GBS ……..CIDP **Issue No: 89. January, 2015.**

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, 22ND FEBRUARY, 2015 AT 1.00PM
Balwyn Library Meeting Room, Whitehorse Road, Balwyn
A small plate to share would be appreciated. Thank you.

Dates to Remember

Sunday, 17th May 2.00pm Guest Speaker to be advised.

Sunday, 29th June. Mid Year Function – Time, etc. to be advised.

Sunday, 16th August 2.00pm Guest Speaker to be advised.

Sunday, 15th November 12.00 noon – Silent Auction and Luncheon

---

Talk by Andrew Kornberg at Winter get-together High Tea

It is not like there has been huge change in the treatment of CIDP and GBS. Everyone would have heard about the **Hawthorn Coach**. I guess the thing about high profile people **getting Guillain-Barre` Syndrome** is that it puts it on the map **and there was a whole lot of interest about GBS after he was affected**.

The **good news is that most people with GBS get better**. It goes away. They may have a bit of weakness but because of the **treatments that we have, e.g. Ivig, plasma exchange, etc**., it has **changed the entire dynamics of that condition**.

There are some things that we still don't understand. Why **a percentage of people don't respond to the normal treatments** and until we have worked out what's different about those people, we really won't know what other treatments we can give.

CIDP, (Chronic Inflammatory Demyelinating Polyneuropathy) is the most common condition that we are actually treating and we are using intravenous immunoglobulin for the vast majority. If we look at all patients with CIDP, the vast majority will respond to treatment with Ivig. It **needs to be given long term, usually between 4 to 6 weekly as an infusion, coming into the hospital and that is for years and years**. There are a percentage of **patients that do well and stabilize** and in fact **some kids go onto the treatment and the disease actually goes away**. In **adults** it tends to be much more of a **chronic** process.

There have been other treatments that we have talked about over the years. We know that you can give medicines that you use for rheumatoid arthritis and other immune conditions (including some leukaemias) where you are **giving a medicine that kills antibodies. It doesn't kill one, it kills them all. It affects the B cells and there are some people where this is actually given when they are not responding to intravenous gamma globulin. The trouble with those sorts of treatments is that there are no real studies, but we have single patients that actually do respond and we also know, from those monotonal antibodies, it does work in an individual patient.**

The problem is it is not funded. The hospital has to pay for that and the hospital is not keen to pay for **those kinds of treatments, but they are available** and I do know that at St. Vincent's and the Royal Children's, **in the right circumstance, we do use those treatments**. **That is something new**. It has been around for a couple of years, but again you have to **pick the right patient to get that.**

I guess **the biggest thing** that has happened over the last year is the use of what we call **Subcutaneous Immunoglobulin**. For individuals who are coming in every 4 to 6 weeks to have their infusions through the vein or a port or something like that, there are now lots of studies to show that **subcutaneous (which means, just underneath the skin**, **not into the vein**), if it is **the right dose, you have the same response**. The good thing about using subcutaneous injections, is you **don't have to come to hospital as it can be administered at home with a little pump. If it works** for the patient, **it actually saves money**. It **saves people coming from the country or to come in to have those infusions and it is overall cheaper to the whole health system because you don't have to have as much care in nursing, pumps, getting all that administration.** It is interesting though, at St. Vincent's when I've talked to some of my patients asking what would they do, it is only **about 30% of people interested in using subcutaneous.**

For people who live in Melbourne it means a trip in, have their day in the hospital and they don't really want to switch. They are also a **bit worried about doing something at home. But it is a safe treatment**. In the **Netherlands** and **America and other places**, that is the way things are going. **In Australia** at the moment **it is not funded**. There is **no funding for subcutaneous**. H**opefully in the next year that will become an option for people**. You may be **approached by your neurologist to say, we can now administer this at home.**

We work out your total dose. Let's say you are on 150 grams every 6 weeks. That would be split up into a weekly amount so you would be given a **smaller dose underneath the skin overnight**.

Member: Every day?

Andrew: It would usually be once a week. It would depend on the total dose because the total dose depends how much volume you can put underneath the skin so it may be split up over a couple of days.

If you are on a big dose the volume that you would need to put under the skin could be a problem, but the good news is that **there are now more concentrated immunoglobulins. It used to be only 5%, then it became 6% and now 10% but there is now a 20% formulation which means the total volume gets down.**

That's the big thing that's going to be available which would help with travel, etc. I know if I got CIDP tomorrow, that's the route I would be going, because I wouldn't necessarily miss work, I could infuse this at home. In children in particular for immuno-deficiency where there is a deficiency of immunoglobulin, subcutaneous is the thing that most people are using.

So that's the big thing that is happening. The National Blood Authority are to look at governance and therapies and treatment so subcutaneous immunoglobulin will be one of the things on the agenda. H**opefully in Australia it will also be funded just as intravenous immunoglobulin is as it gives us different options. It won't work for everyone. It has to be individualized. Some people won't**

be able to administer it at home, but if you have got an option, then you have got an option and it's a much better thing.

The **monoclonal antibodies** have been in discussion before. What we do know at the Royal Children's is that **we have treated a couple of children who had stopped responding and that has helped.** At St.Vincent's I have treated a couple of patients who have **Multi Focal Motor Neuropathy which is a bit different from CIDP but much less common but it works and the hospital did pay for that and subcutaneous immunoglobulin in the right person will work.** It depends on whether you can do it at home or not.

Member: Does the subcutaneous Ivig have to be refrigerated?

Andrew: No it doesn't. It is delivered and stored at room temperature. In the Netherlands self administration, even intravenous self administration has been something that has been going on for years, but it hasn't happened in Australia.

Member: You said that the Government doesn't cover subcutaneous Ivig. What cost would there be and would your private health insurance cover it?

Andrew: No it is still not covered. Immunoglobulins are funded by Federal and State Governments. If you fulfil the criteria for conditions which we call Chapter 5, Chapter 6 and Chapter 7, then you get that funded by the government. Okay, but that's intravenous gamma globulin. There is no difference, except the government hasn't said intravenous or subcutaneous, they have said only intravenous, so until subcutaneous gets funded for chronic neurological conditions, you can't get it. In children who have immunodeficiency it is intravenous or subcutaneous, but not in neurological conditions yet.

Member: Will it ultimately save the government money?

Andrew: It won't save them the money for the cost of the immunoglobulin that will be the same, but the whole system will have a saving. The problem is that when you're the department of intravenous gamma globulin all you look at is the cost of gamma globulin, but the reality is that the cost is paying for an individual to come into a hospital, the days off work, the nursing care, them sitting in the chair within the day medical unit for 2 days, these are the sorts of things that are not usually factored in. When you have other people you want to put in those same chairs, because they are being taken up by someone sitting there for two days, those people are on a waiting list, etc., there is a whole cost where there is a total saving.

But the government is looking at just the gamma globulin cost and there won't be a difference. But to the whole health system, clearly there is a saving.

Member: Have they speeded up the time it takes to give you your 'Intragam'? Years ago it was very slow.

Andrew: They have doubled it. You are talking about the days of 5%. **Now most products are 10%.** There is some 'Octogam' which is still 5% but it will go to 10%. There are some **new ones which are 15%, 16% and 20%** which are in the pipeline. That is pretty good for adults, not so good for kids, particularly babies, as you can't give these concentrations, so there will always be 10%.

Therefore the infusion rate has effectively doubled over the last 5 years. If you get the 20% it won't double again, but it will mean a shorter time frame. **20% will allow you to put smaller volumes underneath the skin.** I remember when people would put 5% underneath the skin. We would find this in America and they would have this huge bubble filled up with fluid, but now when using 20%, (20 grams in 100 ml) you can use much smaller volume**. That would be good,**

particularly if you say do a couple of infusions during the week, either under your arm or into your tummy, you still get the total dose.

Member: Andrew I understand there has been interesting work with MS. Will this have a "spin off" affect with CIDP?

Andrew: Sure. There is one drug which is actually of interest in MS which is an oral drug which actually works in MS and that drug theoretically could have benefit for CIDP. There is a study at the moment looking at that drug which is called Fingolimod which is 'Gilenya' where people are looking at that in patients with CIDP. MS is really like CIDP of the brain. In MS the white matter is affected etc. etc... It is a little bit different, **but the way the pathology works with these nimphosites that are activated, is similar, so that's the hope with those sorts of drugs.**

Member: Do most patients take that?

Andrew: Most MS patients overseas will start off with the injection of interferons. That's the gold standard or the first line therapy, but in Australia interestingly the Fingolimod, (the oral agent) is prescribed as first line. It is the only country in the world where this happens. Everywhere else it is second line. If you have to take an injection versus an oral, you probably would want to take the oral but there are some interesting side affects with the oral agent. Sometimes it is better to know you have 20 years of experience with the drug before you go into something completely different.

Member: What's happening with Research?

Andrew: At the moment at the Royal Children's Hospital we have neuromuscular fellows we are looking at different antibodies in, not just CIDP, but across the board. The IN Group has generously supported our research with the antibodies, etc. over many, many years but over the last few years, as I've said, the neuromuscular Fellow who we train (there is no adult muscular Fellow) many of them come and become adult specialists and they spend a year with us. The money that The In Group has generously donated has always been able to support their research and their work. The reality is that if I didn't have your support, I would probably have a Fellow one and a half years out of three, because that sort of money helps as governments don't give us the money. It is all money which is raised in some way and so it is important.

Margaret: So we will help again. I will hand over to Doug now.

Doug: I've said many times how generous the group of people we have are. We are not a big group but the donations which come through are absolutely tremendous from our people and it has happened again. I have done a quick count and we have made over $700 today. Margaret: I hope afternoon tea measures up. Laughter.

Doug: On that basis, on behalf of The IN Group, from all the people who put in, we would like to present to you again another cheque for $10,000 and we are saying "thank you" for all your time and effort in trying to help all of us.

Andrew: Thank you once again. I think The IN Group may be small but they are big as regards to making a difference to what we actually do. I think I might have said once before that governments provide bricks and mortar, but excellence and the best quality care comes from people giving like you do, to help us achieve what we need to do. So thank you. This actually makes a huge difference to the next generation of neuromuscular people, but also little bits to help us understand all these conditions. Thank you very much and thanks for your hard work.

(The afternoon tea did not disappoint. **Thank you to Margaret and Doug** for opening up their home **and to all those who made and donated the wonderful spread** we all enjoyed so much.)

Notes from the Christmas Auction and High Tea

Margaret: There were a number of apologies for today. Some of our earliest members Barbara, Dorothy and Irma were unable to attend and we send them our best wishes. Also Andrew Kornberg who phoned and didn't sound too well. Get better soon Andrew. Associate Professor Richard Stark and his wife have joined us here today.

We have laminated today's placemats which contain information on **The IN Group**. Please **take them to the hospital where you have your 'Intragam' infusions** and ask that they be placed so other GBS/CIDP patients will know there is a support group for them. Thank you.

We would like to say a really big **"Thank You" to the Committee and some of the committee members' wives who have made sandwiches and helped us today to provide a super afternoon tea** for you all.

As usual the afternoon was most enjoyable with the fun of the Dutch Auction and the friendship shared between all the group. Thank you to Peter Males for conducting the auction and to the "collectors and distributors".

A young mother recovering from GBS and her family came for the first time. It was great to meet the family and to see them enjoying themselves, especially the children.

Email 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 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.

Talk by Assoc. Prof. Richard Stark at Christmas High Tea

Firstly **I should congratulate everyone here who puts so much into this Group**. **I have been involved from the outset and I remember how it started with James Gerrand putting a tremendous effort into this Group.** It has been very fortunate to have people to lead it throughout, from James onwards. It is never easy to run this sort of thing and it always involves a lot of hard work and I congratulate you. I think it is true to say that the focus has changed since the early days when **James spent a lot of time in hospital wards** saying hello to patients and supporting them there and now you give **phone and internet assistance as well as raising funds**. I **know that Andrew Kornberg who reaps the benefit of that more than most is very grateful. I really do congratulate you on all the work and fund raising you have done.**

I guess the thing that strikes me looking around the room is that everyone is different. We are **used to labelling medical conditions as though the label tells you the whole story**. It is probably not true in any condition, but it is especially **not true in inflammatory neuropathies.**

We see people with **Guillain-Barre` Syndrome and other acute inflammatory neuropathies** and if you look at the text book you get a stereotyped idea of what happens with GBS. **But we see an**

enormous range of people with acute inflammatory neuropathies from people who have a little bit of numbness, a little bit of tingling, they come in, they get diagnosed, they get a little bit of Ivig and they are better and go basically back to normal within 2 or 3 weeks. They obviously have a very mild version. Then we see people who spend months and months in hospital and really go through hell and it takes a long time for them to get back on their feet at all and they struggle.

The same is true for **Chronic Inflammatory Demyelinating Polyneuropathy** or different **variants**. There are people who have predominant **weakness**, have predominant **tingling** and **numbing** and people who have **balance** problems. I think it is important that we remember that **everyone is different** and it is great to have support from people who have been through the same sort of thing that you have been through, but **you never meet someone exactly the same as another person with this condition.**

These days**, people have so much access to the internet**. It is very easy to **Google** a condition and it gives you a very one dimensional idea of what is going on. You Google a condition and you come up with an answer or a description. **It is actually bewildering for people who Google when their doctors have said they have this condition but they are totally different** from what is described on Google.

I think a year or so ago I talked about the **different symptoms that people get** with these conditions. It is probably worth just going through some of those things again just to remind people how the condition may behave. **These are conditions that affect the peripheral nervous system. They affect the motor and sensory and autonomic nerve fibres and essentially there are only two things that nerve fibres can do when they go wrong. They can not work, or they can work in the wrong way. They can be overactive when they shouldn't be.**

If you go through the different sorts of nerve fibres it can affect, it will give you the idea of the sort of symptoms people can get with these conditions. **You can mix and match and get any combination.**

If **motor nerve fibres** don't work you feel **weak** in the muscles **around the trunk** and **weakened muscles** in the **hands and feet**. If the **motor fibres are overactive**, you get **cramping** and you get **spasms, tightness and odd feelings** like that and you can get **both** in **different areas at different times**.

For the **sensory fibres, there are fibres that affect the large fibres** that **tell you where your joints are**, when you can **sense your foot is right,** whether you **can feel vibration or fine touch.** If those are **not working the commonest thing is that you have balance problems.** This is because when standing **we rely on seeing, knowing where we are and the joint position sense** telling us **what position we are in.** So if they don't work we feel unsteady, especially when you have got your eyes closed. If the **large fibres are overactive you can get buzzing, tingling vibrations**. The **small fibres affect pain and temperature** so **if the small sensory fibres are not working you won't feel temperature or pain**. This is actually pretty **rare in acute or chronic inflammatory neuropathy**. You have a bit of numbness but it is **usually not completely gone**.

There are **some conditions, other neuropathies where you completely lose the ability to feel pain**. You would think that is great, but the problem is, if **they put their hand on the frying pan they end up with painless burns**. The **more common thing in acute or chronic inflammatory neuropathies is to have overactive pain** so that you get **burning feelings, things feel cold when they shouldn't feel cold or they feel painful when they shouldn't feel painful and that can be quite distressing.**

Finally there is the **autonomic nervous system** which deals with things like your **blood pressure, bowel function** and that sort of thing. People with problems in that area can get just about anything

wrong. A drop in blood pressure when they stand up quickly , they can get too much sleep and not enough sleep, they can get bowel dysfunction. They can get all of these combinations together.

Often symptoms in one person can be totally different to another. I guess what I'm saying is that there is diversity. **You all have similar conditions but every single one is going to be different from the others and the great advantage of having a group like this is you can see other people who have similar problems, but they are not exactly the same.**

I really don't have anything more I want to say only to congratulate you on the work the group does. I know you provide great support for one another but you also give great support to the medical people by raising these funds and I know we are all grateful, and I know Andrew is particularly grateful and he is able to do something concrete. So well done and I am happy to answer any questions you might have.

Member: It seems to us that when we go to a warmer climate than Melbourne it is actually better. Is that true for most people with CIDP?

Richard: Probably **more often than not** it is true. In the **cooler climate** you tend to **stiffen** up and have aggravation of things like those distortions of sensory feelings of cold and so on**.** There are occasionally **patients** who have an active demyelinating condition where the **nerve fibres that have been de-myelinated have re-myelinated** who say they **actually work better when they're not overheated.**

There is a situation, not so much with these neuropathies but it can be, but **with MS** where they have a similar process going on in the **central nervous system**, where **if the body heats up too much things don't work so well.** People with MS often will say that if they get overheated, too much heat in summer, in a hot bath, exercise and get overheated, they feel worse. Now **very occasionally we see similar to this in CIDP**, **but** like you say, I think **most people with CIDP prefer the warmer weather**.

Member: I'm trying to justify a move to a warmer climate or maybe a holiday in Bali.

Richard: It used to be that doctors in England would prescribe time in the South of France.

Member: I just spent time in **Darwin and the humidity drained me** of my energy. It took me a few days to get going again.

Richard: With dry heat you are able to get rid of excess body heat by sweating and so on, but when it is humid your body can't.

Member: I note that some people who have had CIDP for some time are going back to have a booster dose and I'm wondering if there is any evidence that this is worthwhile?

Richard: I think the answer is **sometimes it is**. The thing about **CIDP** is when it is **first diagnosed** in most people **there is a lot of active information going on**. There are **antibodies causing damage to nerve fibres** and **if you can get rid of the antibodies the nerve fibres will be able to recover better**. The thing is using **infusions reduces the antibodies but it doesn't eliminate them altogether. You may not get 100% but you get improvement.**

In the time **where there are antibodies floating around causing the damage to the nerves** they do **cause some permanent damage**. What people often see is you **start treating people and the main problem is due to the antibodies** and we need to get rid of the antibodies, but as time goes by, **the**

antibodies become a little less active, **they burn themselves out**, you are **not producing as many antibodies** and that would be **good**.

On the other hand, **there has been some accumulated damage** and that is **bad**. You will often see **people when they come in they are bad, you give them treatment**, their symptoms reduce, they go along pretty steady and you are **treating them all the time**. If you **stopped treating them they would go down hill**. If you leave it until later on and you stop treating them, or you **leave it too late, you leave it 6 weeks instead of 4** or whatever the time may be, they might **get a little difference but not as much as they would earlier on**.

It is the great nemesis we have always got. **If someone has been treated for a long time, how much of their ongoing problem is actually immune based and how much is just due to accumulated damage. Usually we are not game to stop infusions. In early days you give people a booster and they almost always do well. Later on, if you give them a booster, because of what can be accumulated damage, they are probably not going to respond as well.**

In other words**, early on CIDP is very 'Intragam' responsive**. Later on, **it remains 'Intragam' responsive but not quite as much.**

Certainly, my approach is to **ask patients how they are going at the end of their cycle.** If they are getting an infusion once a month, **can they notice a difference between the last week and the first week?** Early on they say it is **pretty obvious when it is wearing off.** They don't feel very well and **they get a boost when they get the next infusion**. Later on they say they **don't feel quite as good and it is not as dramatic**. **Some can afford to stretch it out a bit.**

Member: I have GBS. When I was first diagnosed I had Ivig in ICU. I had a severe case. **I was in ICU for 5 months and on a ventilator and life support.** Then I went to rehab for 3 months where I had to learn to walk, talk, dress myself and in ICU I only had to have that special blood three times.

Richard: Because, GBS and CIDP are basically different in one respect. With **CIDP the body is producing antibodies that damage nerve fibres on an ongoing basis** basically because there is **a glitch in the immune system**. The immune system has got it wrong. It is producing antibodies that damage the nervous system. In **Guillain-Barre`, you get a virus, an infection, the body produces antibodies to deal with that infection. It is a one off stimulus to produce those antibodies.** Once the infection clears, then the stimulus to produce the antibodies goes away. Essentially **with GBS you have a high incidence of antibodies within the first two to three weeks**, then depending on how bad it is those **antibodies damage nerve fibres a bit or a lot or really badly** as in your case. Once you have **a course of Ivig, the antibodies involved clear away** and what is happening is then you are recovering and **if the nerve fibres are badly damaged they have to grow back by 1mm a day.**

That's the difference between them. They are very similar, but in your case you would have had an infection.

Member: **I had a sore throat. Before that I had a flu shot**. The first time I've had a flu shot and then this **started off tingling in my hands, numbness around my mouth**, then when I was drinking it felt like I was drinking cardboard. **It developed over about 2 weeks.**

Richard: With **GBS you have an infection and you get a huge amount of antibodies at one time. With CIDP the antibodies are ongoing, producing all the time and having to be given ongoing treatment.**

Member: Is there any evidence of flu shots causing GBS?

Richard: Yes. There is a lot of talk about flu shots. There was a particular sort of flu shot for the swine flu when Ronald Reagan was President. There was an outbreak of a different type of flu called the Swine Flu and **Ronald Reagan said, "No American is going to get Swine Flu on my shift" so they rushed this flu vaccine through, a new version of the flu vaccine and it did cause GBS, no doubt about it.** Maybe 1 in 1000 who got a flu shot got GBS.

Ever since then everyone has looked very hard at it. The thing is **people are going to get Guillain-Barre` whether they have flu shots or not. The question is whether your risk is greater if you have a flu shot or not. There really doesn't seem to be any evidence of increased risk in people who have flu shots. If you have flu shots you won't get the flu. If you get the flu you can get Guillain-Barre` from that.** The evidence base doesn't indicate there is a significant risk other than with that one particular vaccine.

Member: Years ago there was a program about MS where a doctor's wife had an infection and was treated with three different antibiotics. Is there anything new on MS?

Richard: I don't think MS is caused by a particular infection. You probably all know of Glandular Fever. If you went around this room you would probably find that 65% would have had Glandular Fever at some stage of their lives. **It turns out, to get MS you need to have had Glandular Fever at some time in your life.** So if you are one of the 35% of people who have never had it, your risk of having MS is very small, probably virtually zero. **If you have had Glandular Fever your chance of getting MS is still very small but it seems that having Glandular Fever (a virus that does actually have some impact on the immune system) is probably the best recognised link between infections and MS.** Needless to say, in Melbourne, with probably 4million people, approximately 3 million have had glandular fever but **only a tiny proportion go on to get MS.**

Member: **Have you heard of people who have CIDP and it burns out and they no longer have treatment?

Richard: The answer is yes. For **most people it doesn't burn out totally** but it may be that you can **spread out your requirement for infusions**. I have **one patient** I have been treating for 20 years. He is an American born chap who in the early days wanted to go back to **America and found that in fact the Ivig over there was charged** for so basically he couldn't afford to go back to America. He is a high performing academic so there was a **"brain drain" and Australia benefited from it**. Over the years his requirements have gone down from **having Ivig every month, then he found he could get out to 6 weeks to 8 weeks and now he has it every 3 months. If he leaves it any longer than that he starts to go down.** Obviously what has happened is that **the immune activity has gradually become less over the years, but it hasn't gone away totally.**

Member: **I have been off Ivig for 12 months now after 15 years and I haven't fallen back.

Richard: Again, if you went around the room you would find **everyone is different. There will be people who have CIDP as long as you have and they can tell when they are due for their next infusion.**

Member: **I used to be like that.

Richard: I think the answer is, **everyone is different, but it can move out**.

Member: How long does 'Intragam' stay in your system?

Richard: Some of it stays in for as long as about two or three months, but obviously it drops substantially. **Most people get benefit for two to three weeks** and then they fade off.

Member: I don't get much difference from say two to six weeks. I'm still at that same level so **sometimes I push mine out, to 5 weeks. I'm a bit toey to go out too far because if you go down too far as Val my neurologist said, "it is too hard to get back."**

Richard: I must say that one of the things I am delighted about here is to hear people talk about their neurologist as so many of your neurologists are people I've trained. Laughter.

Member: What is the difference between CIDP and Myositis?

Richard: Myositis affects the muscle itself. CIDP is an immune disorder which affects the nerve to the muscle. With Myositis you take a piece of the muscle and put it under the microscope and you can actually see inflammatory changes in the muscle itself. It is a similar sort of process but it is just affecting a different part of the body.

Member: Is Myositis treatable?

Richard: Yes Myositis is treatable but again it gets a bit more complicated because there are two or three different versions of Myositis so the detailed treatment varies according to which one it is.

Member: I still haven't been diagnosed after almost 18 months as to what I've got. It started off with **Motor Neurons Disease, then it went to CIDP** and now they are not so sure and I'm having a biopsy as you said.

Member: * My GBS was diagnosed through a spinal tap. Is that how CIDP is diagnosed too?

Richard: The answer is Yes and No. The thing with **GBS is there is a degree of urgency**. The things we **look at today are the spinal tap because typically there is high protein and other changes that fit in with that and the electrical testing of the nerves and muscles. The problem with electrical testing with Guillain-Barre` is in the early days of it you will see an abnormality but it might be a non-specific abnormality so it is hard to be sure.**

With **CIDP**, which has been going on for quite a bit longer, you **usually get characteristic findings from the nerve conduction studies. With CIDP we would quite often be confident of the nerve conduction studies. Sometimes if we are not confident we do the spinal tap as well.**

Member: *If I had another spinal tap now would it show normal or nearly normal and will it ever go back to normal?

Richard: It will probably get back to nearly normal.

Member: This is about research. Are you getting closer to using stem cells for CIDP?

Richard: Most of the research is predominately looking at dealing with the immune system one way or another. There are some new things that will do that. The difficulty we have is that **where there is nerve damage, the nerve cells are in the spinal cord** and the **whole of the nerve fibre is going down to the leg, so often the cell body is okay**. If you are going to **put in stem cells, it is going to replace the cell body**. So it is **not the cell body which is the problem**. It is such **a hard job for a nerve fibre to keep the whole of the cell alive a metre away.** It is a bit like trying to land

Rosette on the comet. You are dealing with things at such a distance away that **the communications are very fragile.**

Member: Do you know of anything that is currently happening in research that is around this area that at least we can understand there is work going on?

Richard: There are lots of people looking at stem cells in neurological disease, but I think it is fair to say it is **several steps away from working**. The first thing you have to do is **get the stems cells to the places they need to be**. Now spinal cord injury is hard enough, but at least if you have had a bullet wound through your spinal cord all the problems are in the one spot**. If you have CIDP you have problems with the fibres in that leg and that leg, that arm and that arm, so they are all over the place. So there is not one spot where we can say yes let's put some stem cells in there. It is a matter of getting the stem cells to do what you want them to do, getting them into the place where you want them to be and getting them to grow so the nerve terminals go to the place you want them to.**

People are working on it but I am sorry to say that this sort of issue is **one of the last where stem cells come good just because you are targeting spots that are in so many areas of the body**. I don't think any of us can foresee what's going to be there in 10 to 15 years because there are **people working very hard**. Applause.

Margaret: I know everyone has had a lovely Afternoon Tea but it is very special to hear Richard speak about all the problems. So thank you very much Richard for coming here today.

The function was very successful financially - we raised a net $1101.92. A mighty effort for such a small number of people. Thank you to everyone.

It was with great sadness that we learned of the passing of our esteemed member John De Ravin following a courageous battle with skin cancer, etc. His "young at heart" approach to life whilst being in his 80's was inspirational. John was a Pharmacist before his retirement. Another CIDP gentleman. R.I.P. John.

Support has been given to a variety of patients over recent months, from visits to rehabs., hospital visits, information forwarded both interstate and in Victoria, phone support for families of newly diagnosed patients both young and old, catch up emails and phone calls to members and information forwarded to various medical and hospital situations.

Thank you to the members who have been willing to give of their time for this support. A special "thank you" to Brian Boyd who visits others while at St. Vincent's for his infusions.

For CIDP patients there is a site called Living with CIDP – Online Support Group. There are over 1300 people registered on this site.

The GBS/CIDP Foundation International site at www.gbs-cidp.org is a great source of information. Their booklets on GBS, CIDP and relevant topics can be downloaded. They are a very good resource for informing friends and workmates on what is happening to you as well as giving relevant information to your health care givers.

National Blood Authority, Patient Information: Immunoglobulin Treatment Form

These forms are being distributed to CIDP patients either before treatment with Immunoglobulin or at their treatment review. **This is causing concern for some of our members**. **Your Neurologist has your best health outcome as their priority.** If you have no noticeable drop in abilities prior to your infusion, stretching the time between infusions e.g. 6 to 8 weeks may be trialled. **We know this is a difficult situation for you but your neurologists will not ask unless they feel it is safe to try. If you feel any deterioration contact your Neurologist immediately.** In cases where patients have been on Ivig for many years with no further deterioration, trialling **stopping Ivig** could be successful as **a percentage of patients are able to cease treatment** and continue as before because the antibodies have been stopped and their symptoms are due to permanent residual nerve damage. Some of our members have found this to be true. **Ivig treatment will resume if required.**

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

Annual Subscription 1/7/14 to 30/6/15.

Initial Joining Fee		$10.00
Annual Subscription		$ 15.00
Other Items		
Booklets- GBS	$3	$
CIDP	$3	$
After GBS	$3	$
The Road to Recovery A-Z	$6	$
- Boy, Is This Guy Sick	$2	$
Recipe Book -$12 plus postage & handling	$16	$
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

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.