

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

**BALWYN LIBRARY MEETING ROOM, WHITEHORSE ROAD, BALWYN
1.30 PM ON SUNDAY, 20TH FEBRUARY, 2011.**

Guest speaker – DR. VALERIE TAY, NEUROLOGIST,

Dates to Remember

Sunday, 15th May 1.30pm

Guest speaker from the Department of Justice on Consumer Rights

Sunday, 17th July, Mid Year Luncheon 12.30pm, at Lawrence Home

Sunday, 21st August 1.30 pm A.G.M. Guest Speaker (if available)

Neurological Physio Therapist

Sunday, 20th November – Christmas Luncheon 12.30pm.

NOTES FROM THE CHRISTMAS LUNCHEON

President, Margaret Lawrence, spoke saying “A really warm welcome to everybody. Thank you all very much for coming and I am sure we are going to have a splendid day. A special welcome to Dr. Andrew Kornberg, Dr. Richard Stark and Dr. Janet Stark.

To all the people who have travelled to get here, thank you also for making the effort; to Ken who has come from Wangaratta and is going to do the auction, a big thank you Ken. To the committee who have prepared and provided most of the delicious food “thank you” and there are other little elves that come and do all sorts of things as well and also provide food. Thank you to all those people.”

TALK BY DR ANDREW KORNBERG AT THE CHRISTMAS LUNCHEON

Thank you to the IN Group for your kind support over the years. I would really like to touch on what’s happening on the **clinical level** in neuromuscular disease, in particular some of the inflammatory neuropathies. I will talk a little about what is happening **in government** and then a little bit about **research**. That is the three major things that have happened over the last year.

Just with regard to your kind support last year with the donation again from The IN Group. I know you work very hard throughout the year to actually raise the money. That money always goes to an important project and as everyone knows, over the years we have been lucky enough to be supported by a number of organizations to train the next generation of people who are interested in nerve and muscle.

I am not going to be around for ever and there are a whole lot of people who are very interested but **we need to actually train those people as they're the ones who are going to be looking after you and the next generation of people affected by these conditions.** We have been very lucky to be able to have support for a **Neuromuscular Fellow** and the good thing is that that **Fellow which we trained through the year is very interested in nerve conditions, both genetic conditions as well as inflammatory conditions and will be going overseas to Toronto next year to do a research project** with one of the researchers that I'm very close to. Again, that's the sort of things we can do to get people across. We provide a salary but that **excellence potion, that extra little bit, is being given by people just like you** to actually make a difference, so thank you very much on behalf of them.

So what's happened in the last year? "Are many people here treated with Intravenous Gamma globulin?" From the **Government standpoint, a couple of years ago there was a review of who gets IVIG because there was a shortage of IVIG a number of years ago. It was actually worked out that there is 250 odd million dollars spent on IVIG by government.**

How do we make sure that the IVIG is being used in the appropriate way and the way that everyone who needs it gets enough? So the government made some decisions about funding and other things, **but there was a group of people with neurologists particularly involved, who developed or helped develop these Statements or Guidelines for the use of IVIG.** There was Chapter 5, 6, 7, 8 which really meant that if you have a condition which is in Chapter 5 it is fully funded; Chapter 6 is fully funded; Chapter 7 is fully funded but those in Chapter 8 don't get it.

So what we did as neurologists, (Richard is aware of the people in the group. There is myself, John Pollard from NSW and others) and I think it is fair to say that neurological conditions overall were looked after quite nicely. I'm sure many people know that they have been getting IVIG when they need it, etc. **That review is ongoing again at the moment and I'm on that committee, and I think what the next stage will be is that again neurology will be looked after. What this means is, you will get enough IVIG because we are not using it for things that shouldn't be using it. I think that's a good thing as well.**

Again, with regards to Government, there is an organization which actually is the **Therapeutic Goods Administration in Australia** which ticks off indications for drugs and everything else. **The good new is many of the conditions that we use IVIG for in neurology particular, will be registered under the TGA.** That's a wonderful thing, because **if there is a change in funding of IVIG one day, i.e. a Prescription, then everyone will be safe in getting the drug.** That's good news, and I don't think anyone here is not getting IVIG when they need it. Is that correct?

With neurologists, particularly Richard, strongly behind making sure all our patients are looked after to the best that we can.

The next thing on a clinical level is that most people who are treated with IVIG are treated with Intravenous Gamma globulin. There are now some studies that we are probably going to be embarking on in the next couple of years, looking as to whether you can use gamma globulin underneath the skin and you could do it at home. That is sub-cutaneous IVIG. (Often referred to as sub-cut.)

We know that **it does work in some conditions with inflammatory neuropathies**, but we don't know clearly if that's the case yet. **So there will be some studies and you may want to participate in them, here in Victoria and around Australia, but what that will mean is instead of coming into the hospital once a month, once every six weeks or spending a day or two days off work or whatever, you can do this at home over night.** That may make a difference to some people. Others may want to come into hospital for other reasons, but that may be another option and could be a positive thing for many patients.

It is a very good thing for many kids that we look after because they don't like coming into hospital so if it can be done at home, that would be a wonderful thing.

The other thing is **"What's with Research?"** I don't have a cure today for **CIDP**, I don't have a cure today for **GBS**, I don't have a cure for **Multifocal Motor Neuropathy**, but what actually has happened **over the last year is there has been again some newer treatments being developed to try to help with some of these conditions, in particular, Multifocal Motor Neuropathy.**

We know that **IVIG is the gold standard but we know that some people get worse over time and we are now just beginning to use other medicines to actually help those patients. They are very expensive medicines, some side effects, but I've now got 2 or 3 people that I look after that are using these new medicines like 'Rituximab' which has made a huge difference to these individuals. That's the next phase; using newer medicines to actually try to help with these conditions because IVIG and steroids can help, but sometimes there are a lot of side effects. We are looking for medicines that have less side effects but also give greater benefit.**

CIDP is what we call a syndrome. It's like a basket of different conditions; multi conditions, causing what we describe as **CIDP** and then trying to unravel by anti body tests what's happening in protein levels, **unravelling what someone may have and then working on using newer medicines to actually help.**

In summary:

1. Government is right behind neurologists looking after our patients in the appropriate way, continuing to fund the medicines as we need.
2. There are new trials going on right now to give medicines that we have been using for a long time in better ways and novel ways.
3. Actually unravelling some of the conditions so we can use some of the newer medicines to make a difference.

That's what's happened in the year. Some of it has been at the **Children's Hospital where we are just involved in a new trial of IVIG in childhood.** There has never been a trial of IVIG in children. There is no study that says it definitely works. **We know it works, but now we are going to do a study to prove it once and for all.**

Once again, **thank you for your support** and I will now take questions and be happy to answer them. Richard might have some other comment to that.

Richard Stark – I guess something I would like to say is that some people in this room will remember the crisis in IVIG which occurred I guess 8 or 9 years ago. Probably the thing that really activated the government and got things moving was the work that patients put in.

There was a 24 hour time when the tap turned off and there were several patients involved in contacting the media and made an enormous impression. I really think that day turned the story around with IVIG.

In 24 hours it went from being something that was going to be an ongoing problem to something that really has been sorted out through Andrew's committee and so on, but really the thing that got us through that was the activity of patients who really made a lot of noise that day; who put a lot of work in. The IN group, in terms of inflammatory neuropathies, has made a huge difference."

Questions to Andrew

Irma : We saw you on television with in recent times with a small child. What did he have?

Andrew: He had a condition called **Bickerstaff's Encephalitis** which is a bit like **Miller Fischer Syndrome** and falls into that broad group of inflammatory neuropathies and the good new is that **he did fantastically well.**"

John: Sub-cut Andrew. **Do you think it will replace intravenous or is it just the quantities we are having means it is too big to replace with sub-cutaneous (under the skin) delivery?**

Andrew: **I think for GBS – no.** You are that unwell, you come in, you have IVIG and there are some conditions where it probably depends on having a very high level of IVIG in your blood stream to re-boot the nervous system, etc. **In other conditions it may mean you need a little bit.** The problem is that we don't know how IVIG works in any particular condition.

There is **now evidence from overseas that some of the chronic conditions, some CIDP's can be as well treated with sub-cut in comparison to IVIG** but you have to have a much **larger concentration of gamma globulin** to get the volumes in. That's the biggest problem with sub-cut. If you are using the 5% or 6% solutions it is really just huge volumes but if you **are using a double concentration or a triple concentration which are being developed**, then the volumes are much smaller and it may very well be helpful.

John: **CSL have developed a sub-cut product haven't they? If it does prove advantageous, do you think the government will fund it?**

Andrew: **Yes CSL have developed a product. I think that there will be a group of people where it will be funded**, because **if you don't have to come into hospital, that's some cost saving**, but the pump actually has some cost, so it will be a balance and **some people will do fine on sub-cut, and some won't.** I think it's again **tailored treatment to everyone.**

Some people who are working full time and don't want to miss work can have their transfusion over night and not come into hospital, but **it will just give us a different way of**

giving the same medicine. I don't think it will take over completely. I still think we'll have IVIG by coming in monthly for some patients, and some people will be on sub-cut, but **we have to know if it's equal.**

John: What about a mixture of both – instead of going into Monash as I do every 4 weeks for 2 days, may I be able to have sub-cut at home and go in every 6 weeks or 8 weeks and **extend out the hospitalization period?**

Andrew: It may be that you could get all **your sub-cut done or all your infusion done at home.** Those are things that are unresolved as yet but there is work going towards that now.

Member: Are the new MS drugs likely to have spin offs applicable to CIDP?

Andrew: Some of those medicines **may be helpful.** Some of these medicines are really medicines used for cancers and everything else. They affect the immune system. We have tried different MS drugs in neuropathies before. Most of them don't work but those sorts of medicines may very well work. **'Rituximab' is a medicine that has been used particularly for some certain types of cancer but it does work very nicely for some people with CIDP, Multifocal Motor Neuropathy, etc.** So everyone's looking at those medicines to try to see if they are actually applicable. So those are the things that will happen.

Member: Do many children under the age of 12 get CIDP?

Andrew: Not many. I think about 10 years ago we published our experience from the Children's Hospital where I worked in St. Louis, and we had the biggest series of paediatric cases of CIDP together. That was about 25 children over many years. The number of kids to adults is possibly **1-40** but it does **occur in children** for sure. It can look exactly the same as it does in an adult. Childhood MS does occur but only about **5% of all MS occurs in children.**

Peter: Well Andrew, as is always the case you have **a clear indication of how important your research and your work is to us** and the clarity with which you present your case and give us an update of what is actually happening at different levels is certainly appreciated

We would not want to do anything else than to **support the researchers work** (like you and Associate Professor Richard Stark) in this endeavour and **it is my pleasure to present to you a cheque for \$10,000.**

Andrew: Just once again **a really huge thank you.** I know you work so hard during the year to actually support us in this way. I can assure you this money doesn't go to waste. **We put it into a fund which is just for looking after neuromuscular patients** and really a big, big, thank you and I guess I come here each year and **you are like old friends.** I have been coming for many, many, years and I can say that **we are partners in trying to make a difference.** **This sort of money is actually that extra bit that makes a huge difference.** **So from all of us at the Children's and all the Adult Hospitals around, thank you very, very, much.**

The Committee would like to thank the wonderful members who contribute donations towards this research and the fantastic support of the Geelong group and others who sell their craft work, produce, etc. with all proceeds to The IN Group.

DUTCH AUCTION AND LUNCHEON

Thank you to all who helped us raise over \$900 on the day.

A very special “thank you” to our generous committee and members, especially Jan and Bernie, Gwen and Peter, Melva and Joe, Margaret and Doug, Barbara, Dorothy and others who donate most of the food and put in the effort, and thanks also to those who assist the committee in the kitchen. This day would not be a success without your efforts

MULTIFOCAL MOTOR NEUROPATHY

If you have MMN and would be willing to speak to a newly diagnosed young mother, please contact Melva on 03 9707 3278 or email behrden@optusnet.com.au.

EMAIL AND PHONE NUMBERS

If you ticked that you could be contacted for hospital visits or contact with newly diagnosed patients and you have changed your email address or phone number, could you please advise Melva or email behrden@optusnet.com.au so our records can be updated. Thank you.

GBS/CIDP FOUNDATION INTERNATIONAL

Patricia Bryant the Executive Office of the Foundation advises that their website is in redesign. Visit www.gbs-cidp.org for regular updates and a wealth of information.

GEELONG GROUP

The Geelong Support Group Christmas Get Together held on Saturday 27th November 2010 at Margaret and John’s home was a very welcoming, friendly, warm and generous occasion enjoyed by all who attended.

The fruits, vegetables, jams, cakes, trees!, etc. donated then sold were so good, also raising over \$150. Member, Jim 83 made his marvellous marmalade too. Perhaps the 5 fruits jam recipe could be published in the newsletter? What a memorable day.

To contact this group ph: Margaret (003)52445311 or Dee (03)52443382

VISIT TO CSL

If you would like to visit CSL to see the process for production of IVIG, please return the slip below. This is just an enquiry at this stage to see if there is sufficient interest. Thank you.

Name:Phone or email

DOMAIN NAME RENEWAL THROUGH VICNET. CSL HAS GENEROUSLY UNDERTAKEN TO FUND THIS RENEWAL FOR THE NEXT TWO YEARS. WE RECEIVE MANY ENQUIRIES VIA THE WEB AND THANK CSL FOR THEIR VALUED ASSISTANCE IN HELPING US MAINTAIN THIS SITE.

A SPECIAL MESSAGE FROM MEMBER VALERIE SIMPSON.

Respite Facility

I use a wonderful facility for respite and wonder if there are any other people in our society who may be eligible to use the service.

It was set up (and fought for!) by people in the Australian Ventilator Users Network (AVUN) and is specifically for people who use ventilators to assist their breathing, either through a tracheostomy or a face mask. The facility is part of the Yooralla network and is staffed by people trained in trache and ventilator care.

The facility comprises four houses with five beds in each house. The majority of beds are for permanent residents but some are available for respite users. The houses are in Clarendon Street in Thornbury, Victoria. (A suburb of Melbourne.)

I use it when my husband Peter is unwell and unable to care for me and also to give him an occasional break from the relentless demands of full-time caring.

It is a wonderful place to stay. The staff do all they can to create a homelike atmosphere and they tailor their care to my special needs. I feel very safe when I stay there and am always thoroughly indulged. I fully recommend it!

If you think you might be eligible to use the service you could ring the Respite Manager, John Puttyfoot, on 9480 8100.

Valerie Simpson

FOR MEMBER'S INFORMATION

Following a phone call from Rod Gleeson of Lateral Grifols, subsequently an email was received which is inserted for information to members.

Lateral Grifols is an Australian company that manufactures blood grouping products and instruments. Part of our portfolio also includes intravenous immunoglobulin (IVIG) that we import from our parent company Grifols in Spain. The website is www.grifols.com

The IVIG product is called Flebogamma 5% DIF, and we began marketing this in Australia in January 2010. Flebogamma has been in the international market since 1992, with excellent safety results. My e-mail is in reference to making your members aware of another alternate product in the Australian market.

Flebogamma has a few differences from both Intragam P and Octagam, principally that it is sugar free (unlike Intragam and Octagam) so is beneficial not only in patients with GBS/CIDP, but also those with combined renal/diabetes disease. Also, it is very highly pure formulation, and has lower levels of IgA than the Octagam product.

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.

REMINDER TO THOSE WHO HAVE NOT YET PAID THEIR MEMBERSHIP FOR THIS FINANCIAL YEAR. THOSE WHO HAVE PAID, PLEASE DISREGARD THIS NOTICE.

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

Subscriptions due on the 1st July of each year.

1st July 2010 – 30th June, 2011.

I am happy to help The 'IN' Group by my membership.

Initial Joining Fee	\$10	\$
Annual Subscription		\$ 15.00
Other Items		
Booklets- The Road to Recovery A-Z	\$6	\$
- Boy, Is This Guy Sick	\$2	\$
- CIDP	\$2	\$
- GBS	\$2	\$
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

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