

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.

ANNUAL GENERAL MEETING
Sunday, 16th August, 2015.
At Balwyn Library Meeting Room, Whitehorse Road, Balwyn 2.00pm to 4pm

Guest Speaker: Associate Professor Tim Day, Neurologist.
Trial of Oral Drug for CIDP

Dates to Remember

Sunday, 28th June 12.30 – 3.00pm Mid Year Function – Family Lunch at McDonalds Balwyn
(See information later in the Newsletter.)

Sunday, 15th November 12.00 noon End of year Luncheon and Dutch auction.

Notes from May meeting.

President Margaret: A special welcome to Ralph and Joan who have joined us today. Ralph is going to speak to us later which will be interesting and thank you very much for coming today.

Apologies: There are two apologies: Margaret Wilson and Dorothy Brennan.

Treasurer's Report: Doug.

Looking at January to March, things have slowed down. Our income was \$570 for subscriptions and donations and our costs were \$318, for Website, newsletter and gift for speaker. In total we have \$11,457. July 1st begins the **new financial year when subscriptions are due**. Thank you.

Doug and I had a visit from Dr. Christopher Fry our new contact from CSL who was really interested in our group. We now have direct contact with him and they are happy to help and they will pay for our website.

Correspondence: We have received a letter from the **National Blood Authority** asking us to inform our membership of **proposed changes to the criteria re Ivig**. (See excerpt from letter printed below) John Burke will forward it to his email list. **GBS and CIDP are covered in these chapters**. This is important information for our members who receive Ivig.

Dear Ms Lawrence

PUBLIC CONSULTATION FOR PROPOSED CHANGES TO THE CRITERIA FOR THE CLINICAL USE OF INTRAVENOUS IMMUNOGLOBULIN IN AUSTRALIA

I am writing to advise you of an impending six week public consultation for proposed changes to the *Criteria for the clinical use of intravenous immunoglobulin in Australia, second edition* (Criteria).

The public consultation process will commence on **15 June 2015** and conclude on **26 July 2015**.

You may be aware that governments determined the Criteria, first published in 2007 and updated in 2012, to ensure that government funded immunoglobulin products are directed to patients whom are most likely to benefit based on reliable evidence or where alternative therapies are limited. The

medical conditions from Chapters 5 & 6 of the Criteria have recently been reviewed by Specialist Working Groups (SWGs) for Haematology, Immunology, **Neurology** and Transplantation Medicine. The proposed changes to the Criteria can be viewed online at

<https://test.blood.gov.au/UAT/IgPublicConsultation/> .

A feedback template will be made available on the NBA website at <http://blood.gov.au/public-consultation> and should be provided by email to IgGovernance@blood.gov.au by 5:00pm Monday 27 July 2015.

We would be grateful if you could assist in communicating the details of the public consultation to your membership.

Yours sincerely, Leigh McJames, General Manager

General Business:

Mid Year Luncheon - Sunday 28th June 2015.

This year for something different we are having a "Family Day" Luncheon at McDonalds at 318 Whitehorse Rd., Balwyn, from 12.30 - 3.00 pm.

Please keep the date free and bring along your parents, children, grand children and anyone else who wishes to come.

A choice of four (4) mains, sweets, choice of tea, coffee, juice or soft drink

ALL FOR ONLY \$16 (part of which will go towards research).

Please RSVP Margaret on (03) 9802 5319 or Melva (03) 9707 3278 if attending by **no later than Thursday 25th June.**

Please advise your selection from the options below to assist with the catering:-

- A. Quarter Pounder with Coffee/Tea, Muffin or Apple Pie
- B. McChicken Burger with Coffee/Tea, Muffin or Apple Pie
- C. Filet-o-Fish Burger with Coffee/Tea, Muffin or Apple Pie
- D. Chicken Aioli Wrap with Coffee/Tea, Muffin or Apple Pie

- Coffee and Tea options
 - Black or White Tea
 - Black or White Coffee
 - Latte- Pronto
 - Cappuccino- Pronto
 - Flat white- Pronto
 - Soft Drinks or OJ can be provided if preferred

Our host will ask what we all want. Doug will print the options and put them on the tables for you to fill in. We look forward to a successful day and a bit of fun. .See you there!

Remember how **Russell used to make the pickled onions?** Well **his daughter Margaret has made some.** We will put a \$1 in with our name and then we will draw it out and see who wins. I will let Margaret know we have done this.

There is a chap in America having **stem cells for CIDP** and he has a blog. <https://jimkickscidp>
It is very interesting watching his journey.

POSSIBLE CHANGES TO PRIVATE HEALTH COVER (A discussion between members.)

B. I booked into St. Vincent's 28 days after my last infusion and they rang up and said Medibank wouldn't pay, but if you book it one day later they would pay. I was told this was the policy of all private health insurers.

P. I went to Medibank Private. They told me they know nothing about it. I went back to my neurologist and was told "What happens is that if you go in before the 28 days, the hospital has to foot the bill because Medibank Private won't pay it, but if you go within the next 7 days, Medibank will pay it.

B. The hospital said they would have to charge me if I went in within 28 days.

P. I rang the hospital and they said you don't have to pay. I don't think they know what they are doing.

N. When I go to the hospital they sometimes ask me Private or Public Patient? I asked "What's the difference?" They said that if you sign in as a private patient you will have a whole lot of paperwork to do, you will get things in the mail and you will have to sort that out and it will be free. If you are a public patient you will have less paperwork because we will just do it here straight away and it will still be free. So it actually doesn't make any difference, so I would recommend people use the public hospital. Of course 'Intragam' etc. is always paid for by the government so is free to the patient.

B. I think what they have done is Healthscope has signed a deal with Bupa, the same sort of deal, the 28 days and St. Vincent's Private has signed a deal with Medibank Private so that is why we have to go over the 28 days. You can go on the 29th day, so if you have to stay in hospital like I did last time I went in, I had to stay an extra day, so I had to change my infusion date and move my date another day.

G. I go to the Alfred. I sign my name on three forms and say yes I will pay through my private fund. Somewhere down the track I get notification from my fund that they have paid it.

P. It happened after Medibank Private was sold.

N. Even if I went private at the Alfred Hospital it is the same room I go into. There is no difference.

P. Box Hill is the same. I went as a Private patient into the public area because it reduces the costs for the hospital.

Lyrica A lady phoned complaining of bladder problems/pain which her doctor told her are probably caused by her CIDP. Since then we have learned that a rare side affect of long term use of Lyrica can cause it.

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.

Talk by Ralph Bailey, Barrister and Solicitor (Retired)

When I was asked to come here I was asked to talk about peoples affairs. I didn't know what to say as I didn't know about their love affairs, but I now understand that it is about what to do with your million dollar assets.

The first question I'm always asked is, "**Do I need to make a Will?**" **The answer is "No"**, because if you die without a Will there are rules that get rid of that money without you having to worry about it. The next question is, "**Should I make a Will?**" **The answer is "Yes"**. You should **make a Will because then we determine what is going to happen and how to manage your own assets.** Going back to the first question - If you die "intestate" the rules go like this. 30% goes to your spouse (if you had one) and the balance goes to your children (if you have them) and then there are numerous rules for if your spouse predeceased you or your children predecease you and it goes down to the most remote relative you might have. They might never have heard of you. Even though they might never have known you existed they could end up with your wealth, if all else fails.

If you make a Will you can determine what happens to your assets. First thing, most people do make a Will and the normal thing is to **leave everything to your surviving spouse, and the balance divided between your**

children and if any child predeceases you, their share goes to their children. That makes sense and is very fair.

If you have huge assets and you want to delve a bit further and you want to leave a bequest to some charity, you can do that, but you have to be careful with that. If you leave it to the Lost Dogs Home in North Melbourne then what is that? There is a charity known as the North Melbourne Lost Dogs Home, but then again it is not. It is the North Melbourne Lost Dogs Home Pty. Ltd. Then someone comes in and says “I’ve got a Lost Dogs Home and I live in North Melbourne.” Then it becomes a squabble and it has to be sorted out. When you make that sort of bequest, you need to be very careful on how you do it.

Do you need a Lawyer? The answer is no, but it is very prudent to get one to make sure it all happens the way you want it to happen. What many people want to do is they proudly produce a new grandchild and they want to leave something to the grandchild, so they set aside a thousand dollars or ten or whatever and that will help them buy a house when they get married. Experience has shown that if that happens, as soon as they get their hands on the money, they go on an overseas trip or buy a new car. A house is something they are not worried about. **If you really want that to happen it is best to leave it to a Trustee to hold in trust for them to go towards a house if they ever do get married.** Then there has to be a cut off date, so if they don’t get married something has to happen with that money.

The other one is **children**. Some children deserve more assistance than others, so they try to provide for that child who needs more help. Ten years down the track that child who needed help is a millionaire and the others are poor. So you have to **think about fairness**. If you are worried about the distribution, leave the money to a trustworthy person who sets up a Trust then distributes it the way you want them to do it.

Now that’s all very well because things change as we get older. **The first thing you need to do when you make a Will is you need to state fairness.** It is very difficult to make a Will and select Executors, because the common thing has been to appoint a spouse as **your Executor**. That’s all very well if they survive you, but if they don’t then you need to pick someone who should outlive you; **someone younger**. The common way to do it is to **appoint your children** (if you have any), because they are going to be younger than you no matter what when you die. They will manage your affairs and distribute the money as you see fit **and if those children are all your beneficiaries it is easy for them to do it all on their own.**

Some people think, well I **don’t trust the kids to do it because they won’t do it so they appoint a Trustee Company like State Trustees** for example. **They do a very good job but they are greedy.** They take out 5% commission on your assets for doing it and they charge all legal costs associated with it and their lawyers are their own and so they make quite a good profit out of doing it and that’s how they manage your affairs, but they do a good job. The other one is to appoint your Lawyer and that often happens. I have been reluctant to do that because **lawyers are not much better** than State Trustees and they will go in for their commission and they will charge their legal costs as well.

If you are thinking of doing it properly, fairly and at minimum cost, trust your children, (if you have them) or otherwise appoint someone who you trust.

Other bequests are that **you want to leave a legacy** for a group such as this. A group such as this has to be an Incorporated Body because who do you leave it to? The Committee? The Members? They might change all the time. So you need to then sort out very carefully how you do it. It is possible to **set up a Foundation** of some sort to do all those things you want.

There are complex features in Wills and I’ll answer your questions later on.

The other question is the Powers of Attorney. We all know the 3 Powers of Attorney. Someone today told me there are four and no doubt they will tell me about the other one.

The first one is the **General Power of Attorney** where **you authorise someone to manage your affairs**, mainly financial affairs, on your behalf, **for a specific purpose** which is usually everything, but you can just make it for a specific purpose to pay your bills while you are on holidays and it comes to an end, **or to manage all my affairs, until I cancel this Power of Attorney.** That is **only as good as the person who is the Attorney.** If you become unable to manage your own affairs, your Attorney **can only do what you can lawfully do.**

The next one is the **Enduring Power of Attorney** where you authorise someone or some people **to manage all your affairs as you would** but the beauty of that one is you have probably heard of, it endures to a stage where you can't manage your own affairs. If you became demented or some other thing, they can still manage despite the fact you can't do it yourself. That is **very good because some people get ill and are unable to do it**. More often than not, they appoint children. You have to be careful. Get a friend. Same problem. You have to get **someone you really trust to do it properly or several joint attorneys who act together**.

The last one and particularly important, or can be, is the **Medical Power of Attorney**. That authorises the **Attorney to deny medical assistance, so to switch off your support system which could keep you alive indefinitely if you can't go on anymore**. A lot of people want that and they do it.

I'm open to questions.

Question: Legally if there is no Will and it is distributed between your wife and your children, how about step-children or adopted children?

Answer: They qualify as children under the Act. They qualify as much as natural children.

Question: Regardless of age?

Answer: Yes. That's why you should make a Will.

I must mention that at a certain point though, **if you make a Will** leaving it all to the North Melbourne Lost Dogs Home **and you leave your wife and children without anything, there are provisions where a court will intervene**. The State shouldn't look after your wife and children and you chose not to, we will change that and **take it off the Lost Dogs Home and give it to your wife and children** anyway. It comes to anyone who is dependent on that testate person **to make sure they are properly looked after with sufficient funds** to make it happen.

Question: Even if they are adult children?

Answer: Yes, anyone who is a dependent.

Member: I remember a case 40 years ago where a chap died and he **had a new Jaguar motor car and he had a mistress**. He left his wife as his Executor and in the Will the mistress was to get the proceeds of the sale of the car. His wife sold his car for \$5 and gave it to his mistress.

Answer: Yes, that's possible if no-one objected to it. But **if the wife had said "Well, hang on, that should be my car" the court might intervene** but probably it wouldn't be worth it. They would decide who should get the car **depending on how much time he spent with the Mistress**. If she was the prime co-habitant, she might get it anyway. Those things happen.

Member: You mentioned about the **State Trustees**. My wife got a cheque from them 6 months ago from a deceased lady she never ever knew. **An old Aunty**.

Answer: Well State Trustees often get appointed when a person is intestate and they can't find any relatives to distribute the money to, so the Court will appoint the State Trustees as the Administrator, (similar to an Executor) and they will delve and hunt around and find the person.

Member: We got a cheque for \$1,200 and six weeks later another for \$6.

Ralph: There were probably about another 100 people who received the same.

Question: What's your advice as to **where to physically keep your Will?** I'll tell you why. **I was executor of my mother's Will. She kept it in a Safe Deposit Box in the Commonwealth Bank. I went and said "I was the Executor of that lady". They said, "We need to see the original copy of the Will before we open that box". The original Will was in the box.** (Laughter) An argument followed. So **where do you recommend keeping our Wills?**

Answer: If this sort of thing happens and **you know where the Will** is you need to see a Lawyer **who makes a demand on them to produce it or if necessary a court order and they pay the costs**.

Question: What happens **if you make a Will and the relatives hide the fact** that there is a Will? Lawyers don't check the Death Notices do they?

Answer: The **Banks do. If someone has a bank account they will freeze it.** They won't freeze it **if it is a joint account.** If it is a bank account in one name and you have authorised someone to **write cheques from an account, they won't be accepted from the date of the person's death.**

Question: What happens **if they find a Will and it doesn't suit them and they tear it up?**

Answer: **If no-ones aware of it there's nothing you can do about it.** Dishonest people do things like that all the time.

Question: If someone is leaving a Will to four children or four nieces, etc., is it wise to make them all Executors rather than one Executor in charge of all of them.

Answer: If I had four children, I would appoint the whole four of them. If there are four they might argue anyway so why not give them the chance to be an Executor and if the Will instructs them to give one Quarter-share to all children, they won't fight. **They have to comply with the Will.**

Sometimes they are given discretion as a Trustee to **support my children who are in need for their education or for health reasons or whatever** and the Executor has a discretionary decision. He has to exercise that discretion very carefully. Usually people tell the Executor exactly what they want them to do.

Member: I heard a case recently where the Executor took half of the proceeds and then divided the remainder between the beneficiaries. **Ralph:** And he wasn't a beneficiary? **Member:** They are still arguing in court.

Question: Two questions. **What does probate mean and can you make a Will on your death bed** as they say?

Answer: **I used to practise at Clayton not far from the Monash Medical Centre** and I was summoned to come to see someone about making a Will. More often than not **they made one so they could die happy.** They usually followed the advice on what to do with their money. The thing is **Wills have to be made when you are of sound mind.** If you made a judgment and the doctor said they were of sound mind, even though they may be dying, you very quickly help them.

Talking about Probate. That's a procedure that you have to go through when you are nominated as the Executor. **Every Executor has to apply to the Supreme Court to be appointed under a Probate Document to gather in all the assets of the deceased and distribute in accordance with the Will.** The Executor has to when he has done it say this is what we did. There is fairly tight control.

If there is a dispute over the distribution of a Will and you can't get agreement between the beneficiaries, you go to the Court and one side puts up their story and their reasons why they should get this and the other side do the same. **The Court comes to a decision.** The costs for both sides come out of the estate.

Question: Are there any circumstances where a non-relative can contest the Will?

Answer: Yes there is. They might say I lived with him 20 years. They have to have a reason why they were somehow entitled to a benefit. They relied on that deceased person for whatever they were doing and that showed a reliance of their income they might have a case. Anyone can make a claim these days. Whether it is successful or not is another thing.

Member: I can't remember exactly what I signed but it was something like the **Enduring Medical Power or Attorney** and I wanted my brother to decide for me if I was in hospital and unable to speak for myself and I wanted to be able to tell him that **if I'm there unable to do anything like with brain damage and unlikely to get better that he is able to say no more medical intervention.**

Ralph: **Did you tell your brother that? Did he agree?**

Member: **Yes.** He didn't have a choice. But if he doesn't do it on the day I suppose I can't do anything about it. **My question is how legal is that document?**

Answer: **As legal as he is prepared to observe it.** If he says I'm not going to do it, it is not worth the paper it is written on. **You can't force someone to do something they don't want to do.**

Member: But he would be **still legally allowed to decide for me.** It could be a medical decision of another kind.

Answer: Yes, **it doesn't have to be only turning off life support.**

Member: Earlier a chappie asked a safe place to keep your Will. I was wondering about that as well. Should you perhaps give a copy to another trusted person?

Answer: With the original. **It should be kept in a safe place, not in your own home**, because if your house burns down, so does your Will. The original should be **locked in a Bank, with a Lawyer, with a friend at some other address. Copies should be distributed to others who may have an interest and tell them where the original is.** This would solve all those problems.

Member: If the original is lost. Can you use a copy?

Answer: You can use a certified copy.

Member: Can you exclude a black sheep child from your Will?

Answer: You can make your Will to include or exclude anyone, but as I said before there are rules as to whether you are providing for those people who rely on you for comfort.

Member: If you have a child who is excluded from your Will can they contest it?

Answer: Anyone can contest any Will. Whether they are successful is another thing. If they didn't rely on you for sustenance over the past few years of their life, it would be very difficult to make a valid claim.

Member: If you marry again does your original Will still stand?

Answer: If you remarry then you should make a new Will because the old one is void.

Member: My grandfather did this and he never renewed it after he remarried.

Answer: They have changed the rules since those days. Now a current de-facto living with you is classed as a wife.

Member: Sometimes it is very hard to get an elderly person to give a Power of Attorney. My sister was elderly and couldn't do her business.

Answer: What does happen is they appoint an Administrator through the Administration Board who get someone who is close to them to manage their affairs.

Member: What is the Administration Board?

Answer: It happens to children who are mentally retarded but they have money and they need someone to help them with their affairs. It is a State Government Board.

Secretary – Peter McInness.

Well I met this gentleman Ralph here 65 years ago and I thought, he's a nice gentleman and I'd like to keep in touch with him. Two years later I married his sister and we therefore are still in touch with each other. The information he has given you today is, I think, extremely important and interesting. I think the success of his approach this afternoon was demonstrated by the range and variety of your questions and for that Ralph I would like you to accept something I know you are going to enjoy because I have been drinking this stuff with you for years. Applause and laughter.

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: **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 your junk mail software is very likely to delete our emails.

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 1/7/15 to 30/6/16.

Annual Subscription		\$ 15.00
Other Items		
Booklets- GBS	\$3	\$
CIDP	\$3	\$
After GBS	\$3	\$
The Road to Recovery A-Z	\$6	\$
- Boy, Is This Guy Sick	\$2	\$
Recipe Book -\$12 plus postage & handling	\$16	\$
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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