

INFORMATION

Inflammatory Neuropathy Support Group of Victoria Newsletter



Issue No.: 124 November, 2024

26 Belmont Road, Glen Waverley
Victoria, 3150, Australia
ISSN 2207- (Online)

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 8th December 2024
12noon***

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

\$20 per head

RSVP NOW and no later than 30th November.

Ring Margaret on 9802.5319
or email 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?

Associate Professor Andrew Kornberg and Dr Eppi Yiu will give an update on their research work.

*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.*

Membership Renewal

**Your membership subscription for 2024/2025 was due on 1st July.
If you have not yet renewed, please use the form on the last page.**



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ANNUAL GENERAL MEETING - 18 AUGUST 2024



PRESIDENT'S REPORT TO MEMBERS

Another year of the INGroup has passed leaving thoughts of happy times with our group still running well after so many years and the difficulties COVID brought to every walk of life.

Our Christmas luncheon finished off 2023 very well, members enjoyed a delicious lunch and bid happily at our auction. Ken Clarke, as always, did an amazing job and a very happy time was had by all. Thank you Ken for your great help.

We started off the year with a getting to know you session which proved very successful so we have continued our meetings with members having discussion groups. It is increasingly difficult to get speakers, partially because after the group has been running for so long, it is hard to have different topics. And also Sundays are not always suitable for hard working professionals to give their time.

I wish here to make a special on all our members behalf to Margaret Wilson for her outstanding newsletters. Everyone is kept well informed of our activities and inner working of the group.

My next big thank you is to each member of the committee who give up their time, not always so easy when they are not as robust, to keep the group running.

I really believe the INGroup has a great purpose and is always there to assist people with their needs, and the wonderful donations received which contribute so much to research.

I would also like to acknowledge the great work that committee member, Brian Boyd, did for the group. Brian passed away at the end of last year. Brian was a great ambassador for the group. When he was having all his hospital stays, his INGroup work continued as he spoke to staff and patients about the group and offered assistance.

It is my privilege to be part of such a great group of people.

Margaret Lawrence
President



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ANNUAL GENERAL MEETING - 18 AUGUST 2024 cont.

TREASURER’S REPORT FOR YEAR ENDING 30 June 2024

Income for the year totalled \$3,925, a reduction from the previous year of \$6,985. The major items of income movement were Subscriptions down \$425 and Donations down by \$4,879. This is an indication of the difficult times many members experienced throughout the COVID period with so many cost increases. Also, the State Government Grant received over the past previous years was, this year, cancelled.

Expenses were lower than last year by \$656. A donation of \$12,000 was given to the Royal Childrens Hospital to be used for research purposes.

Net Result for the year was a cash deficit of \$9,134 and when reduced from the carry forward balance from the previous year the Equity as at 30 June 2024 was \$10,221.

The donation for \$12,000, this year, when added to all previous donations to the Royal Childrens Hospital totals \$187,000.

I wish to thank all members once again, for their support and most generous donations over the past year.

Doug Lawrence
Treasurer

COMMITTEE MEMBERSHIP 2024/2025

The composition of the committee remains the same:

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

We are always very happy to welcome anyone interested in attending our meetings and/or joining the committee.

At the conclusion of the AGM, a video of an interview with Michael Klim made for an article in that weekend’s *Good Weekend* magazine was played. See a report of the interview on page 7.



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VALE Gwen McInnes

We were saddened to hear of Gwen’s passing on the 5th September 2024 in her 93rd year. The following is the President’s eulogy given at the Memorial service held for Gwen in October.

This is a difficult day saying goodbye to Gwen, but what a wonderful smile she has left on all our faces. Gwen spread joy wherever she was, and especially her time dedicated to the INGroup.

Gwen, and her husband Peter, were members for many years. Peter as Secretary and Gwen as a committee member, both assisting in many ways raising money for research. We all enjoyed the asparagus rolls that were made for our committee meetings and then the wonderful dessert of berries, jelly and cream at the Christmas luncheon.

One committee member had a fall arriving at a luncheon and was heard to say that he was off to hospital and would miss out on Gwen’s delicious sweet. This of course was to much amusement for the ambulance officer.

All these wonderful jobs done by Gwen happily but must not always been easy for her. Doug and I had many lunches at her home and it was always so enjoyable. Doug did supply jokes for Gwen to make her friends from another group have a happy time on their outings – always making people’s lives so much better was Gwen’s way of life.

The INGroup was presented with a large number of hand painted dolls to sell for research money and Gwen, in her wonderful way, said ‘store them at my place’ and then like magic began to sell them – even the postman purchased one! This of course was more money for our research programme at the Childrens Hospital to aid people with the complaint that Gwen suffered.

Gwen was always my sensible person for any plans I came up with for the INGroup and her ideas made my work so much easier.

A big hole has been left by her departing, but what support and joy having her as part of the group, even though her disabilities were so severe. What a great lady she was to the INGroup.

Love and wonderful rest to you, our special dear friend.

NEXT YEAR’S MEETING DATES TO REMEMBER

Sunday 16 th March 2025	2.00pm	Ashburton Library	
Sunday 18 th May 2025	2.00pm	Ashburton Library	
Sunday 17 th August 2025	2.00pm	Ashburton Library	AGM
Sunday 14 th December 2025	12noon	Ashburton Library	Christmas Lunch



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Wayne's CIDP Story



Wayne, from country Victoria, joined the INGroup in 2023. He has documented his journey of over five years and this is his personal perspective of life with CIDP. He has given permission for the story to be shared with members.

This is the final instalment and covers his discharge from hospital and living with CIDP.

Chronic Inflammatory Demyelinating Polyneuropathy

An immune system disorder. Attacks the myelin sheath of peripheral nerves.

In my opinion the nature of CIDP is uncertainty and more uncertainty.

Saintly patience is required for nerve self-repair.

If any repair does occur, it often will take years. No one will truly understand the unique symptoms of CIDP damaged nerves. CIDP has many pathways.

HOSPITAL REHABILITATION DISCHARGE

I required home help with housework and to be driven about. I was physically incapable of driving. This service was made available usually once per week for the following several months and was provided by local government providers. I used a combination of a walking frame and a stick. My duration of care was uncertain. Occasionally I attempted a walking stick only. It was a big struggle to walk. Collect mail from my front yard letterbox and feed the cat and dog in the backyard in the initial four months. Walking severely restricted by weakened legs, peripheral neuropathy of both hands and feet, (paraesthesia) and CIDP induced severe tightness around the torso. Symmetrical left and right of the torso. Tightness may be described as banding, tapering to the spine.

My local hospital provided monthly IVIg infusions in their Oncology centre. The same wards, the same familiar nursing staff and the same infusion method my wife received for cancer treatment. The same familiar medical equipment. Two years on. Here I am. Surrounded by everything I wanted to forget. In my mind cancer kills and CIDP cripples. Me, a distressed witness of prior circumstance. I was back in the same environment and building. I reminded myself it's all for the best and left it at that. Accepting the hard physical and mental health challenges. Struggling with poor ambulatory function seven months post diagnosis. For example, the assistance of three people was required to descend a vehicle dealership's long flight of stairs. Assistance required from the front, back, side and guidance of the guard rail with frequent stops. More than nine months passed and I was in-effect housebound and isolated.

The later half of 2019 my mobility had improved and I was not entirely housebound anymore. Medical approval was given to drive a private motor vehicle subject to future review. On the eve of the COVID-19 lockdowns of a 5km radius from home. Bitter-sweet timing as I have always been a driving enthusiast. Thankfully, driving a private vehicle was not permanently revoked. Normal touch sensation has long since returned. For many months everything was like coarse sandpaper to the touch. Even to pat the dog and cat. Initially the first twelve months of abnormal unpleasant foot sensations of crawling ants on skin and sometimes legs to doubt one's sanity. I confronted immobility struggles and home isolation in the twelve months preceding the COVID-19 pandemic.



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As I am immunocompromised COVID-19 vaccine shots were required. Four shots completed. Twelve months of weekly outpatient physiotherapy sessions were COVID-19 interrupted and eventually stopped all together. I needed to think outside the box to address isolation, boredom and limited mobility during COVID-19 and frequent lockdowns. I purchased Virtual Reality hardware and software for the home desktop PC. I watched 3D movies in a virtual reality cinema. VR offered a very real comforting feeling of freedom, experiences and escape from over twelve months of CIDP immobility. I also continued developing my own road trips website. Self-taught through trial and error. I navigated isolation and restriction challenges of COVID-19 without infection.

CIDP LONG TERM

Since late 2021 no mobility aids or home assists are required. I have no comorbidities with CIDP. Never had an infection. Normal eyesight, hearing. No joint or back issues. Not diabetic nor pre-diabetic. No long term muscle atrophy. No foot drop. No nerve pain medications although constant nerve pain was experienced for three years. Abating somewhat after four years. Paraesthesia remains in hands and feet. Along with symmetrical weakness in both legs and torso tightness. All have shown improvement into 2023. No separate health issues.

During the initial three years. The need to rest extremely fatigued legs and arms whilst attending appointments, in supermarket queues and public places. Three years of short daily showering and brief house tasks for the same reasons. Effectively, early labour force retirement. Many easy tasks done before CIDP now require thought and extra effort. I mow the small front and backyard lawns. A long three years from hospitalisation to be able to hand wash a car uninterrupted by multiple rest breaks for fatigued legs. I've always enjoyed road trips. Good to not feel major rib cage discomfort (from torso tightness) over every minor highway jolt and bump. Three plus years to get to near normality. All these personal milestones and more were not guaranteed. An estimate on time taken to gain improvements, if any, cannot be obtained from the medical profession. It's the nature of CIDP. From middle 2022 IVIg streamlined to one large 20g bottle per infusion of *Privigen*. Not less than two and a half hours per infusion. Two infusions are completed over two consecutive days. One per day, six-weekly. The ongoing purpose of infusions (now six weekly instead of four) is to maintain patient ambulation while encouraging a healthy autoimmune response to the peripheral nervous system. I took up home guitar practice. After more than three years of uncertainty guitar noodling is fun. A home based time-filler activity enjoyed sitting. Taught myself basic chords and music scales. I felt I had regained enough finger dexterity and feeling to have a go. Benefits in weekly Tai Chi classes are worth merit also. Any regular light exercise routine is helpful. After four years of incremental improvement and now at last, reducing nerve discomfort. Improvement also shown around the torso. I do not expect a relapse and a wheelchair scenario again. CIDP impacts nerve myelin, nerve axons and causes inflammation of nerve roots. If nerves are too damaged, limited or no long term healing is possible for the unfortunate. Medical papers cite nerve regeneration is 1mm per day or about one inch per month with no active disease. Undertaken not more than twice yearly by a neurologist a nerve conduction study revealed improvements in lower limb nerve conduction and functionality. Had previously been assumed a plateau was attained. This was proven to be incorrect. Small improvements greater than fifty months from diagnosis are still achievable. Although nerve conduction is outside of acceptable parameters. Shows further improvement is possible even after four years.

AFTER FIFTY PLUS MONTHS

A four year MRI scan follow up completed of the spine and cranial cavity. Dye injected. Not less than a one hour process. An investigation into chronic torso tightness since the initial CIDP diagnosis four



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years previously. A scan for demyelinating disease and lesions of the central nervous system. Conclusion was of no central nervous system demyelination or lesions identified. Normal scan result. No nerve entrapment or Multiple Sclerosis (MS) pathology. Those with a CIDP diagnosis live normal life-spans. Unlike some neurological disorders. All of the above gives an insight into CIDP. At least as applicable to one individual's experience. Hopefully all the aforementioned addresses a lack of awareness and knowledge concerning Chronic Inflammatory Demyelinating Polyneuropathy. It's a rare condition. General Practitioners rarely see it, if at all. Time to underscore CIDP. Obviously no progression or relapse in over four years. Discontinuation of IVIG is unlikely. Cessation of IVIG is a medical specialist call. Four years have passed. Almost pre-CIDP ambulatory and strength function, except lower limbs. Walking a moderate distance is OK. No walking aids are required. This is a significant bonus. All things considered, quality of life is good. Enjoy the one handed cup of coffee. Walking freedom and breathing the outdoor fresh air. Simple things most people take for granted and never give a second thought to.

A CIDP diagnosis and pathway is full of uncertainty for all. It is not a life sentence of disability. CIDP is a treatable condition. Don't dwell on anything that may never happen or recur. Be honest and patient with yourself. Do not say why me and blame all health problems on GBS/CIDP or whatever. Despite all the aforementioned I still consider myself fortunate. I don't seek sympathy nor will tolerate patronising attitudes. In my experience empathy for rare hidden conditions is improbable outside of immediate family. CIDP awareness would be a start. We don't get a choice of what autoimmune or neurological disorder afflicts us. But it is our choice how we choose to respond and live our lives.

There is a Latin phrase - *Amor Fati* accept one's fate, find the elusive positives and move on.

Continued from page 3

MICHAEL KLIM INTERVIEW

Michael talked about his shock at receiving a diagnosis of CIDP in 2020 and his efforts to find a path of acceptance and now by establishing the Klim Foundation, to help others reach a similar place.

At the conclusion of the video members talked about the issues which had been raised including a disturbing comment that CIDP is not recognised by Australia's NDIS funding, and the question of whether that also applied to GBS was posed. The group considered what action it could take in this respect, and a letter to the relevant Minister would be one way to go.

Discussion then ensued on whether the INGroup should contribute to the foundation. This was supported by the members and the committee will consider the possibility further. One of the aims of the foundation was to be a repository of information where people could obtain information and/or assistance, and it was agreed that it would be of advantage if the INGroup, as a support group for people with CIDP, GBS and other inflammatory neuropathies offering information and visiting, was listed as part of the referral information the foundation plans to hold. The committee will also look at that aspect.

CIDP is still very much an unknown condition and it is disappointing that many high-profile people do not admit to having CIDP. Whilst it is understandable from a personal view, it could do much to educate the public about the condition, raising the profile for the purposes of attracting more funding.

Other discussion surrounded the availability of IVIg and the dose rates prescribed in Australia compared to other parts of the world.

If you would like to contribute to the newsletter, please email your contribution to info@ingroup.org.au



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**The Inflammatory Neuropathy Support Group of Victoria Inc.
Membership 01.07.2024 – 30.06.2025**


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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
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	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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