

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.

ANNUAL CHRISTMAS LUNCHEON

And Dutch Auction

Balwyn Library Meeting Room, Whitehorse Road, Balwyn

12.30pm.

NOVEMBER, 29TH, 2009.

\$15 per head. A small wrapped gift for the Dutch Auction would be appreciated.

Are you ready for fun and fine food? **Are you looking forward to hearing what Dr. Andrew Kornberg can tell us about his research into GBS and CIDP?** Well, come along to our Christmas Luncheon and listen, learn and enjoy. This is our major function for the year. If you never go, you'll never know, what a great day this is. For catering purposes, RSVP to Margaret on (03) 9802 5319 or Melva on (03) 9707 3278 by 22nd November.

THE GENEROUSITY OF OUR MEMBERS WILL ENABLE US TO PRESENT A SIZEABLE CHEQUE TO DR. KORNBERG. THE COMMITTEE WOULD LIKE TO EXPRESS THEIR HUMBLE THANKS TO OUR WONDERFUL MEMBERS FOR THEIR ONGOING SUPPORT OF HIS RESEARCH

Minutes of the Annual General Meeting

Held on 16th August 2009

At the Balwyn Library, 336 Whitehorse Road, Balwyn.

Present Margaret & Doug Lawrence, Peter & Gwen McInnes, Barbara Rivett, Dorothy Brennan, Melva & Joe Behr, Valerie & Peter Simpson, Peter Males, June Cathcart, Margaret Foster, Barbara & Len Walters, Janet & Bernie Pettit, Margaret & Russell Wilson.

Apologies Barbara Clifford, John Burke, Tom Rivett

Minutes Minutes of the 2008 AGM were taken as read.
Moved: Dorothy Brennan Seconded: Peter Simpson
Carried.

President's Report

My report for 2008-2009 is a pleasure to present as we have enjoyed another good year at the IN Group.

Our Christmas luncheon was a great success, not only did we once again have fun raising money for research; we also enjoyed wonderful food and a happy day.

This year our meetings have taken the form of discussion groups and the feedback has been most favourable with our members gaining from the interaction.

The winter luncheon was another fun day with good friends. Bill Dair gave us a lesson on computers for beginners and everyone went home whipped up with enthusiasm.

Thank you to Melva and Joe Behr for the quarterly newsletter, a most interesting and informative means of communication to members. A wonderful job Melva gathering all the news together.

Our new web site is up and running and already we have received enquiries from new people seeking information. A very big thank you to Stephen Bowditch and the CSL staff for their assistance in setting up this first class site.

We have all the information constantly updated by Doug Lawrence. To all these people, my thanks.

The Geelong Cluster Group is doing very well. Meetings are held at Margaret and John Widdicombe's home and everyone is most welcome.

We had an Awareness Day this year with Janet and Bernie Pettit as well as June Cathcart, interviewed by their local papers. Another member, Steven Cohen, did a charity walk.

To the Committee and Helpers my heartfelt thanks, the assistance is marvelous and I would especially like to thank Barbara Rivett, our Secretary, who is retiring but only in that capacity. Barbara is still a much valued member of the Committee and our Librarian.

I wish to express my thanks also for the donations given by our members, towards research.

It is a pleasure to be part of The IN Group and I look forward to another great year.

Thank you.

Treasurer's
Report

The financial statements were tabled and discussed.

Moved: D Lawrence

Seconded: June Cathcart

Carried

Election of Officers

The following Officers and Helpers were elected for 2009/2010:-

President:	Margaret Lawrence
Vice President:	John Burke
Secretary	Peter McInnes
Treasurer:	Doug Lawrence
Committee:	Barbara Rivett Melva Behr Joe Behr Gwen McInnes Peter Males Brian Boyd Janet Pettit Bernard Pettit

Helpers:

Librarian:	Barbara Rivett
Newsletter:	Melva Behr
Public Officer:	Margaret Wilson
Library Key Pickup:	Dorothy Brennan
Tea and Coffee:	Barbara Clifford

General Business.

Library. Barbara has the library and there are some very good books in it so please see Barbara and borrow. We have bought a few new ones recently which are very interesting.

Peter McInnes moved that the meeting express their gratitude to Barbara for the service she has given as Secretary over many years. Seconded: Doug Lawrence Carried

June Cathcart asked that a vote of thanks be given to Melva because her job is ongoing the whole time. A vote of thanks was passed.

There being no further business the Meeting was closed at 2.15 pm.

Slippers. We have available for purchase slippers which are easy to put on, (like socks). They don't slip off when you walk, are made from very comfortable lambswool, are very warm and yet machine washable. They are ideal for sensitive feet, come in three colours, (cream, pink and grey) and are available in a variety of different sizes. They are not slippery. (Joe said he sleeps with them on if his feet are cold.) We can purchase them direct from the manufacture, with a price to members of \$25 including postage. They sell in shops for up to \$36. If interested, please see the order form enclosed with this newsletter.

WEB SITE

Have you visited our new website? We can be found at www.ingroup.org.au. Each month several enquiries are made through the website by people newly diagnosed with a variety of neuropathy conditions, mostly GBS or CIDP.

GUEST SPEAKER

Bill Stevens spoke on Hydrotherapy. (Bill was dressed in shorts and a T-Shirt as he had just come from taking two classes and didn't have time to go home to change. His fitness was obvious, his smile infectious and his age undetectable.)

I am not a health professional, I'm not a doctor or a physio and I'm not an actor either. The point I am making is that I'm just an ordinary guy. I'm a fitness instructor and teach a lot of classes, aqua aerobic classes, and strength classes.

I take a lot of classes in the hydro field. The difference between an ordinary pool and a hydro pool is just temperature. The ordinary temperature in a public pool is around 28-30 degrees. In a hydro pool it is 34-35 degrees. It is nice warm water. It is like having a bath water wise. Not hot but warm and warm water is very relaxing and it is a very non threatening environment.

Physios specialize in hydrotherapy. People go to them with special problems like a shoulder problem and the Physio would show them exercises to do in water. That's not what I do. I take a normal aqua aerobics class. I don't only do it in hydro pools but work in normal pools too. Younger people can usually work a bit harder but generally if you haven't tried exercise in water, it's of great benefit. It can be relaxing, strengthens your body, gives you something new to think about and you can feel the benefits.

There is a lot of strength training. I know some of you have problems with muscle weakness, foot drop, fatigue and numbness, which I won't say you would overcome, but you can work on in water.

If you take a dumbbell, just the very act of holding it is an exercise. You can stretch your arm out and bring it back, which works on the shoulders and you can push it out sideways. There are many exercises you can do and they are all beneficial. Without becoming muscle bound you can gently work things in the water and you gradually increase your strength. It just happens naturally if you do it a few times. You might find the first time it is even hard to hold the dumbbell, but then gradually you can push the dumbbell out and in. That is if you can hold it in your hand.

Some people find holding a dumbbell difficult so we also use Noodles (tubular foam lengths) that float. They are beautiful to use and you can push them forward, push them down, and you can sit on them as they float, with your legs out and you float in the water like a duck. These are all very easy exercises you can do and they all help. Noodles give extra balance in the water. You can hold on with one hand and probably start to lift your leg up and stretch it out and swing the whole leg and it gives you balance in the water. The water really acts like a corset. It presses into you one way or another so you know you can switch on every bit of muscles in your body standing there. You can hold on, balance, swing your legs forward and back, you can walk up and down in the water, you can jump if you can do it. There are so many benefits of working in water and it feels pleasant.

The class I do is 45 minutes. We start with a gentle warm up and then build up to exercises and there is nothing we don't do. We work our legs, which also works the hip joint, knee and again balance. People get very good after a while and put their arms up and do the same exercises without falling over, because you can't fall over, because the water holds you.

Hydro pools usually have very easy access. I have worked at both Monash and Ashburton. At Monash you can walk down a ramp. If you need a wheelchair, there is a water wheelchair. At Ashburton there is a moveable floor which can be raised and then lowered into the pool and if you need the water wheelchair they raise the floor and then lower it down and the wheelchair just floats away and you stay there. There is nothing to stop anyone from accessing a hydro pool. There is no excuse.

I constantly see people with walking frames who can hardly walk and the miracle is once they are in the water they can do all those things. Then they come out of the water back onto their walking frame. The freedom people get in the water is amazing and the benefit from just the water itself is such a relief. **Muscles relax in warm water, and things you can't dream of doing on land you can do in water without any problem whatsoever.**

I take lots of classes for people with disabilities. We don't call them disabled. We call them people with ability to do things; people with Downs Syndrome, Autism – young and old. On Tuesday nights I have a blind lady. She is not only blind but deaf. She just floats there by herself. She floats on her back with a smile on her face, her hair flowing, she looks like a fairy. That's great to see.

Other people with real disabilities have a great time in the water and it is very rewarding when you see that and it also provides an environment to meet other people. You come across different people and a group I have has its own fan club and they go out for lunch and dinner and always stay after a class and have a cuppa which is absolutely great to see. The group exercise creates a group environment to relax people.

Victoria University at the moment is doing research to see how people with MS can be helped through aqua exercise and one of the research projects is using strength training to measure what sort of benefits there are. They are in the middle of this research at the moment.

There are definitely great benefits to be gained. If you have limited movement you can gradually increase it. Just by using your hands in the water against resistance gives a lot of movement. Just the simple act of the breaststroke with the hands pushing the water away from your chest, keeping your shoulders together nice and straight is really a great exercise in the water and so simple.

If you have any questions, please talk to me, but the benefit of water exercise is nothing new.

Gwen: How did you get into it in the first place?

Bill: I'm not so young anymore, despite my short pants, and I spent 40 years working in the wine industry. I was with the Fosters Group, through different wine companies that merged and were taken over. I was Export Marketing Manager and spent most of my time travelling overseas for the past 20 years. I retired in 1996 but I was always running. I was a fitness addict as when I first got married I started to get a bit of a tummy for some reason. I took up basic exercise and running and have been running ever since, only giving up 3 years ago because my knees started to pack up a bit. I did marathon running. A lot of people know me from that. It was great exercise that you could do any time. Being overseas, not big noting myself, but in Central Park New York you could go for a run before work. It kept me fit during my working career and it was a great job.

Before I retired I had a few injuries and I went to a chiropractor, who said "If you don't stop running you will end up in a wheelchair and the only thing you can do is swimming". I took his advice and took up swimming but it got a bit boring. The pool I attended had an aerobics studio (this is probably 20 years ago now) with lots of beautiful girls doing aerobics so I thought, what am I doing here in the water, I should be up there doing aerobics!

I started aerobic lessons and it agreed with me perfectly, not just my eyes, but my whole body appreciated it. Then to become more proficient I took up a course and became an aerobic instructor and did the course at TAFE and became a fitness instructor for gym, aerobics then added aqua instructor. **I have just been awarded Aqua Instructor of the Year for Victoria which is great at my ripe old age.**

I work 7 days a week, a bit crazy, but keeps me off the street and I enjoy meeting all the people. I have participants from 17 years of age up to 70 odd and it varies enormously and I get great satisfaction particularly if I see people with health problems who I can help in some way. That's most rewarding.

Some people come up to me and say I had trouble with my shoulder and now its okay and this is just by participating in some aqua exercise. It's not competitive; you can do it any day, in an old T-shirt or whatever you are comfortable in.

Margaret: When you get out of the water if you have arthritis and you have aches and pains and you can do a lot more in the water, does that overstretch you?

Bill: No it doesn't. It's the warm water that helps you relax. I did a course with the Arthritis Foundation. Their exercises are very gentle.

In my classes you can do it at your own level. Some people go very gently, other push through the water whoooosh. It's all up to you and what you feel comfortable with. You don't have to use equipment, just your hands if you wish.

The cost is \$7.50 a session, probably less with concession.

Melva: Is there an exercise for sore hips? Our members sometimes get sore hips because of their unusual gait.

Bill: In the water the muscles are relaxed and you can do your hip exercises more easily. The range of motion you get is what is okay for you as long as it doesn't hurt you.

Joe: Sitting in a nice spa with the jets going would that be good for you.

Bill: Yes that's very good.

June: I have had GBS for 20 years and my doctor told me to go to water exercises 18 years ago and I have been going every week since then and it's absolutely excellent. You come out feeling ever so much better than when you went in. It really is great.

Dorothy: I did it for a couple of years, but I had to give up because I got ear infections from the humidity. Have you heard of that before?

Bill: Not so much from the humidity, but you can wear ear plugs if you need to. People should avoid getting water in their ears. Generally, from a hygiene point of view, the public pools are better maintained than a private pool. They are constantly taking samples of the water and adjusting the chloride and they are usually pretty safe.

June: Do you use music?

Bill: Yes. Music is a critical part. We have 60's and 70's music, old favourites and then classical music.

Gwen: I go to Bill's class. I have friends who say "not until I can fit into my bathers" but it doesn't matter. Everyone is too busy to look at you. Why are you so important or why am I so important? Once you get there you will truly enjoy it. When I go home I am exhausted but I feel good for it. And if I don't go I do miss it. You get into the water sometimes and you think "goodness it's hot today" but in 5 seconds you think it feels cool.

Thank you Bill for coming along today and I hope you will enjoy this bottle of wine and stay with us for afternoon tea.

Bill: I am a vegetarian but I do drink 2 to 3 glasses of wine with my dinner.

Hydrotherapy is available throughout Australia. Ask at your local council as they should be able to tell you where the nearest pool to your home is located, and give it a go.

SUPPORT

Lady from Melbourne enquiring for her father.

Another gentleman with GBS in Brisbane.

Mother re daughter. Still undiagnosed now suspected MN.

Sydney mother phoned. Son GBS needing more treatment.

Friend enquiring for assistance for workmate.

Young father seeking neurologist. Suspected CIDP.

Our thanks to the members who pass on information re support at the hospitals, to their GP's, specialists and therapists.

A special "thank you" to Brian Boyd for his work in this area.

E-mail Mailing List

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

If you use *hotmail* or have junk mail filtering software running you will have to include the above email address in your “safe list” otherwise *hotmail* or your junk mail software is very likely to delete our emails.

GEELONG CLUSTER NEWS

The Geelong Cluster will hold their Christmas Luncheon on Sat. 7th November at 12.30pm. \$10 per head. RSVP to Margaret Widdicombe on 52445311 or Dee Cooper on 5244 3382 by 3rd Nov.

All Welcome.

BRISBANE CLUSTER GROUP

Over recent months we have had several enquiries from newly diagnosed patients in the Brisbane area. If you are interested in being part of a “cluster group” around Brisbane, please write to The In Group, Attention Melva Behr or email behrsdn@optusnet.com.au.

EXERCISE

Some of the larger shopping centres now have walking clubs where you can walk at your own pace, in all weather and in a safe environment. Some of our members are enjoying these clubs for the exercise, the company and maybe even discount shopping.

FOR THE DIARY- Tentative Meeting Dates for 2010.

First Meeting - Thursday, Feb.18 – 7.30pm. Then Sunday 16/5, 15/8 at 1.30pm,
Winter Luncheon 25/7 and Christmas Luncheon 28/11 at 12.30pm.

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Australian Business Number (ABN) 77 954 503 188

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