

INFORMATION

Inflammatory Neuropathy Support Group of Victoria Newsletter



26 Belmont Road, Glen Waverley
Victoria, 3150, Australia
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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.

First Meeting for 2023

Sunday 12th March 2023 2.00pm

Ashburton Library, 154 High Street, Ashburton

Speaker: Linda Athans from LifeBlood, speaking on *Facts About Blood Groups*



PRESIDENT'S MESSAGE

A Happy New Year to everyone and welcome to our first Newsletter for 2023.

In October last year I read an article on the struggle that Swimmer and Olympic Medalist, Michael Klim, is having coming to terms with being diagnosed with CIDP. He spoke about going through a 'grieving process' where he needed to come to grips with the reality of the huge changes it would make in his life.

IN Group members will completely relate to that and understand his feelings and frustrations.

But what registered with me in this article was the welcome news that he was shortly hoping to launch a Foundation which will help raise funds and awareness for CIDP research and to help sufferers and carers.

As we know, there is little understanding of CIDP in the general community and we also know how critical funding is to sustain focussed research into CIDP. We congratulate Michael in using his high profile in the community to help raise awareness and support, not just here in Australia, but throughout the world.

With my best wishes to you all.

Margaret Lawrence
President



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Website: www.ingroup.org.au



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2022 CHRISTMAS LUNCHEON

We welcomed Associate Professor Andrew Kornberg to our Annual Christmas Lunch where he was presented with a cheque for \$10,000.

in responding, Andrew reminisced on his long association with the IN Group from the time of his first communication with James Gerrand, and how supportive the group has been of the research conducted at the Royal Children's Hospital – he has always been honoured to accept the group's donation of \$10,000 each year.



Assoc Professor Andrew Kornberg, Margaret Lawrence, Adelaide Krania, Dr Eppi Yiu.

The IN Group support makes a huge difference to the research carried out and to the children who contract GBS/CIDP and donations have gone towards research, salaries of fellows – the young trainee doctors, and purchase of machinery.

Just two examples are a new nerve conduction machine purchased two years ago which is used for teaching, and the purchase of a walking mat which allows clinicians to research how children walk to make sure they receive the best available therapies possible. This leads to published research which is to the advantage of children and adults alike.

Andrew also introduced Dr Eppi Yiu, Head, Neuromuscular at the Royal Children's Hospital and Adelaide Krania, Philanthropy Coordinator, the Royal Children's Hospital Foundation, with him today.

He said this visit was somewhat by way of "good bye and hello" as that although he would maintain contact with the group, he was handing over to Dr Yiu – just the person to lead the department from strength to strength with regard to GBS, CIDP and other neuromuscular research.

Eppi spoke of how she had been at the hospital overnight caring for a GBS patient from country Victoria, and that she considered it a privilege to follow in Andrew's footsteps to be able to continue her passion working with children with inherited and acquired neurological disorders. She mentioned that as a young research fellow, she had been one of several recipients of IN Group donations, so already has an affinity with the group.



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Margaret made a special thanks to Andrew for his support over the years and welcomed Eppi to the IN Group, saying that we look forward to seeing her and hearing about the continuing research at the Children's at future meetings.

In answer to Eppi's query on how the IN Group was so successful in raising money, it was agreed that there was a high level of joy among members in raising funds which came from various sources including the Dutch Auction at the annual Christmas Lunch, from other activities organised by Gwen McInnes from time to time, but overwhelmingly it was due to the generous donations of individuals. Because of the heightened awareness of a possible link between COVID vaccinations and GBS in the past three years individual donations might have increased a little, but overall, these donations have, for many years, been consistently at a very high level which we have found so heart-warming.

The annual subscription has been kept to a minimum and the contribution made to the IN Group by committee members is all done on a volunteer basis so that the maximum donation may be made to the Hospital each year, also Margaret sends a handwritten note of thanks to doners. The IN Group may be small, but the support members give is just amazing – thank you to everyone.



DUTCH AUCTION

After lunch, with Ken Clarke ably filling the Auctioneer's shoes, we again enjoyed participating in our annual Dutch Auction. The net income from the lunch and auction this year was \$1354.

VALE Barbara and Tom Rivett

We were sorry to hear of the passing of Barbara Rivett on 16th January 2023, aged 89. Barbara and Tom, her husband who passed away on 9th May 2020 aged 88, were long time members and big supporters of the IN Group, attending all the functions and meetings. Barbara also held the role of Secretary for many years. They are both remembered as special people and we pass our condolences to their families.

PUBLICATIONS OUT OF STOCK

We will let you know when these publications previously listed for sale, and currently out of stock, have been replenished.

The Guillain-Barre' Syndrome Patient in Intensive Care;
Boy, Is this Guy Sick Booklet;

A Road to Recovery A-Z;
IN Group Recipe Book



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FUTURE MEETING DATES TO REMEMBER

Sunday 21 st May 2023	2.00pm Ashburton Library	Speaker: Ben Loh, Physiotherapist
Sunday 20 th August 2023	2.00pm Ashburton Library	AGM
Sunday 10 th December 2023	12noon Ashburton Library	Christmas Lunch

INTRODUCING Dr EPPI YIU



Dr Eppi Yiu
 MBBS Melb 2000 FRACP 2009
 Head of Neuromuscular, Royal Children's Hospital
 Specialising in Paediatrics and Child Health, Paediatric Neurology

Dr Eppi Yiu is a paediatric neurologist at the Royal Children's Hospital Melbourne and an honorary fellow at the Murdoch Children's Research Institute. She underwent training in paediatric neurology at The Royal Children's Hospital Melbourne and The Hospital for Sick Children in Toronto.

She completed her PhD in 2013 in neurogenetic disorders, and she was awarded a NHMRC early career fellowship for her post doctoral studies. She has extensive experience as investigator in both investigator-initiated and industry-sponsored clinical drug trials in neuromuscular disorders, and recently led development of Clinical practice guidelines for paediatric Charcot-Marie-Tooth disease.

IMPORTANT MESSAGE FROM THE COMMONWEALTH BANK

For those members who have accounts at the Commonwealth Bank, you may have received a letter from them advising that all NEW accounts opened after 3 June 2023 will not have cheque book capability.

This does NOT apply to existing accounts.

The one change is that a request for new a cheque book must be done by completing the form in your current cheque book and forwarding it to the Commonwealth Bank.

At this stage no other bank is making this change. The Commonwealth Bank will accept all cheques from other banks. If you have any questions please contact the Commonwealth Bank.

COMMITTEE MEMBERS

President	Margaret Lawrence
Vice President	John Burke
Secretary/Treasurer	Doug Lawrence
Minute Secretary	Mary Clarke
Committee Members	Melva Behr, Gwen McInnes, Brian Boyd,



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Membership 01.07.2022 – 30.06.2023

Name :		
Address :		
Suburb :		
Postcode :		
Mobile :		
Email :		
NOTE: The IN Group’s preferred communication is by email.		
If you wish to have your Newsletter sent in hard copy please tick here: <input type="checkbox"/>		
ITEM	EACH	PAYABLE
Annual Subscription (due 1st July each year)	\$15	
Donation to support Medical Research (\$2 or more is tax deductible)		
Tick here if a receipt is required →		
TOTAL ENCLOSED 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 pay directly using the following information:

	BSB / Account:	063 142 / 1000 6285
	Account Name:	The IN Group
	Important!	Include <u>your name</u> in the “Description / Reference”. Also, include info@ingroup.org.au where an email field is made available for the transaction.

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.



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