitter in your heart and lungs, which reduces fatigue and increases energy.

One warning - If you are thinking of starting a hydrotherapy program or a water therapy program, be aware of **not doing too much the first couple of times**. The freedom of movement and the warm feeling of the water may make you feel you can do a lot more than you really are capable of and you can end up suffering for that initially.

The last thing is **the role of equipment to help manage better**. Occupational therapists, who are really helpful with things like fatigue management, are also helpful with equipment. If there is a particular thing that you want to do that your body just can't do, physiotherapists and occupational therapists are good at finding answers and solutions that may exist in the "equipment world".

Things are always changing in the community. There are **always new ideas** coming out. For example, in recent years **there has been a lot of electronic stimulation equipment that has come out and helped people after a stroke to lift their toes up when walking and not drag their feet which has been revolutionary**. There are a lot of different types of equipment out there. Sometimes, in your own research on the internet or when talking in support groups like this, **you may know about something before a therapist does, so I often have people come in to my practice and bring up an idea that is just terrific but I wasn't fully aware of**.

I have mentioned some things here like wheelchairs, hoists, mechanical hoists, modifications to cars and obviously different walking devices. There are lots of different ways you may need to consider. It is often not until you get out of the hospital system and get home and it might be a few years down the track or you might,

unfortunately, have a little bit of deterioration in your neurological function and not be able to do quite as much. You realize some of these things are a little more difficult. It may be you know someone who is playing a carer role in terms of doing up shoelaces or helping you to dress, along those lines, or perhaps a carer may unfortunately injure themselves, or you want to stop that responsibility burden on the carer; there are strategies to get around that.

**Member:** (Holding up something) What are those? **Scott:** They are **a pair of shoe laces that you don't have to do up.**

**Member:** I like that. **Scott:** They are elastic, spiral. You basically pull them with one hand and they tighten up and they stay quite tight. **You can put them in a normal pair of shoes.**

It is **little things like this that save you from pain or fatigue** and potentially **give you more energy.**

In summary there is little hard evidence, we know that, but we know that **physiotherapy works.** People with your conditions later down the track, physiotherapists are quite skilled with helping you cope within the community.

**Remember to manage your fatigue as best you can. Find a way to incorporate a little bit of fitness into your routine so that you are staying fit. This will help with fatigue and give you energy. It is really important that the exercise program should be related to doing things you want to do. It shouldn't be there just for the sake of doing it. It is really to help you do what you want to do.**

**Any questions?**

**Member:** **I do a bike ride on an electric bike.** I only do  $\frac{3}{4}$  of the ride as it is hard to know if it would be too much. It is a 30km ride with a group. I feel okay but my calf muscles get a bit tight. **Scott:** You are doing well.

**In some conditions it is not good to overdo exercise. Post polio syndrome is one of them,** where you are **relying on some muscle groups much more than others,** and those muscles are really overworked so **if you do exercise therapy on them too much into your older years you risk totally exhausting those muscles which have carried you for all the other years.**

**Footwear is very important.** There is an interesting concept where **some shoes simulate the bottom of a foot.** **If you are having neurological issues with your feet, particularly with sensation in your feet, your feet really are the point of communication with the ground. If you are getting strange information coming back to your brain and recognising that, it can be very off-putting, so to have something that simulates the bottom of your actual foot can be, in some situation, very helpful.**

**Member:** I would love to get back on the bowling green. **Scott:** **What prevents you from doing it?**

**Member:** **Balance and fatigue.** **Scott:** **How long ago was the last time you did it?** **Member:** **A year ago.**

**Scott:** Is there some sort of adaptive equipment that you could do it with? Do you see a physiotherapist? You do. What does the physiotherapist say? **Member:** We haven't got to that stage. **Scott:** **It would be really**

**good to get you back to it.** I guess one thing you really need for lawn bowls is balance but also knee control, otherwise you just can't get down low enough. **Can you stand against a wall and get knee control? That would be helpful. If you can get that you would be working towards it,** but you need to certainly start in a well supported environment if you were going to do bowls. **It is definitely possible.**



Do you go in the pool? The **pool is a great place you could practice that sort of thing.** I would **certainly raise it with the physiotherapist you are seeing as that is a real goal you would like to work towards.** **There might be a few little goals from being able to get there, but if the physiotherapist has that in mind they should be able to work towards it.** **Do you fall over a lot? Member: I have had 6 falls in the last 12 months.** It took a long time to be diagnosed. I went back to the knee man as I thought they were wearing out.

**Another member:** I had brain scans as **I thought the lack of balance was due to a brain tumour or something.** It took 18 months of various tests. **The doctor had a tuning fork and he put it on my toes and asked, “Can you feel that?” I couldn’t feel the vibrations.** When I was running I would just go off the track. So it is somewhat comforting to have a name for something. **Not knowing what it is, is a really frightening time. That’s why belonging to a group like this is good. You do a bit of networking.** We are not all sort of dying, (laughter) you imagine that is what is happening. **It is good because in a forum like this you can bounce things off people. I had a specialist and he would say, “You’re walking okay. See you later. You have CIDP. Get used to it.” Through here I tried another neurologist and she is great. I now have ‘Intragam’.**

**Scott:** **How many of you have ‘Intragam’? How often are you guys having it? Replies varied from: Every 2, every 3, every 4 weeks. One member told how he had had a booster 5 days treatment and now instead of going every 2 weeks goes every month and his nerve conduction test showed a slight improvement. He said, “A pro-active neurologist is the key.”**

**Member:** **Some of us have a negative idea of what we can do. I took up riding a bike again after not riding a bike for 40 years. I found I could balance better on the bike than I could on the seat of my exercise bike.** I can only go on the flat as I can’t put pressure on my feet. I persuade people to have a go. **An active member of this group came one weekend and I bullied him into it. He kept saying I can’t do it and we put him on a bike and we pushed him around with his feet on the ground. Then he took one foot off, then he took another off and then he started going round and round and we said go down the track on your own and then come back. And he did and he came back crying. He said “I passed ordinary cyclists on the way and not one of them knew I was disabled.” He was doing a normal thing. He had no idea he could do it.**

**Margaret:** Thanks very much Scott. I’m sure everyone enjoyed your talk today.

**Peter:** Thank you for coming and listening to all our gripes, etc. We do get **very good speakers** and so everyone in the group please **come along to the meetings as we really want to see you and you can talk to everyone and hopefully we can help you.**

**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](mailto: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 you 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.

Melva received the following email which members might like to be involved in.

My name is Andrew Markham, I suffer from CIDP and I decided to do something pro-active and set-up a survey into GBS/CIDP to find out more about the illnesses. The only thing I am good at is working with computers, so my survey is on the web: <http://gbs-cidpsurvey.blogspot.co.uk>

I have paid for the survey so the information is not owned by anyone else. I am also doing this entirely independently, for no company, or profit and with no grudges, or preconceptions, I just want there to be more information available about these illnesses and their symptoms so it may help others in lots of ways (e.g. getting diagnosed quicker, so they do not go so far downhill). I was passed your name as a contact for your particular country/region by GBS/CIDP Foundation International. Could you please get your members/patients/sufferers to look at the survey and fill it in (if they wish) so we all can help others. After about 3 months I will do a more detailed report and cross tabulate answers. If you want me to present the results or speak more about them I will be happy to do so. Hopefully I will get over 1,000 surveys completed worldwide and with your help I feel that is possible.

I am contactable via twitter, facebook, email and even have my own experiences on a blog:  
[mycidp.blogspot.com](http://mycidp.blogspot.com)

Please assist and pass the details of the survey on. Thanks in advance

Andrew J Markham (UK)

### **SUPPORT – Hospital visits**

We have been quite busy with support over the last couple of months and would like to again thank Jim Sadler for his visit to a gentleman just out of ICU at the Alfred Hospital. Thanks again. I know Barry and Helen Henzell, have also been doing hospital visits in Queensland. Thank you for the work you are doing for The 'IN' Group. Being able to give information and assistance like you do is truly what a support group is about.

**PRINT POST APPROVED SURFACE MAIL POSTAGE PAID**

**PP 335708/00020**

**AUSTRALIA**

**(ABN) 77 954 503 188**

### **INFORMATION**

[www.ingroup.org.au](http://www.ingroup.org.au) email: [info@ingroup.org.au](mailto:info@ingroup.org.au)

**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: 44 Mavis Avenue, Beaconsfield, 3807. Telephone: 03 9707 3278