INFORMATION

Inflammatory Neuropathy Support Group of Victoria Newsletter

26 Belmont Road, Glen Waverley
Victoria, 3150, Australia

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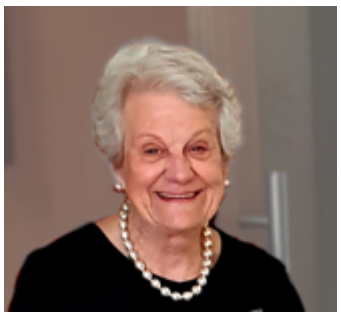
Newsletter of the 'IN' Group: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC., supporting sufferers from acute Guillain-Barre` Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) CIDP), Multifocal Motor Neuropathy (MMN) and other Inflammatory neuropathies. ABN: 77 954 503 188 Reg. No: A0025170R

NEXT MEETING

Sunday 16th March 2025 2pm
Speaker – Yien Ching Ang from Specsavers
Topic - Hearing

Ashburton Library, 154, High Street, Ashburton



PRESIDENT'S MESSAGE

The new year seems to have come round so quickly and I am looking forward to meeting up with you all again at our meetings throughout the year.

In December, Doug and I were pleased to attend a function hosted by The Royal Children's Hospital Foundation held at Parliament House to thank supporters of the hospital, where we again heard how the annual IN Group donation to the hospital is an important part of their research funding.

I do want to thank everyone who attended the Annual Christmas Luncheon and Dutch Auction in December, particularly those who had travelled long distances to be there.
We were glad to have Dr Eppie Yiu, Paediatric Neurologist RCH, and Adelaide Krania, RCH Foundation, with us again and to hear of what has happened in the world of research over the last twelve months.

We also welcomed our Patron, Dr Richard Stark AM, and Dr Janet Stark.

Unfortunately, Associate Professor Kornberg was not able to be with us this time but sent his best wishes.

Margaret Lawrence
President

Email: **info@ingroup.org.au**
Website: **www.ingroup.org.au**

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2024 Christmas Luncheon and Dutch Auction

We were sorry that Ken and Janet Clarke were apologies for the lunch. Ken had recently met with two accidents and was unable to travel. We missed his unique Auctioneer spin but fortunately, were able to secure the services of Peter Lawrence (Margaret & Doug's son) to conduct the auction and it was, as usual, enjoyed by everyone. We raised $510.30 on the day which was a great effort.

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Donation to the Royal Childrens Hospital

Before the lunch got underway, the group presented Dr Eppie Yiu with a cheque for $8000 as our further contribution to supporting research into GBS and CIDP.

In response Eppie thanked the group and told us about travelling to the Netherlands to attend a meeting of the International Paediatric GBS Therapy Group which is looking at new trials for ways to tackle therapy treatments in children overseas. With this in mind she is planning to conduct workshops here, depending on funding. It goes without saying that any breakthrough in the paediatric side can flow through to providing information on new or different treatments beneficial for adults. And perhaps too, for other inherited nerve conditions that Eppie and her team also see in the department.

She also mentioned that her connection with the IN Group was established some years back when, as a Fellow completing her PhD on neurogenetic disorders, she noticed that the ultrasound machine she was using was purchased with funds provided by the IN Group, and she thanked the group for their continuing support.

Adelaide said how much the work and generosity in support of the hospital by the IN Group over the years was appreciated, noting that since their inception, the group has donated just over $200,000.

Facts and figures
As you know, the RCH Foundation funding is spread across the work of the hospital; these are some of the key statistics reported for 2023/2024:

Funding distribution
Grants supported across Patient and Family Centred Care – 68 with funding of $12.7m;
Grants supported across research – 44 and new grants approved – 41 with funding of $23.5m;
Grants supported across Leadership, Education &Training – 44 with funding of $16.8m;
Grants supported across Equipment and Technology – 29 with funding of $8.0m;

Activities
Funds raised = $69.9m
Projects supported = 200+
Emergency Department presentations = 81,401
Surgeries = 19,752
Outpatients Appointments = 410,190
Inpatient admissions = 52,312

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UP-COMING MEETING DATES TO REMEMBER

Sunday 18th May 2025	2.00pm	Ashburton Library	
Sunday 17th August 2025	2.00pm	Ashburton Library	**AGM**
Sunday 14th December 2025	12noon	Ashburton Library	**Christmas Lunch**

Looking back.

Dr Stark, the group's Patron, has been involved with the IN Group since its inception. He took the opportunity to speak briefly about the early days of his connection with the IN Group, and a paper recently uncovered, which he had written in the 1980's at the time when the London hospitals were just starting to treat GBS with plasma exchange which was controversial at the time.

There had been debate in England about how GBS was being treated. In those days there was little information about; IVIg was a new thing, perhaps Specialists did not see a GBS patient for a week after onset when they had already been seen and worked up by another medical practitioner and the on-going treatment results were not seen as convincing so they were not sure it would work

In his paper, Dr Stark had reported on a patient who was treated with one IVIg dose and who showed a difference in just one day – so plasma exchange did work. That single case made a difference and IVIg therapy became an important part of treating GBS and CIDP.

We have so much more information now and rely on IVIg treatment, it is interesting to look back and see how far things have come.

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"Fly for the Kids"

One doctor, one plane, one mission:
Raising $4.5 million for The Royal Childrens Hospital

In July 2025, Associate Professor Andrew Kornberg, a Senior Neurologist at the RCH, will take to the skies in support of sick children across Australia.

Andrew's mission? To help raise $4.5 million, in partnership with the Live Life Foundation, to establish a dedicated centre for gene therapies at the RCH. This centre will help transform the lives of children with neuromuscular conditions like spinal muscular atrophy and pave the way for future generations.

Australian CIDP National Registry (ACNR)

You may be interested in participating in this Register.
As soon as we have more information we will pass it on.

A research team led by Associate Professor Susanna Park at the Brain and Mind Centre, University of Sydney has received funding to develop an Australian registry of patients with CIDP.

This is a national registry, which involves neurologists from NSW, VIC, QLD, and SA, with approximately 20 sites across Australia (with more to be added soon). It also includes representatives from the National Blood Authority, the Australian and New Zealand Association of Neurologists, and Consumer Representatives.

The overall aims of the Australian CIDP National Registry (ACNR) are to capture treatment information and evaluate patient outcomes and phenotypes, develop a research resource, and identify participants for future clinical trials.

The Australian CIDP National Registry (ACNR) will collect health information about people diagnosed with CIDP or related conditions. A registry allows the medical and patient community to learn more about CIDP and related conditions. The sharing of this information is intended to improve the lives of people with CIDP.

The Registry is still in the development phase and not yet operational, however, the Registry team will provide a further update when it is ready to commence, including information about participating.

Newsletter Contributions

We always welcome contributions for the newsletter. If you have a suggestion or an article which you think would interest members, please email it to info@ingroup.org.au or send by post to 26 Belmont Road, Glen Waverley Vic 3150

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The Inflammatory Neuropathy Support Group of Victoria Inc.

Membership 01.07.2024 – 30.06.2025

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: ☐

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 your name in the "Description / Reference". Also, include info@ingroup.org.au where an email field is made available for the transaction.

Email: **info@ingroup.org.au**
Website: **www.ingroup.org.au**

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