Issue 61. December, 2007.

GBS ……..CIDP

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)

ANNUAL CHRISTMAS LUNCHEON

President, Margaret Lawrence, welcomed everyone to the Christmas Luncheon, introduced our special guest Dr. Andrew Kornberg and then read the apologies. She thanked Ken Clarke and Marion for making the trip from Wangaratta especially to conduct our Dutch Auction.

She discussed a visit to CSL being arranged for Wednesday 20th February and invited anyone interested to add their name to the list and then CSL will arrange a bus. If you are interested in coming to learn how 'Intragam' is produced, please advise Margaret on 9802 5319 by 10th February, 2008.

Margaret thanked the Committee and members, from herself and on behalf of everyone, saying all the food (apart from the meat) had been donated and prepared by the Committee and the member helpers.

Following a delicious lunch Margaret introduced Dr. Andrew Kornberg and presented him with a cheque and asked him to open it and tell everybody what we had all achieved. **She thanked everyone who helped to gather this money together.**

Talk by Dr. Andrew Kornberg.

Thank you very much. **It's $10,000!** It is amazing! I think you have to know **we are in this together** in many ways. I have spoken at The IN Group 3 or 4 times and I go back years when James first met me at the Royal Children's Hospital with a cheque to support one of our research fellowships. We are slowly but surely making inroads into understanding the conditions that affect many people in this room. This $10,000 will go a long way in helping our younger, brighter people and support them in actually doing the research which will make a difference to everyone here.

Next year I will set up a time to show you some slides and give you more information, but this is a big, big thank you from everyone involved. **This money will be well spent and next year I will be able to say this money actually helped us to understand the sort of things which will help you.**

I want to update you on what has happened. Many of the conditions that people have include GBS, mainly CIDP, Multi-focal Motor Neuropathy and Miller-Fischer Syndrome. These are the groups of conditions I am interested in and have been interested in after returning from the United States where I worked on that research.

We have, over the last year, **clearly defined different groups with GBS** and were able to predict from how they present and their symptoms, what is the probable cause. That's important, because if you know what causes something you can start to unravel how it has happened and then fashion new treatments that can make a difference.

The most common treatment for GBS is IVIG and most of you would have been given it or plasma exchange.

Over the past 18 months we have review all children who have been affected by GBS over the past 35 years and clearly **IVIG has made a difference, indeed it is as good as plasma exchange.** Plasma exchange has a number of complications, so we have been able to work that out. Through a friend in Taiwan, we have now done some studies comparing the cost of IVIG and Plasma Exchange, taking into account everything that happens. The person who is given IVIG has limited side affects, whereas the person with Plasma Exchange can have some problems with infection, etc. and when you put it all together IVIG costs less. **That is something we have put to the Government and that will make a difference in the next IVIG contract**.

Your contributions in the last little while have allowed us to do that.

CIDP – is not one condition but many conditions and we are now beginning to pick what is the difference between one person and another. It is just early days but like GBS you need to start somewhere and that will lead to something else and that's where we are with CIDP.

Multi-Focal Motor Neuropathy – we now know **IVIG is the treatment of choice; nothing else works**, but what we have found is that you have to have a minimum dose to keep you well. It is not worth saying IVIG is good - **you have to give enough**. So we have been talking to government as they have to supply enough funding.

What this leads to is: - **I have been involved with a select group of people in Australia to write the new guidelines for IVIG use in all these neurological conditions. I can say that if all gets rubber stamped in the next couple of months, there should be plenty of IVIG for everyone.** (Applause)

It is not just the IVIG you are given but to make sure you get enough to keep you functional. What's been happening over the last 4 or 5 years is that everyone gets the same dose every month or 3 or 6 months whatever the doctor has been prescribing and **nobody actually measures how your strength is and how you're doing on a day to day basis.** What we have actually written into these guidelines is that there **has to be very close monitoring of the person who is getting the IVIG. If there is not enough IVIG you should be able to get more. If you are doing very well and you can do as well on less, you will get less**. The objective of this is **there will be more IVIG for everyone** else.

QUESTIONS FROM THE FLOOR:

<u>Are there any new treatments for CIDP</u>?

There are lots of treatments for CIDP. The main stay is IVIG versus oral steroids plus other medications that can help the steroids work better or the IVIG to work better. Plasma exchange also has a place, but as CIDP is a chronic condition, using plasma exchange becomes problematic. There are a few new drugs out at the moment including 'Cellcept' and 'Rituximab'. 'Rituximab' we have used in a couple of children and adults with CIDP and it has been beneficial in half of them. Those are the people who have not responded to the first line of treatment. **There are new therapies becoming available all the time.**

The most important thing is to understand why it has happened. When you know why, then you are able to hopefully make a more selective type of treatment, rather than steroids which is like a shot gun approach.

Why do these conditions happen?

We know all these conditions are auto- immune. Everyone has an immune system and we are walking around in contact with lots of viruses and bacteria in our lives. We may get a cough or cold and our body is able to fight that. **Our immune system** is very important because it knows what is us and what is foreign, but sometimes it **gets confused and it starts to attack us, our bodies, our nerves and our brains.**

We are beginning to understand that there are **some people who have certain genes who are at risk** and when they get in contact with something in their environment that triggers this auto-immune process, you have this cycle going on and on. **If you can break that cycle the disease goes away.** With Guillaine-Barre Syndrome you have this cycle; you break it and the disease goes away and you don't have any problems later on. With CIDP we have to break that cycle and we are working on what has happened.

Why do auto-immune diseases occur?

There are probably genetic factors and environmental factors. We also know that auto-immune diseases, (diseases that affect ourselves) are increasing. Diabetes is more common, MS is more common, childhood MS is more common. Maybe we are too clean as children these days.

There are many diseases where we treat the symptoms. With **IVIG for CIDP we are treating the symptoms.** With Epilepsy, you go on medication to stop the seizures. It doesn't cure the epilepsy but it stops the symptoms and allows you to function normally. With Diabetes, having injections a couple of times a day doesn't actually cure the diabetes, but makes you function and it's the same with IVIG in CIDP. It doesn't cure it but allows you to function normally.

Is there any connection between Encephalitis and GBS?

That is a very broad question because there are some connections but they are different diseases. There is a type of encephalitis which is called bickastar encephalitis that has some connection to different types of GBS. You can have an auto-immune disease which affects the brain but can also affect the nerve. Encephalitis, the way we normally talk about encephalitis - they are two separate conditions. One is a virus that causes problems but you have auto-immune encephalitis the same as in GBS so there is a connection.

What is happening with Stem Cells?

Bernie: I have just returned from England and they use stem cells quite extensively with great success.

Dr. Kornberg: Stem Cells have really no place in treatment for GBS. If you lose a nerve, that is where stem cells may become important. There are very few studies at the moment where if you inject a stem cell into someone (and I have a laboratory where we play around with stem cells) that is going to do everything. It doesn't. There is a lot of work yet to be done. There is no doubt that Stem Cells are the future, as stem cells allow the regeneration of a whole lot of tissues. **There is no doubt that stem cells will clearly have a place in regeneration of nerves and everything else.**

Our researchers here in Australia are excellent. **We have very, very strong stem cell research groups in Australia and most of the work done overseas is based on work already done here in Australia.**

Bernie: I met a man 2 years ago in England who was almost totally paralysed and he had stem cell treatment and he can now do things I can't do. They are having some great success.

Clearly there is going to be some benefit in the longer term but where and when that's going to take place we just have to see.

Editor's Note:	The gentleman Bernie met was in a very, very bad state. He had made no improvement even though all known treatments had been tried. There was no hope for him. To get the Stem Cells he had to be in a totally germ free environment, have his own immune system totally destroyed before being given the stem cells. It is a very drastic treatment.

Vicki: (Wife of Peter who has recurring CIDP and has been very ill recently). This Stem Cell issue - As you know I've been onto you about this. I guess I'm concerned that it is not happening quickly enough here in Australia. Is it not possible to use some people if they wish to be guinea pigs, if it's working in England? Is it not possible to do that here?

Dr. Kornberg: I would have to know exactly what research and which group and who is really doing it in England before I could comment on it. There are a lot of people who say they use stem cells but they're not. For example I have seen GBS patients totally paralysed for a year and a year later they are walking around and are quite normal. They may have a little bit of weakness around their ankles. If I gave them stem cells at the start you would say that's because of the stem cells but in fact it may be because of a whole lot of other factors.

As a Doctor you have to make sure you do no harm as well as helping people and sometimes things are not what they seem to be.

In answer to your question about **whether you can be a guinea pig** and do those sorts of things.

There are **special access schemes** and there are special ways of doing these things in the right situations. So you could actually have your neurologist and there are neurologists in the major hospitals that could look to see whether it can be done. It has to go through ethics. It has to go through lots of things. We sometimes do things that are experimental when our backs are to the wall, but you would have to ask the doctor looking after you.

What part does Stress play in CIDP?

Stress is part of life in the 21st Century. In a person who is not sleeping well or not eating well their immune system may not be working to the optimal efficiency, so when they get a trigger, that may help bring it on. It is difficult to say its stress, or this, or that, but it **does play a small part** in order to make the disease occur.

How do drugs such as 'Neurontin' and Lyrica help in the process?

They don't actually make the nerves grow but they make the nerve cells not feel pain as much.

If you have pain or tingling or numbness 'Neurontin' or 'Lyrica' can stabilise that membrane of the nerve. They work on the sodium channel which is important in pain. They stabilise it and then you don't get those prickly and painful sensations, so it works on treatment of the symptoms but it doesn't actually treat the underlying disease. It helps the pain and the numbness and tingling in the vast majority of cases. Tegretol is also used but the others are the new generation. If 'Tegretol' doesn't work for you 'Neurontin' may, because it may have less side affects at a higher dose. 'Lyrica' is the brand new one on the market but it has more side affects.

Bernie: I use 'Lyrica' and I tried to go off it but I couldn't stand the pain so I went back on.

These **medicines can not be addictive** like Morphine, etc. but you feel terrible so you want to stay on it. It is obviously doing its job so just stay on it. There are no long term issues with it.

You have said that CIDP is still the heading but there is a grab bag of things under it. Are we getting anywhere working through it?

The short answer is **yes**. Anyone who has sub-acute or a chronic nerve problem with demyelination and these sorts of signs will fall into that category and that's CIDP, but there **are different variants of CIDP** that we can work out on the way the nerve tests are appearing, or how patients appear on a clinical basis.

Now we are teasing those out and we have **one group of patients who may have certain antibodies**. In those patients we can measure an antibody in the blood stream that says - okay that is equivalent to this group of patients with CIDP, but now we have to go further back and understand why those anti-bodies have been produced and why it has occurred, in the hope there will be more specific treatments. Once it was all CIDP, but now **we are trying to sub-categorize** it. That is what we have done with GBS and that's the way we'll go with CIDP.

John: Sub Cut. About 2 years ago CSL were talking about a sub cutaneous immunoglobulin. Any update on that?

I was at a meeting where they were talking about a sub cut gamma globulin. It is already being used in some patients with immune deficiencies where they have not enough gamma globulin so they can be replenished with sub cut infusions.

The question really is how does IVIG work in the conditions of nerve and brain? Is it because you have to get the level up very, very quickly or it doesn't matter how high the level, or is it because we just have to get the level up slowly and keep the low level. We don't know, so sub cup may very well work for immuno deficiencies, but it may not work for patients with neurological diseases if it is dependent on a high level. If it is dependent on a high level, you cannot get enough of the gamma globulin in.

But there will be studies (as I am talking to my friends in the U.K.) and once it becomes a bit more available there will be studies comparing patients who have CIDP and getting it intravenously and sub cut and we shall find out if it works as well.

John: Would it be possible say, if I go in for intravenous infusions every 4 weeks and then give myself a jab every day, can I lengthen my time between hospital visits to 6 weeks?

It depends very much in how it works in the neurological diseases whether it works on a level basis or a little basis or whether it doesn't matter what level as long as you are getting anti bodies from everyone else. And that is **difficult to predict**. We would hope that sub cut works because then it will become a lot easier for everyone to administer the sub cut at home rather than go into hospital every 3 months or so.

It is easy to put sub cut in. You just put a little butterfly in your tummy and you just inject into it. It's simple. Anyone can do it. We give it to our parents to give to children with certain diseases and it's easily done but we don't know yet. I can tell you that is the next exciting change. If it does work, it will change people's lives. They won't be tied to hospital as they can administer it at home.

Tom: Any information on how CIDP manifests differently in different people? I have maintained my strength but I have feet that are on fire.

Do you have tremor? You may have a particular variant of CIDP. What you are saying about severe demyelinating is a condition called Magone which may be what your subset is. There is a particular antibody in these people. I wonder if you might have that particular type of neuropathy.

Why CIDP is different in each person is because we are all different beings so a condition that affects nerves can affect us all differently.

John Burke thanked Andrew for speaking to us today and we look forward to learning more at one of our meetings in the New Year.

THEN THE FUN BEGAN!!!

The Christmas Luncheon and Dutch Auction raised $1118.45.

DATES OF MEETINGS FOR 2008

Sunday, 17th February
Sunday, 18th March
Sunday, 17th August – Annual General Meeting
Sunday, 7th December – Annual Christmas Luncheon

Gwen McInnes' jewellery sales raised $260 this year (all donated) and $460 last year.
Thank you so much Gwen.

Contact for Geelong Support Group is: Dee Cooper. Phone: 03 5244 3382

Message from Valerie Simpson re Specialist Massage Therapy

I have found a massage therapist who specialises in working with people with physical disabilities. His name is Matt Beechey. I want to let others in the IN Group know about the service he offers. He has helped me since I came home after two years in hospital with CIDP and he may be able to help others as well.

Matt has a nursing background and is very comfortable working with people like me who have suffered from debilitating diseases. I was in Intensive Care for about a year in all and my body shows some lasting effects from being paralysed for such a long time. I still have very limited mobility (I walk only with a walking frame), I have a permanent tracheostomy because my respiratory muscles have been so compromised and my hands are seriously crippled. All this seems to present an interesting challenge to Matt!

I have felt better since I began having regular massages with him and can recommend his service.

Here are his contact details

Shop 6, 54 Kilby Rd, East Kew
Phone 0414 454 437
Email: matthew@rrcorphealth.com.au

Thank you Valerie for sharing this with us.

E-mail Mailing List

If you would like to be included on the IN Group email mailing list please send an email to John Burke at the following email address **jburke@contracts.com.au**

If you use *hotmail* or have junk mail filtering software running you will have to include the above email address in your "safe list" otherwise *hotmail* or you junk mail software is very likely to delete our emails.

BREAKING NEWS: The Alfred Hospital to begin building 4 new rooms with positive pressure ventilation and filtered air for people with suppressed immune systems. Building to commence January 2008.