GBSCIDP

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.

NEXT MEETING TO BE HELD ON SUNDAY, MAY 16TH AT 1.30PM

BALWYN LIBRARY MEETING ROOM, WHITEHORSE ROAD, BALWYN

WE HOPE TO HAVE AN OCCUPATIONAL THERAPIST AS OUR GUEST SPEAKER

GENERAL MEETING DATES FOR 2010

Sunday August 15th. (AGM) 1.30.p.m. Sunday November 21st. Christmas Luncheon 12.30 p.m.

The wrong times for the general meetings appeared in the previous issue. Please note they are all half an hour later. Apologies... Ed.

Winter Luncheon – Christmas in July on July 25th

The Lawrence Home, 26 Belmont Road, Glen Waverley

\$20 per head. Yummy Roast Dinner and Plum Pudding/Jellied Berries and chocolates! RSVP 11th July to Margaret on 9802 5319

A MEETING WITH A DIFFERENCE

Picture a group of members waiting outside the Balwyn Library, some leaning on the walls, some on their walking sticks or frames, all chatting happily. Not long after they realize that the Library doesn't open on Tuesday nights. They have their "plates" of supper and are in the mood for the usual get-together, but alas no venue. Luckily they are next door to the Balwyn, **McDonalds Restaurant**. Their quick thinking Vice-President, John Burke, disappears and returns smiling saying the meeting is to be held in the outdoor area of Maccas.

The management graciously allowed us to "BYO" supper and the treasurer dipped into funds for our tea and coffees. (Hope you don't mind.) We were more than happy to move up the ramp and under cover on what was a slightly crisp evening.

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A short meeting was held prior to the guest speaker.

Apologies: Brian Boyd, John DeRavin, June Cathcart (who sent Margaret a lovely letter.)

<u>Minutes</u>: The Minutes of the previous meeting were moved by Doug Lawrence, seconded by Barbara Clifford. Passed.

<u>Treasurer's Report</u>: Department of Health giving us \$950 for the self-help program. Committee has given permission for some money to be placed in term deposit with the Commonwealth Bank at 6% as we save for the next donation to research. Treasurer's Report moved: Doug Lawrence, seconded: John Burke. Passed.

<u>Correspondence</u>: We have received a nice email from Stephen Bowditch advising that CSL are picking up the cost of our annual fee to Vicnet which provides our website. \$235. Our thanks to CSL for their generosity and support.

The following letter was received from Dr. Andrew Kornberg.

Thank you for your kind donation from The In Group towards the work we do here with peripheral neuropathy at the Children's Hospital. The size of the donation came as a big surprise and I write to thank you and your fellow members of The IN Group for your support of many years.

As I mentioned on the day, we are in this together and we will continue to strive to understand these conditions in the hope that more specific treatments become available.

The money will go to our Fellow who is working on CIDP research on a clinical level. This will also pay for some of the important testing that we are developing.

Once again thank you for your support of many years.

BOWEN THERAPY TALK AND DEMONSTRATION BY DEBORAH LOWE

I will demonstrate some Bowen. Bowen is a gentle form of bodywork, not massage, and you perform the moves over muscle and connective tissues and that brings up the cellular memory that sends messages to the brain to bring the body back to how it felt when it was well.

I find some people have reactions while I'm working. With skeletal/muscular things I have people who react straight away. The second person I did got off the table and said, "Oh, my knee feels better" and I said "What's wrong with your knee?" She hadn't told me. She said, "Oh, I'm having an operation on my knee." She had arthritis. Anyway, I did her once and that was two years ago, and she hasn't had a problem with her knee since. So sometimes you get reactions straight away or within a couple of sessions.

I have been doing Bowen on a girl with Fibromyalgia and she is doing well now. I can't believe she couldn't walk or perform many tasks during the day when she was unwell.

Bowen is totally different from physio, chiro, etc., and with many hundreds of hours practising, I have had lots of people ring up and say, "What did you do?" What did you do? They had been putting up with pain for up to 20 years and within a few sessions I do well with Bowen. Doctors now suggest people have Bowen sessions. My daughter's friend's mother is a GP and she said "On yes, Bowen fixes things we can't fix and her mother-in- law has a Bowen therapy every 2 weeks for her arthritis and says that maintains her movements.

On the sheet I have given out there are examples of how Bowen can help conditions like Sciatica, Chronic Fatigue, Bowel problems, pain in knees and hips, headaches, sore backs, lower back; the list goes on.

A lady a few months ago was going overseas that afternoon, and I went to do Bowen on her little boy. She was coughing and had blocked sinuses. I said, "I'll give you a treatment." When I was doing the moves the mucus in her chest was breaking up and her sinuses were clearing. She said, "You've got healing hands." Later she went on the plane and did very well.

It is quite amazing. When I did one of your members her sinuses unblocked. As the sinuses cleared, a large lump of mucus dropped into the back of her throat.

(John Burke volunteered to have a Bowen Therapy. He lay on Deborah's therapy table. As we were outdoors undercover at McDonalds, customers would park nearby. They didn't immediately alight from their vehicles, but sat watching the proceedings. It was very funny. Also a large number of crows were roosting on a nearby building, and going gar, gar, whilst Deborah was trying to explain each movement. Therefore, under difficult circumstances she continued.....)

You should drink a large glass of water before Bowen therapy. When you have had Bowen therapy, you should drink lots of water. Those who get the best results drink plenty of water and get up and go for small walks during the day - for several days after their Bowen.

I am going to do some procedures that work on the whole body. Some people only do these three procedures. Deborah told John "Breath in, then breath out, then hold your breath; now it is just a gentle movement over the muscle, now breath again." Deborah did three moves which were for John's lower back, then had a two minute break so his body could process the messages it had been sent. She explained that she was going to do lower back, upper back and head, as these moves cover the whole body.

Deborah gave some background saying, "Tom Bowen developed the therapy. He was born in 1916 in Brunswick, Victoria. Bowen is now performed all over the world. In some countries you have to be a doctor to be able to do. It is not like anything else; it is just gentle moves over the body's muscles and connective tissues." (At this stage she did another set of moves on John.)

Sometimes people like to chat, other people don't like to chat during therapy. A lot of Bowen is about talking to people.

My Fibromyalgia person comes and we will talk for an hour before I do the procedure on her, then we talk for an hour or so afterwards, all about her problems. She was really bad in the beginning, not being able to walk or function very well at all, and I feel that talking has been part of the therapy. Letting people talk brings up other problems to work on.

I met this woman when I gave her mum therapy. Her mother had pain. After two sessions she was pain free. She couldn't believe it and so her daughter phoned and said, "Ok, I'll have Bowen now." She was amazing. She would write down everything because **Bowen can take from 7 to 10 days for the brain to process the moves completely.** The day after treatment you may feel ill, and if you do that's okay, because something is shifting in your body.

People don't tell you everything that's wrong, but this 70 year old woman, the second time I came back she said, "The arthritis in my little toe and finger has gone. Could Bowen affect that?" Her daughter was very quiet and she had back pain, but when I went the second time, she told me all the things wrong with her and we are slowly working through them. I asked her, "Are you an emotional person?" And she said, "Oh Yes." There are specific moves for emotional problems as well.

Bowen it is very gentle. You can leave your clothes on. It works on the facia of the muscles. You know when you have a chicken breast there is a thin membrane of skin, well you have that all over your body.

<u>Question from the floor</u>: Do you have a place where you do this? Yes, I have a room at Rubee Rose Hairdressers in Gembrook at

Shop 1/89 Main Street, Gembrook, Victoria

I also travel to your home and can be contacted on 0428 536671 or (03) 5968 1638.

For muscular/skeletal problems therapy is usually two sessions within a week of each other and after that it is up to you. For more involved problems, (like Fibromyalgia) it can take about 15 sessions.

John's major problems today are cramps and headaches, so I would recommend two sessions, a week apart. See how you feel tomorrow John. Some people do feel a little ill.

The move I am going to do on John now will be on his head. It is very good for lymphatic drainage, circulation, just sleeping – people sleep well after Bowen.

<u>Question from the floor</u>: Is the major side-effect nausea? No, not really. Some people will feel okay. But you know something has changed.

A lady phoned and said her sciatica had been playing up for weeks and I said, "Why didn't you come earlier". She said, "Well when you did my knee I felt sick the next day; my knee ached and I thought I would vomit". As the days went by she was fine and that knee hasn't played up since. I treated the sciatica and she wasn't ill at all.

(Melva - It is quite fascinating, I have had Bowen a few times over the last 12 months and sometimes there is no reaction and other times there is an immediate reaction. My last therapy was for sciatica, but months ago I had a cough which continued for four months which eventually stopped and I thought I was fine. I also had this cough for several months two years earlier. On both occasions I had seen specialists and even had a chest x-ray.

After my last Bowen, the cough returned and I felt most unwell and called Deborah and asked, "Can you reverse this. I feel terrible." She told me, "No, it is your body fixing that cough for good. Wait a week and see how you feel." I must say I haven't felt this well in ages and hopefully I won't have that rotten cough back again.)

How I started was I have horses. I had someone come and do Bowen on my horses. Then I learned to do it myself on horses. Then I did the complete course and am fully qualified.

I do fourteen moves on each horse, that's all I do, no matter what's wrong with the horse, whether it has an abscessed foot, lame or it is not moving properly, and every time it works. (John says, "Could I have my chaff now please?")

Oh, I must tell you that after Bowen do not use heat or cold.

There is one specific move I do which is for upper respiratory and that works for allergies, asthma symptoms, hay fever, glandular fever, influenza, lymphatic restriction, upper respiratory problems, coughs, colds, sinus, sore throats, swollen glands, constantly recurring neck problems, dizziness, dyslexia, ear problems, infection, deafness, Menier's disease, tinnitus, eye sight problems, facial paralysis, Bell's palsy, migraines, headaches, palatal abnormalities, teeth grinding, teeth crowding and clicking jaws. That's just one move and I've had that work on many of those problems.

John: "What you are actually doing to me, is it a short version?" Deborah, "No I am doing a full session on you. I am taking my time, because I want people to be able to ring you and find out how you are feeling."

Deborah told how one lady complained of a sore foot after her therapy. This happened twice, so Deborah asked had she had a sore foot. She said she did years ago. After the third therapy the foot didn't hurt. Deborah believed it was the cellular memory ridding the body of the memory of the sore foot.

One day I was doing a girl and she had back pain from carrying her school bag. She felt quite good when she lay down and half way through she began laughing. She told how during the breaks, the pain in her shoulders was like carrying her school bag. Following the therapy she had no back pain.

I have so many different stories of what Bowen does.

I was treating a person for a sore knee but she also had a sore shoulder. I treated the sore knee with a movement which is also good for the shoulder. After the break she said, "Goodness me. My shoulder went ping, ping, ping, then my knee went ping, ping, ping. She had a very sore shoulder and knee and after that therapy she had no problem.

<u>Question from the floor</u>: Should the patient be quite specific as to where the pain is?

You do treat what the person tells you about but you actually also treat other problems they haven't ever disclosed. The body does it on its own.

It's like with the horses. The owners want to tell me what's wrong with the horse. It doesn't matter really as whenever I do the therapy it fixes everything.

One of my horses a few weeks ago stood on a piece of wire and the vet said "Oh, not good news. It has gone into the tissue and I don't think she's going to be okay". This horse would never let me do Bowen on her. Some horses don't let you do it. This horse's mother died when she was born and she was handled a lot. You could pat her all over and play with her but as soon as I went to make the first move she'd try to bite me. (John said, "I promise I won't do that.")

She was picking up that I was going to do something different. Anyway, when she had this sore foot she let me do Bowen on her. After a couple of therapies the sore healed. The vet couldn't get over it and told me he thought he would have to put her down.

I work on racehorses owned by a lady who lives nearby, and she says, "I don't know what you do, but I know you fix the horses". They may have been in pain or something, but I do the Bowen and a day or two later they are fine.

One had cancer on its nose and I did Bowen 6 times in a couple of months and the vet said "If I dig it out, I don't know what we can do." I rang him and said, "I did Bowen and then one day it had fallen out and had cleared up". It is bazaar.

Sometimes I see people on the street and I want to help them out and say, can I do a Bowen therapy, because it works so well.

We are nearly finished the upper back. John did his breathing in and out while Deborah did the gentle movements. After two minutes he would turn over and she would do his neck.

Again she stressed to drink water, do some gentle walking, but don't do vigorous exercise and also don't have any other therapy like physio or chiro as that would negate the Bowen if done within maybe 10 days. No alcohol either. (John wasn't happy about that.)

One of John's knees popped when Deborah performed the next moves.

A lady who had Guillain-Barre Syndrome, after 16 months was considered healed but was having chronic fatigue and was having a 4 hour time frame in a day when she could do things. After 6 sessions of Bowen therapy, she had 10 hours when she could do something, so it certainly improved her fatigue levels.

Bowen has also helped Parkinsons, MS, and ADHD in children. There are a large amount of things that it does help.

<u>Question from the floor</u>: Do you have to be lying down? No, you can do it sitting up if someone is in a wheelchair. It can be done following car accidents, etc. It is very gentle.

You can't guarantee anyone, but I would say 80% of people benefit from having two therapies within the week and then perhaps another one or two after that.

John: Bowen therapy can be claimed through your private health cover if you have extras cover and may also be available through the Extended Care Plan which people with more than one chronic condition can access. Ask your doctor if this would apply to you.

You receive 5 certificates which you can use for physio, chiro, etc., if they help with your chronic condition.

There is also a Dental component of Extended Care for those with chronic conditions. Ask your GP about this also. See if this applies to you.

Deborah, thank you very much for coming along on behalf of the group and particularly on behalf of myself. I have been in Monash outpatients today and yesterday having treatment and that gives me bad headaches, so I will see how it goes.

<u>Editor's note</u>: John did say he felt better from the next day but he had also just had his IVIG. He said he would be prepared to have another therapy session.

We all picked up our supper and moved into another area where we enjoyed our coffee, tea and a chat between ourselves.

Committee member Gwen McInnes explained how she had seen some interesting new hand wipes. They come as a compressed circular block about the size of a 10c piece but thicker and you just dip them into a little water and they expand to make a moist towelette. Very handy to have in your handbag, the glove box, or case, when travelling. They have no added perfume so are excellent for those with allergies.

Gwen was so impressed she ordered some from Perth and they can be bought at our meetings at \$10 for 20. Great for sticky occasions.

After supper, member David Taylor spoke regarding **new information on MS.** Thank you David for this excellent summary of the findings **re blocked veins in MS patients**. It seems they have found that opening blockages in some veins of some MS patients can stop episodes. Hopefully we will have more on this in our next Newsletter.

Part of an Email received through info@ingroup.org.au from Andrew Belotti.

I am a GBS veteran (1995). Neck down completely. Still have residual in feet. Can walk so no complaints. I am now 54. I wrote a book, "Let Your Spirit Run Free" which can be found at http://andrewbelotti.com/guillainbarresyndrome. I visit people in hospital with GBS or speak to many on the phone from all over the world. Very rewarding. Keep up the great work. Andrew Belotti.

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Thank you to all those who have paid their Annual Subscriptions and for your generous donations. For new enquiries and to purchase items, our form is below.

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				
Subscriptions due on the 1 st July of each year.				
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Email from Peter our member who had stem cells.

Day 1year+49 days

Walking up past the shops down the road and up the hill, puffing a little, I saw a man sprinting towards me. I don't know his name but in fact there are very few people I meet on these walks that I know by name, though almost all will respond to "how are you?", "how are you mate?", or some remark about their dog or the weather.

Anyway, I have seen this fellow a number of times before, always running, always powerful even though he is about my age.

"How are ya going?" he said, "you are looking good" he finished as he stopped beside me panting.

"And you" I returned.

"Well" he replied

"A year ago", I went on, "I was walking 100 meters at a time and then only on the flat, while now I do 2.7 kilometres with my pusher, and I can do 700 meters just with a cane."

"Well" he said wiping a sweat bead from his forehead. "you're lucky. My daughter has a friend who is a paraplegic."

With this he waved goodbye and restarted his run.

I turned and continued up the hill with my mind full of thought and a small smile on my face.

Peter