

INFORMATION

Inflammatory Neuropathy Support Group of Victoria Newsletter



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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) and other Inflammatory neuropathies.

NEXT MEETING

June meetup, 2pm 20/06/21, Ashburton Library

DATES TO REMEMBER

19/09/21 - September meetup & AGM, 2pm @ Ashburton Library

05/12/21 - December meetup & Christmas luncheon, 12 noon @ Ashburton Library

Stay up-to-date and RSVP at [meetup.com/IN_Group_AU](https://www.meetup.com/IN_Group_AU)

IN THIS ISSUE

March Meetup
Welcome
Treasurer Update
Committee Update

GBS NZ
Forms
Transcript



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MARCH MEETUP

Welcome

Margaret welcomed everyone after more than 12mths due to the impact of COVID-19 pandemic.

We'd planned to have Dr Nicholas Crump speak with us but he unfortunately had something come up on short notice and passed on his apologies.

Having said that we had a few new people join us representing three different people – Hugh and John each sharing their own experience, and Gil sharing her husbands experience joined by their son Simon. We thank them for their contribution on the day and for also taking questions from the group.

It was great to have so many join us not only on our first meetup in 2021 but after such a long time.

For anyone seeking support please don't hesitate to reach out, all our details can be found at ingroup.org.au.

See the "Transcript" section below for verbatim account.

Treasurer Update

Doug shared that our income, such as subscriptions and donations, over the past year was lower than for the year prior but this was not surprising given the pause on IN Group activities, especially not being able to hold a Christmas luncheon in 2020.

On a positive note expenses also dropped and the IN Group was still able to make a \$5,000 donation to the Royal Children's Hospital (RCH) for research work. Doug also shared, over the lifetime of the IN Group, total donations to the RCH was now around \$165,000, a marvellous effort from a small group of people.

While the scope of amazing work the RCH does is broad, these donations are target at research related to the inflammatory neuropathy conditions represented by the IN Group.

As we're approaching the new financial year, Doug kindly reminds us all that subscription are due again!

To renew or sign up for IN Group subscription see the "Forms" section below or visit our website.

Details on how to make a tax deductible donation to the IN Group can also be found there.

See the "Transcript" section below for verbatim account.

Committee Update

Margaret gave an update on some changes within the committee. Mary has put her hand up to be minute secretary and Neil has agreed to temporarily cover the Newsletter until a more permanent solution is found. If you or someone you know would be interested in helping with our Newsletter please reach out to Margaret on +61 3 9802 5319.



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These changes come about as we offer out sincerest gratitude to Melva and Joe as they retire from formal duties within the IN Group committee. A bouquet of flowers and a certificate of appreciation for over a quarter century of service was presented to them on the day.

Melva had this to share about her phone interactions “when you’re dealing with people and you’re able to speak to them and say that ‘things will be better, you’ve just got to hang in there’... you make so many friends over the years... I occasionally ring some up off the list and have a chat and they go ‘all my gosh Melva from the IN Group!’ And it’s a real joy”.

Thanks again Melva and Joe!

See the “Transcript” section below for verbatim account.



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Margaret shared that the Royal Childerens Hospital recently celebrated 150 years of care. As part of this Sue Hunt, CEO of The Royal Childerens Hospital Foundation kindly sent us a lovely letter thanking the group for it's generous support along with a commemorative pin as a token of appreciation. This thanks goes out to all of you!

See the "Transcript" section below for verbatim account.



GBS NZ

Did you know there are other GBS/CIDP support groups around the world, like the amazing GBSNZ Support Group just across ditch (www.gbsnz.org.nz). They also produce regular newsletters and kindly make them available through subscription or the internet. In their latest March edition they have the following special stories:

- COVID-19 and GBS: Even more follow-up (Dr Gareth Parry)
- Remembering Ken Ardern (Meike Schmidt-Meiburg)
- Article on Riva Walker-Pitmana (Sunday Star-Times publication)
- October 2020 Wellington Regional Meeting: Q&A (collated by Tony Pearson)
- A Patient Experience - Sallyanne McKenzie
- A Patient Experience - Lance Beste



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FORMS


New Membership Details

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Address :	
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Email :	
<i>To receive your Newsletter by email please send an email to John@bal.net.au</i>	

Order Form

ITEM	EACH	PAYABLE
Joining Fee	\$10	
Annual Subscription (due 1 st July each year)	\$15	
The Guillain-Barre` Syndrome Patient in Intensive Care	\$3	
A Road to Recovery – A - Z	\$6	
Boy, Is this Guy Sick Booklet	\$2	
Recipe Book	\$16	
Donation to support Medical Research (\$2 or more are tax deductible)		
<i>tick here if a receipt is required →</i>		
TOTAL ENCLOSED a cheque/money order (payable to The IN Group)		

Thank you! Please forward this form along with your payment to:
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TRANSCRIPT

Welcome message (Margaret)

It's great to see you all, we've forgotten what everybody looked like after 12mths away from each other so it's terrific that you're all here today.

We were to have Nicholas Crump to speak with us today he's had something come up, and though were made to arrange a substitute it wasn't possible in time and has passed passed on his apologies.

What we can do is have a little word from anyone who's new to us today, which is Hugh, John, and Gil and Simon.

Introductions

Hugh

Hi I'm Hugh, I've be diagnosed with MMN, which is part of a group of diseases so basically my understanding is my neural system is playing up, it gets worse over time goes on, it's mainly periphery and not on the main trunk. I got sick originally in 2011, with fluid, and that was treated basically with prednisolone for a long period of time but in the last two-three years I noticed in particular I was losing a lot of muscle and tone, so walking is a problem and gets more and more of a problem but I'm on IVIG and that seems to bolster me along quite well.

Audience: Welcome Hugh

Attendee: How have you been finding the IVIG?

The two days before I get it, I feel I go down hill, then it takes about three days [after treatment] I come up to a plateau for about three weeks, and then I'm on it again with that cycle. That's what I feel at the moment, it's quite profound.

Attendee: I didn't realise IVIG doesn't help motor neurone.

Another Attendee: It's not motor neurone it's multi-focal

Yes, it's multi-focal motor neurone, so it's not ALS, that was the original diagnosis that I got, which was a bit devastating, but because I'd been going downhill too slowly as against very fast, they're pretty convinced it's not ALS at the moment. So ball's in the air.

Attendee: How frequently is that?

Every four weeks I'm on 45 [g] I think it is, or 55 [g].



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Attendee: How many days are in hospital having an infusion?

I just rip down on the tram, get the infusion, hop back on a tram, so I'm there for four and a half hours. So you get something to read, and away you go.

Attendee: Which hospital do you have that at?

St Vincents.

So basically one of the things when I got really sick in about 2011 was I started build a database of all of the blood tests, and every test I'd been on, and all the details, so a huge number of entries, about thirteen thousand in actual fact of individual test over time, but I'm yet to find a doctor that, well I've found one doctor that was prepared to have a look at those overall results over a period of time, which I find a bit disappointing. I'm an IT person so I was able to get the data there and show that I always fail this test, I always pass this test, I always fail this test within certain parameters, but they weren't able to diagnose the multi-focal motor neuropathy until recently.

Attendee: We did have a member for many many years and it was only, probably about 12 mths before they passed away, before they actually diagnosed him

laughing Well I hope that's not the case with me

Attendee: Has there been any MRI of the brain?

Yes the last one was early last year, when I took a big dip down, I was going quite well then in around January last year, just before covid, I ducked down hill very very fast, so they did all the MRIs, head and so on, and it was still stable. A major test I get done each year is a breathing test just to make sure that doesn't depreciate as well.

Attendee: was the cerebellum analysed?

I'm unsure what that is?

Attendee: I was a mystery also till I got the right person who had a look at the cerebellum and they diagnosed CANVAS.

Attendee: What is CANVAS?

Attendee: Cerebella Ataxia Neurovesibula Areflexia Syndrome

laughter and applause

John

John is my name, I've been diagnose with CIDP, about five years ago I started having problems with being able to walk properly. The difficulty was getting it identified, that's only happened in just under two years, so I was about three years without a proper diagnosis. I have infusion, similar to yours, every 4 weeks. My problem with me is my legs, it's just a slow regression which has been slowed down with the infusions. I had a check recently, with the electrical, what do you call it?



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Attendee: Nerve conduction test?

Yes, and the chap said “the good news is it hasn’t progressed very much in the last 18 months, the bad news is it was pretty bad to start with”. I think I have plateaued to a degree, but feel it still getting worse, I can’t walk as far as I use to.

Attendee: Do you have foot drop?

Yes, quite significant.

I’m told it will possibly come to my arms. I am beginning to feel the beginnings of tingling at the end of my fingers.

Attendee: Who’s your neurologist?

Karina Rearadin and I think she’s very good, I was actually referred to her by another neurologist, and I thought that was very good, for one neurologies to say “I can’t do any more for you, Katrina is who specialises in that”

Attendee: I have pretty bad neuropathy in legs and hands and Lyrica help keep it at bay

I’m on Lyrica too, but I think that’s more for pain

Attendee: yes, neuropathic pain, helps me with tingling

So that’s basically where I am, happy to answer any more questions.

Gil (on behalf of husband Graham)

So we’re new at this, it was about start of November, and it’s sounds ridiculous, but we were each having different pizzas and Graham got gastro. And of course he doesn’t listen, and by Wednesday I say you’ve got to go see a doctor, which he eventually did, and on Thursday he started to feel ok.

On Friday night he went to bed and mentioned he couldn’t really put one leg over the other, and on Saturday morning, he said “my lower leg’s weak”. He was holding onto the wall and I didn’t think he had a stroke but we rang the doctor and she said can you bring him in. It was fairly hard getting him in the car to go down. So we went to Knox but they couldn’t help us and they sent him to Box Hill, and they thought at first it might have been something to do with his diabetes so they said he’d be better the next day if it is.

By the end of the day he had no movement in his legs, no movement in his arms, not much in his chest, but he could move his head. So it came on really quickly, and that’s when they thought it was GBS and would tell by a lumbar puncture which they did after a couple days.

They gave him the five day course of IVIG and that did seem to, not make it better but didn’t make it worse, made it stable. As he was stable they said there wasn’t any point in doing it again. After a couple of days, he went to ICU and had a tracheostomy put in, he was in ICU for two weeks, then he went to Peter James rehab. Just before he went to rehab he started to get some episodes of AF, they sorted that out. He’s been at rehab since mid December. Over Christmas they were all on there holidays so he



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didn't have any physio or anything but now they're back, he's got no movement in his legs, some movement in his arms and his check, he's just started standing up in the pool, they can get him in the sling in to an electric wheelchair, and he's able to put his hand, or they put his hand on the toggle, and he's able to move himself in his wheelchair.

And that's where we are. It's slow, he is getting better but slowly. We had a meeting on Friday for the first time, he's got the axonal variant, which seems to be the worse sort, but he is very slowly getting better. I get the impression from them that he perhaps isn't going to get all the movement back into to his feet or legs to walk, though he has had some tingling in his feet so that's good.

Attendee: so it's diagnosed GBS?

Yes, GBS.

Just something funny, we went down to the cafe and when we were going back he says he wants money, and I say "what do you want money for?", "oh when you're not here I want money so I can come down to the cafe and get myself coffee", but I say "how are you going to do it?", so the nurse takes him down and he gets coffee and it makes him feel a bit normal. He's in IT and he is very bright and some of the staff treat him like he's not. It's got on his thing [in his room] "Involve him in the decision making", don't just let him lay in bed.

Margaret: Thank-you, and when we have afternoon tea people can have a chat to the new members

Treasurer Report (Doug)

Having not had any meeting for many months, it's been a relatively quiet time from the treasury point of view. Looking at the figures and the accounts, which I'm still doing every quarter, due to the COVID situation our income is well down on the previous year. An example there is our subs last year were \$910, this year \$710, and donations have come down from \$6,170 last year, to \$2,092 this year, so there's been a big drop off this year. Expenses also came down which was good, last year was \$1,952, and to date they're \$837, that's a very good movement. The figures I'm comparing to last year are only "to date", as we know there's another two months to go as our year ends on the 30th of June.

During November last year we forwarded a cheque for \$5,000 to the Royal Children's Hospital for research work, and this \$5,000 is given the total donations to the RCH now approximately \$165,000 during our lifetime as the IN Group, so that's a marvellous effort from very few people. I think Margaret might make a comment on that because, they've sent out while our amounts aren't great they are consistent, and they can start research projects knowing that they're going for the next few getting these amounts from us.

Margaret: and can I say to the new members, the research is into your conditions, our money goes into the Children's Hospital but they run all different sorts of research programs and they've got one that's going which is looking towards our problems, so it's not just going into anything, which is very good.

In total we've currently got \$8,400 in the bank, which included an amount of \$1,250 the we get as an application we make each year to the State Government, the DHHS, and that money that we get is to be



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used for expenses for the group, for items such as our newsletter and things that will spread our word and help our members both here and can attend and we are very much a minority compared to numbers we have because they're in all states of Australia. That money we receive we cannot give as a donation, the donations we give are a result of the funds we earn from our Christmas party where we make money and other fund raising activities plus donations we get from our wonderful members.

So I'd just like to say that's the good news, the bad news is that subscriptions are due again on the first of July, so as we're only two months away from starting a new financial year. We are holding the subscriptions at \$15 for 21/22.

In the mean time, as I said, I'd like to thank everyone in the IN Group for their generous donations and everything, which are very much appreciated particularly by the RCH which Margaret will mention shortly.

Attendee: Where do the donations come from? Are they from members or people outside?

Basically all members

Attendee: Because It seems quite substantial, or has been

We've got some very generous members out there which is fabulous, but look every little helps and it all just rolls on. As a group we don't have any paid members in the IN Group, everything is voluntary and a very large portion of the stuff we do is donated by committee, like if we have Christmas parties, which we hopefully we might crack this year again - we missed out last year. The committee puts on a dinner for members, it's paid, say \$20 for a fairly big spread of food there's a lot of it, people will bring a small gift wrapped up and we have a blind auction - you don't know what you're buying, and it's just a fun day, it's our December meeting, our last one for the calendar year and we just have a lot of fun and laughter and we make a bit of money. That is put into the pot that also contains, when people are paying subs where people will put in some more money, and we don't push it we don't ask for that because everybody is in a different financial situation and position and that's something that we don't talk about in terms of people or dollars it's up to them so nobody is aware of where that money comes from, so it all comes from members unless we're doing a fund raising thing like the Christmas party and we have, which Margaret will talk about, Gwen has the odd one or two dolls. So that's where we stand, we are all volunteers, no one gets paid I don't even have a salary list on my accounts, there's no salaries so I don't even list it.

Attendee: Don't we get some grants some corporate like CSL and stuff

We talk to them but we don't get donations from them, CSL of course the company that produces the intragram that most of you are using, we have in the past had a couple visitations there and they've shown us around their operations, which I think at the moment with covid that'd be pretty busy. But no we don't have any corporate funding anywhere. It's very difficult because there's, coming from the corporate field, you get hundreds of requests for funding and corporations will have their nominated charities that they give to and they won't even respond in most cases to requests for funds from a group they've never heard of, even though we can provide documentation to support our group, and I will say too, while we're on that, we are a registered charity, we're a not for profit registered charity and all



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donations made are tax deductible, so that does help a little bit for those that are still earning income, most of us are not anymore, you know a quarter of a half of one percent, divided by six is about the interest rates we're earning on our savings these days *laughter*

Anyway, that's where we're at.

Melva: I'd just like to, let you know our group's been going for quite a while, and when we started our membership were in their 40's and 50's and now after all these years quite a few of them are not there, so when you send out a newsletter you usually get one or two that come back saying no longer at this address and you look back at, years, the date they joined, I know where they are now.

So our funds have dwindled over the last few years for our donations and subscriptions and things because of the age of our members, so and it's a good thing, it means there's not as many getting GBS that require help and stuff like that, but it's not so good where donations are concerned.

Committee Update (Margaret)

I'll now move on to the Committee. We're very grateful to our committee, Mary has put her hand up to be minute secretary for us which is fantastic, Neil has put his hand up to take on Newsletter, in the hope that somebody else would maybe take that on as we say a big thank-you to Melva and Joe for doing the newsletter but they're retiring from that, but not from the Group, just from that. So that's two people, and we always need members, if they're interested to, become committee members, we need help always, and I would like to say a big thank you to the support that you give me and Doug, that's great.

Now Neil's going to be the next speaker, here he comes.

Mary: Could I just butt in here please Neil for a moment, the committee meetings and the usual meetings pre-covid, the supper and the teas are wonderful *laughter*

Neil: So following on from that announcement from Margaret, Melva, about taking a step back, to, focus on yourself a bit more, because that is important, we want to recognise all the effort yourself and Joe have put into the IN Group and, so it's been over a quarter of century when we do the math, so it's very significant and we want to make sure we recognise that and how much we appreciate that, so here's a little something in recognition of that *hands an IN Group certificate of appreciation and flower bouquet to Melva*

Melva: for over a quarter of a century

Neil: Yes

round of applause

Joe: are some of those for me? those flowers *laughter*

Melva: I really don't know what to say, because, when you're dealing with people and you're able to speak to them and say that things will be better, you've just got to hang in there, and you make so many friends over the years, I've got more friends over the phone than at meetings, and I occasionally ring some up off the list and have a chat and they go "all my gosh Melva from the IN Group!" And it's a real



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joy, and I've always said to Joe when the phone goes and you're able to help someone it's a special joy and I always say I've been working for the boss today

Joe: that's me

Melva: no it's not you dear, the people who know who the boss is know who the boss is, so yeah it's has been a joy. And the morning and afternoon teas have been great too.

That's lovely, thank you. I just have a letter from the hospital and our name in their book, I'll put it out on the table over there. It was 150 years of the Royal Childrens Hospital and they sent us a badge. I think Neil you wanted to take a photo of that badge to put in the newsletter so I'll put those out in a minute.

The dolls, Gwen and I have been given about 100 dolls would you say?

Gwen: I'm not sure it's that much but it's a lot of dolls

Are you sure they don't multiply in the cupboard *laughter* Now the idea was they were to be sold and the money to go into the research program. Now we've sold a few but I've had so much trouble, the other night I got into this lady who lives in Leongatha who uses eBay to sell things and takes a percentage which goes into the Leongatha Rotary Club. Now she said she would make a start with the dolls but after we had, back and forth messages, when I went to bed and thought about it, she wanted one doll at a time to sell which meant, if we manage to sell 30 dolls that 30 people to come to that house to collect and the dolls are living at Gwens so it just was the whole scene was too difficult. So in the morning I sent her back a message to say I decided that we should give them to charity. And she sent me back a message "Good idea Margaret, I think you're going the right way", so what we thought we'd do is, well, I friend of mine works in one of those Charity shops in Brighton said she'd take a few, now we're not going to get any money for them but they've got to go somewhere, and then we thought we might perhaps be able to give, if anyone is interested, maybe six dolls, they might give us \$10 for them and we get a little bit in, but we've got to get rid of them, they can't keep, we've had them maybe two years, probably.

Gwen: Would you like me to talk about them?

Yes please do

Gwen: I've been teaching porcelain doll making for 32 years, quite by accident, had a wonderful time, I'm still teaching, like every other craft, which I've probably taught to even though I knew nothing about it. Crafts and doing things that's gone out, and so have collections of things. Nobody, my grand-daughters for instance, nobody collects anything, they don't collect things you've kept forever and treasured. I'm finding they can't knit, they can't crochet and those things so it's really a lost cause. The supplier I've had for the materials has gone to live in Canberra and she's retired anyway, she gave us quite a lot of the dolls and we got some from her students, got them from people all over the place. Some of them, the vast majority of what's left, are quite big, and they're not toys, they're things to collect and treasure, and they're very very expensive to make. I think the materials use to make it are about three hundred dollars and we'll be lucky to get thirty, and it breaks my heart but I realise as I had a similar experience with my



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husbands pool collection, nobody collects anything now. So I've done all I can do I think now, I've tapped all my resources but I'd just like people to know how very very expensive they are and it's just, it's heart breaking. I don't mind having them in the house, I've got plenty of space and I'm emptying my place as quickly as I can so I don't have to look after things.

Do you think if brought some here if anyone would be interested? Because transporting them is quite difficult.

Gwen: Yes they're quite breakable.

Attendee: I've never seen these dolls.

Doug actually has some photo's of them on his phone, if anyone wants to looks at them

Attendee: I can put some on Gumtree, because of my condition I've been getting rid of lots of stuff from my home it's fairly central and I just put it on Gumtree, and if you want it you pay postage or you come and collect. I'm home all the time so I've be happy to rotate through some of them, and of course what every money comes in goes back to the group, that wouldn't be a problem with me.

Maybe we can, for the next meeting, we can bring along some.

Attendee: I think that'd be an idea, because if I have them there I've got a room with nothing in it that I'm trying to get rid of, I put one up at a time, it goes, you cycle through.

So I think that's what we'll do then, bring some along to the next.

Melva: I must say that I've got one, for my seventieth birthday, it sits in a private place on beautify chair that I have at home and everybody walks in and nobody comments about the doll except my son in law and every time he comes in he stands in front of it and says it's the most beautify doll he's ever seen, and what is he now, nearly forty and he's got sons, but just adore's that doll.

Not like my grandson who asked me to hang a blanket over mine because it stared at him and he didn't like it.

laughter

So now I think we're done?

John: I've got something to say, I wanted to talk about the covid vaccine before we break for afternoon tea. Who hasn't booked in for their covid vaccine? I'm booked in for next Saturday, booked it online Saturday night, easy. I saw it on the tele, they said it's happening, did it on the phone.

Attendee: So you were able to book it online?

Booked it online of the phone, they called me back Sunday, said "you're in for next Saturday" boom.

I was lucky my Farther actually goes to a big clinic that is also a vaccination centre they were doing covid bookings via an app on the phone. At some places, when I've checked the covid checker online, they're only doing phone bookings, there's a mixture of places doing phone bookings or online bookings.



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Attendee: I looked at the twenty five sites that came up in my district and all of them were phone bookings, not one was online.

Attendee: When I had shingles and I wanted to get the immunisation the neurologist said there's got to be a three week window, I just wondered whether with CIDP if anyone's heard anything?

Melva: There's no problem with vaccination with GBS or CIDP.

Attendee: Ok, the neurologist never said anything.

Attendee: But you can't, you've got to have a two week time frame between that and if you're having the flu injection, you can't have them together.

Attendee: We have the flu injection every year, so if we have one now we better wait two weeks.

Attendee: The Canterbury one is doing them.

John: There's quite a lot, I checked just before, this morning, there's a few places that have got bookings available. I checked where I'm taking Dad, at Sandringham, so not in this area but they've still got available slots next Saturday afternoon.

Attendee: As long as you've got a letter, or a health summary from your GP, it tells what's wrong with you, what warrants you fitting into the 1B category. Because we're immune suppressed we do qualify.

John: Well anyone over 70 qualifies for a start, and anybody with a relevant condition qualifies

Gwen: Well I'm slightly over 70 *laughter*. My clinic's in Rowville and when I called they said don't worry about the vaccine or flu, we'll let you know.

Attendee: My clinic was the same

Doug: John, where did you check online

John: There's an online checker, just put covid checker into google, I brought my computer along today if anybody who wants to check the checker here. Put in "covid eligibility checker" in.

Margaret: Ok thank you all for coming, I'm sorry we didn't have a speaker but we'll hopefully have [A/Prof] Andrew Kornberg will be our speaker at our next meeting and I'll try and get [Dr] Nicholas Crump to come to our September one, so that's were we are at the moment, and I do hope we can have a Christmas function as well but you just go along and see how things go.



@ info@ingroup.org.au
www.ingroup.org.au
twitter.com/IN_Group_AU
meetup.com/IN_Group_AU



77954503188