

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)
66 Eva Street, Clayton, 3168.

STOP PRESS

Change of Date for Annual General Meeting

Please note that our AGM will now be a Sunday afternoon meeting held at the Balwyn Library on: Sunday, August 12th at 1.30pm.

Winter Luncheon.

The Winter Luncheon will again be held at the Lawrence home, 22 Belmont Rd., Glen Waverley, **on Sunday, 24th June at 12.00noon.**

The menu this year is: A variety of home made Soups, Gourmet Small Pies, Sandwiches, and Scones (both sweet and savoury). The Cost will be \$20 per head.

Everyone is very welcome. This is a relaxing day with lots and lots of chatter. A very social gathering of members and friends.

Please RSVP by Monday, 18th June for catering purposes. (9802 5319)

Meeting held Sunday, May 20th, 2007.

Our President, Margaret Lawrence, welcomed everyone (40+) to our first daytime meeting, especially guest speaker Dr. Russell Gibbs and the Geelong Cluster Group.

She read an introduction to Dr. Gibbs saying "You graduated from Cambridge in 1954 with Medicine and Arts degrees, coming to Australia in 1963 before further training in Europe, the United States and Canada during the 70's and 80's in preventive medicine, exercise theology and health education. This passion produced 5 books and 3 films with national and international awards.

Chairman of the National Preventative Medicine Committee for 6 years and formerly a senior lecturer and examiner in Medicine, you tried retiring for 10 years, came to Mornington in 1994 where you work part-time in general practice. You have a special interest in preventative medicine and have worked widely in rehabilitation and mental health.

After 6 decades competitive sport has taken its toll and you now lose your breath on a treadmill, enjoy opera, European languages, renaissents culture and especially valued time with your wife and extended family and small spaniels."

Committee member, John Burke told us "Russell is not only a Doctor but also a patient. We have our infusions together as he has primary immune deficiency. Russell has seen life from both sides of the medical fence."

Talk given by Dr. Russell Gibbs. (abridged)

How many of you people suffer from GBS or CIDP?

(A show of hands followed.)

There are a lot of people, and the rest have come because you are interested. It is important for partners to be interested.

I am going to talk to you first of all about the basis of exercise. Lots of things are said about exercise; mainly that it is bad for you. Winston Churchill (when they asked him “What did he do when he felt like exercising?”) said “Well I lay down until the feeling goes away.”

About 2-1/2 thousand years ago Hippocrates (who was actually the father of medicine) and who wrote the Hippocratic Oath, said, (and this is important as to when you exercise and when you don't) **If you exercise when you are unwell or acutely sick you just adding a disturbance to another disturbance, so you don't do it.**

The key thing is (particularly with these conditions) that you **don't exercise until you are better** and if you get a bad patch, even for example in the week after your flu' injection it's probably not a good idea to exercise much.

Primarily the conditions we will be talking about are **Guillain-Barre` syndrome and C.I.D.P.**, which is a special variety. Guillain and Barre` were physicians in the 1800's and we used to think this syndrome was mainly due to flu' as we used to see it after the earlier immunisation vaccines but now most of the newer cases **occur in reaction to a particular bacterial infection.**

It started about 10-15 years ago. There is a bacterium called **campylobacter** which is a common infection that you can pick up from eating bad foods in restaurants and it's actually notifiable. If you get an infection or wog - there are two sorts. You can get transitory for 24 hours or so of diarrhoea and vomiting from eating something that's dead but still poisonous. It irritates your system. Then you get something that makes you vomit to begin with and you get diarrhoea that persists for 4 to 5 days and it doesn't get better and you feel unwell and you go to the Doctor and he'll take a swab and if it comes back as campylobacter they go and inspect the restaurant. What they discovered was, (after a great epidemic in China), most of the causes of GBS now are due to this campylobacter infection.

My point of view, (when I was working in preventive medicine) was always to give my patients the maximum information about their disease. **The more you know about the condition the better you can manage it**, because otherwise you only get more knowledge by coming to a group like this or when you go to hospital.

This is what happens. **Shown on diagram 1.**

There is your brain – The brain does two things.

It receives messages from your body as to what's going on.

For example – if you sit on a pin your brain will receive that message very quickly. The message goes to the brain, the brain says ouch and the brain immediately sends a message back “Get off your bottom”. This is called sensory (up) and that is called motor (down). This works through the brain.

Here is your spinal cord which goes down to your bottom and from there nerves go out to your muscles, your gut and everywhere. Now what happens is this. There is a long message that comes down your spinal cord and there is a little signal station that relays the message to another nerve, just like the telephone system and these are called nerve fibres, and this particular bit across there is pretty well automatic. If you have something that's uncomfortable the message will go up there, then across, then come down and miss out that part, so there is a link. Certain conditions affect there.

I worked looking after people who jumped out of windows, crashed motor cars, or dived into swimming pools and they damaged their spinal cords up there. They have a certain amount of automatic or reflex activity, but nothing goes to their brains and that's why these people have to be fed with tubes to their stomachs etc.

I used to see, quite commonly, people who fell off their motor cycles and got their arms pulled out of their sockets. Nothing happened to their spinal cord but they were paralysed there at a lower level and this is called upper neuron disease.

This is lower neuron disease. Now in this group falls Guillain-Barre` and other things like Polio. You don't see much Polio now as everyone has immunisation, but when some of you and I went to school commonly you would be sitting next to somebody and the next morning they would be dead. That was because the virus hit the anterior horn cell and would actually stop all messages going down the spine. That is one cause, secondly you get injury and then thirdly you get people with funny diseases like **GBS and CIDP that actually attacked the lower motor neuron.**

Some attack the long fibre and some attack the cell **and we actually believe it is due to your own immune system being tricked so it turns round and tries to knock itself off. It produces the wrong sort of antibody which instead of protecting the body it does damage. What we call auto-immune conditions**, such as rheumatic fever, rheumatoid and the like can be caused by disturbance of the immune system.

Something which is beginning to happen is called gene therapy. Genetics is a science of how you are made up because **we are all uniquely individual** and if you cross a white chicken with a black chicken you will get 4 khaki ones, 2 black and 2 white ones. That's what we were talking about 60 years ago. Now we know much more. We have, by picking up how peoples' genes work, gone from the general study of diseases to genomics in which we can look at the individual gene makeup of different people and also look at the makeup of some of the drugs, try the drugs against gene patterns and stop a lot of adverse reactions. You read of kids dying from peanut allergy. Those things we will be able to fix in the fairly near future.

They are developing very rapidly now a new science called "Pharmacogenomics" which is the makeup of an individual, matched against drugs and this is particularly so in the field of mental health which I work in some times. You find you can give a drug to three people, one it won't make any difference, the other it will help and the third it will send through the ceiling. To find out which patient is which can be a protracted and uncomfortable experience for patients.

CIDP, GBS and Exercise. When well, why will exercise help?

There are diseases that you can get, that attack you, damage bits, and then go away and you are often, to a degree but not always, able to recover some, if not all, of your function and this applies to GBS and CIDP. Now how does that actually work?

I've drawn another picture which represents a muscle and shows how muscles work. In your muscles you have bits of fibres which when the muscle contracts they shorten and the bits go in like that and when it relaxes they stretch out and there is a message from your brain which says tighten and it does that and relax and it does that.

Now for everyday activity it happens that we don't use all our muscles. That's why athletes when they train (you see the girl swimmers getting bigger and bigger shoulders) develop muscles. **When we were created we were given a lot of extra capacity.** Eg: As we are sitting now you are only using ¼ of your lungs. When you take a deep breath you can get three times as much air into them. **This is a defence mechanism for working at maximum.**

There is a fact called "specific adaptation". **You can adapt to being fit and building up your muscles**, e.g. a weightlifter will build up his arm and leg muscles just to be able to lift things once. A marathon runner wants efficient muscles, a big heart and big lungs.

So for everyday purposes we use somewhere between 0-40% of our muscle capacity.

You notice when you do something unusual or you work harder your muscles can ache. That's because you have gone beyond the part you normally use. That's why this picture is like this. This is the part you use for everyday activity. It's a bit like a telephone exchange. There's the factory. The factory is not in full production and a message has come along to say "work". If you get an increased demand you can gradually use all these extra bit of muscle you don't use. The possums have probably eaten part of the nervous control, but if you try you can, if this bit here has been knocked out, it maybe, not always, but usually, you can get a bit out of what's there and you've never used. And that's why exercise is useful in these conditions. You may have bits knocked out but the other bits you can use. I am saying that you can adapt to training.

When you get trouble with your muscles there are three things that trouble you when you want to exercise.

Firstly – don't do it when you are unwell.

Any little bit helps. People who have been paralysed the first thing they have to do is literally lift their hand against gravity. All do it now. Lift your hands up to there and down. There are people who can only do a small amount but you can do just a little bit at a time. It can take a year or two to get stronger.

First of all you get muscle spasm where your arm or leg is pulled into a different position. Nowadays you get injections of Botox. Does anyone here have that? (Some chuckle.) I mean for their muscle spasms. I treat a man who has Parkinson's disease and his feet cross over, so we gave him some injections of Botox and his feet are now in a straight line. Botox is new, only available in hospitals or cosmetic surgeons at \$400 a go.

The next thing is Pain on Movement. Who gets pain on movement? (A show of hands showed the majority of our members had pain on movement.) Good.

The third thing is contractures. You all know what spasms are well contractures are like this. When I stick this arm out it goes all the way, but the other arm (shows audience) only goes to there. That is contractures. They are due to bone changes but commonly the contractures are due to tight muscles.

How many of you find that you can no longer get your legs or arms or whatever out straight. That is one of the things that happens so what do we do about those? You can go off to a physiotherapist who will work on you hard and you can have either injections of Botox to release those contractures or in the old days we used to cut the muscles.

Has anyone here heard of Sister Elizabeth Kenny? What did she do? Answer : "She was involved in exercise programs for Polio." Yes. She (was born in Australia) pioneered treatment of Polio to restore people's function and get people who had been paralysed by polio but still had muscles and things to work. She worked at them in a way that the doctors couldn't and interestingly her work was done in 1940. She went to America to teach nurses there to do physiotherapy.

Her work is simply this: She felt that if she applied hot packs or else put patients in whirlpool baths (jet spas) you could warm up their muscles and gently massage them and try to get them out straighter. And that actually, (in spite of all the new techniques) works well. All the old things we used to do seem to have been forgotten and this is where my little bit at the beginning about the patient being aware of what to do becomes important. You can learn to do that.

When we talk about exercise, I have spent time talking about why we exercise in GBS and CIDP and what goes wrong, i.e. we get muscle spasms, we get contractures and we get pain on movement. It is perfectly obvious that if you are going to try and move something that's painful, if you warm it up first to increase the blood flow through it and do just a little bit at a time and just slowly increase it and I mean slowly increase it by 10% a week, it will be better for it.

I teach exercises to people with bad backs because they have weak tummy muscles.

I say to them do three of these twice a day for a week. It may be a lady of 75 but no more than three a day. The next week I say go on to 4 the next week 5 and over a period of 2 months they can not only do from there to there 10 times. Arms crossed over chest, lean back slightly to begin with, then lean forward the same amount, then return to the sitting position. Slowly day by day increase the amount you lean back and bend forward until you have gone as far as you can. That's how you increase exercise.

When we talk about exercise we mean being fit. Who thinks only young people can be fit? Nobody good! Anybody got an idea what fitness means? **Simply fitness is the ability to carry out your work with vigour and alertness and to enjoy an active recreation.** (I sit next to John every month and he tells me he chases around a hockey field with a first aid bag. That's his active recreation.)

The last thing is to have a bit left over for emergencies. And that's important because if you have a heart attack whether you survive it or not depends on how big the heart attack was but also how much extra work your heart had to do. I am not making a point of this because obviously if you are disabled you can have a problem with your weight and also as you get older, but I see young people 35 with heart attacks who don't survive because they have 50 cigarettes a day, drink a lot of grog and just generally knock themselves around and their heart isn't in good condition and if a bit gets knocked out and if what's left over isn't good enough they die. **That's fitness.**

When we get older we need different fitness. Sometimes I say to a patient, "Why at your age do you want to go push a lawn mower around? It's not only hard work but its overload for you. You've got a lot of arthritis and you don't want to do that because you'll rub your joints together for too long." "If you want to go dig in the garden do it but stop after half an hour." It depends on your age.

There is general fitness which is heart/lung fitness and that mean endurance. Endurance means to be able to do your work without fatigue and have a bit left over. Now you can get local endurance like the lady doing sit ups because when she can cope with 20 within a fortnight she can cope with 100. If you have particular needs like difficulty getting out of a chair, you tend to use ancillary muscles. You use your hands, to push yourself out of the chair. **You should do leg lifts when you sit in the chair because (put your hands on your thigh muscles) you will notice that that muscle gets stronger.**

Once I had a disaster with my leg and all I did was sit, pulled up my toes and lifted my leg. **You can do this if you are in a wheelchair or not. Just start off slow with 5 and gradually work up to 10. I was doing 100 eventually and I built up my muscle.** Then I sat on a stationary bicycle.

You need to use your muscles in the full range of movement. If you don't use them through their full range of movement they don't benefit. It's use it or lose it.

Question: You say we shouldn't exercise when we are ill. How do you decide when your ill?

Reply: **When you live with a chronic disease that doesn't mean you're ill.** You have a condition - you are not ill. If you get a germ and you exercise your increasing your lung capacity and you spread the germ around. So don't exercise when you have a germ.

You also exercise tolerance. You listen to your body. When you first start it can be uncomfortable as you are bringing more muscle bits into the act. E.g. as you're sitting here the amount of blood going through your leg muscles is about 500mls., which is a pint a minute. If you go for a brisk walk the blood flow through your legs will go up to something like 5 litres a minute because the blood redistributes itself to the muscles you are using.

Question: If you have wasted muscles will exercise help them?

Reply: **Yes** because you are exercising the bits of the muscles that are left over and you can stimulate those parts. That's the whole point of exercise - it does three things, increases the physical size of the muscle fibres, makes them chemically more efficient and brings more muscle fibres in.

Question from Fred: I have recently been invited to join a program organised by Monash University called something like Exercise for Living for Living for Older People (Aged over 70). Do you know of this program and do you endorse it or not?

Reply: I'll answer your second question first. **Yes -I do endorse exercise for everyone.** The only thing is I would have thought that in terms of research, all the exercise research had been done many years ago.

Question: Some years ago we did a survey of Members and asked them could they find anything that they thought may have caused the CIDP & GBS and one of the things that came back was that some people had increased their exercise prior to GBS. We had a young girl who was a marathon runner who came down with GBS and we had quite a few people who had started doing physical exercise after quite a few years and they had come down with CIDP and I just wondered if anything has ever been looked at in that regard.

Reply: Because I work in this field I can answer this reasonably well **that if you over exercise you can overload your body quite seriously.**

People who do marathons, and now kids who over train (as a lot of kids are playing out their parents wishes) by swimming 6 days a week or training equivalently and increasing the intensity in order to go into a competition and win, **what happens in those cases, if they overload themselves consistently they get an overtraining syndrome.**

First of all they get very irritable. Secondly they can't sleep. Thirdly they get what I call reversal of sleep rhythm, i.e. they sleep in the daytime and can't go to sleep at night. They also get raised pulse rates, and abnormality in heart rhythms.

The other thing (which is most particular and may refer to CIDP) they get internal changes in the blood, usually caused by muscle destruction from over training. If you get a system in which you can meet the load but the load is increased and the person goes on doing it, you get a breakdown in the muscle and there is an enzyme in the muscle called CK. The upper level is approximately 45 and you see in these children and some of the adults it can go up to 600 or 1000. When you get that it is not surprising, particularly if you get any of the intercurrent infections, viral infection, that the body can normally knock off, the body is unable to respond in a normal way therefore it will respond in an abnormal way. I can only give you that in general terms.

What I have here is a little program that says "Exercise is for the Elderly". I will get John to copy them for you. These are fairly simple. I will get John to copy them. They have been published all over Asia. About 300,000 of these and I get people from all strange places ringing me up for copies.

I write books and I'm always interested to read what I wrote. I think "did I write that?" More and more doctors are convinced that **exercise counter-attacks the ageing process. Without ample exercise our hearts and muscles become flabby. Regular exercise can change your level of fitness to that of a person 10 to 20 years younger and is considered an important factor in preventive medicine.** But start your exercise program slowly and gradually increase the amount of work performed in progressive easy stages. The mind ages more slowly than the body. It is our greatest resource against ageing and it too benefits from exercise through improved circulation. A sound mind goes hand in hand with a sound body. (What I do with some of my elderly patients is tell them to do those Sodoku things. Has anybody tried that? It's quite interesting to do.)

Consider these benefits of exercise: It enriches the blood while improving circulation, restores elasticity and strengthens the muscles, builds endurance, improves posture by keeping the body straight and erect, improves morale, improves confidence and makes you feel and look better.

If you exercise start gradually, about 10 mins. per day. Do it 3 times a week and gradually increase. If you are doing repetitive exercises like the ones here you avoid dizziness with a brief pause between exercises. Also take deep breaths between exercises. Always rest when needed.

Make exercise part of your daily routine.

Necklaces, Bracelets and Earrings.

One of our members, Gwen McInness who has a love for craft, makes necklaces, bracelets and earrings which she donates to The IN Group. All proceeds go to research.

They are made with either a magnetic clip or fob closure so are user friendly for people with disabilities (and others) as they are very simple to do up and undo. Necklaces are priced at \$15 usually, Bracelets \$10 and Earrings \$5.

Gwen will display her wares at the meetings. \$200 has already been bought by the Committee!
Editors Note: They are great!

Thank you Gwen for this generous donation.

Support News

On Friday 14/5 Janet Pettit rang Yvonne in Violet Town. She and her husband, Bernard, both spoke to Yvonne then sent a copy of the small Guide to CIDP and a copy of "Boy Is This Guy Sick".

Jan rang Yvonne again on 1/6 and was told her Doctor was very interested in the booklets and is sending Yvonne to a Rheumatologist to check previous diagnosis of Fibromyositis. Yvonne was also very interested in the medication LYRICA which Bernard has been prescribed to ease the pain in his legs.

As Bernard and Jan are visiting Echuca from 8/6 for a few days they have arranged to meet for a short chat and to bring a copy of A Road to Recovery – A-Z. They will ask Yvonne to put the IN Group support posters in both the Shepparton Hospital and her doctor's surgery.

Bill Andrews (Queensland) Friday 1.6.07...has been diagnosed with CIDP which started after both his knee joints were replaced in 1998. Bill has seen a few neurologists but he is not convinced that he has CIDP. Bill is currently seeking further advice.

He also said his initial IV treatment with 'Intragam' could not be done in a public hospital in Queensland. This being the case he had to go Private which cost him \$125 a session. After much negotiation he is now receiving his 'Intragam' in a public hospital.

He speaks of having an epidural anaesthetic for his knee operations and coincidentally I also had an epidural for an ankle operation shortly before the onset of CIDP.

There may be no connection, but just for the record it would be very interesting to hear of any reports of similar circumstances prior to the onset of Peripheral Neuropathy.

Bernard Pettit.

New Member, Peter Alway from Sydney has spoken to me a couple of times. He has been diagnosed with CIDP and was sent the CIDP Booklet. On 7/6 he phoned again to report he had tripped and fallen breaking a toe and injuring his hands. We had a lovely chat and I am sending him a copy of The Road to Recovery A-Z.

LYRICA. A drug for relieving pain in people with Peripheral Neuropathy.

If you suffer from pain in your feet and/or hands perhaps this drug could be mentioned to your doctors. This drug has been mentioned in three different conversations I have had during the past week.

The first time was with Ann Braithwaite from Queensland who phoned looking for a book called "Numb Toes and Aching Soles" by John A. Senness. It is an American book. Can anyone help?

Melva Behr (03 9707 3278)

New Zealand GBS Support Group Conference

In April this year my husband and I were lucky enough to attend a conference held by the New Zealand GBS support group. We knew about this group through my sister who lives in New Zealand and joined it when I got sick way back in 2002.

In some ways their support group is like our IN-Group. The population of New Zealand is roughly the same as the population of Melbourne, so the number of people affected by GBS and CIDP is probably similar too. However in New Zealand people are more geographically spread so it is not possible for them to have regular meetings. Small groups of people do meet in 'clusters' in different towns and cities, but much of the support is offered in other ways: through a regular quarterly newsletter; a conference held every second year and a very informative website.

We found the conference very stimulating. There were presentations from people (like us) whose lives have been affected by the neuropathy and there were presentations from doctors who work in this field. We were particularly interested to hear the talk by a neurologist called Dr Gareth Parry who is a professor of neurology at Minnesota University in the USA. He started by saying, 'I have a message of hope' and then talked about new treatments for people with CIDP and GBS.

I bought a copy of a book that Dr Parry has written recently with one of his colleagues, Dr Joel Steinberg, called 'Guillain-Barré Syndrome'. It is published by Demos Medical Publishing, Suite 301, 386 Park Avenue South, New York, NY10016 USA. I do not know who sells it in Australia. The book deals with every aspect of GBS, from diagnosis to rehabilitation. It includes stories about some of Dr Parry's patients and has the most clear and comprehensive description of the neuropathy that I have ever read. There is a whole chapter on CIDP as well.

The web address for the New Zealand support group is. www.gbsnz.org.nz. On the website they have posted copies of their recent newsletters, they have stories from various members and they have links to research. They are planning to post a conference report in the near future.

The next New Zealand conference is in Auckland in 2009. I know that they would welcome Australian visitors.

Valerie Simpson

A Message from Margaret Lawrence

Doug and I spent 2 1/2 hours discussing The In Group aims and how CSL can be assist.

We sat in the Board Room with - Jeff Davies General Manager Aust. & NZ.
 Dr. Elizabeth Campbell Director Sales & Marketing
 Dr. Darryl Maher Medical & Research Director.

Some of the suggestions that came out of our visit were:

- help to set up and maintain a proper Web site
- the offer of transportation for a proposed visit to CSL.

We learnt that \$50000 per year goes to Andrew Kornberg for research purposes - at Andrew's discretion.

We enjoyed a tour of the plant and learnt much about how the blood products are derived at and all their production methods and safety checks etc. - extremely interesting!

We came away feeling very pleased CSL are so interested in us and their wish to help.

Email: If you want your email address on The IN Group list email jburke@contracts.com.au.

ANNUAL GENERAL MEETING
Sunday, 12th August 2007 at 1.30pm
Balwyn Library Meeting Room
366 Whitehorse Road, Balwyn.

1. Confirmation of Minutes of 2006 AGM.
2. Reports from President and Treasurer
3. Election of Officers and Members of Committee.
4. Receive and consider statement under section 30(3) of the Act.
5. Any special business of which 21 days notice has been given.

Nomination Form - Committee

Position: Nominee:
 Nominated by: Seconded by:
 Accepted by: Date:

To be returned to: The Secretary, The IN Group, 66 Eva St., Clayton, 3168
5/8/07.

The In Group Committee has received copies of two publications.

1. REVIEW OF AUSTRALIA’S PLASMA FRACTIONATION ARRANGEMENTS.

Fractionation is the separation of a substance into its basic constituents, and is the process by which ‘Intragram’ is produced from Plasma.

This report, prepared by a panel of experts, was presented to the Federal Minister for Health in December 2006.

The report, in 243 pages, considers the advantages and disadvantages of allowing Australian Plasma to be processed overseas.

The panel of experts concludes that “overseas fractionation of Australian Plasma is NOT an advantageous option for Australia”.

The report also stresses the need to increase the involvement of Australians in voluntary blood donation programs.

2. GBS/CIDP FOUNDATION INTERNATIONAL THE COMMUNICATOR.

This publication is a quarterly Newsletter of a volunteer, umbrella, non profit organization, based in The U.S.A

It operates under a Board of Trustees, a Board of Directors, and has 25 doctors on its Medical Advisory Board.

It organizes symposia and educational programs in America and overseas, and although no actual figure is mentioned, it is clear that the organization has substantial financial resources.

In 2006, 70% of their funds came from corporate donations.