

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.

NEXT MEETINGS

Sunday 25/09/22 - September meetup & AGM, 2pm Associate Professor Andrew Kornberg

Sunday 04/12/22 - December meetup & Christmas luncheon, 12 noon

All meetings at: Ashburton Library, 154 High Street, Ashburton

MEMBERSHIP RENEWAL

Membership subscriptions are due on 1st July 2022 – see page 4 for details.

MESSAGE FROM THE PRESIDENT

In welcoming everyone to the first meeting of 2022, Margaret outlined how the IN Group has changed over the years and although there have always been members supporting the group and willing to take up positions on the committee and assist in other ways, the group is currently looking for new volunteers to help with:



- General Meeting support
- Social Media updates
- Assist with support requests (phone, email & potentially hospital/rehab visits)

This small group provides immeasurable on-ground support to the GBS/CIDP community and over the years has raised many thousands of dollars for research into inflammatory neuropathies. We want to keep the group and the valuable support it gives strong and healthy.

If you would like to assist in any one of the above areas, please contact Margaret on +61 3 9802 5319

We apologise for the late despatch of this newsletter which has been quite beyond our control.



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MARCH SPEAKER – LAUREN MERAKIS



Margaret welcomed Nutritionist and Dietitian, Lauren Merakis to the meeting.

Ms Merakis has practised in various settings, from the various wards you'd find in a hospital, through to supporting government initiatives around healthy eating. Currently she works as a Product Developer at retail giant Coles Group.

NUTRITIONIST & DIETITIAN

First Ms Merakis explained the differences between a Nutritionist and a Dietitian. We learnt the two are different each requiring a different type of study focus.

To be a Nutritionist involves a three-year Bachelor degree, covering:

- science of food
- science of microbiology
- cooking and understanding the interactions of fat, carbohydrates and proteins

Then, which was the case for Lauren, a Masters of Dietetics was completed, which focuses on subjects such as:

- chemistry
- biochemistry
- looking at, a molecular level, how food interacts with the body

Lauren gave the analogy of a nutritionist being like a GP, they can help you with:

- general health promotion advice
- healthy eating

A dietitian will focus on more specific disease states and typically in a hospital context which can include:

- Type 1 & 2 diabetes
- Heart disease
- Cardio-vascular disease
- Weight management

Question from the audience: “Who looks after the Micro-biome, is that a dietitian?”

Lauren: Yes, a dietitian, but typically with even further specialist study. From a dietetics perspective it really takes a couple more years of study to be competent in undertaking a gut micro-biome test and to be able to read the results adequately. The gut-biome is a niche area of Dietetics but I expect it to become more prominent. There's a lot of research coming in at the moment and we're really beginning to understand so much more about the micro-biome and the gut-brain connection, about how the types of foods we eat affects our gut micro-biome and can in turn affect our mental health. I'll touch on a bit of this later but an example of research relates even to faecal transplants, the study involved transplanting the faeces of a slender mouse into an obese mouse, with the obese mouse subsequently developing a healthier BMI.



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PLACEMENTS AS PART OF STUDY

As part of the study programme, students take placements in the Food Service system such as: low security prisons, hospitals, community and clinical placement. Lauren served her placement in a hospital.

Hospital food can often be high sugar, high calorie.

High energy and high protein is very often what required. Not well post-surgery, loss of appetite, losing weight and muscle mass can affect hospital discharge. You often see sweets and desserts, but also sauces and gravies.

Question from the audience: I was surprised to see the hospital serving sausage rolls and party pies.

Lauren: Yes, if you think a typical teenager requires 2k calories a day, and as an example if they have burns to 80% of their body, which is quite severe, you'd double their intake to 4k calories. So to make that happen, especially with a younger patient, it's important for that to be achieved that the food is palatable.

Comment: You get a menu at St Vincents Private

Lauren: Yes some say it's better than at home, I don't tell their partner though!

Comment: Are you saying people often lose weight when they go into hospital? When I was first diagnosed with acute-onset CIDP in hospital, I went in around 84kg and at my lowest I dipped just below 70kg, I didn't understand it because I wasn't moving.

Lauren: Yes this is common. What people may not realise is they often lose muscle mass first. It'd be nice if was the fatty areas we didn't like but that's unfortunately what happens.

Prioritise your plate - start with custard, desserts and gravies, then perhaps your potatoes, then your meats, and finally have your veggies last. This is in a hospital setting and tailored to the individual, it's not the normal everyday recommendation but "enjoy it while you can".

Clinical placement

Looking at why have they come into hospital and what can we do to get them discharged on time. Lots of time in a neuro ward - traumatic brain injury, unconscious, semi, or slowly gaining consciousness. Looking at texture and so important to plan an anti-inflammatory diet to enable the best outcome for the patient.

If they couldn't eat they'd need to be fed through a tube that goes via the nose, or a peg which is tube fed through to stomach, we then advise on calorie and nutrition requirements. This is quite different and requires a very targeted investigative approach as they are either very tired or not conscious at all.



This type of placement can be quite challenging but at the same time very rewarding, seeing people from first entering the ward through to discharge in a much happier place.

The afternoon concluded with a presentation to Lauren.



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Renewal of Membership 01.07.2022 – 30.06.2023

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ITEM	EACH	PAYABLE
Annual Subscription (due 1 st July each year)	\$15	
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A Road to Recovery – A – Z	\$6	} out
Boy, Is this Guy Sick. Booklet	\$2	} of
Recipe Book	\$16	} Stock
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
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	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.

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