

INFORMATION

STICK WITH IT SLOW BUT SURE

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)
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**NEXT MEETING IS THE ANNUAL GENERAL MEETING
1.30PM SUNDAY, 18TH AUGUST AT THE BALWYN LIBRARY
WHITEHORSE ROAD, BALWYN
GUEST SPEAKER – NEUROLOGIST - ASSOC. PROF. RICHARD STARK
A small plate for afternoon tea would be appreciated.**

Our Winter get together this year was High Tea at the Lawrence Home with our special guest Assoc. Prof. Andrew Kornberg. His update is printed later in this newsletter. Thank you to all who attended and/or donated as together we raised \$760 for research. Special thanks to Margaret and Doug for opening their home and the committee members who prepared and donated the yummy morsels.

Notes from the February Meeting.

A big welcome to everyone. Thank you all for coming. I don't know if there are people who have travelled a distance, but Ken certainly has and thank you Ken for coming from Wangaratta. It is great to have you here. A special 'Hello' to Irma who we haven't seen for awhile so we are very happy for you to join us today....Irma: I'm very happy too....and also a warm welcome to our speaker today who is a Clinical Nutritionist and I think we are all going to go home and have to look at the larder aren't we. It is great to have you Lina and thank you for coming.

Treasurer's Report.

The finance report is really for the quarter January through March. During this time we have had total income of only \$275 because we are towards the end of our financial year. Of this \$25 was added to our Christmas Luncheon and \$100 was donated from craft sales. Again, thank you very much to Gwen McInness. The only expense for the quarter was \$122.11 towards newsletter costs.

I would like to remind all members (and I say this for the members not here today as well as those who get our newsletter via email), our financial year does end 30th June, so we start our new financial year and our new **subscriptions are due on July 1 for the year 2013/2014**. The committee has agreed that the subs. will continue to remain at \$15.

I received an email from CSL advising that a new user had registered at the Inflammatory Neuropathy Support Group Victoria's website and we thought this was rather strange and we didn't know if it was a scam, so I contacted Vicnet who are our service providers. They advised me that tech savvy people can put links onto our website. They use ours as a conduit to get people to get onto theirs. Vicnet gave me instructions on how we can prevent this from happening by going in as the administrator and doing things so I have changed it and now no-one can get into our website other than our own administrator which is me. We have locked it out and our website remains ours.

Peter Mc: You were talking about the website and I spoke to four people this afternoon who are here for the first time and asked them how they found out about our group. They all found it through the website.

Doug: That certainly makes it worthwhile to keep it up to date and maintained and we say welcome to those people. We also thank CSL for their ongoing support of our website.

General Business.

Our mobile library is here if anyone wants to borrow a book on CIDP/GBS.

The next gathering on June 30th will be an afternoon tea which is written up in the newsletter. I have put a sheet of paper on the table and if there is anyone who wants to come to the afternoon tea at our home, please put your name on the list. The cost is \$20 a head and it is going to be a **High Tea** so you get much more than a biscuit! Hopefully we get lots of names and we look forward to seeing those who can come. Assoc. Professor Andrew Kornberg will be joining us.

Gwen is going to speak regarding the trading table and also we have finally produced our **Recipe Book** which is on sale for **\$12**. It has easy recipes for those who find it hard to mix by hand.

Gwen: The trading table has scarves, hats and coat hangers, jewellery and things I make. We had the Knox Occupational Therapist around the other day and I showed her the can opener I had. She was wrapped, so I brought it along today with a whole lot of tin cans for you to try it out. You just pop it on and with a light touch it cuts the top off. I have photocopied some order forms and you can send them off. They are \$19 plus postage but if you get more than one the postage is cheaper so maybe you would like to order them together. So you are welcome to come and play.

Talk by Lina Capovilla

I am a **Clinical Nutritionist** so for those who don't know the difference between a nutritionist or a dietician, I work very similarly to a naturopath, so **we are very holistic in our approach**. We look at overall health and wellbeing.

I work with clients looking at their health and lifestyle but **primarily as a nutritionist my big focus is diet. Diet has a massive impact on our overall health and wellbeing but particularly in a condition like this either the Guillain-Barre` or the Chronic Inflammatory Demyelinating Poly/Peripheral Neuropathy. These are inflammatory conditions. There appears to be an auto-immune link, so those particular elements to these conditions means there is a lot we can do from our diet to help to reduce some of the complications and support the body in speeding healing.**

Who thinks they have a good idea of what a healthy diet might be? **Gwen: Lots of fruit and vegetables, meat, roughage, fibre things, occasionally chocolate, (her husband Peter puts in – wine)** Ah, a few anti-oxidants – my favourite thing. **Gwen: Yoghurt and milk.**

So really for the most part having a balanced diet is simple. A good portion of fruit and vegetables every day, particularly vegetables and there is a new initiative now where **we say 5 serves of vegetables, 2 serves of fruit.** It used to be different. We used to have much more fruit. The main reason for that is that **vegetables are just as nutritious as fruit but have far less sugar.** Sugar in moderate quantities is fine. It is when we have lots of sugar it is not our friend.

Water is very important. Absolutely, **water is imperative.** Having a balanced diet of good quality meats, fish, eggs, some dairy, depending on what is going on in the body and different complications which might be associated with the condition. Having **protein with every meal is very important and avoiding lots of sugary things.** We know they are the bright, colourful **biscuits and cakes** – all those yummy things that are so attractive to us all. In moderation they are okay but if we are having a lot of them or they form the basis of our diet, they **are very inflammatory.** So if you are experiencing, especially **with the CIDP, constant consumption of these high GI products, they are going to create more inflammation in the body.** It makes it much harder for the body to repair itself. We want to support the body the best we can. Good quality grains, whole grains ideally, what we call low GI.

Does everyone know what GI means? **Len: Glycemic Index.** They are food which turn into sugar very quickly, so sugar would be one of those and white bread, white pasta, white rice, they turn into sugar really quickly in the body. Our diet as Westerners is predominantly based on those foods, especially with my Italian background. What it means is we have something to eat, our blood sugar goes through the roof, we are running

around with all this energy then suddenly we get the afternoon lull. Does anyone get that? Where we are craving something sweet because we have had all this sugar and suddenly it is all gone. We always reach for those sugary things to give us a bit of a pep up or caffeine.

Once again, with these conditions, maintaining your energy as much as possible through the day is paramount for your overall health and wellbeing in general but definitely for recovery. **Low GI foods turn into sugar much more slowly so they give us a slow sustained release of energy which is really important to help us keep going all day** – like the little Bunny which kept going and going, your low GI foods are much better. If you think **whole grains, they are the best examples** of that.

Your nutritional needs are at their peak because your body is going through sustained chronic inflammation. If you think of inflammation as a big scratch on your arm and if it is really red and sore and if you put lemon juice on it you know how really sore that would get. We really don't want to be doing that; we want to be soothing it as much as possible. **That is what good nutrition is essentially and this is how it can help us in recovery and in the long term.**

Although nutrition is my main focus another is lifestyle. **Stress.** Who can tell me about stress? **Melva: One of the five things our members say may have caused their condition, is stress. Irma: In my case it is.**

More and more **research is showing that stress is actually under rated.** We don't realize how much of an **impact it has on our health, particularly with the onset or the flare ups of conditions like either Guillain-Barre` or CIDP.** While there may be several factors that have contributed to the onset of a condition like this, **stress is a major, major , factor.** When you have a condition it is stressful in itself so often the stress levels can be increased but **general external stresses can definitely impact you and make the condition more chronic.** So **learning how to manage stress is really, really important.**

It might be doing some things you really enjoy like going for a little walk, having a cup of tea with friends, or having a swim if your mobility allows it, or different little things, like listening to some nice relaxing music, whatever it may be, managing stress is really important and if stress is a major factor for you and you feel you really struggle with stress, then I highly recommend that you get some support from an expert in that area who can educate you on how to deal with stress. That is definitely a major factor. The other one is **sleep.**

Does anyone have an issue with sleep? Yes. Did you have issues before the onset of the condition? So some of you are saying "yes" and some of you are saying "no". For those of you who were experiencing issues with sleep before the onset of the condition, **sleep, like stress, can definitely make a big impact on our body's ability to restore itself** in general because of course when we go to bed at night our body is busily repairing all the damage that happened to it over the day and when we are not sleeping well of course the body's ability to repair itself is impaired. When we are not getting enough sleep, often times our ability to cope with stress becomes worse.

Everyone knows that if they have had a sleepless night and they get up in the morning and something trivial happens and you snap because our ability to cope with stress is so much less. We have all experienced it I'm sure and the worlds so crazy and busy and often times things get overlooked because we are busy soldiering on and getting on with our day. These two factors, **stress and sleep in particular, aside from diet, are really important. They support quality of life across the board, but particularly when you have a condition such as either of these, they really make a big difference in making your life far more comfortable and helping to minimize the indications and duration of the condition.**

So who finds that in the middle of the day or in the afternoon or maybe even first thing in the morning they have a nice cuppa? If you get a slump in the afternoon do you think "Oh I could really do with a nice cuppa or a bit of chocolate". Once again a lot of us were brought up on a nice tea or coffee. With my Mediterranean background definitely we were almost bought up on coffee, but **caffeinated drinks and food are really not great for us, particularly when we are experiencing these types of conditions because what they do is they rev up our body.** Without getting too technical and losing you along the way, **with these conditions there is an association with an auto-immune component** and you would be familiar with that. What stimulants do, particularly things like coffee, cola, chocolate, tea (tea does have caffeine in it) it helps to rev up the body even more.

Anyone familiar with the Adrenal gland? The Adrenal glands secrete something called adrenalin. Millions of years ago when we were all roaming the earth and we saw a big bear and we either ran or we fought the bear and our adrenalin kicks in and gives us super human strength and we can fight the bear and then we calm down. **Len: Fight or Flight.** Yes, absolutely. What happens in this day and age **because of stress and because we don't sleep very well, a lot of the time we don't have time to eat very well. As we are always on the go go go, our bodies constantly secrete too much adrenalin or another hormone which is very similar called cortisol and when we have caffeine, more caffeine to keep us going, it secretes more. There is definitely an association with revving up the body and the onset of an auto immune condition. So in these conditions caffeine is not really our friend.**

Now, the ideal is not to let it past your lips but the reality is that a lot of us enjoy it. So I'd always say – **in moderation. One or to cups a day** but I would definitely **avoid things like soft drinks** because they are full of sugar, full of nasties that really are not ideal, but enjoy a cup of tea or coffee or a little bit of chocolate every now and then, it is okay but I wouldn't have a lot of it because once again it is going to **drive the inflammation in the body which perpetuates the condition. Does that make sense?**

Ken: So what's the substitute for tea and coffee? Alcohol definitely comes into a similar realm and once again in moderation but it depends on how much you want to look after yourself. If you think "That's it. I'm not happy with the way I'm feeling and **I want to do everything in my power**" I'd say **no coffee, no tea, no alcohol. If you think "I still need my little indulgences because without those things really what's the point" then a good alternative – herbal tea. Herbal teas like Camomile - beautiful and relaxing things like Peppermint.** There are lots of beautiful herbal teas. **Peter: What about Green Tea? Green Tea is good. Lots of anti-oxidants but it does have some caffeine in it.** If you were having a couple of cups a day, no problem, but I wouldn't have them late at night, especially if you are sensitive to caffeine and it interferes with your sleep, but **green tea or herbal tea are good.** Then have your cup of tea or coffee but just not 10 a day. **Gwen: Warm milk I find good.** Yes, warm milk can be a nice substitute.

Now something else to be mindful about **caffeinated drinks and alcohol** is that it **actually depletes the body of essential nutrients.** Your body is busily trying to fight this condition, trying to get you back on an even keel but while you are having these caffeine drinks, alcohol and/or chocolate, the more **they are stripping your body of the essential nutrients that you really need to maintain energy, to maintain mood, to help you deal with stress and to sleep well. To help your digestion to function, to help your nerves particularly to function properly and the myelin sheath that lines the nerve cells. In these conditions the myelin sheath is affected,** so I'm sure I don't have to explain it to you because you are all very familiar with that, **so when you are drinking these things they are stripping the body of the essential nutrients necessary for myelin sheath production and nerve cell conduction.**

Costas: Is decaf coffee alright? Decaf coffee has much less. Decaf is a better alternative. **If you are having something like decaf I would always recommend the Swiss water method extraction, which is a much more natural type of process to decaffeinate coffee than the normal chemical based.** The normal chemical based just uses lots of chemicals and **we don't want to be putting more chemicals into the body.** Your body is having a hard enough time to look after itself, so **decaf,** not so bad but once again **in moderation.**

Peter: What about dark chocolate? Once again, have it **in moderation.** Dark chocolate is good because it has **lots of anti-oxidants,** so similar to the Green Tea, **but it is high in caffeine.** I don't know if any of you have had dark chocolate and thought "Oh that's nice" then suddenly thought "Wow, I'm feeling a bit buzzy." Has anyone felt that? Well I have a condition that means my body runs at a million miles an hour. My volume is turned up a bit too high and when I was studying I would have a bit of dark chocolate as a treat and then my heart would be pounding and I'd think what's going on? It was like I'd had a triple short black. It was the caffeine in the chocolate. The darker the chocolate (you know 85%), the higher percentage of cocoa, therefore the higher the caffeine, so once again, **moderation.**

Who finds their energy fluctuates through the day? Yes. Do you find that your mood follows that too? If you have energy you feel better so you might go and do things out in the garden but when you feel depleted of energy you feel flat and just can't bring yourself to do anything because you have no energy. So those different types of things like caffeine, high sugar foods, highly refined foods, **high GI foods,** like all those yummy cakes with all the lovely icings and colours these are the foods that **deplete our energy.** So if we are having breaky, lunch and dinner and we are having these high GI foods, we get that nice little spike, then we crash. So we have more, get that nice little spike and then we crash again. Once again our bodies are up and down all day and in the long term, yes we might be able to cope, living with all those sugar hits during the day, but **in the long term**

it affects our body functioning and it can lead to things like Diabetes and whatnot. We definitely don't want to complicate the situation. We already have enough to contend with the GBS and the CIDP.

What we can do is make sure we **eat consistently during the day**. So who has three square meals a day, breaky, lunch and dinner? Great we are all taught **you must have your breaky. It is very important. Len: We steam all our vegetables - have done for years. Yes, three square meals are good, but better is having a few good quality snacks in between. Once again that is helping to moderate our energy** and when we are having smaller meals rather than a big dinner – does anyone have a big dinner – no, so you are model students. I was brought up – A big dinner, breakfast, lunch, but always a big dinner. **Irma: Since I'm alone, my main meal if I can is at midday, because I didn't feel good at night with a full stomach.** Fantastic. Very good. **Now that's what we want to do. Have smaller meals more frequently.** We are not putting so much pressure on our digestive system having this big meal that our poor stomach says, oh my god we have to try and break it down, so what we are doing is having **the energy release far more slowly and that also helps our mood.** Okay. When we are having energy released slowly into our body that maintains a more even mood. So **small meals, more frequently, is really really good.**

Who knows what protein is? **Peter: Baked beans. Others: Meat, fish, eggs, tuna, lentils, tofu, nuts** perfect. **So protein is very important to the body but particular in these conditions where the muscles waste away.** They can easily waste away, **particularly if there is some paralysis.** It is easy for people to not have protein in their diet as it is much harder to digest and often we will have the rice or the pasta or the toast because it is quick and easy to make, quick and easy to eat and quick and easy to digest. But **protein is absolutely essential,** particularly in these conditions **because we need it to help our muscles.** Of course **movement is imperative,** but protein is really important. All those proteins you mentioned are ideal. **Member: I can't have eggs because they are high in cholesterol.**

Like fashion there are different styles that come and go. In science, in medicine, in nutrition with diet we find over the years we have been taught lots of things. **Eggs are bad.** They raise your cholesterol, then more research comes out, more people investigate it and we discover that that **is actually a fallacy. Eggs don't actually raise cholesterol.** If cholesterol is an issue I would always say – **moderation,** but the most important thing is **balance and variety. Lean meats, good quality fish,** - we are lucky in Australia because we have fantastic produce and it is good to **have them regularly and ideally at every meal** during the day, even your little snack, so you could have some nuts and some fruit, some Hommos (if people like it), some ricotta and some vegies and those sorts of things.

Who's familiar with Inflammation? **Len: We all are.**

This is an inflammatory condition through and through and **inflammation is perpetuated by lots of different foods. The western diet is a highly inflammatory diet. It is not so great. But things like I've mentioned, high sugar, lots of alcohol, coffee, caffeine are all pro inflammatory, create even more inflammation. Think most things in a box often will have lots of additives and flavours and sugars and whatnot which all create more inflammation. So the closer we can have food to nature, the better. So the simpler food we can have the better. Bananas and apples are perfect. They come in their own packaging. An orange, brilliant. Carrots, celery – you can eat them as is. All of these foods are fantastic because they are much closer to nature and this is what our body was originally designed to eat.**

Len: It's antibodies in our blood that's causing our inflammation. In having an anti inflammatory diet it definitely helps to reduce the inflammation so therefore the activities of those antibodies. All auto- immune conditions have the presence of some sort of anti bodies to what ever it might be. It might be a specific organ or **in this case it is nerves and nerve conduction.** So creating more inflammation, **having more of those pro inflammatory foods will just give those anti bodies a little bit more ammunition** if you like, help to keep them nice and stimulated, **but we don't want to do that, we want to send them to sleep.** We want to send them off to bed. We don't want them around.

Does anyone know about **Omega 3 and Omega 6.** Yes. What are they in? Fish oil, fish, nuts, krill. Yes they are all different types of Omega 3's. Particularly Omega 6's are present in lots of different foods, lots of animal products. **Omega 3 is highly anti inflammatory and once again we have talked about bringing down inflammation, so giving good servings of fish (if you are not a big fish fan then fish oil) is really important in helping to support reducing inflammation but also very important for the nerves and nerve conduction.**

There are particular fish which are highly oily – **things like Salmon. Sardines are one of the best.**

Costas: They don't taste good. They are not one of my favourites but **from a nutritional perspective they are fantastic.** If you eat the bones, if you cook them well, the bones get really soft and you get the calcium from the bones as well. They are rich in Omega3's and because they are little baby fish they don't have many toxins. The bigger the fish, the more small fish they eat, the higher the possibility of mercury. Fresh sardines are best but if you eat tinned I would definitely look for something in olive oil. If you haven't been eating sardines and you introduce them now and then, you are doing better than not having them at all.

Peter: Olive oil, is it better for you than margarine or butter? They say that it is 99% fat free. Yes they say that about lots of things but they don't tell you how much sugar there is in things. Marketing is very misleading. They will tell you one thing, but they don't tell you the full picture.

Margarine – **I would never recommend margarine.** The closer to nature the better. The less adulteration, the less manipulation the better. The body is not designed to break down these foods that are made in a lab. **Our bodies haven't changed in millions of years, but our diet in the last 100 years is totally, radically different to the way it was even 40 or 50 years ago.** There would be a lot of foods you would have at home that didn't exist then. The body hasn't caught up in being able to break down this food or to know what to do with it, so the closest to nature, the better. So my point on that would be that I would sooner say **butter or avocado.** You can certainly buy unsalted butter but in moderation salt is not that bad. If you are having **a little butter with salt in it with your food as opposed to having processed foods which is full of salt then that balances out. And there is always the unsalted option.**

Does anyone have any food allergies or food sensitivities? **Melva: Yes. Fructose to wheat.** That's a nuisance – me too. Anything else? **Member: Dairy.** That's a big one. Very common. Lactose, dairy.

There is a **big link between food sensitivities and the body not being able to break down different foods and the onset of inflammation, the onset of anti bodies and the onset of auto immune conditions.** When you do have a diagnosis of a particular food sensitivity or even if you suspect something doesn't quite agree with you as every time you have it you don't feel quite right, I'd definitely avoid it in your diet altogether. **Once again, it is pro-inflammatory, creating more inflammation in the body.** Think of that red raw skin. It is like pouring salt on a wound. It is harder for your body to cope with the condition that you have got and then when you are eating normal food it means that you are not digesting it properly and then all the good nutrients that you should be getting you are not going to absorb.

Food sensitivities and allergies are very, very, important when it comes to auto immune conditions and these two conditions in particular, so if you do suspect that you do have any sensitivities, then I would definitely recommend having them checked out or definitely cut out those foods in your diet.

Len: Do we have any Celiac in the group? You usually find a few people with Celiacs. You have brought up a good point. **Often in auto immune conditions the body might develop one sensitivity, then over time, another might come along.** It is because we have those auto anti bodies. They are attacking our body. **Our immune system gets confused. It doesn't quite know when a foreign pathogen has come into the body – like a cold or a virus or if it is the bodies own self.** Often times, particularly in the longer standing CIDP but also in the GBS that is auto immune driven from the research I've seen, having all these pro inflammatory things, being stressed, not sleeping, would increase the chance of developing a secondary auto immune condition.

We want to look after the body ourselves as much as we can.

The most important thing I want to impart to you is that a good balanced healthy diet is the best way to go. If we think about what we were taught probably by mum when we were kids, you know mum and grandma and grandad and dad they were pretty wise. **A lot of those old remedies I was taught and no doubt everyone was taught are things that we are taught as practitioners in this day and age and we are seeing more and more research actually validating it.** Isn't that nice? Camomile tea when you have an upset tummy – fantastic. **Definitely having breakfast, eating regularly, having good quality proteins, minimizing sugary foods, minimizing caffeine, have a good amount of water, lots of coloured fruits and vegetables because they are full of all the anti oxidants and have lots of vitamins.** Eating in season is also a very good point. **Nature gives us different fruits and vegetables that have all the different nutrients that are necessary –**

like now, citrus and those kinds of fruits are coming into season, wow they are packed with vitamin C. What does vitamin C do? It helps our immune system in Winter, perfect, so eating things in accordance with nature is always ideal.

I hope I've been able to give you little bits of information that help to give you a bit more knowledge about how you can eat well and support your condition.

Does anyone have any questions? Is there anything else you would like to ask?

Question: Canola oil and oils in general. Can you say a bit more about that?

Canola predominantly and different products, corn, soy, they are highly genetically modified. Are you all familiar with genetically modified foods? Once again, in a laboratory they have played around with some of the DNA from different plants and animals, crossed them together to give these disease resistant, high yielding seeds and now we find that the market has been flooded with these products that are all genetically modified. The reality is in the long term. In the short term, fantastic, it looks great. We are getting much more food. We are feeding the world. It is much cheaper to produce. We don't have to worry about so many pests but in the long term we don't know what effect this will have on our body. They have only been around about 10 to 20 years, probably not even 20 years. We don't know the effect. The body is not designed to break down things that don't come from nature. It just doesn't know how.

Irma: Pro active margarine is highly recommended by the Heart Foundation. I use it to lower cholesterol and it does. It is very disturbing if you think it's no good.

It is a mine field out there in terms of information. It is hard. The best thing I can say, **when it comes to oils the best kind of oils are olive oil cold pressed for condiments. Don't use it for cooking because it is an unstable oil and when we heat it we actually change the structure. Rice bran oil which is available in super markets is great for cooking. Canola oil is not so great because of that GM component. Coconut oil is a great oil to cook with. It is a hard saturated fat and we have been taught that saturated fats are bad, this is another thing that science has taught us and it has changed over the years.**

With regard to things like the margarines or the butters, you just need to be discerning in terms of what works for you. My recommendation is **always as close to nature as possible**. If you have found that it has worked for you, then I'd go with that for you.

Member: You walk into a pharmacy today and they are trying to sell you lots of different vitamins, fish oils, krill oils, and you could spend a thousand dollars easily for something that helps you or nothing that helps you. Why bother taking any of those things if my doctor is not prescribing them so isn't it just a marketing thing.

Yes and no. The same could be said for pharmaceutical drugs. **Except that my doctor is prescribing them and when I take them I feel better. But I spent \$50 on a vitamin pill and feel exactly the same.**

A couple of things to consider; once again it is about **being discerning, making an informed decision and doing what's right for you, because what's right for this person is not right for the next**. I can't speak on pharmaceuticals as that is not my expertise but there are **lots of vitamins and fish oils that are fantastic**. There are lots that aren't. The challenge is with the products you buy in the supermarket they are usually quite low dose, they are usually not the best quality in the context of, they are not often the form that is most easily used by the body, but they are readily available and yes there are a lot of companies out there that make lots of different products and are making money. Like I said, like pharmaceutical drugs there are lots of different companies that are making lots of different products and are making money. That's what makes the world go round at the end of the day.

When it comes to supplements, I would recommend speaking to someone who is a professional or an expert in that area and asking them, or if they think anything is necessary for you. Vitamins and minerals, fish oils can interfere with pharmaceutical medications and they can impact your health adversely, particularly if you have an existing condition. That's why some things you buy are quite low dose. It's like Panadol. We can buy Panadol outside the chemist but we can't buy Mersyndol which is a really strong pain killer, because the possibility of us doing damage to ourselves by taking Mersyndol without being

taught how to take it are far higher than taking Panadol which is reasonably low dose and easy to understand. So the same applies to vitamins and minerals.

I suggest to clients to **speak to someone who knows**. If you think there is a particular nutrient which will help you **go to a health food shop as a minimum. If you really want detailed information go to see a nutritionist, go and see a naturopath, go and see someone who has expertise in that area** as most doctors are not trained about nutrients, that is not part of their training. Just like us, we have a minimum part about pharmaceutical drugs and the potential interactions with what we do, so we are trained on that, but we are not trained about pharmaceutical drugs like doctors are.

Peter Mc: Can I bring the subject back to sugar. I take sugar-free mints. They are sweetened by something. Is that something less dangerous than sugar? It depends what they are sweetened by. These are again **artificial sweeteners created in a laboratory** and more and more **research is showing that some of them are implicated in a whole range of conditions**. They might not be a causative factor, but they do contribute, so once again **with auto immune conditions, I would avoid anything with an artificial sweetener**. I would sooner go with a mint with natural sugar than with a sugar free mint. Because it has those chemicals it is questionable as to how it reacts in the body. I say again, everything in moderation.

Gwen: I would like to recommend a book I have which is called Food Remedies written by Dr. Warwick Carter.

Fantastic, that sounds like a great book. If you have that interest in learning more about different foods, finding books like that is very good.

Nature, diet, looking after yourself is always the best way to start. That's the foundation. Build up from there. Sometimes there is a need for drugs or maybe supplements but if you don't have the foundation right you can take as many drugs and supplements as you want but you are still not fixing the actual cause.

Peter: I get cramps because of CIDP so my doctor said to take Magnesium in the morning. Also CoQ10 which helps your muscles. She sounds like a very good doctor.

Salt in moderation. The best types of salt are Celtic Sea Salt, Himalayan Salt - **the closest to nature**. Most salt has fillers to make it not stick together and the Iodine is again made in the lab. The biggest concern around salt is around the pre packaged, pre formulated products that have lots of salt, lots of sugar, lots of flavour enhancers so they taste nice. Whereas when you are cooking at home, if you add a little salt to your cooking, it is not a major issue.

Irma: Thank you very much Lina for coming here today. You are very welcome.

AGENDA ANNUAL GENERAL MEETING

The Inflammatory Neuropathy Support Group of Victoria, Incorporated
To be held at the Balwyn Library Meeting Room, 366 Whitehorse Road, Balwyn on

Sunday, 18th August, 2013 at 1.30 p.m.

Confirmation of Minutes of 2012 AGM.

Reports from President and Treasurer

Election of Officers and Members of Committee.

Any special business of which 21 days notice has been given.

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

Talk by Andrew Kornberg at Winter get together.

Thank you for inviting me here to your home and as always I make one appearance at least once a year to The IN Group. The first thing I should say is **with the passing of James Gerrand** it has been a big thing for me because **James** was in fact the person who **conscripted me and supported me**, with **Betty**, early on. I think of him as a **very important person to The IN Group and also support for people who have had GBS and CIDP and his legacy will always be remembered by us.**

The IN Group is in great hands with Margaret and the whole group here, so thank you.

I thought I would talk about **the five things that have happened in literature and research over the past year.**

Everyone here knows that IVIG is a very scarce commodity and supply of IVIG has not been hard to get because there has been both local CSL product and imported product, but I know by being on a number of committees in Canberra, **that governments are looking at the costs of providing this sort of medication and looking at better ways of administering it, etc.** The actual budget is about \$250 million. That's what it costs for the supply of IVIG and that is a significant cost to the government so **the government is trying to cut the use of it, trying to review the situation.** There have been papers where a **number of studies** in Europe, the United States and Australia have looked at **the best way to manage the supply.**

Many of you may be going in to **have your IVIG** once a month, once every 6 weeks; it varies from person to person. More often than not it is **the same dose** month after month, year after year and **it is one of the things we have to do better and understand what the optimal dose is for an individual.**

With GBS which is acute, you get treated and it goes away. It is different to CIDP. With CIDP everyone is made up in a different way. **Some people need more IVIG, others less; some people need it more frequently, some less frequently but it is really important for Doctors to look at what is the best treatment for you.**

One of the studies which has been done and a very important one, is **a simple measure to see if you are getting benefit and whether you need more and that is by using hand grip on a meter to actually measure your strength to make sure that you are getting the adequate dose.** That is really the aim. That may be **something that your neurologist will be starting to do to gauge whether you need more or less or less frequently, etc.** **What you have to do in CIDP is to make sure that your strength stays as good as it could be and not have these huge fluctuations. If you do have fluctuations, what that really means is you are not getting it frequently enough. Doctors will be looking at this hopefully over the next year because of the scarce supply.**

The other thing is we know about IVIG being one of the most important treatments for patients with Guillain-Barre' and CIDP. There may be a variety of people who are on other medications like Imuran, Cyclosporine and others. Now there has been a **Cochrane Review** which is a review based on **evidence** where they look at **every study ever published to see which drugs are the best.** It has just been published in the last few months, looking at **what drugs are best for patients with CIDP and the good thing is that we have got it right. IVIG, steroids and plasma exchange are the best and then there is a second tier of medications that in an individual patient may have some benefit.**

Again, it gets back to you **talking to your doctors** and saying **I am doing well or I am not doing well so that medications can be adjusted.**

What has gone into all this is to understanding the mechanisms as to why this happens to people, then **using the right medications to make you as good as you can be.**

The third important thing was: If I asked you how **common is CIDP** you would say "pretty common, look around, we are here", but governments need to know how common conditions are because governments have budgets and other things like that and if they see that something is really expensive and there are lots and lots of people affected, they get worried.

There was a study in the UK which now has identified what is the prevalence, i.e.: what is the number of people per 100,000 who have these conditions. GBS is pretty straight forward – it is about twice as common as brain

tumours – about 1 in 50,000 people would be affected, but it is a once off, it goes away, and that's it. In CIDP and other conditions it tends to be a chronic problem. So the actual prevalence is that males are more affected than females with CIDP which is clear from the populations study and there are approximately **3 per 100,000 people who are affected by CIDP.**

So in Melbourne's 4 million people, that's **120 people in Melbourne in one point in time.** That's how many people you **would expect to be affected.** **Multi Focal Motor Neuropathy is about .5 people** and we know that it is much less common for us to actually treat. There are a few other neuropathies which is about 1 to 100,000 and in the context of **all nerve and muscle problems, that is 1 in 1000 in the population,** i.e. muscle problems, inherited problems, all those things, but for **CIDP which is treatable** (many of the others are not) we are looking at **3 in 100,000.** In the scheme of things **it is relatively common.**

The next thing is **antibodies.** What we know is **when we measure different antibodies from different people we find antibodies against a whole lot of different things in nerves.** That can be helpful to identify what you may have, but it may also be helpful **to work out what is the best treatment.** If you have **an antibody with IgG a better treatment is if you use IVIG or plasma exchange.** In comparison, if you have **IgM antibodies we tend to have to use different sorts of medicines.**

We have **never been able to identify one cause for CIDP or MMN.** We don't know. We don't know why it happens. We know there is something about the individual, plus something in the environment that together makes this condition occur. **CIDP is not one condition,** it is not one disorder, it is **probably a whole basket of different disorders** that when we measure **the nerve tests looks the same, but they are all different.**

There was a study and it looks like there are some **targets in myelin.** Myelin is like - if you look at an onion which has the onion rings in it, that is **myelin** and that is what is the **insulation around the nerves which help the nerves conduct, etc.** What we now know, in parts of **the myelin which is on the outside, it looks like these antibodies are targeting that** and affecting the myelin and therefore **causing a problem in the nerve** as a secondary effect. **So if we can define and begin to understand a little more about what it is affecting in the myelin that may lead to other treatments.**

We say that each year and there are new treatments becoming available. I don't know if anyone has had **Rituximab,** but these are the sort of medications **targeting these antibodies.** There is still **hope that one day** we will be able to work out maybe three or five different targets which will mean **something can actually be done early to prevent it from getting any worse.**

The last thing is **subcutaneous IVIG.** Most people are getting IVIG through the vein. The big thing at the moment is **converting people from IVIG to IVIG underneath the skin.** The doses we have to use in an individual are really high and if you have to do it underneath the skin and if you put the IVIG in there you have this huge bubble and it can be painful. What is happening now is the **concentration of IVIG is much more.** Intragam P is 6%; others are 5%, others are 10%, so now there are solutions being **developed to be 20% which is 20grams per 100 ml of IVIG.** **Those concentrations will allow you to have that underneath your skin.**

The beauty of it is you don't have to come to hospital. On the other hand coming to hospital is not so bad, but for some people they will be able **to infuse the IVIG at home, a little bit every week.** That's where things are going at the moment and that is **a big thing for CIDP.**

Once upon a time it was not possible. You would have to be infusing every day and lots of people would have lots of complications, but as it is becoming more concentrated, it is now a feasible proposition for some patients with CIDP. **That is something over the next two years which will become more used in Australia than it is overseas.**

In CIDP it is not just the actual dose as we don't know whether you need a big dose or a little dose as no-one really knows, but **the important thing is that you have to keep looking at trying to get the dose right in each individual.** If you think it is a cook book (which a lot of people do), **1g per kg every 6 weeks, that is not the way it works.** Every person is a bit different so **your neurologist needs to find out whether you may need a smaller dose but more frequently or less frequently,** but that's what you have to **trial and you will know when the dose is right because you live with it everyday.**

Your neurologist also has to **review the diagnosis**. Recently I saw someone from interstate for a second opinion. That person had been on IVIG for 5 years, with monthly infusions. Guess what, they didn't have CIDP.

Any questions: **Tom:** My neurologist tried giving me my dose more often but it made no difference so I'm back to my normal timeframe.

Maria: My little boy who is 6 had a relapse a month ago. At the hospital he was given one dose and following that he had physio and measured 24. At home I could see he was not right. I took him back and they gave him the double dose and he measured 32 or 34 which was quite a significant amount that he was stronger. My question is: I know you don't like to give a lot to such a little person but **maybe he does need two bottles of IVIG**.

Andrew: One of the things we do at the Children's is the measurements. In our nerve and muscle clinic all our kids (whether they have CIDP or muscular dystrophy) get what we call the North Star test and what we need to do is **actually measure responses so we get the right dose**.

John: I'm more wobbly and so is another member the same age. Do we need to adjust our dose or is it just old age? **Andrew:** The problem may be that **everyone is a little bit more wobbly because there hasn't been enough medicine and therefore you have had effects on the nerves**. What we have to do is **prevent those secondary effects on the nerves**, because once you lose nerves **they grow back at 1 mm per day, that's a long time**. That is the importance of that measurement, because **if you measure you can adjust the doses in accordance with the measurements**.

Anyone who has trained under me that's what we harp on about, because it is easier to just write the same dose forever, but **you have to review things**.

Tom: If they miss the vein giving IVIG it is very painful. **Andrew:** The **subcutaneous** will not be at the back of the hand where there is not much fat. The subcutaneous is in areas like your tummy or **where there is a little more tissue** where it doesn't hurt. Because it is **infused at such a slow rate you don't even feel it**.

Some people really are wanting to have that, others not. It will be **an individual decision**. **The government does not fund IVIG for it to be given subcutaneously for CIDP** but the overseas experience is that probably **50% of people with CIDP could have subcutaneous** if they wanted it.

Peter: We were told when Gwen was diagnosed that it was chronic, progressive, degenerative and incurable, but Intragam could slow the progress of the condition. How strong is the body of evidence for that, that Intragam does actually slow the progress of the condition?

Len: That's similar to my question. There are three measurements. There are antibodies, nerve conduction tests and nerve biopsy. They are the three things that define that you have CIDP. Now the count of antibodies seem to stay the same, why doesn't that decrease if you are getting cured, or is there anybody that has that antibody and that antibody has gone which proves they are cured? You know what I'm saying? A measurement of some curative because **my motor nerves are getting better in the nerve conduction test but the antibody level is still the same so you have nothing to measure except how your feel**.

Andrew: **But that's probably the most important thing**. Once you have had the diagnosis **the most important thing is how you feel**. If we did your nerve tests weekly and they were getting better but you felt worse, what should we be treating? **We should be treating you, not your nerve conduction. Your functional status is probably the most important**. Maria with your son where **his North Star goes from 24 to 34 which is virtually normal and you notice his improved strength, then that is the most important thing**.

The antibodies are very interesting. They are just something that we know could be related. Now IVIG blocks those antibodies affecting your nerves and therefore you feel better but it does not change the antibody levels because that's the auto immune, that's what you are producing, that's constant, so the only way to change the antibody levels is to use medicines that work on those cells that produce the antibodies, like Rituximab or other things like that.

Having IVIG, your antibodies will be the same. Your nerve tests may change because we know that can improve nerve conductions, but the most important thing is the functional measure, what you are doing. Now if you were on Rituximab, a medicine that drops antibodies, those antibodies would be really important to measure. What we would expect is for it to go down. IVIG, how you feel and how you are doing is the most important.

John: Are children getting this more often than adults? **Andrew:** CIDP is much more common in adults. We are talking about over a 10 year period seeing 15 to 20 kids and the Children's Hospital looks after one million kids. It is much less common, but we also know now that these auto immune conditions, whether it be CIDP, MS, Type 1 Diabetes, have gone up expeditiously over the last 20 years. Why that has happened, there is a whole lot of things, environment, vitamin D, which are really interesting, maybe we should be doing something different. We need to understand why this is triggered.

The last point I want to make is **CIDP is not curable at this stage**. But insulin diabetes is not curable either. There are lots of things in our lives which **are not curable but are manageable**. It really is so important, **that your doctors use the right medicines** and we have evidence of that; **look for the right causes**, we have evidence for that and **give appropriate doses**. We have to **get that right and make sure that you are not being given medicine if it is not helping**. That's the message I give to all the young ones coming through and training with us that we have always got to make sure we are not making some harm but we are doing good.

Melva: My husband who feels like he is cured then is not really? **Andrew:** He **may be cured if he is staying stable off treatment**.

Doug: Andrew we are very fortunate to have someone like yourself who is taking our problems under your wing and looking at them and I know everyone here does certainly appreciate the work you put in. Thanks for that update and if we could just say thank you to Andrew...applause..and as a show of some of our appreciation I would like to once again hand to Andrew a cheque for \$8,000 towards his work in helping us.

Andrew: Again, our department, the hospital have been supported for many years by The IN Group and all this money goes to great things, whether in the laboratory, a review of understand how these conditions occur, training in young neurologists like Val Tay, this actual money helps us to train them so that you have another generation of neurologists who are going to make a difference to everyone. Thank you.

Support: The following people are some who have received support over recent months: Helen, Tracey, Graeme, Deb, Jeannette, Robert, Keith and Phil.

We thank Mary McAlister from the GBS Association of NSW for her continued assistance in passing on names of Victorian patients whose initial contact is with them. Also the GBS/CIDP Foundation International www.gbs-cidp.org and GBS Support Group www.gbs.org.uk.

Thank you to members who have visited patients in hospitals.

Information forwarded to physiotherapists and occupational therapists was distributed to their peers. Thank you.

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INFORMATION

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)
Postal Address for Newsletter only: 44 Mavis Ave., Beaconsfield, 3807. Telephone: 03 9707 3278

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 1/7/13 to 30/6/14.

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Thank you. Please forward this form along with your payment to:
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**THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA, INC.
NOMINATION FORM**

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

Nomination Form - Committee

Position: Nominee:

Nominated by: Seconded by:

Accepted by: Date:

Signature of Nominee: Date:

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.

Member **Dan Smith** wears ankle-foot orthosis (AFO's) which he now purchases from Florida. He wants to help other members who use them. Part of his email reads:

These 'Ossur' brand AFOs I got from The Brace Shop in Florida are exactly the same as the earlier ones I'd bought locally for about \$250 each, so I'm inclined to think those from The Brace Shop are the same product. For example:

- they weigh the same;
- they look exactly the same;
- the adhesive-backed padding strip inside the top rear section looks exactly the same;
- their thickness at various points I chose to measure was exactly the same;
- their flexibility appears to be exactly the same;
- they are just as easy to trim with scissors or shears as the ones I bought locally;
- apparently, they're made in Iceland, which is where I was told the ones I bought locally were sourced.

I'm using the first of the two pairs I bought from The Brace Shop – having learned (by experience!) how best to look after them, so far they've performed faultlessly and show no signs of developing cracks (although it's quite obvious that they have been used a lot).

Beneath the large triangular 'hole' there's a smaller one, with its base over the heel end of the sole of this AFO. This smaller 'hole' allows the wearer's heel to project through, which means that this type of AFO takes up virtually none of the length of the footwear. The sole of the AFO is thin enough to be easy to trim to shoe size with a decent pair of scissors.

A few notes that you might find useful. I went onto the website I gave you after we spoke and confirmed that the braces I bought are still available at a much lesser price than here in Australia. They're **about \$US50.00 each and they come in at least two sizes.** You certainly don't have to consider trimming the leg sections, but the sole sections are easy to trim with good scissors or shears, so you simply trim them as necessary to fit your feet and footwear. Believe me, **they'll make a big difference to how easily you can walk and they'll largely overcome the risks of tripping and stumbling and help you regain a normal gait when walking.** They have a 'Velcro' strap that wraps across your shin. **To eliminate the nuisance of chafing on my shins, I glued thin strips of soft polyurethane foam ('Clarkfoam') to the inside of these straps where they contact my shins – works brilliantly!**

Below, I've set out the steps I took on Tuesday afternoon on www.thebraceshop.com to check that the same devices are still available at approximately the same cost. I hope this helps you,

Go to: www.thebraceshop.com then select **The Brace Shop.** Knee Braces, Ankle Braces and more at discount... then Go to SHOP BY box on LHS of screen & select 'Braces and Supports' then Select Ankle Braces then Double click on 'FOOT DROP BRACES' (3rd from left in first 4-item row of illustrations) then Double left click on this illustration then Refer to 'Ossur' AFO Leaf Spring in the 'Featured Brace' illustration box...

Sale Price: \$49.99 (You Save: \$35.01). then Go to the bottom row of illustrations on this page, and select 'MORE DETAILS' beneath the 'Ossur AFO Leaf Spring Foot Drop Brace' – this will get you to both the ordering area and the 'Sizing Chart'. Postage is extra.

I hope all this inf. and comments are useful to you,
Dan Smith.