

# 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.

ABN: 77 954 503 188 Reg. No: A0025170R

### **Annual General Meeting**

(see advance notice inside this issue)

**Sunday 18<sup>th</sup> August 2024 2.00pm**

Ashburton Library, 154 High Street, Ashburton



### **FROM THE PRESIDENT**

This newsletter carries advance notice of the Annual General Meeting which will be our next meeting. Do put this date in your diary and come along.

As always, we invite any member who would like to, to nominate for the committee. The committee meets four times a year – usually a few weeks before each of the general meetings, and the meetings are friendly and always interesting. New ideas are very welcome. If you would like to find out more contact me by email on [douglawrence26@optusnet.com.au](mailto:douglawrence26@optusnet.com.au) or by telephone on 9802 5319. A nomination form is also included in this issue.

And don't forget to renew your membership for 2024/2025:

Annual subscriptions remain at \$15.00 and are due and payable on 1<sup>st</sup> July 2024.  
Please complete the form on the back page.

Recently, Doug and I attended an occasion at the Royal Children's Hospital which provided insight into how the donations received by the Hospital Foundation filter through to the nurses, providing training and professional development opportunities to enable them to continue to upgrade their skills in the care of GBS/CIDP patients. Annual donations made by the INGroup to the Foundation assist in supporting these nurses in achieving their goals.

In this issue we continue to follow Wayne's CIDP journey and were interested to receive an email from him apologising for the May meeting, saying: "I will be away on a nine day road trip to Birdsville Queensland.



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Up the Birdsville track. Travelling in a one vehicle Landcruiser tour leaving from Adelaide. I as a passenger and overnight accommodation in hotels. I hope the rough roads will not disturb my CIDP much as I am sitting as a passenger and not driving at all. I shall find out. It is a trip I wanted to do for many years before CIDP and then with CIDP thought would be impossible to ever do. I consider myself improved enough now to go on such a trip with others." - we are looking forward to hearing all about his trip when we next see him.

We also bring you an update on Scott Earle, author of 'The Wave of Guillain Barre' Syndrome', who contracted GBS in 2011 and who first spoke of his experiences to the INGroup in 2014.

Should you have any items you think will be of interest to other members which we could include in future newsletters, please forward them to me at the contact details above.

With my best wishes to you all.

Margaret Lawrence  
President

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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 second instalment and covers his hospitalisation and in-hospital rehabilitation.

### **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.*

### **HOSPITALISATION**

My first hospital admission as a patient in over forty years.

I began **intravenous immunoglobulin (IVIG)** infusion of *Privigen* that night, Friday. Each infusion takes about three to four hours, administered through a catheter needle inserted into a vein in the arm to overwhelm the immune system's own antibodies attacking the nerves. The third consecutive day of IVIG had a late finish of 3am. The end of the loading dose of IVIG treatment. Within days I had a lumbar puncture (spinal tap).

A **nerve conduction study** showed total blockage on some leg nerves. Symmetrical left and right of the body. Multiple blood tests and other tests were carried out. One doctor told me a blood sample



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was sent to Western Australia for analysis in a laboratory. Apparently testing for this one particular pathogen could only be undertaken in Perth. Why? I don't know!

The result returned negative. Good. All tests showed no evidence of recent viral or bacterial infections. Nothing.

All the staff treated me well. I could not walk and was dependent on a wheelchair. A walking frame provided some standing support for very limited room use. Complete loss of balance. Numb from backside and legs down. No leg reflexes. Paralysis of all four limbs. Acute abdominal tightness caused moderate breathing constriction. Tested twice daily for breathing capacity in anticipation I needed artificial breathing assistance via a ventilator. Daily stomach injections to prevent blood clots because of immobility.

I have always been a non-smoker. I took solace in this. Additional complications I could do without.

I could hold light weight items such as a spoon, fork and knife but all extremely hard to use. Unable to open served food or drink lids. Unable to write or use a cell phone, buttons, zippers, tie laces or hold a small cup of coffee in one hand. Initially, a few instances where vision was blurry but became quickly focused again. Mild shortness of breath due to tightness around the torso. Facial movements unaffected.

Doctors asked if I could wiggle my toes up and down. I did to our surprise. My condition did not deteriorate any further after the first few days while in hospital. By weeks end doctors assessed my condition as somewhat stable.

With mutual agreement, my public hospital bed was moved to other wards five times during my lengthy hospitalisation. Even down a floor to another ward. All wards at full capacity. I was stable and under supervision.

I was later told the first course of IVIG probably stalled the progression of CIDP. I understood progression meant reliance on a ventilator and total immobility before likely incremental improvement.

I agreed to be wheeled in my wheelchair to the once every Friday specialist meeting. On an overhead projector my condition and possible diagnosis was discussed in front of twenty or so experts including the department head Professor of Neurology. Doctors posed questions with pen and notebook in hand. I answered what I knew. Specialists later diagnosed CIDP and not GBS as my symptoms were at least eight weeks.

A little more than two months before diagnosis I paid for a family paintball day in Melbourne. My legs gave way underneath me on short sprints. No pain. Just momentarily weak legs. I thought this odd and amusing at the time and attributed this to overworking myself. Normally I don't jog. In hindsight, the first symptom of CIDP that I can recall.

St Vincent's Hospital Melbourne had no other patients with GBS or CIDP.

Both are very rare conditions. Apparently there is a one in one hundred thousand chance of a CIDP diagnosis.



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The isolation of a big city hospital, placed in the Neurology Ward with many seriously ill people, away from familiar faces is very confronting. An adjacent patient had suffered a mild stroke and was up and about unassisted walking, talking and using all four limbs very well within a few days - a lucky man. Not so for myself, diagnosed with a crippling condition. Prognosis unknown. During most of my hospital stay my only regular visitor was a weekly visit from a volunteer inter-church counsellor. These visits were really helpful and appreciated.

A family member paid me a day visit. I was pushed around the large hospital city block in my wheelchair. Along busy Victoria Parade avoiding able-bodied pedestrians. It can't be understated how great it felt to feel the fresh air and warm sun on your face after one month inside. Myself wondering if this is permanent now? **Wheelchair dependent.** Medical staff were not telling anything. Not wanting to give false hope.

Autonomic nervous system dysfunction can occur. In my case, hints of autonomic system involvement appeared but thankfully no progression occurred. These serious symptoms range from incapacity to breathe, double vision and sight deterioration with optic nerve damage, bowel & bladder dysfunction, total loss of ambulatory function and cardiac irregularities. All due to nerve and muscle interactions within the body.

Symptoms as mentioned may or may not occur. Hence, why my five week hospitalisation.

## **INPATIENT REHABILITATION**

I spent five weeks in this major Melbourne hospital followed by nearly a week of inpatient rehabilitation. In a facility even further from home in the eastern suburbs of Melbourne. I used a walker now.

I watched through the window from my hospital bed a pair of hot air balloons very low above buildings. Nightly TV news said they made an emergency landing nearby. At least these people had access to the outdoors and were not confined to hospital.

Transferred again, for a period of almost two weeks to a large regional rehabilitation facility in Ballarat. Transferred between by ambulance. I sat next to the driver for the two hour trip. There was another patient in the back of the ambulance for the entire drive. A sedated female stroke patient, by appearances not yet at retirement age, nearing end of life. We drove her to the same palliative care facility where my wife spent her last weeks. A solemn two hour ride for me.

Admitted to rehab. My own room. Walker wound with red tape. Red tape is replaced with green tape once walking is assessed as safe unsupervised. Mixed in with recovering stroke and cardiology patients. I spent regular physio sessions among patients clumsily sliding Domino pieces around tabletops. Myself much more advanced than those with stroke recovery. Creatively and carefully building multi levels of Dominos. Of course no one had heard of Chronic Inflammatory Demyelinating Polyneuropathy. Both my feet are equally affected by CIDP induced peripheral neuropathy. Can I eventually learn to walk normally unaided? CIDP uncertainty plays mind games with you. Twice a day morning and evening I decided to attempt a circuit walk around the ward corridors and nursing station outside of structured daily physiotherapy sessions. Pushing a walker hopefully progressing from red to green tape. The aim was to complete ten laps. All exhausting work. Roll past other inpatient rooms. Mark, who was paraplegic from a diving accident and found it hard to face the day. Blankets pulled over his head.



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Thinking I'm not wheelchair dependent anymore as I was nearly two months before and now able to use a walker these last seven days, I self-recalled a road trip to Townsville Queensland. How fortunate Max the pilot and I were from the Tiger Moth joy flight forced landing on the Mackay Ring Road in 2018 with a broken crankshaft sustaining no injuries. Especially spinal injuries like Mark. Thinking of the inhouse gym physio sessions both Mark and I attended. He is in his wheelchair. Apparently a potential fate I have now avoided twice within the space of twelve months. I rolled my walker past the longest inpatient resident - Leslie, a double amputee. Foot and one arm past the elbow. He wanted the rehab. facility to become his permanent home.

I rolled past the recreation area with its chairs, television and books. Towards the end of my stay two female physiotherapy staff were to take me to an adjoining building with a two storey stairwell. Attempting the stairwell was very exhausting. Supported all the while taking small steps and resting legs. Could have taken a cut lunch with the time it took! Still, it was something achieved. Physiotherapy staff were faultless guiding and physically supporting me on how to walk. Dealt with my strong safety concerns and poor expectations. Self-balance was still an issue.

Once every four weeks IVIG infusion of *Privigen*. The initial loading dosage was calculated by patient weight. Future dosage unchanged even with weight variability. Daily an *Azathioprine* (immunosuppressant) tablet. Given as treatment to counter progression of CIDP. Doctors unable to provide a prognosis.

Using a walker in rehab. Now with green tape I asked a visiting neurologist if this is true. One third of CIDP patients are wheelchair bound for life. One third recover to near their former self and one third are somewhere in between. CIDP by definition is often characterised by a relapsing–remitting course. Severity and duration unknown. The neurologist agreed with this and replied I wasn't in a wheelchair anymore. I also now thought at least I could walk with a walking frame and green tape. Will this be the new normal? Walking stick wound with red or green tape is still far beyond my capability.

One of the facilities visitors was the minister of my local church. A coincidence chance meeting. Together we attended the adjoining palliative care facility to give thanks again to staff from two years ago. Greatly appreciated. But the staff had moved on. I was visited only once in Ballarat Rehab. A long-time friend agreed to drive me home and back for a day on an upcoming weekend. Return drive of three hours. However, on presentation at the main entry reception the facility doctor-in-charge refused me a pass out. Judged too high a risk to health. Summer heat-wave conditions. Disappointment prevailing. I apologised to my driver for the wasted long drive. I would have liked a short break from the hospital environment. Now unable due to doctor's orders. Approaching two months of unbroken hospital stays and still cannot return home.

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Next instalment: Wayne's discharge from hospital and living with CIDP

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### Scott Earle – an Update

Scott first spoke to the INGroup in 2014, and this update is compiled from a video of an interview he gave to Channel Nine at the time AFL Coach, Alistair Clarkson, was reported to have been diagnosed with GBS. You can read the full report of Scott's original presentation to the group by downloading INGroup newsletter number 88 from the website: [www.ingroup.org.au](http://www.ingroup.org.au)



Scott published his experiences 'The Wave of Guillain Barre' Syndrome' in 2013 and he described it as – *“a story of hope, survival and proof that a positive mindset can overcome the most dire of situations. Written from the bed of a rehabilitation hospital with only slight use of one hand, this first-hand account is of the day to day challenges of fighting for survival in the fight with Guillain Barre' Syndrome. Throughout life there are moments you never forget - your first car, first job, the day your child is born, first date with a partner and I will always remember the day I died. I have memory of the fifth time my heart stopped, as clear as day.”*

Scott remembered that in 2011 he had a pretty active lifestyle. Played every different kind of sport at a pretty good level. At 17 he trained with Richmond in some of their junior squads and was teetering on becoming an AFL footballer. But chose to divert off and concentrate on completing a sports coaching degree and again trying to remain fairly active. He was really fortunate growing up to be able to travel a lot and did what most people do in their twenties – backpacked around the world. He very rarely fell ill and no-one in his family had ever been touched by severe illness.

Genevieve Tole, Scott's Physiotherapist, spoke about working with disability such as GBS and how each person is affected differently. There are many variants and experiences and the intensities are always different. She talked about how the nerves and muscles are affected and how slowly the process goes, teaching patients to stand, walk, use their hands and fingers again. She said Scott was one person who worked hard to achieve optimal results and how rewarding it was to see a patient gradually return to a more normal life.

Scott talked about being run down, the numbness in his feet and fingers and losing function/capacity. He lost weight and experienced wide ranging paralysis. But said [*as most GBS patients say*] that his mental capacity was not diminished. Scott was hospitalised and when his lungs were affected, put onto life support in ICU. At the same time he temporarily lost sight in one eye. He was placed in an induced coma for several days and in that time experienced heart failure.

He talked about how his relatives coped during this time – stressful for everyone, touched on how the seriousness of his condition affected him personally and noted that not all people with GBS have such severe symptoms.

He commenced rehabilitation at Caulfield for a couple of months. He was determined to 'walk out' and settled to the hard work of physiotherapy. This determination was supported by him using his mental ability to urge his body to succeed in at least one goal each day – simple things like achieving a thumb and forefinger exercise.

Asked how he is now, 10 years later, Scott said that he considers his physical capabilities are back 100%. He works in a successful IT company and leads an active life - always up for physical challenges



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such as triathlons and he has worked at bulking up since his episode. He said his first time on a surfboard and also on a cycle were very emotional times.

His message to other sufferers and their families was to keep strong and continue to work hard at rehabilitation to achieve results.

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## **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)

## **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.

## **NEXT MEETING DATES TO REMEMBER**

<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

This is always an enjoyable and fun-filled day – we look forward to seeing you then.

## **COMMITTEE MEMBERS**

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

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**The Inflammatory Neuropathy Support Group of Victoria Inc.**

ABN: 77 954 503 188 Reg. No: A0025170R

**2024 ANNUAL GENERAL MEETING**

Advance notice and Agenda for the Annual General Meeting of the Inflammatory Neuropathy Support Group of Victoria Inc. to be held on Sunday 18<sup>th</sup> August 2024 at the Ashburton Library, 154 High Street, Ashburton commencing at 2.00pm.

**AGENDA**

- 1. Confirmation of Minutes of 2023 AGM
- 2. Reports from President and Treasurer
- 3. Election of Officers and Members of Committee
- 4. Confirmation of membership subscription
- 5. Any special business of which 21 days notice has been given.

Positions to be filled are:

President, Vice-President, Secretary, Treasurer, Membership Co-ordinator, General Committee Member/s

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**The Inflammatory Neuropathy Support Group of Victoria Inc.**

**Nomination form for Election to Committee 2024/2025**

Position: ..... Nominee: .....

Nominated by: ..... Seconded by: .....

Accepted by nominee:

Signature ..... Date: .....

To be returned to:

The Secretary, The IN Group, 26 Belmont Rd., GLEN WAVERLEY 3150 by 8<sup>th</sup> August 2024.



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**The Inflammatory Neuropathy Support Group of Victoria Inc.**

ABN: 77 954 503 188 Reg. No: A0025170R


**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
<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)		
<b>Tick here if a receipt is required →</b>		
<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 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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