GBS ……..CIDP Issue 77. January, 2012.

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, 19TH FEBRUARY, 2012 AT 1.30PM

BALWYN LIBRARY MEETING ROOM, WHITEHORSE ROAD, BALWYN

GUEST SPEAKER, SCOTT EDWARDS, NEUROLOGICAL PHYSIOTHERAPIST

Scott Edwards qualified as a physiotherapist from La Trobe University in 2003. After working in neurological rehabilitation and Sports Medicine in Melbourne, Scott has travelled and worked overseas. In England Scott continued his interest in neurological rehabilitation through work at a number of specialist hospitals. Currently, Scott works as a senior clinician physiotherapist with the Neurological Rehabilitation Group based in Melbourne, and is enrolled in a Masters of Public Health course at Melbourne University.

Dates for our meetings for 2012.

February 19th. May 20th. August 19th. AGM November 18th. Christmas Luncheon

---

Notes from Christmas Luncheon.

Thanks to Barbara, Ken and Jane. A warm welcome to new members here today Alison, Murray and Kate.

Gwen has produced a Recipe Book with recipes containing limited ingredients which are easily made by those with limited dexterity. It will be available in the New Year. Two recipes are part of our dessert today at the luncheon.

Talk by Associate Professor Andrew Kornberg.

Before I talk about research that is going on around the world with regard to CIDP and Guillain-Barre` Syndrome and Multi-Focal Motor Neuropathy, everyone knows I work at the Children's Hospital. On the 26th October we had the Queen come and visit and open up the New Children's Hospital and it was an amazing time. We have got 10 more sleeps and we will be in the new hospital. Next week I will be packing my office and the department and the kids move over on the 30th Nov. Essentially we will work in two places up until the 30th and then everyone moves over so we are all excited. It is fantastic for the kids, the families and also for research. Laboratories are next to the hospital. The MCRI has got new facilities, new labs. It's just a fantastic, fantastic place.

So what's happened in the last 12 months? I guess there have been probably 5 things which have been very important and interesting for CIDP in particular.

Over the years I have talked about that **CIDP is not really one condition**, it's really like Multiple Sclerosis in a way. It is probably **many things or many causes that gets you down and it causes the problem that you have in the nerve.**

We know on a clinical level, when we see people with CIDP, everyone is just a little bit different. Some people have more numbness, some more weakness, some more issues with their feet, etc. So there are some differences between people but we treat everyone in the same way.

We use steroids, Intravenous Gamma Globulin (IVIG), some other medications, combinations, plasma exchange, etc., so we are treating everyone the same rather than looking at what's different between people and **maybe there will be different treatments for different people.**

In the last year what's **really come out is from the MS information**. MS is very common but with MS **the reasons why things happen has really been unravelled in the last few years**. Where there was one treatment 10-15 years ago, **now there is at least 10 different treatments**, because people worked out that some people have more problems in this part of their immune system, etc. **Now that is also happening in CIDP.**

There was a **big study done out of Europe, the United States and Australia that has unravelled some of the clinical differences between patients. For example, there are some people with CIDP who come into the hospital and look like Guillain-Barre`. They have had this terrible abrupt onset of their condition. We now know that about 16% of people with CIDP present in that way and we are beginning to work out that's what they have got. They have CIDP rather than GBS and then we are treating them differently right from the start** rather than the ups and downs for a long period of time. **We are beginning to group out different patients.**

There is **a big Japanese study,** published in the last year but it is 3 years worth of information, where they **looked at the genes in all people with CIDP and they found some differences in, not one gene, but lots of genes, between people who respond to IVIG and people who don't.** That will be, (I think in the next year or two), information as to – **here we are – we are going to take off your blood sample – if you have some change in that gene you're going to respond to IVIG so that's what you're going to be on**. That's fairly new. **Instead of lumping everything together, we have to split everything out because there are more treatments occurring that may actually help this group but not this group.**

We also know now that **in CIDP one third of patients don't respond to anything, or not completely. What is exciting** is that now **there have been markers identified in CIDP which will allow new treatments to be specifically used for those patients.** It is still probably a couple of years away but there are some **new anti-bodies which we have manufactured against the thing that is going wrong in those patients.** There are expensive treatments but it has happened in MS and it is also going to happen in CIDP.

So in the last year we have had a better understanding of what is different between people. We have now identified groups of people based on their genetics; what they should respond to and now we have actually pulled apart people's conditions and are looking at specific changes in their nerves, etc., which will lead to better treatments. That's really one of the most exciting things.

In the last year also **at the Children's** we have re looked at **all our kids with CIDP and GBS** and we have **identified the same sorts of sub groups** of kids as there are in adults. **So there is hope for our kids that we are going to have some better treatments.**

IVIG. There is plenty of supply. The government has okayed a little bit more (up approximately 14%) for the coming year. **There is going to be new ways of giving IVIG**. A lot of people go to hospital each month or 6 weeks to have their infusion, but we are now looking at **using IVIG underneath the skin.** You have that sort of **infusion at home, rather than in hospital**. That means, **more frequent infusions**, but **you can do it** in the evening times, etc., so that is the next thing **that is about to start happening**.

It has been trialled for CIDP. There are at least 3 studies and they are comparable. People **who get it subcutaneously, (if given the appropriate dose), will also have benefit at the same level as they would if they had it intravenously**. It is **a lot cheaper** as well as you **don't have to come to the hospital.** The **pump costs a lot of money, but that is a single outlay**. It does work. A lot of people may not like it. It is what you prefer. Some individuals if they have to use a huge dose would get a lot of swelling so they won't actually get the medication. We tried with a couple of our children and it does work.

Questions from the floor: Can you tell us about 'Rituximab'?

Okay that is one of the monotonal antibodies. In the 1/3 of patients who don't respond to the normal conventional therapy, about 1/3 of those will respond to 'Rituximab', therefore 10% overall. 'Rituximab' is an expensive medication; it has some side affects, immune issues, but there is now a big trial that has actually shown benefits of 'Rituximab'. It was done by one of my colleagues in the United States. I have used 'Rituximab' in a little girl who has a combination of CIDP and MS. It occasionally happens together and she's responded beautifully to'Rituximab'. In another patient with CIDP, who failed a lot of treatments, she has responded to 'Rituximab', etc. and I do know that a couple of patients also had that treatment in St. Vincent's and one of my patients at St. Vincent's with a different condition has also responded to 'Rituximab'.

So lots of things have been happening and it doesn't seem a lot, but it is, **huge amounts of information have happened in the last year.** Now that **we are beginning to unravel the genetics; why people were different with their therapies and now unravelling why this happened, why the nerve is being attacked, that leads to bigger and better treatments. In MS** where there wasn't a whole lot of treatments, they are coming out and every few months **we have got a new treatment and it has made a huge difference for the longer term.** That is the hope and **it will be the same story with CIDP**.

When you say people are improving with specific treatment, what is actually happening to those people? Is there less inflammation in their bodies? Are the nerves being repaired? How are they actually improving? I get a lot of fatigue. Will that go away?

The other thing in the last year is that **we now have better measures to say whether someone is better or not.** With a big international collaboration we have now **looked at these parameters to see if you are actually better or not** and that is for studies.

When you are treating a condition which is **chronic**, which is **there all the time** and we know that the **problem is inflammation of the nerve and secondary damage to the nerve, a treatment stops that inflammation and damage, the next phase is that there has to be regeneration** or new nerves being laid down.

I think I have said this before; **a nerve re-grows at 1millometre a day**, so if you can **stop whatever is causing it, then you get regeneration at 1 mm per day**. Now I'm not that tall so it wouldn't take me as long as it would some of you tall people here, but **1mm a day takes a long time**. And it is going to be **one fibre here and one fibre there**. What that means is that you get **stronger and your muscles are stronger and you have a little less in the way of fatigue. Fatigue is the hardest thing to treat**, because people with **Guillain-Barre` Syndrome** ten years later they are running, playing tennis and everything is all better, but they have **profound fatigue** and unfortunately we haven't been good enough or smart enough to understand why they are fatigued and we know in **MS fatigue** is a bit problem, we know **in GBS it is a big problem** and also in **CIDP it is a big problem** but we haven't got great treatments for that yet.

There is **a new medicine that has helped nerves work** a little bit better. **It's not on the PBS at the moment. It costs about $700 for a month's supply**. **Hopefully that gets funded** and that may very well **help with fatigue**, but **it is not readily available at the moment.**

What is it called? '**Fampridine SR'**. It is **specifically for patients with MS.** That is where it was developed. It is better for walking, etc. How it works **would work very nicely in nerve problems such as CIDP but we have to work on getting a study done so that it can happen.**

Peter: I was **getting 'Intragam' every 2 months for years** and **in June** my neurologist decided to give me the **5 day treatment and then infusions every month**. I had **a nerve conduction test** in **March and last Thursday** I had a nerve conduction test after having the treatment described. There has been **an improvement in my nerve conduction test**, so would that say that I have a little **bit of regrowth, or is it just the time that it reacts with me?**

It is an important point that you bring up. We assume when we give IVIG that we need to give it about a month apart. **We believe that you replenish when you get a big hit of IVIG and it takes 21 days for it all to go away** and that's where the 28 days or 4 weeks comes about.

There are some studies, particularly with the Dutch, where **the same total dose, but more frequent injections, may actually make a difference in the longer term**. Maybe you are one of the people who respond to more frequent but lower doses and we know that **IVIG doesn't cure the underlying condition but it blocks anti-bodies** and that's probably why you have improved. But that's the **importance of working out who responds to IVIG and whether you need it more frequently**. **Subcutaneous injections, given more frequently, may be beneficial to you**, but we don't know as yet.

Can you use the two in combination, intravenous and subcutaneous?

It is either all or none at the moment. It may be that there will be people who get combinations of treatments but overseas, particularly in the Netherlands where a lot of this work has been done, most of them are either all subcut. or all IVIG**. If you did subcut. and you did that every week; it would work out the same total dose so an intravenous dose is not worthwhile.**

What sort of volumes could you deliver with subcut?

You need to have high concentration of the **IVIG** so when it was **5 – 6%** IVIG it is really hard to deliver that, so the new **subcut concentrations** are somewhere between **12 and 20%,** so then you are using much lower volumes for that number of grams. So that is where things are going.

What would the maximum be that you could deliver with subcut?

Probably, the **maximum you can actually deliver in one site is 100mls**. When you get subcut you actually have **multiple sites** going. 100 mls. at each site. It balloons up and then quickly dissipates.

Can you deliver an equivalent of 100grams IVIG?

You can but you would **probably have about 4 sites**.

If you are getting **100 grams every month, that would be 25 grams per week** and would be what you would infuse in that week. You might **do it 2 or 3 times in that week.** You get **the same total dose but rather than in one hit, you are getting it in small doses all the time**. It probably is the way to go with chronic conditions because it is not really the level of IVIG it is probably other factors. A **lower dose more frequently** (like with Peter) **is probably the way to go**.

Is it into the vein?

It is **administered just under the skin. It is like if you have diabetes**. It just goes under the skin, **into your tummy**, so it is actually underneath the skin, **into the layer where there is a little big of fat** and it goes in and gets absorbed.

What is a Nerve Conduction Test?

There are **conditions where it is mostly motor nerves** and there are **conditions where it is mainly sensory nerves, but in CIDP you typically have both affected**, on nerve condition tests and on clinical levels and we believe it is the same problem in both.

When we actually take **nerve biopsies**, (we don't do that often) we **actually take a sensory nerve to** have a look underneath the microscope. The **more disability in the vast majority of people is in the motor,** because that is what you do, you are walking, climbing stairs, etc**., but the sensory is also affected and both respond to these treatments**. **A nerve conduction test is for measuring both the motor and sensory nerves.**

Will there eventually be an oral medication for CIDP?

There are **already medicines that you can take orally but many of them have quite a few side affects**. IVIG out of all of the therapies probably has the least side affects, but you know **'Prednisolone'** the steroid can be **taken orally**. It does work **but there are issues if you have been on it a long time.** But there are **some new oral agents** which have been developed, initially for MS for the same sort of immune conditions so **they will also be able to be used in CIDP. They have not been studied as yet.**

'Rituximab' was predominantly used for cancers and then for different nerve conditions and **it is now finding its place as well in treating CIDP.**

Margaret: Thank you Andrew.

Peter Mc: Andrew I think you would judge the success of your talk this afternoon by the rapt attention displayed by your audience. When you mentioned the fact that it may be possible to have your 'Intragam' treatment at home, Gwen, (my wife) turned and smiled at me. I know why, because I have been driving her to the Alfred Hospital every 4 weeks for 8 years and she and I have agreed that we will have to give that up when I reach the age of 107, so I suggest you try and push that situation before I reach that stage.

Doug: Before we finish I would just like to say **as Treasurer I am delighted to be associated with so many wonderful people here in The IN Group** and you will understand why in a moment. I look at our **Committee who are very hard working and very generous**.

We then **have the group of support people who do a lot of side things for our activities**.

Then we come to **our members**. Our subscriptions are $15 a year. I will stand corrected, but I don't think that has been adjusted since The IN Group Victoria was first formed back some 30 years ago. What we have are **members whose generosity is exceptional and as a result of all the generosity and all that help, I would like to present to Andrew a cheque for $10,000 again to help you and your support staff to find the answers to the many unanswered questions that are asked about GBS and CIDP.** So Andrew, with our thanks I present this cheque to you.

Andrew: I have been coming here quite a few years and the generosity of **The IN Group is amazin**g. I just know how hard you all work during the year. This just doesn't happen.

This has been supporting some of the young people who are actually the doctors of the future who are going to be looking after nerve and muscle conditions. They are also **working hard at looking at children or coming with me to St. Vincent's to look at a whole group of patients with CIDP and without your generous support we wouldn't be able to do what we actually do.** It is really just an amazing, amazing thing that you do. Even though the years go past so quickly (it feels like just a couple of weeks since I was here) **I really want to thank you for all your hard work and generosity over the last year and being able to continue your support. It is just amazing.**

Following Andrew's address we held our **Annual Dutch Auction** and **together with the Luncheon raised $1,048.40. Thank you to all who attended, made a donation or who donated gifts for the auction. It was a special day.**

Beth's Internet Searching

I read with interest last night the IN Group newsletter. Then I went to the IN Group website and read one of the past newsletters that I haven't read before. I came across Valerie's report on a conference she attended in New Zealand. One thing led to another and two hours later I was e-mailing this link to **Jenny** :
http://clinicaltrials.gov/ct2/show/NCT00962429?term=Chronic+Inflammatory+Demyelinating+Polyneuropathy+%28CIDP%29&rank=3
Beth

Circulation Booster An email received from Jenny.
I'm wondering whether anyone in The IN group has had experience with the Circulation Booster which was promoted on TV by Dawn Fraser.

I think my condition has reached a plateau now. With a lot of hydrotherapy, physiotherapy and daily exercises my mobility has improved considerably. I also go to a gym twice a week. When I go to the physio, apart from him massaging my legs and feet (which get very stiff in between visits) I go on a **Galileo machine** which is **a 'whole body vibration machine, which improves my balance and also helps my circulation.**

The neurologist has me on some **medication** known as **micophenalate (or cellcept)** – an immune suppressant often used with renal patients. **I am his only CIDP patient for whom it is working** and he is very pleased. It's amazing how different treatments suit different people.
(If any member has a Circulation Booster and is finding it beneficial, please email Melva at behrsden@optusnet.com.au or phone 03 9707 3278 and I will pass on the information .)

GETTING TO KNOW YOUR COMMITTEE – Rebecca (Bec) Engsmyr.

It was the first grand final day of September 2010. I was admitted to the Alfred Hospital for a 'mild' case of GBS. I was fit, healthy, happy and working as a graduate nurse at one of Melbourne's major metropolitan hospitals. A week before I got sick, I was thinking to myself how lucky I was and that I was finally reaping the rewards of all the hard work I had put in over the past 4 years. After diagnosis, I thought I would be up and out of hospital in a month or so. It didn't quite register what was ahead of me and my family.

That was the start of a 3.5 month hospital admission and many more months following doing outpatient rehab at Caulfield hospital learning all the basics like balance, walking a semi straight line and trying to get myself off the floor if I fell. All the things I had taken for granted before GBS took over. It was the scariest and most horrifying time in my life. The body and life that I once had was gone and something entirely different had replaced all that I knew. There were a couple of months after being discharged from hospital that I was finally able to grieve for all that s taken away from me. There was a lot to digest and a lot of time to think. I got through the entire experience with the love and support of my boyfriend, family, and friends. I also got through it with all the excellent care I received from the dedicated Health care professionals of every modality at the Alfred and Caulfield hospitals.

There is just too much to put into words; what the GBS experience has been like, but I can definitely say that it has been humbling and a life affirming experience going through it. I know that I am very fortunate and back to 95% pre GBS form 14 months later. It has been challenging; a lot of hard work and pure determination to get back to the life that I lead prior to GBS. Finding The' IN' Group and connecting with members has also been an integral part of the healing process for me. Finding a support network of people that understand what it is truly like, does lighten the load and create a community for others out there going through it too. That is why I have joined the committee to be there for others and be a helping hand when needed. Most weeks I meet or hear of someone that has been touched by GBS or CIDP in some way and feel that it is important for them to have somewhere to turn to. That is what The IN Group is to me.

Here are two recipes from Gwen's Recipe Book.

Jenny's Sponge – All mixed with beater.

Sift together – ¾ cup cornflour

½ teaspoon carb. soda

1 teaspoon cream of tartar

1 tablespoon custard powder

¾ cup sugar (castor sugar is best)

4 eggs separated

Beat egg whites with pinch of salt until peaks like Pavlova.

Gradually add sugar, beat until combined, then add yolks

and beat. Fold in sifted dry ingredients.

Preheat oven to 180 degrees. Put mixture in 2 x 20cm greased pans.

Bake 20 mins.

Fruit Cake

1 kg. mixed fruit

600 ml. Big M

Soak overnight.

Stir in 2 cups S.R. flour

Cook in 20cm. square tin in moderate oven about 1-1/2 hrs.

Also makes a slice, cooked in lamington plan.

Lemon icing.

(We had this lovely cake at our Christmas Luncheon)
You can always add a little tipple of brandy too!