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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)

**\*\*PLEASE NOTE CHANGE OF DATES FOR 2017 MEETINGS!!** Unfortunately we were not able to secure the dates previously published for the 2017 Meetings. The new meeting dates are:-

<u>Sunday, 12<sup>th</sup> March</u>	<u>Sunday, 11<sup>th</sup> June</u>	<u>Sunday, 13<sup>th</sup> August</u>	<u>Sunday, 3<sup>rd</sup> December</u>
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<p><b>NEXT MEETING</b> <b>SUNDAY, 12<sup>TH</sup> MARCH, 2017 AT 2PM</b> <b>ASHBURTON LIBRARY, ASHBURTON COMMUNITY CENTRE,</b> <b>154 HIGH STREET, ASHBURTON</b></p>
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### Notes from the Christmas Luncheon.

Margaret: I would just like to say a few things.

Firstly, a big warm welcome to Dr. Richard Stark and Dr. Janet Keys-Brown. Thank you very much for coming. And "thank you" to special guests who have arrived today. There are several around and that's great as well and also to Ken who has come from Wangaratta to do the Auction. I will tell you that Ken has been elected Mayor of Wangaratta which is just great.

Many thanks to our Committee. They are marvellous. They donate most of the food so it is a great help, so thank you to all the Committee members.

Now unfortunately Andrew can't come today. He sent me an email that said "Sorry, sorry, sorry." He is going to Adelaide to a Conference and they moved it and so he had to leave this morning instead of this afternoon. I will try and get him to come to one of our general meetings. **We are going to send him a cheque for \$10,000 because it is a shame to leave it wait.** He sent me the information today as to whom the cheque has to go to. **It is thanks to all the members of The IN Group that we have \$10,000 to send him** and you all deserve a clap for that. Applause.

Thank you to all who sent apologies today. I won't list them but it is nice when people take the time to apologise.

**We are going to be in Ashburton all of the New Year. Initially it was to be a couple of sessions but they have told us we won't get back into the Balwyn Library Hall until who knows when but we will be here for the next 12 months.**

I would like to now ask Gwen to talk to us because she has some things to say about her dolls. There is one thing I will say. These little boxes contain Christmas Cakes that Gwen has made and these are for sale later on.

Gwen: I want to explain about the dolls and dolls outfits and all sorts of things including some Christmas decorations that we have over there and how we came by them.

I have been conducting Porcelain Doll Making Classes for umpteen years, (more than thirty) and we actually had a class here in this room. The first was when I was teaching remedial reading and upon retirement, along with a fellow teacher, Barbara, (put your hand up please) who happens to be Dr. Janet's mum.

Over the years we must have introduced hundreds of ladies to porcelain doll making. This is absorbing and expensive. We have had classes in the TAFE College at Holmesglen, at The Council of Adult Education and numerous friendly houses that we liked very much. The last 17 years has seen these friendship groups at my home. We built the house to accommodate the kilns and everything else.

Just before Christmas 2015 one of our group (I'll call her "T"), unexpectedly died. She left 30 boxes full of "dolls stuff" in various stages of completion, from almost barely started to almost finished, including parts of dolls, some fabrics, some wigs, some trims and they were destined for the tip. They were out on the nature strip. Fortunately the person who lived opposite was coming to the class too and she rescued them.

In addition to her help, my supplier of "green ware" which is the raw clay shapes (her name is Ann Pekarsky of Anushka Dolls) very generously donated many of the completed dolls of the highest quality, dresses, outfits, etc. There is one door stop piece too.

Members of my class, some with 35 years experience and more, worked tirelessly to complete the dolls. We are trying to sell them with the proceeds to go to The 'IN' Group. I have made most of the clothes. A big doll known as "Tom Sawyer" was sold at the last meeting. Several have already sold and they would normally be priced at \$200 plus but we felt it was unrealistic to ask for prices like that as we are intent on disposing of them. The prices reflect the basic costs of green ware, fabrics and wigs which can be terribly expensive. I didn't put an expensive wig on the large doll there as it would have cost \$80 and with all the labour donated free, you have the chance to purchase some tremendous bargains. Already some of my friends and The 'IN' Group members have bought \$520 worth, a grand tribute to "T" a lovely lady who had no children of her own, but delighted in making them for others.

Please have a look. They are fragile. Don't drop them. Don't let their hands clap. I don't mind you touching them but remember they are fragile. Thank you.

Margaret: Now I think we will enjoy the lunch.

## **TALK BY DR. RICHARD STARK AT THE CHRISTMAS LUNCHEON**

I was given instructions “Don’t be too long.” I certainly won’t be that as I learned of this as I walked in this afternoon. Doug when I first walked in said, “Have you been busy?” Yes I have been busy. Thank you, Margaret for the opportunity to speak.

I might just tell you a little bit about one of the things I have been doing. I have become involved with the **World Federation of Neurology**. In fact I am the Treasurer. It has been an interesting thing to get involved with.

You probably don’t know what the World Federation does but essentially it is quite interesting. **Its aim is to try to get neurology and neurology treatment up to speed in as many parts of the world as we can.** One of the things that we do is we run **Conferences** every couple of years which are held **in far flung parts of the World**. The last one we had was in Santiago, Chile and the next one is going to be in Kyoto, Japan.

The group of people we work with has an office based in London with committee members from **Tunisia, from Senegal in Africa, Canada and the United States and other parts**. It is **interesting to see how neurology is done in different parts of the World** and to get things up and running.

**One of the activities of the World Federation in the last little while has been to look into Zika Virus. Zika you have probably heard about as it was in the news at the time of the Brazil Olympics. You may guess what the World Federation of Neurology has an interest in. Part of it is the concern that the Zika Virus does potentially cause damage to the brains of unborn babies. That has been the big news about it, but the thing that you may not know is that it is actually very concerning for Guillain-Barre` Syndrome as well. All the areas that have a lot of Zika virus and all these unborn babies that have been affected being born with microcephaly with small heads is a tragedy but even larger numbers of people have actually been affected by Guillain-Barre` Syndrome.**

It is really **an important time to deal with that**. Of course **the parts of the World where Zika virus is occurring are not necessarily parts of the World that have all of the facilities we would like to have to treat GBS**. As you may know **some people with GBS are so severe that they need respiratory support; they need ventilators and so on. In these parts of the world these are not easily available.**

We know that **GBS is treated well with IVIg** which we are fortunate now to have pretty **readily available here in Australia**, although there would be many people in the room who would remember the days when it wasn’t so readily available, when we had to worry about where the next dose was coming from. I have to say, **it is thanks to some people in this room and this group that actually the supplies and security of IVIg have been established**. But there are parts of the World where it is not so easily available. It is a matter of putting in place plans to try and deal with all that and I don’t know if you know anything about the **Zika virus** and I certainly didn’t know anything about it before being involved with all of this, but it apparently **is a virus that has been around for quite some time**.

It was first **identified in the Zika forest which is in deepest darkest Africa** and when it was identified it was really a pretty trivial virus. It gave you a bit of a flu’ and that was it and no

further trouble and really nothing more was heard of it for a long time until **a version of it emerged in the Pacific Islands (I think the Solomon Islands). It had mutated and it was a different virus and it was producing more serious illness not at that stage associated with microcephaly, but there was in fact a flurry of Guillain-Barre` Syndrome in the Solomon Islands and that was about 5 or 6 years ago.**

Then it appears that **this mutated version moved to South America.** There is speculation that **it may have been the World Cup Soccer crowds** coming to see that and some of them had this mutated virus with them and they then became **involved in spreading the virus.**

One of the **great concerns about the Zika virus was the Rio Olympics** and whether people involved could be bitten by mosquitos and contract the mosquito born virus. They could **bring it back to the Northern Hemisphere, Europe and the United States** and be a reservoir for this virus there.

As you probably know **there have been some home-grown cases in the United States** since then. Of course there are bits of the USA that are very good for growing mosquitoes, i.e. **Florida and Louisiana** and so on. Not quite so good in Europe and fortunately it was starting to get **a bit cool in Europe by the time people were coming back from the Olympics.**

It has been an interesting thing and certainly **the World Federation has put together an expert working group to provide advice to Government** and to other peoples, particularly in the areas of the world not endowed with facilities, to help tell them how they can assist best, what sort of priorities they should have in spending dollars and so on.

That has been an interesting thing and something I didn't ever think I would be involved in, but there you are. **That's just a little bit about Zika and the World Federation of Neurology.**

I'm sitting next to **Rob** there and it is his **first meeting.** Welcome Rob. I asked him **what he hoped to gain from this and he said "Well you know. I want to see people with things just about the same as me that I can discuss it with."**

I think probably the thing that has always struck me (and I have probably said this before), is that with **CIDP and GBS they are basically the same sort of condition; they are caused in the same way; their symptoms are in general terms similar, but the details are different.** There is a **huge range of severity.** There is a **huge range of the types of symptoms** that people get, so **everyone in the room has probably a slightly different story.** No-one is quite the same but I think there are enough similarities that **people like to hear what other people are up to.**

I think probably when I last spoke at the Christmas Luncheon I had some slides with me and we went through some things, but I think it is probably worthwhile to remember that in these conditions they are caused by the immune system misbehaving and in **Guillain-Barre Syndrome` this misbehaviour is usually triggered by a virus or some other infection.** **The body is trying to fight off the virus which produces antibodies** and so on and those **antibodies do fight off the virus or the infection, but they also cross react with nerve fibres and cause some damage in that way.**

**Again GBS is usually a “one off” phenomenon triggered by a virus and it may leave you with damage to the nerve fibres but basically the immune process is over and done with early on. With CIDP, again it is caused by the immune system misbehaving but it is usually a “glitch” in the immune system which keeps on producing antibodies which are not good for your nerves. In CIDP there tends to be an ongoing requirement for keeping the immune system under control.**

**We are fortunate that we have IVIg which seems to be a very effective treatment. There are a number of other things we can use to damp down the immune system.**

**I was asked whether there was some new research going on. There is or course always research going on. One of the problems we have is that the neuropathies tend to be a little bit of a poor cousin to a degree and I think that is partly because everyone is a bit different so it is always difficult to measure how things are going. It is partly because, although it is not a rare condition, there are more common conditions like MS that get the headlines. There has been a huge explosion of research in MS over recent times and we know that MS is likewise an immune disorder.**

**It is quite probable that some of the advances that are made in MS will actually flow through and be a benefit to the immune neuropathies, CIDP and GBS as well.**

**All of those treatments for MS are based on dampening down the immune system one way or another and preventing damage to the central nervous system. Many of those things will probably work for the peripheral nervous system as well. We would hope, but of course you have to prove that it is safe and all of these treatments have their own set of side-effects and problems. It is always a question of balancing out what is going to be the benefit and what’s going to be the potential side effects. I think in the next 5 to 10 years probably what we will see is that there will be new and different treatments for CIDP and GBS. I wouldn’t mind betting that some of them do derive from the MS research and that probably we will find that drugs that have been demonstrated as effective in MS, that we know what their profile is, and we know what their side effects they may produce, will then be trialled in patients with CIDP and Guillain-“Barre` Syndrome as well.**

**I know Andrew Kornberg is involved in research of various types of these conditions and has young people working with him and some of the money you donate goes towards getting those young people up and running and running projects so I know he is very grateful for the money that he receives from The ‘IN’ Group and you do a phenomenal job producing the funding that you do.**

**That’s probably all I want to say. Just very happy to answer any questions people might have and again, needless to say, everyone is going to be different. The peripheral nervous system has motor fibres and sensory fibres. The motor fibres affect all different parts of the body. Most neuropathies affect those that are furthest away, so we get what is called a length-end neuropathy. Your feet tend to be affected more than your hips but it is not the case with everyone. Some people with CIDP do get weakness around the hips and the trunk as well. Sensory fibres can be affected and they can be under active and over active. You can get numbness of your feet or you can get an inability to know where your foot are in space so it affects your balance or you can get positive symptoms; you can get tingling; you can get nerve fibres firing off more than they should so tingling, burning or pain. All of those things can be different from person to person.**

If you go around the room probably the symptom which is giving everyone the most trouble may be different for each person.

That's all I wish to say but I'm very happy to answer any questions.

**Member: I am actually on a trial drug at the moment** at Peter McCallum because I have Waldenstrom's but it's not active. I have been told it is going no-where and it has been going no-where for years and it could go no-where for the next 20 years. So I am on a trial drug BGB 3111 which is tablets which I take. It has lowered the protein level and my doctor said if I get this protein level down it may help your CIDP. You will never run the 3 minute mile and it could take a year but it could help your polyneuropathy. I said "I'm in for a penny or a pound." **If it does work it may help other people with CIDP.**

Richard: Waldenstrom's is a condition where there is actually a group of plasma cells (which are the immune cells which make antibodies) that essentially go berserk. They make too much of one particular antibody. It's again the same sort of process that is happening in CIDP where there is an excess production of antibodies, but it is a very focused excess production where one set of cells makes one particular antibody which go churning out and make very large amounts of it and you can actually measure easily so you would be having levels of what is called IGM with one of these antibodies which are much too high. We do have a number of treatments that are effective at stopping plasma cells from producing antibodies, at least to a degree. There is a drug called 'Rituximab' which is used in treating some certain blood cancers which is very effective at dampening down antibody producing cells and we use it in some immune disorders as well.

One of the things people are looking at is using 'Rituximab' and similar things in neuropathy. The drug you have been given is obviously not 'Rituximab' because it is an established one that is given by infusion, but I suspect that it is aimed at doing the same thing.

I think we will see advances in those areas.

Member: I only take 4 capsules in the morning. For the first two weeks I had to go in 3 days in a row and have ECG's to see if my body was coping with it. I have had no bad reactions and when I saw my doctor last week he said "Guess what, that protein level is nearly right down. He said it is working so we will see after a year what happens." What happens after a year. He said because you went on the trial you will continue to get the tablets.

I hope that it works and if it does work for my polyneuropathy I will be the first one to stand up and tell people. .

**Richard: Hopefully if it works well it will go on the market.**

**Margaret:** Thank you Richard. That was **very interesting and I'm sure every time we have someone come to speak our members gain a little something from that and that helps them,** so thank you. Applause

Then we enjoyed the lovely Sweets Course during which there was lots of conversation between old members, new members, family members of past members and the children of members, all having a good time with like minded people.

**The Auction moved at a steady pace and we raised \$1280 for the day. Thank you to the members who also made separate generous donations towards the day.**

Thank you to all who attended and made this such a special occasion.

**Our Vice-President, John Burke received this email from A/Prof. Andrew Kornberg.**

As you may know, there are two things in life that I am passionate about – helping sick kids and flying. That’s why in March I will fly out of Airshow 2017 from Avalon and start on my journey circumnavigating Australia, flying solo to raise money for The Royal Children’s Hospital (RCH).

In my 30 years at the RCH, I’ve been fortunate to be able to care for thousands of patients and their families in the Neuroscience Centre. Each one of these kids and families has helped me to become the paediatric neurologist I am today.

***Fly for the Kids aims to raise \$1 million*** to support the introduction of the Complex Movement Disorder Program at The Royal Children’s Hospital, Melbourne. These disorders cause patients to have uncontrollable violent movements, twisting postures and or spasms throughout their bodies. This causes significant pain, physical disability and can interfere with movement, speech, communication and feeding. It has a profound impact on the quality of life for both the children and their families who care for them. Children seen by the Program need care through a variety of disciplines. More about the program can be found here <http://flyforthekids.org.au/what-is-fly-for-the-kids/>. I see this challenge as something I can do to hopefully make things easier for our kids.

After countless hours of planning, my journey is now mapped out. I’ll be flying more than 27,000km, spending more than 64 hours in the air (not at one time!) and stopping at 37 locations around the country. I’ll even get to meet some current patients along the way.

This will be gruelling, and a major challenge, but not anything like the challenges that our kids and families face every day.

Come fly with me and support me on this journey so together we can raise much-needed funds for this great hospital. **What would help now, as I prepare for this trip, is for you to consider donating and share the information with your friends and colleagues.**

Find out more and donate at <http://flyforthekids.org.au/donate/>

Thank you!

All best wishes

**A/Prof Andrew J Kornberg**  
Senior Neurologist

