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INFORMATION

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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)

NEXT MEETING

SUNDAY, 21ST FEBRUARY, 2016 AT 2.00PM

Balwyn Library Meeting Room, Whitehorse Road, Balwyn

Guest Speaker: Dr. Les Roberts – Research into CIDP

A small plate to share would be appreciated. Thank you.

Dates to Remember

Sunday, 15th May 2.00pm Guest Speaker to be advised.

Due to renovations, the following two meetings will be at Ashburton Library, 154 High St., Ashburton.

Sunday, 14th August 2.00pm Guest Speaker to be advised.

Sunday, 20th November 12.00 noon Silent Auction and Luncheon

Talk by Associate Professor Andrew Kornberg at Annual Luncheon.

It is nice to join you at the end of another year here at The IN Group with lots of old friends and some new friends. I was just talking to John at our table as to when **the first time I spoke** and it was **in 1999**. 1998 was when I first actually met someone from the group and it was the founder of the group, **James Gerrard, who came to the Royal Children's Hospital** years and years ago.

Today I wanted to **bring everyone up to date with regard to inflammatory nerve conditions.**

There is an organisation called the Peripheral Nerve Society that we are a member of and it is an international group that looks at conditions affecting the peripheral nerves. These are all the conditions that have affected many of the people here, **such as Chronic Inflammatory Demyelinating Poly/peripheral Neuropathy, Guillain-Barre` Syndrome, Multi Focal Motor Neuropathy, etc.** The good news is that **each year The Peripheral Nerve Society meets as a group and we are actually planning different studies to understand what is going on in these disorders, but also talking about treatment trials, etc.**

Just talking amongst ourselves at the table brought up two of the things that we were studying over the last year.

One of the studies was in fact people who ultimately get diagnosed as having CIDP who present like Guillain-Barre` Syndrome. That is **one of the studies** and it was **published in one of the Journals a couple of years ago; looking at how can you predict what someone is going to have when they first present?**

I don't know the story pur say, but that **comes from putting a lot of information together** to try to understand **when someone comes into the hospital and has some weakness, how do you know what they have got?** Part of that is the **clinical data** that you actually get. **Has this happened before? Is it slowly progressive? Are there nerve studies? What do they look like?** This actually **helps to predict to that person what is going to happen in the future.** Sometimes **when you come in and it is all scary, you do want to know what is going to happen in the future.** That comes from some of the research that the PNS is actually doing.

One of the big studies that actually happened is the ICOS 1000. It sounds like a funny name but it is an **international Guillain-Barre` outcome study** and they are **trying to actually get 1000 people into that study.** People have been followed in many of the large centres in Melbourne. The usual talk when someone has GBS is they know you have an **85% chance of being completely normal, 15% chance of having some disability, (5% really quite severe, but the**

other 10% are really functional), etc. This study is **being done at the moment** and there are **800 people enrolled** and **all our children from the Royal Children's Hospital are enrolled**.

We are **beginning to understand things that happen 10 years down the track about fatigue** and **what you can actually do about fatigue**. Also from that study we are picking out that **there are some people who present with GBS who are very severe right at the start**, within hours, or within a day, but **what's different about them compared to someone who is less severe?**

The **importance of understanding** that is; **should we be using combination treatments or some other sorts of treatments if we can pick who is going to be more severe?** That is some of the information that is coming out.

There is also a trial being done in **GBS**. Some of **you have had GBS**, (most will have had CIDP), but **whether you should be given the second dose of IVIg**. It doesn't sound much but **it can actually make a big difference to that person in the longer term**. These are the sorts of **things that are actually happening** and I have **12 studies** that we are a part of and **doing in multi centres round the world**.

The one that is **most important is the ICOS study** where we are studying the **outcomes of CIDP**. When we look at lots of **people who have CIDP and they are on IVIg and it is thought to be life long**, it appears that **probably 40% could come off IVIg at some stage**. That is because either:

1. **The condition is cured** – goes away by itself.
2. Their nerves have had damage and **the condition has burned out** or **some better treatment has eventuated**. **Those people can actually be switched over to some other treatment**.

I have talked about **monoclonal antibodies and other things** like that and **people are beginning to use that more often rather than coming in every 4 – 6 weeks, every 2 weeks in some cases to get an IVIg**. Now that doesn't sound a lot but **that is 2 days of your time every month** and it really hampers what you can actually do.

From that **ICOS study** what is really coming out is that **some groups of people who have CIDP – what they should be on or whether they can come off IVIg**. There are also some newer drugs being used in CIDP, but also some drugs that are used in MS now being trialled in CIDP. This is because **Multiple Sclerosis is a condition where you have white matter problems in the central nervous system, whereas CIDP is in the peripheral nervous system, but the way that drug works in MS, it should work or could work in CIDP**. It is a **once a day tablet, that's all it is, so wouldn't that be great?**

Having this **Peripheral Nerve Society** where we are all members and now part of all these sorts of **trials will add lots of information** and give us more and more **information as to who should be treated with this drug, what is their outcome** and in particular, **are there newer drugs which are being used for other conditions that could be used in CIDP or GBS**.

There are **12 studies going on right now** with all these conditions and also **outcomes which are very, very, important**.

The things that you should know is that I might not be able to come and tell you that this year I have got a magic medication, or anything like that, but it is like the little Turtle on The IN Group newsletter, **"Slowly but Surely"** we have little bits of information, more data, that will ultimately make a huge gain and an outcome for everyone affected with these conditions, in particular everyone here.

That's all I've got. Anyone who has a question, I am happy to answer them.

Question: In the diagnosis of CIDP **do you look for blood test type antibodies** to confirm you have got these conditions, because that would be fairly specific as well as the **nerve conduction test?**

Andrew: In GBS there are antibodies that typically do recur. **In CIDP it tends to be a whole variety of different antibodies as I think CIDP is not one condition, one disease, it is really the end point of many different factors**.

I did a lot of research on antibodies for CIDP and GBS. We found a couple of antibodies in CIDP but the antibodies were **not in everyone**. If someone had a particular antibody it **would be a predictor**, but it is actually very, very difficult to do that antibody.

At the moment it is a clinical diagnosis with the blood test. Typically it is how the person appears, their examination. The nerve conduction studies are still the most important. Sometimes a lumbar puncture, sometimes an MRI, but the antibodies are not that helpful.

Question: What about 'T' cells?

Andrew: Any condition where you have auto-immunity, where your body is fighting your nervous system, you have increases in different "T" cells. It is not specific. It is just what you can actually see that would go along with auto-immunity. You have these changes. You would see that in MS. You would see that in Myasthenia Gravis (MG). You should see that in lots of other conditions where there is auto-immunity. It is not that helpful. It helps the Doctor to decide it is auto-immune and not a genetic problem, but it is not that good.

Question: I have a severe case of GBS. I had a second dose and I found it a great help at that particular time in rehab. It meant that I could get going on exercise and get out of there.

Andrew: The problem is that we know in individuals it looks like you need a second dose or a third dose or whatever because it hasn't treated the fluctuations, but the question really is whether everyone should have a second dose. You know there are always difficulties with getting IVIg and it is quite expensive too. You have to ask yourself, are you being efficient. Not to say you don't deserve a second or third dose, but the studies will tell us, in a person who has some treatment fluctuation and they come down to this level, they are the ones who need to have a second dose. The vast majority of people get their dose and that's all you need, but a group of people will need a second dose. So these studies could be very important.

Question: How do you determine if somebody has perhaps diabetic neuropathy as opposed to CIDP? How do you make that judgement?

Andrew: It is a really excellent question because if you read the literature, CIDP tends to be a disorder of adults. It can be young adults or it can be older individuals. A lot of the time you may also have diabetic neuropathy occurring in someone who is at risk and it can happen together. Then there is this whole argument: Is it the diabetic neuropathy that is exposing the nerves to the plaque and some antibodies are being made and then you get this immune process? That has not been proven as yet, but it is through nerve tests, spinal MRI or spinal tap that helps differentiate.

In diabetic neuropathy you would not see any increased protein, whereas in CIDP you would. It is those other tests that are really helpful. The nerve tests are also helpful because in diabetic neuropathies it tends to be very sensory. It tends to be the same in all the nerves, whereas in CIDP it is a little bit different from one side to the other. But there isn't a test which is going to help differentiate. It is really how good your doctor is to interpret.

Member: For some months we were told it was diabetic neuropathy. The Diabetic Specialist said my husband was well controlled and the diabetes was not the cause. It went back and forth until the neurologist ordered the nerve conduction test and the spinal tap. The nerve conduction results were an indication and also increased protein was seen from the spinal tap, so then the diagnosis of CIDP was made.

Andrew: There is other information you can do and help to differentiate it. When I talked about 40% of people coming off IVIg, the problem is, if you have a group of 100 people who are diagnosed with CIDP and let's just say 20 of them really have diabetic neuropathy and because no-one has done the investigations correctly, they are getting IVIg for no good reason. They are the ones who could come off. That is why you have to have really good strict criteria for diagnosis to come into these studies so we know what we are dealing with. That is what the Peripheral Nerve Society is doing.

Member: I have CIDP and I am also diabetic and I have another question for you. I am part of a study with Dr. Sue Corcoran as I have times of very low blood pressure and other times of very high blood pressure and just a couple of months ago there was mention of the possibility of CIDP affecting this.

Andrew: If you have both low and high blood pressure it could be that your CIDP is also affecting your autonomic nerves. There is a sub-group of people with GBS and CIDP who also have that.

Peter McInness, Secretary

Andrew, thank you very much for your talk. We always look forward to it as you are very clear and concise and we can understand it which is very helpful, so I have pleasure in giving you this cheque for \$10,000.

Andrew: We have a really **young person at the Children's Hospital** at the moment **who is doing ultra-sound of nerves to help to work out if it is a genetic nerve condition versus CIDP or GBS** because sometimes it is impossible to tell the different. **She is doing this huge study across multiple centres of ultra-sound of nerves** and some of her **studies are being published at the moment** and it is fantastic. **This money will go towards that study, so thank you very much.**

Doug: Andrew, you know that we have a fairly **small membership base and the monetary value that comes through for our donations is quite incredible.** Therefore I would like to put **on record a thank you to all our members Australia wide for all their donations,** which we put together to **pass on through you for research. To all members Thank You so much.** Applause.

Andrew: Each year I am here and your generosity is incredible. You need to know that this money makes a difference. Governments provide bricks and mortar like hospitals, but **excellence comes from charity and philanthropic donations that you guys do for us. So thank you for the excellence you allow our hospital to get to.**

The Committee would like to thank the family of our late member Russell Wilson for their bequest of \$1,000. The placemats for our luncheon were laminated copies of Russell's famous Pickled Onions recipe.

Thank you to our wonderful members and guests who attended the Luncheon and Dutch Auction which allowed us to raise \$939.60. Special thanks to Ken Clark the auctioneer.

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: John@BAL.net.au

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.

Subscription: If you have not paid your subscription of \$15 for the Year 1/07/2015 to 30/06/2016 then they are now OVERDUE.

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	\$ 15.00
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Supporting sufferers from acute Guillain-Barre Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

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