

# 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)  
Postal Address: 26 Belmont Road, Glen Waverley, 3150. Email: info@ingroup.org.au

**NEXT MEETING - SUNDAY, 18<sup>TH</sup> MAY, 2014 AT 2.00PM**

**BALWYN LIBRARY MEETING ROOM, WHITEHORSE ROAD, BALWYN**  
**A talk on assistance products for those with limited dexterity, etc.**

**A small plate of afternoon tea would be appreciated.**

## DATES FOR 2014

<b>Sunday, August 17<sup>th</sup></b>	<b>(AGM)</b>	<b>2.00p.m.</b>
<b>Sunday, June 29<sup>th</sup></b>	<b>Winter Afternoon tea at Lawrence Home</b>	<b>2.30 pm</b>
<b>Sunday, November 16th</b>	<b>Christmas Luncheon</b>	<b>12.00p.m.</b>

## Notes from February Meeting

Welcome everybody and a very warm welcome to Dr. Robbie Hunt and Dr. James Allen. Thank you very much for joining us today and I'm sure it will be very interesting to us all.

**Treasurer's Report:** Subscriptions and donations have been coming in and thanks to our members for their continued generosity. Subscriptions remain at **\$15 and are due on 1<sup>st</sup> July** each year, so **subscriptions not yet paid for 2013/14 are now well overdue.**

We have had to find a new web poster and very much with the assistance of CSL, we have transferred. Our **thanks to CSL who have paid our next 12 month's fees for the web posting and we are very grateful for that.**

**General Business:** President: We have had a request from Catherine Brooks, a physiotherapist at Caulfield Hospital for a donation towards a wheelchair for a young GBS patient. They are waiting to see if the government will fund some of the cost. They will send us forms later.

**Gwen:** Does anyone know what this is? (She held up a gadget.) I have been going to Knox Council **Independent Living Group** and this is for helping us get in and out of the car. Inside your **car door where it opens there is a rectangle of strong metal.** This **handle like gadget** sits in it and you can use it **for either the passenger or the driver to hold onto as a support when entering or leaving a car.** I didn't know of it, so if you are interested, talk to me about it later. It is available from **Victoria Health Care Products on 1800 888 541 or your pharmacy may order it in for you.**

Member: I think you **can also break a car window with it and cut a seat belt.** This would be a very handy gadget to have in your glove-box for assistance and also in case of an emergency.

## WINTER AFTERNOON TEA

**This year's mid-year function will be an Afternoon Tea at the Lawrence Home on June 29<sup>th</sup> at 2.30pm. \$20 pp. Come along and enjoy the occasion. RSVP by Friday, 20<sup>th</sup> of June to Margaret on 9802 5319.**

## Talk by Dr. Robbie Hunt - Chiropractor.

I am Robbie and this is James and we are Chiropractors who work in private practice in Pakenham. I was asked to talk and I thought I would come out and put together some information designed to help with the condition and a little bit about some other types of therapies which you could consider may be of benefit.

I've been a Chiropractor for 10 years. I want to tell a little about how I arrived at being a Chiropractor because it is important to **learn what inspired me to do what I do. I was 17 and I was in a car accident, a serious car accident. I was in a Taxi and I got cleaned up into the door and I went into a coma as a result of head injury. I had other injuries, 6 fractured ribs, a clavicle fracture, a fracture of my wrist, a punctured lung and I was in a coma for 10 days. I was at Box Hill Hospital and after I finished my coma I was at Bethesda Hospital which is a branch of Epworth for a further 6 weeks as an inpatient.** During that time as a 17 year old it was pretty traumatic. I had to learn how to talk, how to walk, how to function again and it was a journey and after I was discharged as an inpatient I went as an **outpatient to rehab. for another two years at the Epworth/Austin rehab.** So school went out the door and eventually I finished that phase, finished school part-time and started University.

At the end of two years of rehab., after seeing countless physios, speech therapists, psychologists, doctors, you name it, I decided I wanted to do something that involved all of this and **at the end of the two years I saw a chiropractor and he was speaking to me about my situation. Before that I never knew what a chiropractor was** and he opened my eyes and we formed a relationship and he gave me some treatment. It was less about the treatment and more about his philosophy and what he had seen as a chiropractor. I decided at that point (I was 19) that I would become a chiropractor. **After six years of University I came out a chiropractor.**

Having been in practice for 10 years, **I have seen a lot of cases.** I've seen a lot of people with a variety of conditions and I have been able to help many. Unfortunately I can't help everyone, but **the philosophy of chiropractic is what I want to talk a little about today and also some basic components of the body and how they interact with health and wellbeing.**

I will be talking about three ingredients. The first ingredient is something called **Innate Intelligence;** the second is **Maximizing the function of the nervous system** and the third is **Having a functioning spine.**

**What does being healthy mean?** Member: Being able to get up in the morning without a sore back and being able to know that your body is functioning correctly. Robbie: Does everyone know how that feels? Member: Not being in pain all the time. Robbie. That's a good one. Member: I think it means different things at different times. At one stage for me it meant being able to walk. Now it means being able to run or swim or whatever, so it changes. Robbie: **It is very much a personal thing.** The classic definition of being healthy is that it is all about function. The World Health Organisation says **"It is a state of complete physical and mental and social wellbeing and not merely the absence of disease or infirmity."**

A lot of people get confused and say health is just about not feeling pain. It is a lot more than that. It is about being able to do the little things at different stages of your life and I think this would relate to all of you.

**Do you ever go through a phase in life where there may be a flare up or whatever the phase is and it will change?** Health is not just the absence of pain. It is about **how your body is working on the inside** and as a chiropractor and as a wellness chiropractor, which we will get into, I am really **focused on function** and not merely seeing sore backs all day.

Actually, I would probably see 90% of people who come for a primary reason whether it is a painful neck, headache, migraine, menstrual problems; they come to me initially with that. What we do is **address the problem but then we focus more on improving the function of the body** so not everyone is coming to work seeing people in pain. I am actually seeing people who feel pretty good but they want to keep feeling good or they perhaps **want to keep their body working well.**

I talked about something earlier called **Innate Intelligence**. **Does anyone know what that means?** We call it different things. Anyone know what that is? Member: Genetics. Robbie: Yes, that's part of it. Member: The brain. The mental state. **Your body knows.** Robbie: Yes. **Innate Intelligence** is in other words - **The Wisdom Within.**

**Our bodies know it is good.** If we put our hand on a hotplate we have a **reaction** and then after reaction you have got the early **phase of healing**. The body starts to go red, it bubbles and blisters and then it might let out some fluid, it might swell, it might start to sweat, whatever the case, **it starts to heal. That is innate intelligence. It is really important to talk about that as without innate intelligence expressing itself freely you are not going to be able to heal yourself.**

\*We are going to talk about this next slide. I assume you know, but we are going to teach you a little bit more. So you have got this intelligence, but there is **no point having intelligence if you can't communicate.** So this is the communication. **The basic function of the nerves around your body is to send signals from one cell to another.** An example: The brain up here. **How does your small intestine know what to do? It is getting messages from the brain transported by this nerve. How does your big toe know how to move? It is through a message which is generated up here and goes all the way down through here.**

So I'll ask the question: **How many nerves are there in the body?** Does anyone know the answer? Member: 43 pairs. (Laughter as everyone had read it on the slide.) Robbie: **How many individual neurons are in the body?** There are a lot more than 43. There are **over a million and these little nerves allow this communication, allow this innate intelligence to talk to the body, so this nervous system truly is amazing and it is evolving and the central nervous system (there are actually two types but we won't go into that) is connected by 43 pairs of nerves. 12 nerves go from the brain and 31 pairs going from the spinal cord. There are almost 45 miles of nerves running through the body. So there is a massive network of nerves.**

Second: **What are these nerves encased in?** They are encased in **this hard bone. This bone is called the spine and at birth it is going to have 33 stacked layers and when we are born it is a soft spine made of cartilage and the cartilage hardens over time. Eventually it fuses. Now this bottom fuses and becomes the coccyx and that happens at the age of around 16. It is quite soft and then it fuses and becomes bone. So you have this full body structure and inside you have these soft nerves coming out of these holes. Now you have 7 here and 12 here and when you are a baby you have 5 and when you are about 16 it hardens into one.**

**Ligaments:** You have a lot of ligaments (220) which **hold this spine together and that enables it to function properly and as a chiropractor I am very interested in this.** Later we will talk about why I'm interested in it. **Joints:** The joints are **stacked on top of each other and allow it to move freely.**

Now I'm going to talk about **something I look for every day at work.** It is a term that a lot of chiropractors get excited about. **Who has been to a chiropractor by the way?** (Show of hands) A lot of patients gathered here. **Subluxation - Does anyone know what that means? Member: The joint goes out.** Robbie: Couldn't have said it better myself. **It is when a bone is out of place and as a chiropractor I am interested in it because when I feel someone's spine I am there to look for areas of the spine which aren't working properly and could be irritating nerves. I talked earlier about this amazing nervous system, but what's going to happen if the nerves are not allowed to flow freely? What is that going to affect? Function. It may cause some pain but it may not,**

**but it is definitely going to affect the function and the research shows that there only needs to be the amount of pressure you put with a five cent piece on your skin and that's the type of pressure there only needs to be on that nerve to affect it. That's called subluxation.**

This is a bit of research. (Another slide.) This is a specimen and it has been cut in half so what we are looking at here is the spinal cord which has been cut down the side. These are the **disc spaces** and what we have here (a pathologist did this) he identified that **that area there had gone out of position and put pressure here and that pressure would have caused some problems. In this particular case it is stated that they got two hundred cadavers and laid them all out and they dissected and found that the greater area of irritation to that nerve, the greater level of disease or poor function in the organs. The finding was that organs supplied by a pinched nerve tend to reveal pathological change, so they reveal damage. The more serious the pinch the more serious the damage. That is a sign of long term subluxation.**

So now let's go through some cases Jim. The first one – **if you have subluxation in your neck it can be leading to headache, neck pain, fatigue or dizziness.** I have a lot of people who come to me and they say "I've got these headaches. I think it has something to do with my diet". They have tried a few things that have made a difference. In some cases it is coming from their neck.

**A subluxation here could be causing shoulder problems, weight issues, hormone imbalance or pain to the arms. If you bring your memory back to the earlier slide the nerves from here actually go down the arms so that's why an area is out here it could be affecting your hands.**

**Middle part of your back. When I was a student we did a study and we got 100 asthmatic patients and we actually did some areas of examination of their spines and we found a very much consistent pattern for many of the people of the study who had areas of their back here which was not working properly. So a common symptom of a subluxation here would be shortness of breath, chest infection and rib pain.**

**The lower back; down through here; if your bones are out of position you could be getting digestive issues, gut issues and again weight issues. And down the very base we are looking at menstrual issues, reproduction and prostate issues.**

**What causes these bones to go out of position? Hands up who can give me a few reasons? Member: Falls. Robbie: That's a big one. That's an easy one. Give me some more challenging ones. How could your spine go out of position? Member: Lifting. Robbie: Exactly. How did you all get here? Driving - prolonged. What were you doing this morning? Who read the paper? Sustained postures. Jim will put the slide up to make it easy for you. Postures. Driving, reading, computer use, believe it or not puts your spine under pressure. Back packs, particularly for kids, computer games, sleeping awkward, sleeping twisted, is going to put pressure on your nerves. Believe it or not, if you are stressing about something, it is going to put pressure on your spine. If your spine is out it can not only affect your spine, it can affect your whole body.**

I will just go back a bit. We would see **a number of people who come and they may think that they have asthma but a lot of the time they have only got a bone out of position in their spine. So these can mimic other symptoms.**

Now everyone in the room with **inflammatory neuropathies, chiropractic doesn't claim to fix the neuropathy. What we try to achieve is to get the body working at its best, so the body has the best chance of healing itself or the best chance of actually combating the stresses whether the stress be environment, whether the stress be psychological, whether the stress be emotional. Now that's a really important point that I want you to remember. Come and see a chiropractor. It is not necessarily about healing or trying to actually fix the neuropathy, we try to actually get your body to work better.**

I know a number of you haven't been to a chiropractor before and **you probably wonder what you can expect when you come to see a chiropractor.** This is what they will do; well we do at our practice. **We want to know that your nerves are working. We have a scanner. It is called an EMG scanner and because nerves are so important, we want to actually go from the neck to the base of the spine, called the coccyx and we want to see how the nerves are working.**

This is a typical readout and it is going to show areas of low activity, medium activity and high activity and this is indicative of a patient who may be experiencing difficulty with their nerves. **Red is typically a sign of irritation. Now the irritation is not always coming from the spine being out, it could be coming from a variety of reasons. The key point is to at least do the assessment.**

The second thing we like to do is to **assess posture. Why would I be interested in checking someone's posture?** What is posture a window to? What's that showing me about this woman? What do you think her spine would look like? **It gives clues as to what is happening with the spine. Posture is a part of diagnosing subluxation.**

Any chiropractor you go to will do a **private consultation. They will do the nerve irritation, the posture and they will also do any relevant neurological tests. So, they will do a spinal exam and x-rays. We like to see how the spine actually looks because if the spine is looking shifted then it affects how we are going to give some treatment.**

In summary, I wanted you to all know that **chiropractic helps in cases where anyone has conditions, whether it be inflammatory neuropathy, asthma or digestive issues, we are trying to maximize the function of the nervous system. Unfortunately, if your nerves have some demyelination or have some actual nerve pathology, we are not going to be able to correct that. The focus is going to be to keep your body working as good as it can, so that the body can combat it so maximise the nerve function, which in turn helps the body to heal itself more efficiently.**

**Chiropractic spinal adjustment therapy improves joint movement and joint position which assists in minimizing pressure. That's a fact. Chiropractic adjustments are effective at reducing pain and reducing symptoms. Less pain symptoms mean you may feel like being more active.**

The reason I wrote that is because **exercise has been shown to improve muscle strength, function, and mobility and minimise muscle tension atrophies.** Atrophies are where the muscles and ligaments actually change their size. They atrophy. They actually become smaller.

**Exercise.** In order to exercise you want to be feeling good and typically **a chiropractor can help you to feel a bit better and then you are more inclined to exercise.** By making these improvements and others, a chiropractor may be able to **improve your wellbeing and quality of life.**

**If you are interested in seeing whether a chiropractor can help, an excellent resource is the Chiropractors Association of Australia.** In Victoria there are over 1800 chiropractors state-wide. **There are a number of chiropractors that do different techniques.** I will leave my card so I encourage you to give me a call if you do want to see a chiropractor and I will give you some guidance as to someone you can see. **Not every chiropractor is the same.** Some chiropractors are just interested in getting you out of pain and that's it. A lot of chiropractors which are generally called **wellness chiropractors are more interested in the function of the spine** and they will have experience in the sort of things I've talked about.

This is a good starting point. They have a register of all the chiropractors in Victoria. You can certainly have a look there. I am also happy to discuss it, and as a thank you for inviting me to share this talk with you, if any of you here today want an initial assessment (at my expense) then I can either refer you to someone else who may be closer to you or alternatively I can do some treatment if needed.

I will be hanging around so at this point has anyone any questions - fire away.

Member: I see a chiropractor myself and **my little boy has CIDP and he is 6 years old.** My chiropractor has been thinking about him for a long time and obviously you don't want to crack a little boy's spine, so she says there are other techniques and other ways she can adjust him because **he does have a lot of falls.** Last month I got him knee pads as he doesn't know how to stop and he loses his balance and falls. Obviously with falls the body is not going to function correctly. **I just want to know how would you adjust a 6 year old child?** Robbie: **It is an individual case.** Firstly, you can adjust a 6 year old. **I adjust a lot of 6 year olds.** It really depends **what he is presenting with as to what you would do to try and help.** The first thing I always say to anyone is that we don't know if chiropractic can help. **Firstly we test the spine to see how it is working. There may be something we can improve, but it would depend what we did find as to what we could do.** But certainly you can adjust a 6 year old.

**I assess a lot of babies.** Babies have been bunched up for 9 months and whether the delivery is traumatic or not there can be some areas where the baby's spine is out of position. A lot of you who see a chiropractor would think Oh you can't do "that" to a baby. We are not interested in doing "that" to a baby. **The technique with a baby is finger pressure.**

**My eldest patient would be over 100 years old now and the technique for him is drastically different to someone I see who is my age. Typically in the elderly you use lower force technique. We have a couple of different machines** we use and there is no cracking or popping on a lot of my patients. Probably on my patients I do 60-70% of the manual stuff, 30% we do the lower force. There are many patients where we do a mixture of both. It depends. I certainly would get your little boy checked.

Member: **I had a child that had a traumatic birth and I didn't take her to a chiropractor. She ended up with very bad scoliosis and I just wondered if that would be something that could be helped with chiropractic at an early age?** Robbie: **If identified at an early age it can. When a child gets to about 15 years of age it is getting a bit old to make corrective changes to its spine** but you need to manage it with perhaps bracing, but **chiropractors often pick up scoliosis and manage it accordingly.** She is now an adult? Member: Yes and she does see a chiropractor.

Member: **How often do you see a client or does it vary between patients?** Robbie: Good question. **I will use myself as an example.** I am fairly active. **I do a lot of running, a lot of swimming, a lot of bike riding** and I have **an intense job and I drive a lot and I am under stress,** whether psychological, work or pounding the pavement, so **I like to get checked every 3 weeks.** I have some people who like to get checked every 2 months. **Everyone is different.** I have some people who are having a very stressful life who may see me once a week or once a fortnight.

Typically **I encourage people to get checked because there is no one in this room who hasn't had falls or some kind of stress in their life and it can be causing some areas of their spine not to be working properly.**

The question I get from people is **that once you start seeing a chiropractor don't you have to see a chiropractor for ever and my response to that is I encourage people to get checked over their lifetime.**

**It doesn't have to be every week, every month or every couple of months, but get checked, because things go out of position and that pressure on the nerves can affect how you are functioning. It is more a prevention thing.**

Member: I know in your practice you have a sign that says that **if you have chiropractic treatment you don't go to the doctor as often** and I must say my husband and I don't know when we last went to the doctor because we were sick. We go to get our prescriptions but **we haven't been because we have been sick for more than a year.** Robbie: **The old style of health care is also termed sick care because you go to a doctor when you are sick.** I try to steer away from that and move towards **wellness care.** I encourage people to come to me to get checked **when they are feeling pretty good to keep them feeling good and working properly.** **The classic sickness care is wellness care.**

Member: **With a degenerated disc and associated nerve problems bordering on surgery, can you advise on that?** Robbie: It would be worth checking to see **at just what stage it is.** Unfortunately, with an underlying **degenerative condition we can't repair the damage already done,** but perhaps we can **improve motion and prevent it from getting worse.** It is such an **individualized assessment** that needs to be done. I see a lot of people who come to me after they have had surgery. Typically someone seeing me after surgery means they haven't been happy with what happened. **Our focus may not be working on the area that has been operated on. It may be on associated areas because they may be subsequently stressed as a result of that area being damaged and be over compensating.**

**Degeneration is a big thing.** A lot of people think **degeneration is normal** and that it is a normal aging process. That is not true. **If your spine is working properly throughout life it shouldn't deteriorate at a rapid rate. Spines do age,** but in terms of the **degeneration** I see in people's spines, **it is not normal for if they had taken care of their spines throughout their life.**

Member: **Is there any particular nutrition that stops degeneration of discs like perhaps fish oil?** Robbie: Definitely there is growing thought for **fish oil and glucosamine and chondroitin and msn.** I was watching the TV the other night and they were recommending calamari oil. There is a lot of marketing that goes along with it but the **research does support chondroitin.** You have to take it for **two to three months before you can see the effect.** **Fish oil** has been around a long time but research continues to support it and **you need to take it with chondroitin, msn and glucosamine.** **That mix has been proven to be the most efficient.**

Member: **If you have damage to the nerve, does the nerve repair itself?** Robbie: Good question. Typically (I use **my case as an example**), I had a head injury, bleeding on the brain. I was **supposed to be a vegetable.** **Over a two year period I went from not being able to open my eyes, dribbling, to being back at school, so my nerves repaired.** **The latest research suggests that nerve repair is a slow process as you all know. They say nerves don't repair after two years from the date of the injury or the trauma. I disagree with that because in my case I felt different even after 5 years. I still saw improvement. I also know of some people, particularly in the area of brain injury which is what I am most interested in, who do continually see change for longer than 2 years. To answer your question: Nerves do repair - but slowly though and it depends on what the underlying pathology is as to the rate of repair.**

Member: **Did you lose your sense of smell and taste?** Robbie: **I lost it for about 6 months.** I remember it came back one day and it freaked me out. **I lost smell, taste and in my case my injury caused a lot of nerve damage** particularly to the upper neck and brain. It creates a lot of emotion and for two years **I was fairly emotional and that was just the natural progression after my particular injury.** But I was lucky as it depends on **the actual nerve damage** and the area of the brain that is damaged. I made friends and recently I bumped into one I was in hospital with but unfortunately the area of his brain which was damaged affected his speak and he still has quite a lot of speech issues.

Member: **I was wondering if there is anything you could recommend for fatigue as those who have/had GBS and CIDP seem to have residual fatigue.** If my husband has done too much work, the muscles in his throat relax and he can't talk properly and he gets wobbly. The question asked most by those who have had GBS or have CIDP is **"What can we do about the ongoing fatigue?"**

Robbie: **My specialty is the nerve system and the spine and so firstly I would say check the spine.** I do get a lot of cases that come and see me and **one of their symptoms may be fatigue.** Very rarely do I see someone who presents with GBS or CIDP, but it doesn't matter because **if the spine is out of position it can affect their energy levels. That's well documented.**

To answer your questions: I would **get your spine checked** and I would also **look at nutrition. An easy way of boosting up energy is to take Vitamin B12 as most people are deficient in B12.** I give them sublingually on the tongue. \$10 from the pharmacy. I have a stack at my practice and **I give them out to people because I know I use them. That's an easy way.** Obviously **if there is an underlying reason, something I could help would be with the spinal nerves.** Everyone is different.

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Just finishing the newsletter when I received a call from James a gentleman from Queensland who had GBS 10 months ago. He told me his neurologist in Bundaberg diagnosed him quickly and treated him very well. James has offered his support for those with GBS in Queensland. If anyone in Queensland would like to contact him I can pass on his details. My contact is [behrsdn@optusnet.com.au](mailto:behrsdn@optusnet.com.au) . or 03 9707 3278. Melva.

### **Email Addresses**

If you would like to be included on the IN Group email mailing list please send an email to John Burke at the following email address **[jburke@contracts.com.au](mailto:jburke@contracts.com.au)**

If you use *hotmail* or have junk mail filtering software running you will have to include the above email address in your "safe list".

**Disclaimer** Information presented in "INformation" the Newsletter of the Inflammatory Neuropathy Support Group of Victoria Inc., is intended for information only and should not be considered as advising or diagnosing or treatment of Guillain-Barre Syndrome, CIDP or any other medical condition. Views expressed in articles are those of the authors and do not necessarily reflect the opinions or Policy of The IN Group.

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