Issue No: 95. July, 2016

STICK WITH IT
SLOW BUT SURE

INFORMATION

www.ingroup.org.au
info@ingroup.org.au

26 Belmont Road,
Glen Waverley, 3150
Victoria, Australia

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)

NEXT MEETING
SUNDAY, 14TH AUGUST, 2016 AT 2.00PM
ANNUAL GENERAL MEETING

******PLEASE NOTE CHANGE OF VENUE ******

ASHBURTON LIBRARY, at ASHBURTON COMMUNITY CENTRE, 154 High Street, Ashburton
Parking is available in High Street and side streets.
There is a very good ramp outside the building in High Street and on entering the building our meeting room is just on the left through glass doors.

Our Guest Speaker will be from CSL who will speak on the production of IVIg.
A small plate to share would be appreciated. Thank you.

Dates to Remember !!!**PLEASE NOTE THE FOLLOWING INFORMATION!!!**

Due to renovations at the Balwyn Library, the following meeting will also be at Ashburton Library, 154 High St., Ashburton.

Spring "High Tea" Sunday, 25th September at 2.30pm. *See note on Page 7.

Christmas Luncheon Sunday, 20th November **12.00 noon**

Notes from the May Meeting

Apologies: Brian Boyd, Peter Bellis.

Finance Report

In the last quarter **subscriptions** slowed down as they are **due from 1st July**, so **we hope by the next quarter most of our subs will be paid.** We only received $120 in subs but against that we had some tremendous donations given to us and we recorded **over $1500 in donations for the quarter. To all our members and our members' friends (because there are some groups that are working and donating to us on behalf of a member who is part of their group)** so to all those **we would like to say "Thank You".** Our **total income** was **$1645**. The total for the 9 months is $8,000 so we are doing well and when the **July subscriptions start to flow in, I am sure we will be able to make another very generous donation.** In January there was our next internet cost of $95. That is subsidised by a grant from CSL which came in last year. We locked in our room hire for all of this year, 2016 and the cost was $72.

Today is the last of our meetings in Balwyn Library **for this year** because of work they are going to be doing on the Library. **Our next two meetings which are the August and the November Christmas meetings will be held at the Ashburton** Library, which **is still part of the same group and is in High Street Ashburton in the shopping centre**.

Margaret: We had a note from **Andrew Kornberg. "**Dear Margaret, I am sorry for my tardy letter of **thanks for the kind donation that The IN Group gave me at the Annual Meeting. I just really wanted to say a big "Thank You" for all the hard work The In Group puts in to raise these monies. As always the money will be used for ongoing research to provide support for our neuromuscular fellow who is able to do this work."**

So that is what our money goes into for the doctors to do this research. The Royal Children's Hospital sent a receipt as well.

We also received another letter which I will read because this is nice and some of you would remember him.

"Please accept this small donation to your amazing organization. My father Keith Colwell was diagnosed with Guillain-Barre` 19 years ago. He was aged 78 and treated in the Alfred in ICU for 15 weeks and then for further treatment and rehab. in Fairfield. It was a very intense time for the family and the support of your organization quietly answered questions they could and educated us along the way, informing us via your newsletters and group support.

My dad was born on the 5th of May 1919 and is now looking at celebrating his 97th year in a couple of weeks. (Margaret: I have had this for a little while.) **He made a good recovery after 8+ months in hospital and for the 19 years since the Guillain-Barre` disease he has had diminished feeling in his feet. However, this seemed to be a small price to pay for another decade plus of a productive life. Every day he got out of bed, checked those feet and walked out into the World.**

I have just read your most recent email newsletter and am always impressed by the level of information you share with your readers. Hopefully those dealing with Inflammatory Neuropathy diseases will feel wonderful work is being done and feel confident they are getting the best treatment available. Thanks for continuing your support." Signed: Jan Hooker

Margaret: This is **lovely to hear and keeps us going**.

Melva: Could I just say something about **Brig. Keith Colwell**. He is **one of our early members** who became **totally paralysed by GBS,** so much so that **only his eyes moved**. **Every time his grandson visited his eyes would blink madly.** The family asked, "Why do granddad's eyes move like that whenever he goes near him?" **The young boy twigged and said, "He taught me Morse code. Maybe he is talking to me."** He bent over and watched his grandfather's eyes and **he <u>was</u> talking to him.** I can't remember word for word but I remember hearing something like **he told everybody to be calm and not to worry as he was doing alright in there** and that **he would get better** and be able to tell them about it later."

Margaret: Another thing is I went to the **CSL Dinner and it was just lovely**. It really was a fabulous affair and apart from the fact that I had a beautiful dinner, **nobody wore a name tag**, so **everybody came up and said** "**How come you are here?" I thought that was a good thing.** It was amazing **when I said "The IN Group" as they said "Oh, I know about that." A doctor** seated two along from me asked why I was there and what my name was and then **said to me "In 1979 I was one of the first to give patients treatment for this problem"**. The person opposite said, **"I know somebody who knows about that"**. Then up came **a lady** who **said** "Do you mind if I **chat to you** for a while**. I am the Federal Member out Maribyrnong way and if any of your members need any support or help, I am there for you."**

It was interesting as firstly I thought, I don't know anybody. I did sit beside **Dr. Christopher Fry (Snr. Brand Manager)** and he is lovely, but **they all wanted to know about The IN Group**. In the last newsletter it said it was 150 years for **CSL**, but it **was** really **100** and the building we were in was 101.

Gwen: At 83 I still teach craft and making porcelain dolls and recently one of my group died and she left a lot of stuff unfinished, so the rest are busy working on it, getting them ready for sale to raise funds to be donated to The IN Group. I'll show you some. **There are coat-hangers, caps and little sugar dolls, fancy scarfs, etc., so keep an eye out as there may be something you might like. Making porcelain dolls is an expensive hobby but later there will be porcelain dolls, (clowns, Bru, Hilary, Paul, Little Googly, Half Dolls for Potpourri etc.,) and they will be available for sale at later meetings at very good prices.**

Talk by Dr. Valerie Tay

Thank you very much for having me here today. I have been reading through your last couple of newsletters and you have had **Les Roberts** here recently and **Tim Day** and **they have talked about trials and things**. **I thought today I would do something slightly different by just going through CIDP again, from start to finish in a way, so maybe you can reflect on your experiences.** This is just a general session. It is not about anyone's particular management.

In terms of **CIDP**, as you know it stands for Chronic Inflammatory Demyelinating Poly-radiculoneuropathy. It is a long name. Where did it even come from or where did it originate? If you look back in history **it was first described in about 1890 by a German physician. He actually noticed that there were people who were getting a recurrent neuritis. A few years after that another physician came up with that it was recurrent, but also fairly symmetric as well. This was all in about 1890 to 1894.**

If you contrast it to **AIDP which is Guillain-Barre`, it was actually noticed much earlier, back in the 1850's by a French Physician. His name was John Battiste Octave and he noticed that there were people who had this acute neuritis and made lots of observations about it, but it was another 50 to 60 years later in 1916 when three physicians George Guillain and then John Alexander Barre` and Andre Strohl who described a series of people and that is where the term Guillain-Barre` comes from.**

So from the **1890's we had CIDP. 1850's AIDP, but then in 1916 they came up with Guillain-Barre`**. It was after that, **in 1958 or so, an American physician called Dr. Austin noticed that this actual neuropathy was recurrent and it was actually responsive to prednisolone. It is only fairly recently in 1975 that Dyck, a neurologist in America, came up with this term Chronic Inflammatory Polyneuropathy.**

So if you think back to the history of medicine, it **is a fairly recent medical disease** that they have come up with, but it was also after that he found, with the histology of the nerve, it was **demyelinating and in 1984 the term CIDP added the "demyelinating" to it.**

Now what exactly is CIDP and how do we actually diagnose it? With anything in medicine **we look at the history, the examination; the features**. We look at tests, so there is **neurophysiology, electrophysiology and sometimes we do a nerve biopsy and sometimes we do lumbar punctures as well.** So then we reflect on all what we call "your history". You may not have had all those tests because they are not always necessary.

In terms of the actual **"clinical"** it is basically where people get a **symmetric,** generally it is **fairly even, right and left**. We can have a slight **asymmetry where the right is weaker than the left** or **left is weaker than right** and it tends to be a **more motor dominant neuropathy meaning that there is more weakness.**

In Australia, the top two neuropathies are caused by diabetes and alcohol. Most of them have more numbness and tingling. **In CIDP, yes you can have numbness and tingling, but there is more weakness as such. They get motor weakness; they can get fatigue, they can get numbness and tingling (as you know) and sometimes there can be pain as well.** The pain can be described as **burning, jabbing or sometimes a tight sensation. Again it is motor dominant in general**. As with anything in medicine there are **always variants and exceptions** to the rule.

There are patterns of CIDP. Some people have broader, **more sensory** as well, **very sensory**, **not much motor weakness**, some people have **just small motor** and not **a lot of sensory and there are a lot of other variants**. We have **MADSAM which is Multifocal Acquired Demyelinating Sensory And Motor neuropathy.**

In terms of the **clinical cause**, again if you think about it, some people have a **relapsing motive, so they have a time when they get a bit weaker, they get better and then they get weaker and then they get better.** Some people have a course where **they get a bit weaker, they plateau for a while, then they might get weaker, then they plateau.** Some people have a more **generally gradually progressive course**. So if we compare it month to month we don't notice a big difference, but **if we compare it year to year, then you might notice that the foot is a bit weaker than a year ago or two years ago.**

CIDP generally **affects more adults** but can affect people of any age. We do see certain patterns. For some reason **males are affected more commonly**. That's **not to say woman are not affected**, but **generally more males** and **we are not sure why**. In terms of the actual pattern, if people are **younger – less than 20, they tend to have more weakness and the more relapsing course.** Aged **20 – 40 they have more relapsing**. If they are **diagnosed between 50 -70 they tend to have more progressive, gradual weakness more than fear of relapse. It is a clearer progression**.

Now that is the clinical part. In terms of **diagnosis with tests** and things, when you think back to all the tests the **most common** one would be the **nerve conduction study.** Now **what exactly is demyelination?** Your **nerves are literally like wires**. You think about **electric wires**. There is **a cable and there is a coating** around it. So the **cable in the middle is called the axon** and **the coating is the myelin**. **In CIDP it is demyelinating, so we are losing the myelin.**

Myelin is for all sorts of reasons, but one is it **protects the axons** so it protects the cables. If we **lose the myelin the axons are exposed and can get fragile and it can start to fracture** but also the **myelin allows the nerve signals to literally hop down the nerves** so it's a lot quicker. If we **lose that myelin then everything slows down**, but **over time the cables can fracture and that's how we get more weakness, etc.**

In **terms of the diagnosis**, the **nerve tests reflect** that as well, so when you are doing nerve conduction tests there are **things to look for**. Remember the test where they put stickers here and then they jolt the nerve. **Normally when you zap the nerve the muscle will pick up the signal, but in CIDP you get a delay**. So let's say when you zap the nerve here the signal comes out here. In **CIDP** it could be here, because we have **lost the myelin so the signal takes a little longer**. They look at things like that. They **look at the sleeve along the nerve** itself. Again they record the distances where they zap you here and zap you there, **measure the distance and see how fast it takes to travel** and in **CIDP again and with demyelination and loss of myelin, the signals slow down.**

They do another response. It is called the **'F' wave**. That one is quite painful. That one **looks at the nerve signals as they move up and then move down again**. If there is demyelination **there are standards where they measure the actual speed it should take to move and if it is slower it is CIDP. So there are certain criteria we look at on nerve conduction studies as well.**

Some of you may have had **Lumber Punctures**. With the Lumber Puncture, what they are **looking for is the protein level** mainly, as **with CIDP the protein levels are elevated**. It is not always necessary as sometimes the diagnosis is quite clear based on clinical and the nerve conduction studies.

Some of you would also have had **a nerve or muscle biopsy**. Now with the **nerve biopsy** the nerve we tend to **take is the sural nerve which is on the outside of the foot** here. (Dr. Tay shows where on foot.) We usually take it from here but sometimes higher up. **The sural nerve is a sensory nerve. It supplies sensation to the outside of the foot**. It is not **always diagnostic in CIDP**, again as **sometimes people have more motor weakness rather than the sensory** presentation and then because when **the nerve can be patchy and its demyelination**. Even though **the nerve is that long it might be demyelinated here, but okay here**, so when they cut the nerve here, **it might still be normal**. The things they see might point to demyelination as **we can actually see nerves losing myelin and attempting re-myelination**. **You can see axons being lost and again because it is an inflammatory process they see inflammatory cells as well.**

You may have had a muscle biopsy in tandem with that. **With a muscle biopsy they only take muscle close to the nerve they are doing at the same time.** The **calf muscles** are very **common** but **sometimes they take a thigh muscle**. **If they do that it is more to rule out other things as well**. We don't always do the biopsy because the diagnosis may be very clear because of the history, the examination and the nerve test. Any test that is **an intrusive test is a balance of risk versus the benefit, because if you cut something there is a risk of causing infection and sometimes because they cut a bit of the nerve they don't cut the full nerve out, we can get pain at the biopsy as well.** Sometimes we do it, sometimes we don't. So again **we look at the history, the nerve conduction, lumber puncture** and also the actual **biopsy** if it is done.

In terms of CIDP **we don't know why you get CIDP**. It is one of these medical mysteries at the moment. We are not exactly sure why it happens. About **30%** of the time **people may recall an infection or vaccination before the onset of CIDP. That is not always the case** and it is **hard to know exactly what the link is between the infection, vaccination and the onset.**

How common is **CIDP? It is relatively uncommon**. Say with a population of 100,000 people, we think that **1 or 2 might have CIDP out of the 100,000**. As the age group increases to **70 to79 age group you might have maybe 6 out of 100,000 with CIDP**. The rough average age of **onset is 57 years old but some people have it at 20, some at 60 plus**.

In terms of **treatment of CIDP**, the **two most common medical treatments** at the moment are **steroids and IVIg**. Steroids we tend to give the **oral prednisolone** initially and they start off the dose quite high and it **tapers down over 3 months** or so, then some people have **a maintenance choice** and some people can **come off the steroids** at this stage. Bear in mind that there are **different courses**. Some people have **relapsing**, some have more a **step** way and some have **more progressive**. The steroids can start high then come down and if you are on long term steroids, again **we look at side effects as well, like sugars, checking bone density**, that sort of thing. Sometimes at the start when there **is a lot of weakness we might give intravenous steroids, lets say prednisolone, where we might give you a gram or 500 mg. or so over 3 hours for one day and two extra days.**

The **other treatment we use a lot for CIDP is obviously IVIg**. What exactly is IVIg? IVIg is **a donated blood product**. People sit down and donate blood and **it is a pooled product**. **Basically it is antibodies**. It is **used for** a lot of things in medicine. They use it for people with **immunodeficiencies;** people that have a lot of **recurrence of virus infections**, **chest infections**. They might get IVIg infusions because they have all these antibodies to try and fight these infections as well. **Within neurology itself we use it for CIDP**. We use it for other immune based conditions as well. There is one called **Myasthenia gravis** where we **also use IVIg** and they only have antibodies targeted against what is called the **neuromuscular junction of the nerve and muscle** and they get **antibodies targeted at that junction. We will soon use IVIg in some muscle conditions as well.**

The IVIg as you know we give you **an induction course** and then there is **the maintenance**. There are no real hard or fast rules about the best way to do an induction course. Some people do the **5 day course where they give you the standard .4 grams per kilo over 5 days**. **Sometimes** they give you that dose, but **within 3 days or so**. Sometimes they give you **a day between each dose**, **if you have side effects** whichever it might be. Occasionally there are some people **in the States** who do the induction rather than 5 days they might do **1 day a week for about 4 weeks**. Then they have maintenance and the maintenance will be the **same dose as you get over 5 days but instead of 5 days you get 1 day or 2 days every 4 weeks.** Sometimes **in the States they halve that dose** from **.4 grams as the induction dose** and then **.2 grams for the maintenance dose**.

The other treatment that is **equivalent to IVIg is Plasma Exchange**.
If you think about it **IVIg is** where we give you **an infusion of antibodies to try and fight the inflammatory response that is targeting the nerve. Plasma Excha**nge can be thought of as **trying**

to filter out the antibodies. So you sit down and blood comes out and goes into **a machine which filters out the antibodies** and then returns your blood to you.

Two thirds of patients will respond to each. Some people do better on one than the other. Some people just **do very well on IVIg and not on Plasma Exchange** and some **do very well on Plasma Exchange and not so well on IVIg.**

In general **IVIg is a lot easier** to do. You just sit down and we put **a drip in** and you have an i**nfusion**. **Plasma Exchange,** because they are filtering blood they need to filter a good volume of blood and so **they need bigger veins, bigger IV access**, and because we are taking volume out, **some people get dizzy spells and it might take out your calcium** with it and you **get spasms**, etc. Again **Plasma Exchange is not as available** as it needs to be **in bigger hospitals like the Peter Mac, or The Royal Melbourne, etc.**

The **other treatments** that we use are **Prednisolone, IVIg, Plasma Exchange** and sometimes there are the **immunosuppressants** as well. One of the more common ones being **'Imuran'** which is **a tablet** that is taken and **there have been lots of different trials**.

I am not sure if any of you were part of a **trial of a drug used in MS** that they **may be able to use for CIDP**. There is some suggestion it may help with CIDP but at the moment **it is not shown to be superior to IVIg but also in Australia it is not funded for CIDP.**

They are also looking at **the Subcutaneous IVIg.** At the moment it is **not approved** for use here yet. There is some suggestion that we **might be able to use it for CIDP** as well.

The other thing that is **really important is good health and nutrition and a gentle exercise program**. **With exercise always use your common sense and know your own limits.** It is good to exercise and **exercises should include stretches, cardiovascular exercise and also weights and things like balance**. If you think about the physios that you see, some get you to do more **balance exercises**, stand on one foot, etc., and then do **stretches, cardio and weights**.

The one to be a little careful of is weights, especially if there is weakness. If you have a **foot drop don't try and strap weights on your feet and try and force it to lift because then the risk is** actually that **you could tear a tendon** or that sort of thing.

Balance is important if you can and **also stretches** because again, let's say you have your foot like this your muscles are in opposition so if you lift your foot up this muscle will lift your foot up and this one at the back will pull your foot down. **Sometimes in CIDP you might have a muscle imbalance so it is important to just do gentle stretches**. **If it is too much and it hurts then obviously pull back.** Just **keep the joint moving**, so again there is **balance,** there is **stretches** and there is **cardio** and there is **weights**. **Cardio is good for general cardiovascular health.**

Hydrotherapy, most people find useful but hydro again is very gentle. Hydrotherapy is good because the **water tends to give you a good range of balance**.

Melva: A lady who had GBS 18 months ago has been in touch saying she **is having tingling in her hands and feet and on her face and neck** and she **wonders whether she should go back to the neurologist** and tell them that she has these **minor tingles** as she is concerned about them. I have **told her to contact her neurologist**.

Valerie: I am a strong believer in **using your common sense, so she should go back and talk to her doctor**.

(To be continued….)

ANNUAL GENERAL MEETING
The Inflammatory Neuropathy Support Group of Victoria, Incorporated
To be held at the
Ashburton Library Meeting Room
154 High Street, Ashburton.

Agenda

1. Confirmation of Minutes of 2015 AGM.
2. Reports from President and Treasurer
3. Election of Officers and Members of Committee.
4. Any special business of which 21 days notice has been given.

Positions to be filled are: President, Vice-President, Secretary, Treasurer,
Public Officer, Newsletter Co-ordinator, General Committee Member/s

ALL POSITIONS HAVE BEEN DECLARED VACANT. PLEASE GIVE SOME THOUGHT TO NOMINATING FOR THE COMMITTEE. NOMINATION FORMS AVAILABLE AT THE MEETING

Nomination Form

Nominee: ……..

Nominated by: …….

Seconded by: …….

Accepted by: ……

Date: …….

To be returned to: The Secretary, The IN Group, by 5th August, 2016.

Signature of Nominee: ……. Date: ……..

Please be advised that 21 days notice has to be given on any matter to be raised at the Annual General Meeting.

Bereavement

Our esteemed member Barbara Clifford has passed away. Barbara was a gentle lady who for years was in charge of the Tea and Coffee for our meetings. Our condolences go to her family and friends. Sadly missed.

SPRING HIGH TEA

We are planning a "Spring High Tea" at the Lawrence home on Sunday, 25th September, 2016 at 2.30pm. We require sufficient numbers other than the Committee before going ahead. A list will be available at the August meeting or email **douglawrence26@optusnet.com.au** by 10th September. We hope to make this a special day.

Email Mailing List. If you would like to be included on The IN Group email mailing list please send an email to John Burke at the following address: **jburke@contracts.com.au**

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.

THE 'IN' GROUP

The Inflammatory Neuropathy Support Group of Victoria Inc.
Supporting sufferers from acute Guillain-Barre` Syndrome (GBS and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
Registered No: A0025170R

Annual Subscription 1/7/16 to 30/6/17.

Annual Subscription			$ 15.00
Other Items			
Booklets - GBS		$3	$
CIDP		$3	$
After GBS	$3		$
The Road to Recovery A-Z	$6		$
- Boy, Is This Guy Sick	$2		$
Recipe Book plus postage & handling	$16		$
Donation to support medical research			$
(Donations of $2 or more are tax deductible)			_____
(Tick if receipt required ……..)			
Total Payable:			**$_____**

Enclosed is a cheque/money order (payable to The IN Group)

Membership Details

Name: _____

Address: _____

_____

_____Postcode _____

Telephone: (Home) _____ (Work) _____

Email Address: _____

Signed: _____Date: _____

Thank you. Please forward this form along with your payment to:
The Treasurer, The 'IN' Group, 26 Belmont Rd., GLEN WAVERLEY 3150