



**STICK WITH IT  
SLOW BUT SURE**

# **INFORMATION**

[www.ingroup.org.au](http://www.ingroup.org.au)

[info@ingroup.org.au](mailto:info@ingroup.org.au)



26 Belmont Road,  
Glen Waverley, 3150  
Victoria, Australia  
ISSN 2207- (Online)

Issue No: 105

Date: February 2019.

**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) and other Inflammatory neuropathies.**

**Due to flood damage at Ashburton Library our First Meeting for the year will be on**

**SUNDAY, 17<sup>th</sup> MARCH, 2019, at the BALWYN LIBRARY,  
Meeting Room 1, Whitehorse Road, Balwyn 2pm to 4pm.**

**Guest Speaker: Dr. Nicholas Crump,  
Neurologist, Neuroimmunology/Neuromuscular Clinic,  
Austin Hospital, Heidelberg, Victoria.**

**A small plate to share would be appreciated.**

Dr. Nicholas Crump wrote: I am undertaking research into the best assessment of patients with CIDP, using formal clinical testing and ultrasound of the nerves both for diagnosis and monitoring progress and treatment response.

The current study is a one-off assessment to confirm we can find the changes on ultrasound reported in other centres. We are hoping to be able to include ultrasound in the diagnostic criteria. However, I am starting a bigger project mid-year looking at monitoring patients over 12 months, hoping to find measures that predict outcomes, or allow better monitoring.

**Dates to Remember** Please note venue.

Sunday, June 23 <sup>rd</sup>	Ashburton Library, High Street, Ashburton	2pm to 4pm
	Guest Speaker: Scott Earle	
Sunday, August 18th	Annual General Meeting- Ashburton Library	2pm to 4pm
Sunday, December 8th	Annual Christmas Luncheon “ “	12 noon to 4pm

## **Notes from the Christmas Luncheon December, 2018.**

Margaret: Welcome everyone. It is great to see you and I can't believe another year has gone by. A very warm welcome to Assoc. Prof. Andrew Kornberg who is going to speak to us and also to Ken who has driven down from Wangaratta to be our Auctioneer. After Andrew has given his talk he is going to leave as he started at 4am this morning.

### **Talk by Assoc. Prof. Andrew Kornberg**

I think it has been two years since I was here last. Again, it is like meeting old friends. I have been coming for many, many years and I really thank you for all your support.

I think last year people may know I flew around Australia in my little plane raising money for the Children's and there are lots of stories. I might tell you some stories before I get down to the nitty gritty.

That was a very successful trip, fundraising for a new clinic at the Children's Hospital. Each year **you** go out there and somehow **you always manage to give and you are amazing. Our department has been the recipient of your hard work** for many, many years, so it was **time for me to actually go out and try to raise some money.**

So that is what I did last March. I flew around Australia all by myself in a single engine rented plane, at the wrong time of the year (because you should never fly North in the wet season). I had cyclone Debbie chasing me down the east coast and thunderstorms everywhere going up from Broome. I was stuck in Darwin for days, but **it was just an incredible trip and I raised \$1.2 million.** (Applause).

**We have been able to start up a brand-new clinic which is the only clinic for children who have complex movements. You think about Parkinson's Disease and all those conditions. They do occur in children and we have been doing deep brain stimulation in these kids over the last year since the clinic has been established.**

**Two stories I will tell you.** One was in Western Australia in a place called Carnarvon. I had flown right across from Melbourne, from Avalon Airport, down the southern part of Australia and there is no coffee anywhere and being from Melbourne you need your café 'Latte' or flat white or your Cappuccino. I got into Carnarvon and I couldn't go up to the next place because of thunderstorms so I said, "I am going to walk around Carnarvon and I am going to find a cup of coffee." There I am walking past this store and there is a big coffee machine with plungers, etc., and I thought, "This is heaven." So, I go in there and I say to the lady "Can I get a flat white?" She says, "Of course sir." She turns around, pulls the grip handle out, turns around, opens up a can of International Roast, (laughter) and I thought, okay so that's the best I can get. So that was my first story.

**The second one** was a place called Burketown in the Northern Territory. It is an interesting place. I went down to the Burketown pub and was having a beer after a long day of flying. I'm sitting there and there are photos of guys right across one of the walls. I said to the owner of the pub "Are they sportsmen or are they famous people from Burketown?" He said, "No, No, No. Those are the guys who can't come into the pub." (Laughter) If you have ever murdered someone, Burketown is the place to actually hide.

I just really wanted to tell you an update about things. **A number of years ago we talked about anti-bodies, because many conditions of nerve are auto-immune. It is either genetic, auto-immune or diabetes. Those are the three broad groups for nerve conditions.** This support group (The 'IN' Group) looks after people who have **CIDP or Guillain-Barre' Syndrome** in particular or other inflammatory conditions where the **immune system is fighting their own nerves.**

I talked about different anti-bodies that we have looked for over the years, but what has happened **in the last couple of years, some anti-bodies have been identified in people with CIDP and there is a very, very, strong correlation with certain anti-bodies and bad, or not responsive types, of CIDP.**

People who have CIDP either go on **steroids or IVIg** obviously, but if you measure these anti-bodies in people very early on, then **you know that they shouldn't be on steroids or IVIg, because they won't respond.** You actually use different medications. **It has taken a long, long, time but it has actually come to the fore and people are now doing panels that will help identify the group of people who need different sorts of treatments. Rather than just steroids or IVIg, there are treatments that we can give.** Over the years we have talked about **different "chemo type" drugs** and those are the things people would be using **if people were found to be positive to those anti-bodies.** I started doing those anti-bodies I think 25 years ago. There are different anti-bodies which have come from those anti-bodies. **It is a wonderful thing.**

The other thing, the **money which has been donated by The 'IN' Group** has been used over the years to **support a young Neuro-Muscular Fellow at the Children's Hospital.** Not the same one, otherwise he would be old by now, (laughter) but **a new Fellow each year who has been trained to look after people who have nerve and muscle conditions. Our last Fellow is now going to be a Consultant Neurologist in the Department.**

We have been part of a study looking at Guillain-Barre' Syndrome. **There is an international study looking at outcomes, disabilities and different things that happen with GBS and our Centre is the only Paediatric Centre in the International Study which actually has been able to contribute, because we have a Fellow which has been part funded by The 'IN' Group over the years. That means that we are beginning to understand more about the long-term issues of GBS, in both children and adults. Right at the start you**

can talk to people about what they should expect over time. That is the sort of thing your money has been able to achieve.

We do the studies, we get the recognition, in the sense because our names go on the paper, but you need to know that all your hard work through the year is contributing to that and you are just as important and should be named on the actual papers as well. So, thank you very much.

Things are getting very exciting in nerve and muscle conditions both with auto-immune such as CIDP and GBS with new treatments becoming available; more specific treatments. There is a revolution in genetics for some of our kids with muscular dystrophy or spinal muscularity like Motor Neuron Disease in paediatrics. There are now treatments becoming available and have transformed lives. We are at a very lucky time and I think we are all happy, overworked but we have a lot of hope.

Thank you for all your hard work over the years and I'm happy to answer any questions.

**Member:** With the funding, say ten grand, do you get a matching amount from the Government because it's from a Charity?

**Andrew:** No. Not really. People who have been to the Children's Hospital will know it is one of the most beautiful places. Governments give bricks and mortar for the building but excellence and great things come from people who give, so from Philanthropy, the Foundation at the hospital, The Good Friday Appeal, The "IN" Group. We don't get matching funds.

For example, this Muscular Fellow. We used to get money from CSL at one stage, but because of circumstances and drug companies pulling out and not able to do these sort of contributions any more, we have had a short fall. How do we pay for that? When we see patients in our Out-Patient Clinics, they get bulk billed. That money goes back into the Department and from that, what we call our Private Practice Fund, is what we use to pay for our Neuromuscular Fellow. The \$10,000 which is contributed makes it a little bit easier for us. I guess it is a partnership with lots of people to actually make it happen.

**Member:** Would Tourette's Syndrome come under the umbrella of things you are treating?

**Andrew:** Yes: Tourette comes in under the Complex Movement Clinic, the new clinic we have established at the Children's from the flight, so for kids who have really severe Tourette's Syndrome. Most Tourette is towards the milder side, but the very severely affected kids would be coming to that Clinic and we would be using different treatments, etc. to help. Again, with Tourette's Syndrome there is something that looks like Tourette, that may very well be auto-immune, where the person's own immune system, related to some infection, can make things worse. Again, that is something we are interested in at the Children's.

**Member:** It's not CIDP, but I read a story about Professor George Jelinek who was diagnosed with MS and started degenerating. He started taking Flax Seed Oil and the lesions in his brain disappeared. He has a Clinic now.

**Andrew:** He is from Western Australia and Professor Jelinek is very interested in diet. He is on a very natural sort of diet himself.

**Member:** It is very useful for MS and he has lost all the lesions. Quite an intriguing story I read.

**Andrew:** Absolutely. It's very important that we know that for all medical conditions there are a whole variety of things that you can do for yourself. Eating healthy, dieting, exercising, all of those things and he is a good proponent.

**Member:** Flax seed oil is at the crux of his treatments.

**Doug:** Thanks very much Andrew. Thanks for giving up your precious time and we won't keep you because you might dose off having been on deck so early this morning.

All I can say is all our members are very fortunate to have someone like you leading the work that you do to try and find the causes and we realize there is never enough money that will receive results. It is just out of human endeavour of all these good people to try and find solutions to resolve what is going on. To that end, it

**gives me great pleasure, on behalf of The 'IN' Group, (as usual), I would love to present Andrew with another cheque, this time for \$12,000 to put towards his good work and thank you on behalf of us all.**

**Andrew:** I know how hard it is. Your Christmas Luncheon, all the things you do, yes there is not enough money, but **this money will go to training the next generation of people and from the bottom of our hearts at the Children's Hospital Foundation and families, thank you for all your hard work.** Thank you.  
(Applause)

### **Talk by Assoc. Prof. Richard Stark at Christmas Luncheon 2018.**

I wasn't intending to do a talk so I will just speak "off the cuff" about what I have been up to.

A couple of years ago, I told you I had been involved with the World Federation of Neurologists as one of the Trustees and the Treasurer. It has been very interesting to do. Certainly, you get to learn there are places in the world that astonish you as to what is going on there.

One of our main projects has been to improve neurology treatment in Africa, as throughout Africa there is not enough neurologists anywhere. The current program is to help train some new neurologists in Africa, **in Africa**, as it is very expensive and difficult for people to travel away from Africa to other parts.

The interesting thing to find is that there are bits of Africa that have well established Neurological Centres that can actually train others. I don't know if any of you would have been able to predict where they are.

They actually have four teaching centres in Africa set up now. You would like to say one of them would be in South Africa; you might suggest one could be in Egypt – Cairo. Would anyone like to guess where the other two might be?

Nairobi? No not one in Nairobi. Zimbabwe? No not in Zimbabwe. The two that I have given you are both English speaking ones and the other two are in parts of Africa which speak French, so one is in Morocco, in Rabat and the other is in Senegal. Amazingly, they are very well set up to train neurologists. We now have six different positions in Africa which have been funded by the World Federation and it is going to make a huge difference to what is going on there.

The other big thing the World Federation does is run a huge Conference, every two years. The last one was in Kyoto Japan; a huge Conference with eight and a half thousand people with Nobel Laureates speaking and that was a terrific Conference.

Lots of speakers from Asia came to that Conference. It is obviously not just to do with neuropathy and muscular disease, although we do have a very strong link with the International Neuro-muscular Disease group and we support their Conference. I am pleased to say as the Treasurer of the World Federation that we actually made a profit this time and it was able to give us a little bit back. So that's one thing to tell you.

The second thing is, as many of you would know, I work at the Alfred Hospital and just for a bit of local information, we have had a huge transformation at the Alfred over the last little while. Our former Head of Unit was a wonderful neurologist with an interest in cognitive

neurology, who ended up retiring a little bit early, so we had a little gap where I was Head of Unit on a part-time basis.

I'm delighted to say we now have a new Head of Unit. He is an epilepsy specialist, which is not terribly relevant to what is happening here, (at The 'IN' Group) but he has brought with him a large number of academic neurologists from his former position at the Royal Melbourne.

Our Academic Department of Neurology has expanded enormously and we now have a huge academic unit. Along with that, we have been able to fund an academic sub-unit which is in fact dealing with neuropathies and neuro-muscular diseases.

Our Neuro-Muscular Clinic has gone from having just one neurologist, to now having three. Two are very bright young women who have both trained at Queen's Square, which is sort of the premier neurology hospital in London. The other is a chap trained at the Mayer Clinic. Those three are the nucleus of a Neuropathy Clinic. Having that number of people, bright young people, means we can get involved in doing research and great trials and that sort of thing.

The third thing I wanted to mention is a little bit "off topic" for neuropathy. It's about serendipity in neurology; how good luck can sometimes be helpful. I have been involved with treating patients with headaches for a long time. It has become quite a big part of my Practice. Some 15 to 20 years ago in America, there were quite a lot of ladies having Botox injections for their wrinkles. You might wonder how that works. Botox is actually a chemical that stops nerve terminals from releasing a particular chemical that activates muscles and makes the muscles twitch.

We have known that you can use it in neurology to treat pains from spasms of the neck, intramuscular, to loosen them up. People who have had a stroke and have got spasticity tightening up the muscles, you can put it in the muscles and loosen them up. Well for the same reason, if you put it in the muscles around the wrinkles and sort of loosen them up, the wrinkles get better. People in America discovered this early on and they did a roaring trade.

The interesting thing was that some **people who also had migraines were saying "My wrinkles are better and my migraines are better too."** No-one believed them, because why would making wrinkles better or loosening muscles make migraine get better. Anyway, there were enough people which referred to this that they looked into it further and **ended up with a massive trial for the treatment of headache. In fact, the people with the most severe migraine, chronic migraine, people getting 15 days of migraine or more, found Botox to be very, very helpful.**

Why would it work? It was crazy why it should work. Migraines are not caused by muscles seizing up. It turned out that **not only did it stop the particular chemical we knew was being released by the nerve terminals, but some other chemicals as well, including one called CGRP and it probably works by actually preventing CGRP from being released and activating the migraine process.**

**Treating people with very severe migraine with Botox has become by a "good luck" observation a treatment which has become a routine practise. It has actually transformed my Practice.** The usual way that we were able to deal with migraine in the

past was to put patients on the best treatment we could think of and send them back to their GP to prescribe it. These days, **treating with Botox has to be done by a neurologist, every three months.** I have a large number of patients coming back every three months to have their Botox injections. It makes life pretty busy as **there is not much space to set up new patients. It is not neuropathy,** but it is true that we **sometimes do see serendipitous things happen.**

**Where should we look for serendipitous things in neuropathy? Most of the people in this room have an inflammatory neuropathy and it's an immune based condition.** The condition in neurology that has the most money poured into it is an immune based condition, which of course is MS. **We have seen a huge expansion of MS drugs in the last 10 – 15 years. All of them affect the immune system in one way or another.** Obviously, you can't just wipe out the immune system because that's not good for fighting off bugs or fighting off cancer and so on, but **we are getting a targeted approach to the immune system that works very well for MS. It is likely that some of this will flow through to inflammatory neuropathies as well.**

What we may see is that these drugs designed for something else can flow through and turn out to be helpful for neuropathies as well. I don't know if there is anyone in the room who has been treated with a drug called '**Rituximab**'. (Members answered - Yes.) '**Rituximab**' has been around for a while and in fact **it has flowed the other way, because there is a drug that is very similar to 'Rituximab' which is now being used for MS treatment.** There is similar action between the two.

The last thing I just wanted to say and I'm not sure if you are aware of, is **that IVIg has been available for a long time and the government has been supporting it. There has been a little bit of a change in the way the bureaucracy regarding getting IVIg has been set up.** Some of you have nodded. Some of you may know about this already. It probably doesn't make a huge difference to you. **It does make a bit of a difference to the doctors who are prescribing IVIg. We used to be able to say, "Yes. They are doing very well. Can we please have some more?" We now have to quantify how well you are doing. Some of that is quite tricky as we have to look back at how you would have scored on certain scoring systems before you were treated with IVIg.**

**I have patients who have been treated with IVIg for 20 years, 25 or even 30 years. It is actually quite difficult to look back into the mists of time to find out, if we had done a score back then, what that would have been.**

**You may find your doctors are scrambling through old notes trying to work out what your scores might have been before you were treated with IVIg. They might be asking you questions they haven't been asking before, in terms of being able to fill in these forms and documents to get IVIg.**

**I would hope it is not going to make a difference to the availability, but it is a little bit more bureaucracy and probably will change the way the questions are asked.**

**Richard: Has anyone experienced that IVIg issue? (Several members answered "YES".)**

**Member:** I had to fill a form out and send it back to my neurologist. You had to rate yourself a score on it. But the questions aren't relevant. They don't ask "How are your hands for eating?" They just ask "Can you do up your buttons?" That's it. They don't ask other questions that are relevant to your problem.

**Richard:** Its certainly true that bureaucrats love to measure stuff. Going back to the Botox experiment. It is expensive and the government is subsidising it, so people have to demonstrate that they have improved with their headaches. The headaches now need to go from whatever it was before you started to half that. If they start with 24 headaches a month they have to get down to 12. But what about someone who starts with 24 days of terrible headaches. They're in bed, vomiting and they go to having 15 days of headache and its very mild and they can take a Panadol and go about their activities. They say that's a terrific result, but in fact it doesn't meet the government criteria.

**Member:** That's the hard part. The government don't realise. I have been on 'Intragam' for 14 years and I asked my neurologist what would happen if I stopped it. She said, "You could go downhill and it's too hard to get you back again". The government don't know that.

**Richard:** The other boxes they are asking is to consider spreading it out a bit more, so those of you who have been stable for a long time, who have been getting it every 4 weeks for example, you may find your neurologist will say "What do you think will happen if we spread it out from 4 weeks to 6 weeks?" It is certainly something they are encouraging us to do.

**Another Member:** This is what happened to me.

**Question from Member:** About Botox. I have a lot of pain in my back which gives me what they call The Rainbows. Is there a possibility that Botox would be good for that?

**Richard:** In general, it seems to be best for pain that goes with a headache. What tends to happen though is, if you have someone who has very frequent migraines with all the other associated features and you make them less frequent, migraines almost seem to grow from migraines. The more you have, the more likely you are to have them.

**Member:** I have them every day.

**Richard:** It seems to roll on and roll on. Breaking the cycle often does help, but it certainly seems to be designed more to deal with the pain of the migraine rather than the other things. Sometimes these things improve, but it seems to be secondary.

**Doug:** Thanks very much Richard.

We can always rely on Richard to come up with something interesting. We hadn't planned any of this. It is always interesting as his work is so far reaching it has now gone global as you hear. It makes us aware that there is so much going on around the world all the time in every specialty field. Resulting from that, we are all living longer, getting better lifestyles, but there is still so much work to be done with the unknowns.

I am a little cynical being an accountant. I am sure the government are trying to save money. What would concern me (and I don't have the problem) with this type of approach given by the government, with the directions coming from the government to the medicos, not the other way around, is they will push you out to the point where it ceases to be working and that's where you will be left. You may never get back to where you are now.

Richard: Their intension is that IVIg is expensive and they (the government) would prefer it is used only when it is necessary.

**One practical thing I will say is that you can actually get hold of the Neuropathy Rating Scale that is now part of the Blood Star process. It is very helpful to your neurologist if you have seen the questions and thought about the questions on the "Tick the Box" sheet before you go to see them. It is designed that it will deal with some questions about your hands and arms, some questions about your legs and some questions about other things.**

**If you go in prepared, you and your neurologist are going to be on the same team and you are both wanting to get the IVIg continued. It is just a matter of getting through the paperwork and getting it done.**

Doug: I hope if it doesn't work for some people they will return to where it was working.

**Member:** Say if you went off 'Intragam' and you went downhill, what's your next move? Nursing Home.

**Richard:** It should work. When you look at what is written, it is not unreasonable. The practical difficulties are, particularly with people who have been on stable doses for a long time and have kept their neuropathy stable for a long time, to demonstrate that they need to keep on going, as you actually have to go back and demonstrate that there has been an improvement over three IVIg's. Sometimes that is difficult to determine, particularly if people change doctors and so on. Say you came from interstate and I met you for the first time and you are doing well on IVIg, it is very difficult for me to say what you were like before you started IVIg.

**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.

**NEW MEMBERSHIP AND ANNUAL SUBSCRIPTION**

<b>Item</b>	<b>Each</b>	<b>Payable</b>
Joining Fee	\$10	
Annual Subscription (Due 1 July each year)	\$15	
The Guillain-Barre` Syndrome Patient in Intensive Care	\$3	
Boy, Is this Guy Sick Booklet	\$2	
Recipe Book	\$16	
Donation to support Medical Research (Donations of \$2 or more are tax deductible) Tick if a receipt is required .....		
<b>TOTAL Enclosed</b> a cheque/money order (payable to The IN Group)		

Thank you. Please forward this form along with your payment to:  
**The 'IN' Group, 26 Belmont Rd., GLEN WAVERLEY 3150, or**  
**You can now pay directly via internet or at any Bank Branch using the following information.**

	BSB / Account: <b>063142 / 10006285</b> Account Name: <b>The IN Group</b> <b>(Include Your Name in "Description / Reference")</b>
---	---

**MEMBERSHIP DETAILS** (please Print)

Name:	
Address:	
Suburb:	
Postcode:	
Mobile:	
email	
To receive your Newsletter by email please send an email to <a href="mailto:John@bal.net.au">John@bal.net.au</a>	