

# INFORMATION

## Inflammatory Neuropathy Support Group of Victoria Newsletter



Issue No.: 120 November, 2023

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.  
ABN: 77 954 503 188 Reg. No: A0025170R



### ***DON'T MISS OUR FAMOUS CHRISTMAS LUNCH!***

***Sunday 10<sup>th</sup> December 2023  
12noon***

***Ashburton Library, 154, High Street,  
Ashburton***

***\$20 per head***

***RSVP NOW and no later than 30<sup>th</sup> November.***

Ring Margaret on 9802.5319  
or email [douglawrence26@optusnet.com.au](mailto:douglawrence26@optusnet.com.au)

*Where else can you enjoy convivial company, a buffet lunch and an exciting Dutch Auction all for this very reasonable cost?*

*We have had it confirmed that either Associate Professor Andrew Kornberg or Dr Eppi Yiu from The Royal Children's Hospital will be attending to give us an update about their work with GBS and any research generally about CIDP, and also a member of the Hospital's philanthropic section.*

*The date is fast approaching, so do make an effort to come along – bring your friends. It is our major fund-raiser for the year and all we ask is that you bring a wrapped gift for the Dutch Auction with a tag indicating the value of the item to aid the Auctioneer.*

It would be an enormous pity if we had to cancel the event due to lack of numbers.  
**RSVP no later than 30<sup>th</sup> November**



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## **PRESIDENT'S MESSAGE**

Once again, Doug and I have been invited to a *Celebration of Giving Function* held by The Royal Children's Hospital.

This annual function is held to thank all those who support the work of the Hospital through *The Royal Children's Hospital Foundation*, and it is where our donations are directed each year to be used in GBS/CIDP research. You will recall that the Treasurer reported to us at the AGM that the INGroup has donated a total of \$175,000 to the Hospital since 1992.

The special evening will include the opportunity for us to speak with the dedicated and world renowned clinicians who are responsible for the amazing inroads which are being made in treating GBS and CIDP.

I am looking forward to being able to give you an update at our meeting on 10<sup>th</sup> December.

You will remember that there was a short item on Michael Klim's travels with CIDP in one of our newsletters this year. Recently, some contact has been made through Michael's website and we are hopeful this may result in a face-time message with Michael which will be able to be played at one of our future meetings.

A reminder that Membership subscriptions were due on 1<sup>st</sup> July. If you have overlooked your renewal this year, do use the form on the back page. We not only rely on your membership to keep supporting GBS/CIDP research, but we enjoy meeting up with you all at our quarterly meetings.

And last but not least, I wish you and your families all the very best for the Festive Season and I do look forward to seeing you all at the Christmas Luncheon and Dutch Auction on 10<sup>th</sup> December.

With grateful thanks.  
Margaret Lawrence  
President



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**VALE** Brian Boyd

We were sorry to hear of the passing of Brian Boyd on 28<sup>th</sup> October 2023, a member and committee member for many years. Brian attended all the meetings as his health allowed and was a helpful and interested committee member. He is remembered as someone who enjoyed conversing with others, who provided support to members and was always interested in the medical inroads which have been made in the treatment therapies for CIDP and GBS. We express our condolences to his family.

**Membership Renewal**

**Your membership subscription for 2023/2024 was due on 1<sup>st</sup> July.  
If you have not yet renewed, please use the form on the last page.**

**DOCTOR 'IGNORED' SICK CHILD**

This item appeared on page 6 of the Herald Sun 16<sup>th</sup> August 2023.

A mother feared her son was going to die after a doctor ignored his excruciating symptoms, which left him paralysed.

Maysen, 12, was rushed to Sunshine Hospital after experiencing severe pains throughout his body on July 31.

His mother, Jessica Bye, said she became “extremely concerned” when Maysen had stopped eating and had constant headaches.

“He was assessed in the paediatric emergency department and we were told by a doctor that they thought his symptoms were exaggerated and that possibly he wanted to stay home from school.”

Ms Bye said she was “shocked” by the doctor’s remarks saying she knew her son was “visibly suffering”.

“He was then discharged”.

Ms Bye said as she was driving Maysen home she noticed the left side of his body had become completely limp.

“We immediately went back to the Sunshine Hospital and they did take his condition seriously on this occasion.”

“Maysen was diagnosed with a rare condition called Guillain-Barre Syndrome. He is now getting the best care at The Royal Children’s Hospital.”

Ms Bye said her family’s experience at Sunshine Hospital had prompted her to warn other parents about Victoria’s “failing” health system.

\*\*\*\*

Comment: The INGroup Family will recognise this scenario too well. GBS is still not readily recognised by medical practitioners in the general community, and it reminds us that we always should be persistent in searching for answers and the proper treatment for any medical condition we experience. What is heartening about this item is that we can be assured that the donations the INGroup has made over the years to Associate Professor Kornberg and The Royal Children’s Hospital have helped in so many ways, people like young Maysen to receive the appropriate treatment.



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## NEXT YEAR'S MEETING DATES TO REMEMBER

<b>Sunday 17<sup>th</sup> March 2024</b>	2.00pm	Ashburton Library	
<b>Sunday 19<sup>th</sup> May 2024</b>	2.00pm	Ashburton Library	
<b>Sunday 18<sup>th</sup> August 2024</b>	2.00pm	Ashburton Library	AGM
<b>Sunday 8<sup>th</sup> December 2024</b>	12noon	Ashburton Library	Christmas Lunch

## Donating to the IN Group

The IN Group is a registered charity and as such any donations you make of \$2.00 or over are tax deductible. It is easy to donate when you renew your annual subscription.

However, there is another way that you can make an online donation. When you make a purchase via *PayPal*, you may opt to donate to your chosen charity when finalising your payment.

The donation is facilitated via the *PayPal Giving Fund* which is a public ancillary fund and charity registered with the Australian Charities and Not-for-Profit Commission, and forwarded to the IN Group bank account.

## PREFER TO RECEIVE YOUR NEWSLETTER IN HARD COPY?

As you know the IN Group's preferred method of communication is by email, and you may currently receive all communications in that form but would prefer to receive your newsletter in hard copy. This can be arranged if you will email that request to - [info@ingroup.org.au](mailto:info@ingroup.org.au)

## COMMITTEE MEMBERS

President	Margaret Lawrence
Vice President	John Burke
Secretary/Treasurer	Doug Lawrence
Committee Members	Melva Behr, Mary Clarke, Gwen McInnes, Janice McNamara



**Don't forget to renew your membership.**



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**The Inflammatory Neuropathy Support Group of Victoria Inc.  
Membership 01.07.2023 – 30.06.2024**


Name:	
Address:	
Suburb:	
Postcode:	
Mobile:	
Email:	

**NOTE:** The IN Group’s preferred communication is by email.

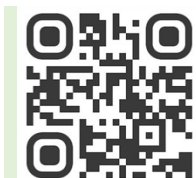
If you wish to have your Newsletter sent in hard copy please tick here:

ITEM	EACH	PAYABLE
<b>Annual Subscription (due 1<sup>st</sup> July each year)</b>	<b>\$15</b>	
Donation to support Medical Research (\$2 or more is tax deductible)		
Tick here 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 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 <a href="mailto:info@ingroup.org.au">info@ingroup.org.au</a> 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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