GBS ……..CIDP **Issue 74. April 2011**

INFORMATION

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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)
26 Belmont Road, Glen Waverley, 3150. Victoria, Australia. www.ingroup.org.au email: info@ingroup.org.au.

NEXT MEETING
1.30PM SUNDAY, 15TH MAY, 2011 AT THE BALWYN LIBRARY
WHITEHORSE ROAD, BALWYN
GUEST SPEAKER FROM THE DEPARMENT OF JUSTICE
ON CONSUMER RIGHTS
Please bring a plate to share for afternoon tea. Thank you.

Dates to Remember

Wednesday, 25th May, Visit to CSL Plant at Broadmeadows
Sunday, 17th July, Mid Year Luncheon 12.30pm, at Lawrence Home
Sunday, 21st August 1.30 pm A.G.M. Guest Speaker (if available) Neurological Physio Therapist
Sunday, 20th November 12.30pm Christmas Luncheon

Notes from February Meeting

Margaret: Welcome. It's great to see so many here and a very happy 2011 to you all.

A short meeting was held including the Treasurer's report and after expenses were paid we have a bank total of $5,409.

Margaret read an **e-mail from Stephen Bowditch of C.S.L**. saying a **tour of the plant** would be possible at 11am **Wednesday, 25th May. Any member interested in the tour and who was not at the meeting can phone Margaret on 03 9802 5319 by the end of April.**

Our next **Guest Speaker will be from the Department of Justice** who and will speak on **general consumer rights. We should be very informative. They will answer questions.**

SPECIAL THANK YOU. We have a member who has been marvellous, has supplied all the tea and coffee and trundled it along to all our meetings and is now retiring. It is my pleasure, from us all here, to give a great big "thank you" to Barbara, a lovely lady who has done a terrific job. Barbara Clifford was given a lovely pot plant. Thanks again Barbara.

Notes from talk by Dr. Valerie Tay, Neurologist.

Good Afternoon. My name's Val and I am a neurologist. I work at St. Vincent's in Melbourne. Thank you for asking me to come along today. **I have been given a list of questions, so I'll start by just going through things you know very well, like what CIDP is, then try to answer your questions.**

Most of you have **CIDP** is that right? Reply: **Yes**. Others have had **GBS**.

As you know CIDP is a **chronic neurological condition**. It tends to affect the nerves at the end and it can have **various causes**. Some people have **relapses** where they are cruising along and they get **episodes of weakness** and then they get better and some people **slowly progress over time and get weaker**. CIDP very much affects the nerves. It generally doesn't affect the brain or the spinal cord.

There was a question about **axonal neuropathies**. A lot of nerve problems tend to affect the long endings. Imagine the nerve from the spinal cord has to go down the arm and down the leg and it tends to be the longer nerves affected first. **In Australia the very common neuropathies are due to Diabetes and alcohol.** A lot of people have non CIDP neuropathies. In the general community if you have a friend with neuropathy, most of them might have a diabetic neuropathy or an alcohol related type neuropathy. **Those neuropathies tend to affect the nerves right at the end**. So they tend to be numb in hands and feet more than say hips and shoulders. They tend to be weaker in the toes and fingers.

CIDP/ GBS are part of these immune neuropathies and one of the main things about them is there can be a lot of **proximal weakness**, which for some people means their **hips and shoulders can be very, very weak, not just the endings**. That's how it is quite **different from the typical diabetic, alcohol or nutritional neuropathies**.

As most of you know **with CIDP/ GBS the main thing is a lot of weakness**, especially at the start. There can be **numbness**. Somebody asked about **burning feet**. You can get pain as part of a neuropathy. With **CIDP about 20% have pain** just over time. Normally nerves are for touch, feel and strength, so **when they are not working you can lose function** so it **becomes numb or it becomes weak**. The nerves when not working properly can **also become very irritated and they gain abnormal function**. Instead they generate pain when there should be no pain.

As you know there is **general weakness as a hallmark** and sometimes there can be **cranial neuropathies, uncommon,** but some of you may have had or known someone who has had sometimes facial weakness, which can **look like Bells Palsy** at the start. Not common but it can happen.

Lung problems. There is another question about breathing. Breathing difficulties tend to be **uncommon with CIDP** whereas at the start those with **GBS can have severe breathing problems** and some people end up in Intensive Care. You can get a lot of breathing problems with GBS; a lot of **autonomic instability** where the heart rate going up and down, the blood pressure goes up and down. It tends to be very, very rare with CIDP but can occur as part of GBS.

So there is weakness, not only hands and feet but hips and shoulders as well. You can get cranial weakness, numbness, burning in 20% also.

There is a question about **diagnosis**. With diagnosis your neurologist will do a history and cross off what does or doesn't fit. **Testing will then be done**. Most of you would have had the **electrical testing**. **CIDP is called a demyelinating neuropathy**. Your nerves are like telephone wire with a cable and a coating. It allows the **signals to "kangaroo hop" along the nerve quite quickly**. **In CIDP it strips off the coating. The cable tends to be intact at the start but if you strip off the coating for long enough the cables get exposed and they can fracture and break.**

<u>The cables are axons so that is more the answer to the other question of axonal neuropathy</u>.

If you strip off the coating the speed becomes very slow. Instead of jumping from station to station, the signal has to crawl down the nerve and becomes very, very slow. The **nerve conduction tests** tend to be quite typical. You basically see changes or slowing. The **nerve speeds in the arms should be about 50-55 but with CIDP you can get speeds of 30, 20** so the nerve really slows right down**. Overtime if you have CIDP for many, many years you might see then the axons starting to break down** because the coating has been stripped off and then **the size of the nerve can drop**. **So with the nerve test we look for speed and size. The size tends to reflect the axons and the speed reflects the coating**.

Sometimes you may have had a **lumber puncture where we look for protein levels. In CIDP you get a very high protein level**. Sometimes your neurologist or doctor might have done **a nerve or muscle biopsy**. **That's uncommon**, but they do it more **if they are not sure**, or sometimes **if they think your condition is more severe**. They **want to justify because later in CIDP there are a long list of things that can be given. Some of them have lots of side-effects, so if they not sure at the start to be able to justify treatment later, putting you through therapies that are not without risk, then it is important to be absolutely clear of the diagnosis as much as possible**.

So they will normally do a **nerve biopsy down near the ankle**. In that one **they see the typical myelin changes**. Occasionally they would have taken **a piece of muscle as well**. Why would they take muscle**? Because it is a nerve condition and at the end of the day the nerve supplies muscle so you see changes reflecting nerve damage in the muscle**, but the muscle biopsy is normally to rule out other things.

One of the things **we like to rule out is vasculitis** which can be a very painful, sudden neuropathy. The treatment is very, very strong immunosuppression and **you can see changes in the muscles**, but not all of you would have had all those tests.

Sometimes the clinical presentation is so typical they might have gone straight to treatment. Mostly they would do a nerve conduction study, sometimes a lumbar puncture a nerve and muscle biopsy. They would do **MRI scans** normally, but MRI scans are **to rule things out**. They would scan the brain or the spine but **CIDP is not a brain or spine problem**, they do it to rule out, let's say, if you have lots of **arthritis in your back pinching on lots of nerves** then you **can get that effect of numbness and weakness in the hands and feet**.

Over time **clinical response is also part of diagnosis**. If you respond to treatments for CIDP you know that everything else on the cards is in order then there is a more secure picture. In terms of treatments, as most of you know **the main treatment we use is 'Intragam'**. **CIDP** is an immune disorder. **We don't know exactly why or how it happens**. For some reason a switch just gets turned on and the body starts attacking the nerves. **It tends to produce antibodies or cells that run around and attack nerves**.

GBS is a little bit different. **GBS tends to occur after infections**, sometimes vaccinations and then the bug is quite clever and **sometimes the body might over do its immune response to try to kill the bacteria**. In GBS there might be a chest infection, cough, cold, sometimes there is diaharria, gastro or that type of thing, but the body in trying to fight the bug produces all these antibodies which are like little soldiers trying to mop up the bug in the

bacteria and in doing so sometimes it overdoes it and **these antibodies run around and attack nerves**.

There is also something called **molecular mimicry where the bug is so clever it plucks off a bit of nerve and wears it like a mask. Then the body in trying to fight the bug learns to recognise nerve and then attacks nerve as well. That's what happens in GBS.** Normally there are viruses beforehand, normally respiratory, sometimes gastro, but as you know viruses are par for the course just from day to day living. We can't really prevent them and considering the population and all the viruses we are exposed to **GBS is quite uncommon**.

CIDP, we don't know the trigger but the treatments are basically what most of you have had. The one we tend to use a lot is **'Intragam' because it is a very good treatment**. We are very **lucky in Australia** as we have relatively lots of 'Intragam' in terms of **government supply and support**. There was that time about 2003/2004 as most of you know where they tried to wind down a little bit. The **Australian blood supply in general is safe because of technology and testin**g. We **test at various levels** and what's also good is **it is a voluntary system**. Because it is voluntary (you know we don't pay people to donate blood) that weeds out a lot of people who don't do it for the right reasons. So generally the **people who donate blood here have to declare their risks honestly**. There is a questionnaire you have to fill in that asks many questions. It keeps the blood supply safe and clear **plus there are all the testing steps they do at the blood ban**k in South Melbourne.

As you know **'Intragam' is pulled from many many donors then it produces bottles of antibodies**. Because CIDP is an antibody driven disease, imagine your blood is like warfare, the antibodies are running around trying to neutralize all the bad ones to try to reduce the attack on the nerves.

The **other alternative we have is plasma exchange**. **Plasma Exchange is the physical removal of antibodies**. Basically you sit down, blood goes out one arm, it goes into this big machine, it **filters out all the antibodies, then it returns your blood back to you** and normally they return some fluid, usually albumin fluid as well.

'Intragam' and Plasma Exchange are fairly equivalent. **Some people respond better to one than the other but by and large with most people the response is fairly equivalent. Then it becomes a logistic thing**.

'Intragam' as you know there is the hassle of coming into hospital, having a needle, there is a **risk of side-effects but generally it is fairly gentle**. It is an immune product so some people **feel a bit achy; you might feel like your body is fighting the flu; you might get tired or fatigued; occasionally there are rashes**, that sort of thing. Sometimes **if you are more sensitive to it they might give you some steroids or antihistamines before you get the 'Intragam'.**

Plasma exchange is very good, but **it is fussy and there are not many centres that do it**. It is only big hospitals like St. Vincent's, Alfred, Royal Melbourne and Peter McCallum as well. Because I work at St. V's we tend to send people to Peter McCallum to have plasma exchange. They have a very big unit there.

Plasma exchange is used for a lots of **haematology** things, for people with l**ymphoma, leukaemia, stem cell collection, etc**. that's why Peter McCallum have lots of plasma exchange units. With plasma exchange you need a bit drip because **you have about 5 litres of blood volume that has to be filtered out to get rid of sufficient antibodies to make a difference to the actual neuropathy itself.** Because of that you need a big drip to push through quite large volumes and then it becomes **a problem of IV access**.

The normal small needles that you have for 'Intragam' don't work for plasma as you need a bigger one. Then there are **central lines**, vascular catheters, deciding if you will put it there each time for the infusion or do you put in a **permanent line** where there could be the **risk of infection, it's hardware that's foreign to you body**, but also because you are **filtering a lot of volume and a lot of people don't tolerate them**. They get **dizzy spells**, they actually **leech out calcium sometimes**, and they have low calcium reactions. Sometimes **if you have high blood pressure or heart problems plasma exchange may be difficult because of the fluids going in and out.**

As a treatment plasma exchange is very good and is equivalent to 'Intragam'. Occasionally **if 'Intragam' doesn't work it is a good option to think about plasma exchange** bearing in mind all that goes with it.

Another treatment we use a lot in CIDP is steroids because CIDP tends to be very steroid responsive, but Steroids have a long list of side effects. **If you take steroids for long enough, something will happen, generally weight gain, your sugars will go up, diabetes, thin skin, easy bruising, risk of cataracts, thin bones,** all that sort of thing, but let's say **we are stuck in a situation where you are very weak, we've tried 'Intragam', tried plasma exchange, then we need to do something so we try steroids as well.**

The doses tend to be quite high at the start. We generally go by weight, say if you weight about **90kgs it would be approximately 100mls of steroids**. **We treat for 3 months and then wind it down**. Sometimes in winding down we hit a wall because ideally you are able to come off the steroids but **sometimes at about 10mls you may start to feel weak or tired** or whatever it might be, so **what do we do then**. Do we bump up the steroids or **sometimes we add** what is called **a steroid sparing agent** to try to reduce the exposure to steroids long term. Some of you may have had 'Imuran', Cyclosporine, etc., **chemotherapy immune type of drugs. Those drugs also have side effects, but the side effects are unpredictable. Some people get them, some people don't**. There is **monitoring blood tests** also.

A lot of these medicines like steroids and steroid sparing agents are what's called T cell agents. The immune system has T cells, E cells and then the antibodies, but more and more we find there is actually a lot of E cell activation so there is a lot of looking at E cell drugs.

There is one called '**Rituximab'** which could be used for conditions like **CIDP**. At the moment it is licensed for lymphoma and haematology conditions but we are **trying to borrow it in neurology**. Practically and realistically **the problem is funding** because it is not funded and a course of treatment **can cost like $15,000** but in some **studies it might work in some of these immune neuropathies**. There is another immune neurology condition called mycenobravis where we have used it in limited settings where occasionally patients funded half and their health funds funded half of it.

It is exciting. **We have looked at plasma exchange and 'Intragam' (both anti-body based treatments), Prednisolone and steroid sparing agents are T cell agents generally speaking and now there is this area of E cell agents like 'Rituximab'.**

The other area about treatment in terms of numbness, tingling and pain, is obviously **treatment of the pain itself**. Tingling is a bit trickier but with **burning and pain** there are **options for treating the pain**. **As part of neuropathy sometimes the circulation is not working properly either**. **You might experience cold hands or feet**. Then there are the practical things like **gloves or warming your hands**, but when there is **burning pain**, some people find that **wearing socks or gloves actually helps them. The medical term for that is "second skin phenomenon" as what happens is the brain focuses on the glove or the sock as your skin and it distracts it from the underlying pain.** If you know people with neuropathy, especially diabetic neuropathies, they might intuitively **wear socks at night** and feel a bit better. **It is a distraction for the brain**.

Again there is a long list of drugs that can be tried. They are called **neuropathic pain agents**. **Are any of you on them? Members answered: Neurontin, Lyrica, Tegretol, Endep**.

The **classes of drugs we have are either depression drugs, epilepsy drugs or drugs related to codeine or morphine. We are not using it to treat depression or epilepsy but they stabilize nerve membrane. Nerve membrane gets activated in neuropathy and they get irritated and cause burning and pain**. In general, the doses that you would be on for pain would be a lot less than for treatment of depression or epilepsy. For **Endep** let's say, psychiatrist would use 200 – 300 mgs., but **for pain we start with 10, 25 maybe 50** or maybe **100mgs.,** but we don't go much beyond that. **Neurontin and Lyrica** are similar, like cousins, but the doses can go up to for **Neurontin 1800 – 2400mgs**. and for **Lyrica** normally **we stop at 600mgs., per day maximum.** Some people are on 75mg. twice a day.

So there are the depression and epilepsy drugs and occasionally **if they don't work, we might use codeine based ones.** We don't like using them because of the side effects like sedation, constipation, **the risk of getting hooked** on the drug; these are problems with the **codeine** based products. With all these things it becomes risk versus benefit. **If it is really painful, really burning, really irritating, you have tried X, Y and Z, then obviously for quality of life we need to try something else.**

Occasionally there are **topical things like Capsolin cream - like a chilli cream**. In America they have a topical Lidocaine type of cream. Lidocaine is a local anaesthetic but we don't use that here.

The other area for **CIDP** and neuropathy in general **is the non-medical, the physical things.**

Diet. It is important to have a **normal healthy diet**. There are no specific dietary studies for CIDP or neuropathies but **you need to make sure you have vitamins and nutrients because a deficiency of both can cause a neuropathy as well. Then there would be a double hit on the nerves, eg: a vitamin B12 deficiency can cause a neuropathy. If you already have an underlying neuropathy the nerves cannot take added stress on top of that.**

Occasionally **in hospitals if there is a lot of weakness we might try to push through protein just to make sure that at least they have the right nutrients to make up muscle** if they can, but it is not a therapy. It is **for people with a lot of wasting**.

Member: When you have your 'Intragam' how long does it last in your system?

We would say **the average peak effect in your system is roughly about 20 days, but it can still hang around sometimes for awhile after that because it peaks and then trails off**. **You are the best judge** of how you are going. **You will know if you are weaker at whatever your infusion time might be**. Most **standard treatment for most people is 5 days of 'Intragam' at the start and then you might get monthly infusions of 'Intragam'. That has been worked as an efficient durable way of giving 'Intragam' but some of you are getting 'Intragam' every 2 weeks which is uncommon,** but it does happen. We had a very stable CIDP patient and he clearly responded to 'Intragam' but he was getting infusions once every 3 months for just one day. He obviously had a milder CIDP.

It is **not just how long 'Intragam' lasts in your system, because it goes in and neutralises antibodies and also modifies the immune system a little, so it may not be there any longer but some of the effects are still there. The main thing is there is no hard and fast rule with 'Intragam'.** If you are **feeling weaker** than we can sharpen the treatment, giving it **more frequently or a bigger course** to try to get on top of things. On the other had **if you are feeling very stable** and are wondering why am I coming every month for 'Intragam' you can try and **space it out** a little big.

Do many people with CIDP get cured? Yes. Some do very well. Some we diagnose who get the initial 5 day course we never hear from again. The only way we know about them is when they pop up in the hospital system for something else and we find they have been fine.

Member: When your body repairs the myelin sheath does it repair it differently for everybody?

Yes definitely. **Myelin can repair but the rate of recovery or the extent of recovery is quite variable from anywhere from 1% to 100%, but normally the myelin recovers somewhere in between.**

Is there anything you can take to accelerate the repair?

Not at the moment. The **treatment is to try to reduce the immune attack** so that at least the nerves are not stressed and we can **focus on recovery** rather than focus on getting rid of invaders.

Member: Can CIDP cause pain around the chest area? Dr. Tay: Yes, do you have this? Reply: Yes.

The thing with CIDP is that as a neuropathy it doesn't only affect nerves at the end. It can affect the nerves right at the start, so as the nerve leaves the spinal cord it can affect it right at the start so it can cause a band of pain.

With GBS it can present initially as a band around the chest. People sometimes come to hospital 3 days in a row with severe pain, with no numbness or tingling and it is hard to make the diagnosis. But yes, CIDP can cause pain, but if it is something you have always had it may be the CIDP otherwise **if it is something new your doctor will look at discs, muscles, heart and other things.**

Member: I have had 'Intragam' every 2 weeks for a year now and I have Prednisolone and I really don't think either is any help. I have numbness going through the whole leg as I walk.

Dr. Tay: Is your strength better? Have you spoken to your Doctor about this?

With CIDP 70% of patients we generally can get on top of it with treatment. The other **30% we are getting more treatments and trying different things**. There is a very small percentage, let's say **in the past 10 years I have seen 3 that are very, very hard to treat**. We saw one at the Alfred and 2 at St. V's they ended up with a very protracted course and were very sick. They were in hospital for 6 months to a year.

The bulk of people we can treat with normal 'Intragam' and plasma exchange. There are **some with mild disease where we stop infusions** and wait and see. Some are okay, **others** where we might get a call **6 years later** saying asking to **come back for some 'Intragam'** then there is **the tail-end where we need more treatments and therapies**. Sometimes the recovery is incomplete. We might maintain it in that we stop things getting worse or we slow the decline with treatment. **There are some people that need more or we need to change treatment, or give**

Exercise is very important. **It is important at some point to see a physio that you trust or know**. Sometimes you may know a private physio, or initially through diagnosis and being in hospital you might have been sent to rehabilitation where there are private versus public, outpatient versus inpatient. **Occasionally if you feel you are a lot weaker, we can do a burst of inpatient rehab., for two weeks or so to try and get things moving, but the thing with exercise is that a lot of it is to do stretches.**

There was another question on **posterial tendon dysfunction**. A lot of neuropathies can cause foot drop. When you walk on your heels the muscle you are using is the tibialis anteria muscle or the calf muscle. With **foot drop** the **muscle in the front becomes weaker and the muscle at the back of the calf becomes, not strong but relatively stronger than the muscle that's weak up the front** and what then happens is that **muscle tends to pull at the back** so the **achillis tendon tends to tighten and shorten**. It is very, **very common especially with foot drop.** Sometimes children with neuropathy present as toe walkers because they can't heal strike so that muscle tends to pull the foot up so they walk of their toes.

With exercise you want to **do stretches**. Even **if that muscle is weak** you want to **passively stretch it to loosen the joint itself and move the tendon so it doesn't tighten over time.** This can happen in the **ankle** where you get **tightening of the achillis**. **Some people can't straighten their knee over time as the hamstring tightens, and the quad muscle at the front of the thigh gets a bit weaker.** Overtime the knee might bend a little and then the foot might go down a little because the achillis tightens. **Part of physio is to do stretches at**

home. You need to do these stretches. **The muscle may not get any stronger because the nerve is damaged, but you need to keep the joints supple and the tendons supple**.

Sometimes people get **contractions in the hands**. Your **hand therapist** either locally or through the hospitals **might give you simple stretche**s. It is the **same concept** because the **joints tighten up** and that can **cause pain and also disability** later. If something is tender, it is harder to put a shirt on or just walking as well. So **you need to do your stretching exercises. Don't overwork a damaged muscle, but work on it passively and work on the muscles around it that are strong and a lot of physio exercises work the whole body to get the balance going.**

With neuropathies balance can be down. What you **need for balance is your two eyes, your two ears and your feet mainly and your brain integrating all the signals**. As I stand here looking my eyes will tell my brain I am this far from you, this far from what is next to me. The balance centre in the ear will tell that I'm here standing straight. The feet send back signals of how far from the ground, how far apart my feet are, then the brain integrates everything. **For balance with CIDP the nerves in the feet are numb, tingling and we have lost that sort of input and some of you will find that in the dark you are worse or in the shower because then you have lost that vision aspect. Your brain integrates eyes, ears and then the nerves.** Let's say you are sick for some other reason, an ear infection, you have vertigo, you might find your balance really goes haywire with that because you have lost the ears and the nerves. A lot of **balance is to work the whole body** and also to get the **brain to respond and integrate the inputs** a bit quicker. **There is no magic cure, but a lot can be gained through rehab and physio.**

Around Melbourne there are lots of **Balance Centres** and **St. George's Hospital in Kew** have **Balance Rehab**. Some of you may have tried standing on foam and shutting your eyes and that is trying to get your brain to respond and integrate a bit quicker. As with everything some things work better than others. **Rehab. is worth trying for balance**.

Supplements – Unfortunately there are no supplements specifically for CIDP. You asked about **Ginkgo Bilobar, Vitamin B and Fish Oil**.

Ginkgo Bilobar - initially a lot of studies were for dementia but the Jury is out and the latest is it doesn't really help with dementia but some people take it for memory. **It has not been shown as helpful for neuropathies.**

Vitamin B you can actually test blood levels for. Vitamin B you have to be a bit careful. **Anyone presenting with a neuropathy will be tested for B12 deficiency as it causes a very severe general neuropathy** if it is very low. **Vitamin B 12 deficiency** can be commoner later in life because the stomach lining actually thins and Vitamin B 12 absorption can go down. **Elderly people** come into hospital, they have nothing else related to their nervous system, say they come in with a heart attack or whatever it might be, but you might find they have **lowish Vit B 12 levels** as levels can drift down over time. **If something is actually low, it needs to be replaced because B12 can cause memory problems, it can cause a neuropathy** as well, but we don't want to over replace B vitamins in general. **Too much Vit. B6 can actually cause a neuropathy. B6 toxicity can cause a sensory neuropathy.** Everything in moderation**.**

If you have a healthy diet you can take a normal multi vitamin rather than a high potency one, unless you know you have a deficiency. Sometimes people take a multi vitamin that has B in it, A, B and everything. Then they have cramps and take magnesium but some of the magnesium supplements are not pure magnesium. You need **to read the bottles very carefully** as some contain B6. Then they take a multi B as well. They are getting B from 3 different sources. Then they get B6 toxicity.

Fish Oil. It has some anti inflammatory effect. Some people **use it for arthritis** but we **don't have enough studies as to how good or bad it could be for neuropathies**. We use it **medically for cholesterol**. **Fish oil has been shown to reduce some cholesterol levels**.

Co-enzyme Q10. **Sometimes we suggest you try Co-enzyme Q10 to help muscle energy**. It is quite expensive. **If you find it doesn't work then stop it. Some feel better taking it.**

Member: Someone once told me that if you take Cholesterol tablets it is a good thing to take Co-enzyme Q10 as well.

Cholesterol. Statistically the **biggest medical problem for all of us is still vascular disease**, heart attacks, strokes, mini strokes, that sort of thing, so when we look at vascular problems we look at what is called **modifiable and non-modifiable risk factors**, so the non-modifiable one is **age** and the other is **genetics**. There might be a 40 year old that comes in with a heart attack, never smoked, never drank, but because of a strong family history they have a heart attack.

Then there is the modifiable risk factor, things that we have some control over, those are things like **blood pressure, cholesterol, diabetes, smoking**. For a lot of people now if they find **high cholesterol** levels their GP's will treat them by **diet** or they might suggest **margarine** or **fish oil** or they will start you on a **cholesterol tablet**.

Now **the statins, the cholesterol tablets**, are generally **well tolerated**, but some people will get **muscle problems** from them. When they get muscle problems sometimes it is called an asymptomatic elevation, like their **CK muscle enzyme rises in the blood**. They are feeling fine, running around, going to the gym, but when you check their blood counts their CK level is high **yet before they started treatment it had been completely normal**, so you just monitor it.

Then along that spectrum, **some people just get muscle pains or cramps**, some people then **actually get weakness**, where **the muscles are weak in the shoulders or hips** and then **cholesterol can cause a very devastating almost muscle breakdown**. Sometimes they end up in **kidney failure** because the **kidney tries to excrete all the broken down muscle** but in those groups where they have the **myopathy** or the muscle breakdown when they have done biopsies they have shown sometimes **mitochondrial changes**.

Mitochondria are part of the energy cycle of muscle and that is where the **Co-enzyme 10** comes in. Co-enzyme 10 is for muscle energy so **we use it medically for mitochondrial disorders**. Some people may take 9 or 10 Co-enzyme 10 per day. When this condition is found as therapy when they come into hospital we sometimes give them a large dose of Co-enzyme Q10, obviously stop the cholesterol tablet and then neuro physios supporting them giving them giving fluids, etc., but that's the **origin of the Co-enzyme Q10 and cholesterol tablets.**

We are not sure whether taking Co-Enzyme Q10 would prevent the myopathy in the first place, but **Co-enzyme Q10 is fairly safe,** the main limiting factor is cost. It is quite expensive. If you feel it is something you want to take then by all means try it. As with anything you can **try it for 6 weeks or 3 months**, keep a little diary and **if you feel better** you can **keep taking it**. **If not** you can **stop** taking it.

higher doses of steroids for longer to suppress the immune system a bit more and then start again in a way.

Some of our Interstate Members who have been on a dose for a long time advised that they had **been given a "booster" dose**.

There are no set rules with 'Intragam' in a way. Sometimes when you go to a conference the Europeans might do something different from the Americans or the Americans from the east may do something different from the Americans from the west let's say. Sometimes these things are driven by something someone said at a conference last week and they implement it, **but generally speaking there is no specific need to do that if you are stable**.

We would definitely offer another induction course if you were sliding, even on your 2 weekly or 4 weekly infusions. Your doctor can offer an induction course of 3 or 5 days or occasionally increase frequency.

Also check that you are getting the right dose as supplies from the blood bank go up and down. If you were supposed to get 39 grams but you get only 33 grams one day because the supplies are low the next thing you know you are on 33 grams for the next year or so. **Always keep an eye on how many bottles you are supposed to get and make sure you get the same amount of product each time. If for once you miss one small bottle that's okay but make sure the next time it goes up again.**

Generally speaking you don't need a booster course unless you are sliding. As you know medicine is always changing. Every time you go to a Conference they say something slightly different and occasionally someone might have heard something from somewhere and changed practice but so you know, in Victoria it is not happening with you just yet.

If you have vaccinations can you get a recurrence of GBS?

Make sure they are stable first. **GBS rarely returns but it can**. Normally **it is risk versus benefit**. It depends what the vaccination is for. Let's say you are going somewhere and they want you to get the maninjacocul vaccination and your risk of contracting it is quite high, then generally you would go ahead and do it, but normally if you still have active disease and the immune system is a bit up and down, we might hold off. **Different neurologists do different things.**

Question: I am a nurse and wanting to go back to work but they want all your immunisations up to date before you go back.

Generally we still immunise. The only condition we worry about immunisation is MS where it can trigger things. Let's say if they have really bad MS and they are at risk of swine flu, we would vaccinate as if they contracted Swine Flu they would be on a ventilator, but if

they had a mild MS we would ask them to hold off**. This is very individual and it depends on what your own doctor wants to do with you.**

Usually vaccinations can trigger the immune system so if you were a bit unstable, normally we would hold off a bit.

Member: I was told never to have flu injections. Yes. If they told you that then stick to it as they must feel it could trigger your immune system, but **normally if you are very stable and your risk is quite high then we would vaccinate, but if you are unstable we wouldn't vaccinate.**

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INFORMATION

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