

INFORMATION

Inflammatory Neuropathy Support Group of Victoria Newsletter



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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 notice inside this issue)

Sunday 20th August 2023 2.00pm

Ashburton Library, 154 High Street, Ashburton

Speaker: *Anne Graham, Blood Matters Project Nurse (SClg), Lifeblood*

Subject: *Benefits of SClg therapy*



FROM THE PRESIDENT

Time comes round so very quickly, and it will be our AGM before we can blink! Notice of the meeting is included in this newsletter.

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 or by telephone on 9802 5319. A nomination form is also included in this issue.

And don't forget to renew your membership for 2023/2024:

Annual subscriptions \$15.00 are due and payable on 1st July 2023.
Please complete the form on the back page.

We extend a warm welcome to all the new members who have joined us this year. We hope that you will benefit from the great experiences we have at the IN Group – both at the personal networking level and in the number of qualified speakers from the range of specialties and professions who treat CIDP/GBS, who are willing to spend quality time with us at our general meetings. We look forward to seeing you again in August.



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Everyone knew Father Bob Maguire, social justice advocate and parish priest to the Saints Peter and Paul Catholic Church in South Melbourne for 40 years, who died on 19th April 2023. He is remembered for his tireless work helping the needy and providing shelter and food to the poor and hungry.

But what you may not know is that as his health deteriorated in the months leading up to his death and he lost mobility and balance, he was treated with Immunoglobulin which he was very excited about as it enabled him to walk again. So many of you know full well how effective this therapy is in treating CIDP/GBS and of course we are looking forward to hearing what Anne Graham has to tell us about SCIg at the AGM.

With my best wishes to you all.

Margaret Lawrence
President

PILATES 21 May 2023

Compiled from speaker notes and a recording taken at the presentation.



Ben Loh
Sports Physiotherapist
B.Physio (Hons), Grad Cert. (Sports Physio), APAM

Ben graduated with a Bachelor of Physiotherapy (Honours) from Monash University in 2016. He is currently the Head Physio at VFL team Northern Bullants, is a Pilates Instructor and Sports Physiotherapist at Lifecare Ashburton, Physiotherapist at Narre Warren Sports Physio and a NDIS and Aged Care Package home visits Physio. He has a passion working with people from all walks of life and loves to develop rehabilitation programmes to ensure they are injury free and enhancing their quality of life. Outside of work, Ben enjoys keeping fit by playing futsal and recently completed his first Olympic Triathlon.

Ben mentioned the differences between people who live with CIDP and using the experience of our Vice President, John Burke, explained he would discuss the use of Pilates in exercise.

He then went through the symptoms and impairments of demyelinating inflammatory disorders of the peripheral nervous system – a characteristic of both CIDP and GBS.

These include -

- *Muscle weakness
- *Balance problems
- *Impaired sensation
- *Loss of tendon reflexes



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which lead to abnormal walking and difficulty with functional activities, with the lower limbs usually affected first. The cause is not completely understood and neither CIDP nor GBS is contagious.

It is vital that any exercise therapy is tailored to the individual needs, and this is where a Physiotherapist can be beneficial in designing a programme to improve strength and endurance, minimizing muscle shrinkage and improving functional mobility. So finding a health professional to help you set the best frequency, intensity, time and type of activity is an important first step. Be prepared to discuss with them what you want to achieve so the therapy can complement that. Take care that exercise is not overdone - muscles can be easily overworked. Some soreness is not unexpected but should dissipate within 24-48 hours.

Ben spoke about the *Otago Exercise Programme* (OEP) which was developed and tested in New Zealand, to reduce falls in older persons. It consists of 17 strength and balance exercises and a walking programme, performed by the older adult in the home, outpatient or community setting. Exercises can be done individually or in a group setting.

In a systematic review, based around the OEP, carried out in 2018 by Canadians, Ian Janssen and Allana G LeBlanc, their goal was to maximise walking and functional movements required for maintenance and recovery. Each person was prescribed an individualized exercise plan to do three times a week as well as 30 minute walks twice weekly for a total of six weeks. The results demonstrated that a tailored exercise programme had a positive effect on a participant's walking speed and balance in patients with CIDP. Although more studies are needed to completely determine the long term impact, these positive results should be considered when treating someone with CIDP.

Case study –

In late 2020, John Burke presented with multiple ailments including right calf pain, neck and shoulder pain including headaches, tight right hamstring and gluteal muscles, and right plantar fascia (heel) pain – nothing that would generally point directly to CIDP.



Ben started John's therapy with an intense programme of massage and home exercises, then dry needling and kinesotape which provided temporary relief.

He then introduced a clinical exercise Pilates programme targeted to John's impairments – increase core muscles, increase lower limb strength and improve lumbar spine mobility - not for John to lift heavy weights and potentially injure himself.

Ben showed slides of the type of exercises prescribed for John, using the reformer bed for a variety of strength exercises – side stretches for hips, 'rowing' leg push and standing step actions, combining lower limb strength, core and balance.



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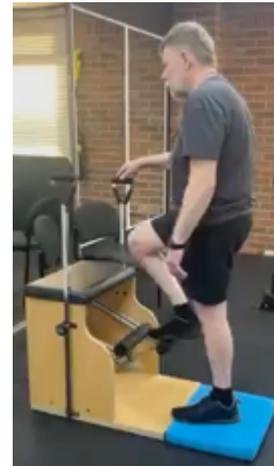
Since February 2022, John has experienced no flare ups and has not required individual sessions. He has the occasional niggle but that is targeted in the weekly classes he attends.

Q Is it better to do more sets or less sets with more weights?

A Depends on what you want to achieve. Generally, if you are aiming for muscle endurance, you would aim for more sets and more repetitions. I would recommend aiming for 10-12 reps, 3-4 sets.

Q Are home visits an advantage?

A The equipment is not the same, but the therapies are designed to have the same result. One advantage is that the Physio is there on the spot to ensure the work is done – otherwise (as we all know) the individual can lack the motivation to do the exercises unsupervised.



At Ashburton, Ben co-ordinates an over 60's class for around 10 people – general stretching and completing their personal gym programme, and also clinical exercise classes limited to 5 people for closer supervision of their tailored programme.

One thing that we should remember is that mental and physical health is fundamentally linked. There are multiple associations between mental health and chronic physical conditions that significantly impact people's quality of life.

They are:

1. Poor mental health is a risk factor for chronic physical conditions;
2. People with serious mental health conditions are at high risk of experiencing chronic physical conditions;
3. People with chronic physical conditions are at risk of developing poor mental health.

.....so it is important to be aware of your own body and take care of both.

As with the case study on John, access to Pilates is one way of providing exercise strength therapy.

If you have no access to regular classes, use these suggestions for home exercise:

*Walking is an excellent way to keep active – build up to walking 15-30 mins three times a week.

*Take part in strength training twice a week.

*Consult a physiotherapist for a tailor-made home exercise programme.

Do be careful about consulting “Dr. Google”, remember he has not had the opportunity to perform a personal consultation with you.

Q Are physiotherapists qualified within say the last 10 years more suitable?

A Not necessarily – you are measuring experience against more recent innovations.

Q What about osteopaths and others?

A Check that they are registered, and it is a good idea for you to ensure that they have routine access to gym equipment – does not necessarily need to be a full-on gym. Just consider the convenience and how you will be motivated – going to a class or more personal home visits etc.



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Comment Ataxia – balance and walking, is a real problem.

A Yes, and once a week classes may not be enough to sustain an acceptable level - try to do home sessions, but in either case, fatigue is a big problem. Also, motivation is higher when there is an expectation you will attend a class – it is much more difficult to be motivated at home.

Comment 14 months into GBS and devouring as much information as possible about the condition. Working hard in the gym, also using hydrotherapy. Perhaps working too hard and feeling some burn out – but just want to get to the end result as quickly as possible.

A Certainly exercising on land is better, although hydrotherapy gives you that extra balance, warmth benefits of the water, and makes exercises easier due to the buoyancy of the water. Make sure you include a few rest days in-between exercise sessions to maintain your strength level. And do consult regularly with your neuro exercise professional. Strength and balance are most important – learn to pace yourself.

Comment We know that balance is a problem with CIDP, and this is where hydrotherapy is of great assistance.

A Yes, however it may depend on where you are in the CIDP cycle.

Comment Finding it hard to get more than 6 hours sleep at night. Many at the meeting agreed on that, and the need to have a nanna nap in the afternoon!

A This can be an example of the mental/physical affect we talked about before and the need to take care of both.

Ben then invited members to take part in a short exercise class, following which he was presented with a gift and our thanks.



Members taking part in informal exercises at the conclusion of Ben's presentation.



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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

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, we have recently received advice that 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. The group has recently received \$229.39 this way.

NEXT MEETING DATE TO REMEMBER

Sunday 10th December 2023 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, Brian Boyd



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The Inflammatory Neuropathy Support Group of Victoria Inc.

2023 ANNUAL GENERAL MEETING

Notice and Agenda for the Annual General Meeting of the Inflammatory Neuropathy Support Group of Victoria Inc. to be held on Sunday 20th August 2023 at the Ashburton Library, 154 High Street, Ashburton commencing at 2.00pm.

AGENDA

- 1. Confirmation of Minutes of 2022 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

Guest Speaker: Anne Graham, Blood Matters Project Nurse (SCIG), Australian Red Cross Lifeblood

The Inflammatory Neuropathy Support Group of Victoria Inc.

Nomination form for Election to Committee 2023/2024

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 10th August 2023.



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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
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
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 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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