

# INFORMATION

## Inflammatory Neuropathy Support Group of Victoria Newsletter



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Victoria, 3150, Australia

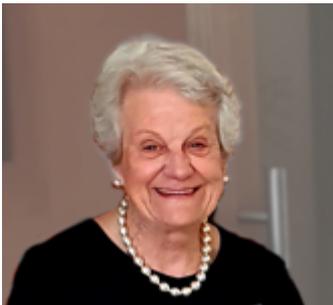
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Newsletter of the 'IN' Group: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC., supporting sufferers from acute Guillain-Barre` Syndrome (GBS) & Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), Multifocal Motor Neuropathy (MMN) and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

### **MEMBERSHIP SUBSCRIPTIONS 2024 DUE 1<sup>st</sup> JULY 2024**

***The fee has been maintained at \$15.00***

***An early reminder not to forget to renew your annual membership by 1<sup>st</sup> July. The easiest way to pay is by direct credit to our account. See the form on the back page for details.***



### **PRESIDENT'S MESSAGE**

It was a jog down memory lane for long-time members at the last meeting as we revisited the origins of the group and remembered the hard work of James Gerrand and his wife Betty, starting in 1992 when James was diagnosed with CIDP, to establish a group which could provide support and information to people who were grappling with a difficult and painful illness not understood within the community at large but also not well known within medical circles.

Members were kind enough to share their experiences with us on the day and in the pages following we have summarised their comments. How others are getting by is always informative.

Also in this issue, we have the first instalment of the story of Wayne and his journey. I'm sure his experiences will resonate with everyone.

With grateful thanks.  
Margaret Lawrence

### **NEXT MEETING**

***Sunday 19<sup>th</sup> May 2024 2pm***  
***Scott Earle author "The Guillain-Barre Wave"***  
***Ashburton Library, 154, High Street, Ashburton***



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Report of meeting held on Sunday 17<sup>th</sup> March 2024.

## History of the formation of the INGroup.

It was 1992, and the first President of the INGroup, James Gerrand, realised, after speaking with his doctors about his Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) diagnosis, there was a great need for information and assistance for patients diagnosed with this very difficult and painful illness, so along with his wife, Betty, he set about forming a support group, entailing as you can imagine, many hours of work - without the help of the electronic assistance we have today!

In November of that year, the first meeting of the Inflammatory Neuropathy Support Group of Victoria Inc was formed. Twenty-five people attended the meeting in Balwyn, some travelling long distances from country Victoria.

Consultant Neurologist, Dr Bruce Day, addressed the meeting on two inflammatory neuropathy disorders CIDP and Guillain-Barre Syndrome (GBS) which was followed by an extensive question and answer session.

The meeting also established the purposes of the association, namely:

1. To arrange personal visits by former patients to those in hospital;
2. To provide emotional support to patients and their families;
3. To publish a newsletter providing ongoing information;
4. To advise patients regarding resources for vocational, financial and general assistance;
5. To organise group meetings;
6. To encourage research into cause, treatment, prevention and other aspects of the illness;
7. To promote financial support for the group's activities

The joining fee was \$5.00 and Annual Membership \$10.00 and members received a regular newsletter to keep them up-to-date – which continues today.



By the time of the first newsletter in December, membership had grown to 46 and the group was awaiting advice from the ATO that they had been accepted as a benevolent institution and granted tax deductible status for donations. (This was confirmed in due course.) This first issue carried news of the experiences of several people who had contracted CIDP or GBS, a report from Associate Professor John Pollard, University of Sydney, on the latest research developments based on his recent work in Germany and, a report on a visit to Fairfield Hospital where a copy of the 1991 "Review of GBS treated at Fairfield Hospital" by Dr Hugh Newton-John was made available.

[Dr Newton-John, yes Olivia's brother, was well known for his work in infectious diseases and led many key research projects, particularly among patients requiring care in the hospital's intensive care unit. These included projects related to tetanus, Guillain-Barre Syndrome, improvements to ventilation methods for polio patients and new approaches to preventing airway obstruction among patients with chronic upper airway weakness. Sadly, he died in 2019 after a long battle with debility and decline.]

The initial research project supported by the group, via Associate Professor Pollard, was to assess the prevalence and incidence of the acquired demyelination neuropathies, and a letter authored by Dr



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Bruce Day was sent to all Victorian neurologists seeking their assistance in establishing the Victorian Register for GBS and Related Disorders.

Later, the group established a connection with the research section of the neurology department at *The Royal Children's Hospital* and Associate Professor Andrew Kornberg and by annual donations, continues working to keep these services active, helping many in the community. Over the years the group has made donations of \$190,000 for research into GBS and CIDP.

The group has links to the following organisations:

Guillain-Barre Syndrome Support Group of New Zealand

GBS/CIDP Foundation International -USA

Guillain-Barre Syndrome Support Group of the United Kingdom

Departments of Neurology and Neurosurgery at John Hopkins Hospital

The Neuropathy Association

Neuromuscular Disease Centre

CIDP USA Foundation

For many years the group was connected to CSL and were able to visit their laboratories. CSL provided the immunoglobulin vital in treatments of CIDP and GBS and, at one time, sponsored the group's website. Today, due to demand for supply, immunoglobulin products also arrive from overseas.

As the years have progressed, the active work of the group – personal visits to patients in hospital has gradually scaled back as the number of treating specialists and hospitals increase and the treatments vary considerably.

It is just over 31 years since the INGroup was established and it continues to provide information on GBS and CIDP – now via a website and regular newsletters sent by email, as well as maintaining quarterly meetings with interesting and informative speakers.

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## MEMBERS EXPERIENCES

Members generously shared their CIDP/GBS experiences at the March meeting, and unsurprisingly, each instance of either illness was different to the next. This is a de-identified general summary of the discussions.

### CIDP

Members were of varying age groups and living with CIDP for different lengths of time. Everyone experienced different initial symptoms and severity which led them to seek medical help. Symptoms included extreme tiredness, tingling hands and or feet, vaccine complications and balance difficulties. Conduction tests usually confirmed diagnosis. For some, the diagnosis was long in coming which made for a difficult and trying time before any treatments could commence. This was made even more frustrating where there were other underlying conditions which perhaps masked the recognised pointers to CIDP. Also, where symptoms were initially mild or slight, it was easy enough for people to



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put off seeking medical help, perhaps minor changes in lifestyle justifying why these changes and odd sensations occurred.

Once diagnosed, most people were put on an IVIG regime which in some cases was given very frequently in the first month or so and then to settle at once every three or four weeks although one person is on a plasma exchange fortnightly treatments for 6 months reducing then to once a month. As with all therapies, these infusions have varying long term success but everyone agreed there was an initial positive improvement. Dose rates and the importance of maintaining that level is critical to keeping people stable and it has been frustrating when from time to time, a lack of supply of Intragam often resulting in a reduced dose rate, meant more high and low swings between infusions.

There are regrets at not being able to be as active as you want – either sport or just around the house, ability – particularly balance, gradually diminishes. But most people are benefitting from a regular exercise programme. The combination of IVIG and exercise over a period of time, has led some to improve to extent of being in remission and gradually reduce infusions before ceasing altogether, in one case, an inadvertently received double dose enabled them to walk unaided and who, at a time of short supply, decided to cease IVIG with no ill effects, but there is no crystal ball on why or how remissions occur. Every case is different.

Members spoke about the need to be mentally strong, learn to adapt. Try to map out a plan for survival – adopting new sporting interests perhaps, maybe take up more passive interests, doing those simple things differently to achieve the end result. Learning patience!  
So, it continues to be an idiopathic condition and in the words of one member “it is what it is”.

## GBS

Again, age groups and the length of time from diagnosis varied. Weakness in legs and arms led most to seek medical help. Some also complaining of a ‘bad cold or flu’ or ‘reaction to vaccination’. Not surprisingly diagnosis was often not immediately confirmed.

Several progressed to quite serious cases of paralysis and all had experienced a period of hospitalisation, some in ICU. As with CIDP there was a diminishing of physical ability to do the simplest things, but this weakening was rapid, usually reaching worst case within a couple of weeks.



As with CIDP, IVIG is also a treatment for GBS. Physiotherapy and exercise featured large in treatment regimens and people gradually recovered their ability over time, sometimes needing to cope with frustrating periods of plateauing in

the meantime.

Recovery in GBS varies, taking up to two years in some cases while the body learns to re-generate the nervous system communications with the brain. Not all cases result in complete recovery, some continuing to live with residual weakness in hands and/or feet - or something as simple as a tickly throat, which can mean changes in lifestyle to accommodate new abilities, and training yourself not to be impatient with the length of time it takes to do some tasks you used to do ‘in a minute’.



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Maintaining an activity level, be it with a prescribed exercise programme or a more low-key routine such as walking or a home exercise programme, is vital to maintain that gradual recovery.

It is very important, in the early stages of GBS, to set yourself up to be able to live with the effects – perhaps not dissimilar to needing to modify your lifestyle as you age.

Everyone agreed that having contact with the INGroup helped to strengthen resolve, was the opportunity to share experiences with others and also to learn much from the various medical speakers who present to the quarterly meetings.

### GBS and CIDP INFORMATION PAMPHLETS

We now have a supply of information pamphlets for both GBS and CIDP – pick one up at the next meeting.

### Wayne's CIDP Story



Wayne, from country Victoria, joined the INGroup last year. 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. It will be serialised and this is the first instalment.

#### *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.*

Hi, my name is Wayne.

I live in a small regional Victorian city. It is January of 2019, no health issues, and 59 years of age. Working as a food industry employee on the factory floor involving physical work and long periods of standing. Although physically demanding work, I had no problem carrying out work duties.

I thought I should get a doctor's check-up. Something didn't feel right. I booked a GP appointment and explained I was experiencing numb toes and tingle sensations. The gist of the consultation was to come back if things did not improve in three or four weeks.

Shortly after, a weekend day drive to a coastal tourist town left me wondering how safe my driving was. I own two sedans - one manual and one automatic. Driving my automatic transmission car in



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the busy main street I stopped in traffic - a car behind and a car in front. I depressed my right foot on the brake unaware the side of my foot was still on the accelerator pedal. Smelling tyre smoke and engine revving I turned the ignition off. I did not have enough feeling in my feet to feel the pedals. An accident avoided and a cautious drive home.

It was suggested acupuncture may be beneficial. Unsure of my driving ability, I travelled by train to Melbourne. Sceptically, I agreed to get a two hour consultation. The Chinese acupuncturist inserted needles in my feet and upon withdrawal all were bent at right angles. The acupuncturist commented the normal needle curvature was severely bent out of shape on all needles. There was evidence of extremely taut tendons. He recommended daily use of a foot spa diluted with whisky and two more sessions. I returned home unconvinced acupuncture made any difference and I declined further expensive sessions.

I was struggling to lift my feet for no apparent reason. All my fingers tingled and my toes felt numb. Accessing my car, I stumbled backwards and fell on my lawn. I overturned a coffee mug at a local café with family and friends. I had weak hand grip coordination. Within two weeks I returned to my local GP for a second appointment.

The doctor referred me to a Melbourne neurologist a few hours drive away. The first appointment was ten days off in Ballarat. I spent the time housebound and unable to work. My leg strength and balance are getting worse. No feeling in my feet. Weak gait.

Six attempts to park the automatic car in the garage behind the roller door. Unable to drive. No public transport available. I live alone as my wife of twenty-three years passed away with breast cancer two years before. Connie, my wife, would have been whole heartily supportive one hundred percent, as I of her. I remembered getting the all-clear result of a routine scan over eighteen months prior from a prominent doctor who happened to be my wife's surgeon. I was sitting in the doctor's clinic unable to speak when asked questions. Maybe ten minutes or more. Memories of the cancer clinical setting all around me suddenly and unexpectedly affected my speech. The surgeon walked me to reception.

This was a few months preceding my solo eight week road trip around much of Australia in a sedan. For me, long drives addressed trauma. Now, nearly two years later I needed to see a specialist. What is it?

At least I knew I didn't have cancer.

I have no home support. After several days I could barely walk around inside my home. I telephoned the Melbourne neurologist's reception twice and tried to bring the appointment date forward. I offered to get myself to the Melbourne clinic as my condition was deteriorating. My walking is becoming weaker. Reception replied the original appointment was the earliest date and all earlier times were fully booked. I asked if I could speak to the neurologist. *'No, he's with a patient'*. OK, so I waited at home with a stoic attitude thinking everything will be OK after a week or two of rest. My respiratory condition felt normal during this time.

A further five days passed housebound and I was then driven to my neurologist appointment. I attended a medical consulting clinic used by visiting Melbourne specialists. Located in the large regional city of Ballarat. Upon seeing myself struggling to walk and assessing absent nerve reflexes the neurologist immediately admitted me to St Vincent's Hospital, Melbourne. Telephoning the hospital on the spot.



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Luckily I carried a small overnight case, allowed no time to return home to pack a bag. My driver kindly agreed to drive directly to the Melbourne hospital. I distinctly remember the neurologist telling me I think you have GBS or CIDP. Let's hope not CIDP. Of course, I was clueless of these remarks. Myself, like many, not realising the serious health implications of these unheard of conditions.

In both **Guillain-Barré Syndrome** and **Chronic Inflammatory Demyelinating Polyneuropathy** one's own healthy immune system turns rogue and attacks the peripheral nerves. Classified as autoimmune disorders.

CIDP origins are idiopathic, (unknown). Although, one United States research paper documented a small cluster of GBS/CIDP cases among workers in a piggery attributed to **Campylobacter Jejuni** sometimes found in slaughtered pigs, sheep or chickens.

I worked in the food industry for years with daily exposure to dried blood from thousands of freshly slaughtered sheep. The provided cotton hood head/face and body protective clothing ineffective as a 100% barrier against dried blood contact. Medical publications such as *National Library of Medicine*, *Journal of Neuroimmunology* etc, cite up to 40% of those diagnosed with GBS/CIDP showed a viral infection with Campylobacter in the few weeks prior to symptoms appearing as the result of the onset of nerve demyelination.

No Campylobacter was found in the many blood tests I had in the hospital. I don't recall having common symptoms of Campylobacter. The short answer is I never had a Campylobacter infection. Although I can't state this with one hundred percent certainty. Medical literature cites livestock workers with a positive viral infection to Campylobacter Jejuni have a one in a one thousand chance of acquiring GBS or CIDP. For the general population there is a one in a one hundred thousand chance of a GBS/CIDP diagnosis with no exposure to livestock.

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Next instalment: Wayne's admission to hospital ..

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## THANK YOU

At the beginning of the last meeting a presentation was made to Margaret Wilson in appreciation of her work in producing the newsletter each quarter. In responding, Margaret said it was a pleasure to be able to contribute to the work of the INGroup in that way, and how much she had learned in the two years since she had taken it on.

## FUTURE MEETING DATES TO REMEMBER

<b>Sunday 18<sup>th</sup> August 2024</b>	2.00pm	Ashburton Library	AGM: Assoc. Prof. Tim Day
<b>Sunday 8<sup>th</sup> December 2024</b>	12noon	Ashburton Library	Christmas Lunch

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

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