

INFORMATION

GETTING BETTER SLOWLY

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)

GUEST SPEAKER – DR. RUSSELL GIBBS

Anxiety and Depression

15th February at the

Balwyn Library, Meeting Room, Whitehorse Road, Balwyn, 1.30pm.

Dr. Gibbs asks that members invite any friends or family who could benefit from knowing more about these life-changing feelings.

Dr. Gibbs lives with an immune disorder and understands first hand how our members are affected. This should be a very interesting meeting.

A small plate would be appreciated.

ANNUAL CHRISTMAS LUNCHEON AND DUTCH AUCTION

What a great day we had of festive eating, spirited bidding but most of all support. It was a great day to welcome new members Kath Jinette, John DeRavin and Gary Moglan, who attended their first meeting and soon got into the spirit of the occasion.

It was especially good to see stalwart members Fred Hooten and Peter Malcolm at the meeting and continuing their recoveries.

Patron, Dr. Richard Starke and his wife Janet lent their support to our special day.

Special thanks to all the wonderful ladies who did the arranging and catering and of course our Auctioneer, Ken Clarke and his elves Doug Lawrence and Margaret Wilson (the money collectors) for their tireless work. We were exhausted watching them in action.

We raised an amazing \$900+ Thanks to those who generously supported this day.

DATES FOR 2009 MEETINGS AT BALWYN LIBRARY MEETING ROOM.

General Meetings:	Sunday, 15 th February	Dr. Russell Gibbs
	17 th May	
A.G.M.	16 th August	Bill Stevens – Hydrotherapy
Christmas Luncheon	29 th November	

WINTER LUNCHEON AT LAWRENCE HOME - RSVP 9802 5319 BY 20/7/09

Winter Luncheon 26th July

KIND WORDS FROM DR. RICHARD STARKE. (Between Courses.)

We are delighted to be here. You really should be very proud of this association. It is a terrific association. Inflammatory neuropathies are a particularly difficult group and I think it is enormously important to have a good support group to help people who have been newly diagnosed.

Inflammatory neuropathies are not all that rare, but no-one has ever heard of them. Most people here, the first time they have heard of the condition is when they are diagnosed. To have a condition which is so intrusive, (in some cases really disabling and in other cases just an ongoing damn nuisance) and just keeps on getting at you, it seems unfair that no-one has ever heard of it, so it really is important to have support group backing. I don't think there is any doubt this group "punches above its weight" and is very influential.

The amount of money you have raised to assist research is extraordinary and I think you know from the medical point of view we are very grateful. I know Andrew Kornberg is grateful and I'm sure the whole medical fraternity is grateful too.

Looking at the Newsletters, the thing that has always impressed me is the number of people from overseas who see the Newsletters on the internet. They comment "that this is a terrific resource and better information than we get from our own people." These comments come from America, Canada and all over and I think it's marvellous.

A lot of you will be receiving 'Intragam' as intravenous infusion and other treatments to help your inflammatory neuropathy. 'Intragam' is one thing that has made a big difference in treating disorders of this sort. It becomes a routine. You go in and have your 'Intragam' once a month or every 3 weeks or whenever it might be and it works so well and it keeps things stable and people tend to just keep rolling on. I do think it is necessary to keep under medical review. There are things that are changing. Not a huge amount because 'Intragam' for many people is so good, but I think it's true that the Blood Bank has made a decision that people should be reviewed every 6 months. Speaking from the Neurologist Association's point of view, we think that's a good idea too and would encourage you to do it. Often there are minor other adjustments to be made as well.

I don't want to spend time telling you what neurologists think you should be doing, but I really think you should all be proud of this association which does a terrific job and has done for a very long time. It is obviously in very good hands and now I think you should enjoy your dessert.

(Editor's Note: Our members appreciated Dr. Starke attending and allowing them to speak to him in a casual environment. I'm sure we all did enjoy dessert – I know I did!)

“Thank you” to John Burke for making name tags which we wear at our meetings.

DONATIONS FOR MEDICAL RESEARCH

The generosity of our members allows us to make significant donations to medical research into peripheral neuropathies. More on that in our next issue.

GBS/CIDP CONFERENCE IN NEW ZEALAND – MAY 1 – 3, 2009.

A message from the President of the New Zealand Inflammatory Neuropathy Support Group, Mr. Bob Stodart.

For me, the conference is the highlight of our support services. We attempt to assemble the best possible programme, with something for everyone. So this little homily is a thinly disguised ploy to urge you to attend if you possibly can.

Speakers will include Professor Gareth Parry, a world authority on GBS/CIDP, especially the associated pain that some patients experience. Gareth always brings fresh insight to his presentations and he is determined not to leave the conference until he has answered everyone's questions. He will be supported by Dr Forbes Bennett who works in the Intensive Care Unit in Hastings. More than 40% of GBS/CIDP cases are admitted to hospital through ICU so Forbes will unravel for us what goes on during those early, stressful days. Dr Pralene Mararaj is an Auckland doctor who recently had GBS herself and she will share with us a very personal view of her experience.

There will be other speakers and a FORUM especially set up to answer questions from the floor of the conference. And a particularly popular session is when the whole conference breaks into small groups for people to share their GBS/CIDP stories. These sessions usually produce good questions for the Forum session. The conference is for patients, caregivers, family and supporters and the medical specialists attend to help us understand this strange medical malady that is GBS/CIDP. I firmly believe that the social interaction is of equal importance to the new, medical information. Friendships are made, experiences shared and fresh hope is engendered.

Make plans now to be in Auckland at the Airport Gateway Hotel, on 1,2,3 May 2009. I hope to see you there.

Anyone interested in travelling to New Zealand for the Conference can obtain more information from Melva Behr on 03 9707 3278.

MILLER FISHER SYNDROME INFORMATION

We have received an information leaflet on Miller Fisher Syndrome from the U.S. group. Available from Melva Behr.

THANK YOU TO CSL.

We are so grateful to CSL for their generous support in helping us get our Website updated. It shouldn't be too long now before we are up and running with updated information and contacts.

TWENTY YEARS ALONG THE ROAD TO RECOVERY 2008

August 6th 1988

I was teaching at Stawell Special School. It was morning recess when we all gathered for a cuppa. I had a peculiar sensation of tingling in my hands and didn't feel well. At lunchtime I went to my Doctor who sent me home with antibiotics as well as instructions to stay in bed. Little did I know that I would be in that bed for over 5 months.

As the days passed, my condition deteriorated. My husband, as well as my youngest daughter (who was in year 12 at the local Secondary College), were doing their best to care for me as I had lost the use of my arms. I found it difficult to walk, experienced excruciating pain in my limbs and a burning sensation in my hands. After 6 weeks I was sent to Epworth Hospital to see a Neurologist who diagnosed G.B.S. I hadn't heard of Guillain-Barre` Syndrome (GBS). I wasn't hospitalized as my husband and daughter opted to look after me at home. This suited me as I found it difficult to tolerate any noise. When in so much pain all one wants to do is to rest. The only medication prescribed was 'Clonazepam' and 'Panadol'.

As the weeks went by I was becoming anxious to hear any information about this illness. We discovered there was a Support Group at Queen Elizabeth Hospital Adelaide.

After making contact, we were sent a letter and Newsletter from the secretary who also had GBS. I joined the group and received many more Newsletters as well as private letters from this lady who told me of her progress. I was surprised and interested to read letters sent in by others whom also had been diagnosed with GBS. There were published in the Newsletters.

Gradually I was **Getting Better Slowly**. During this time I had many visits back and forth to Melbourne, returned to teaching after 10 months for several hours a week, then increased the hours according to how I was coping. I was fortunate to work with a wonderful staff and students who did everything to make things easier for me. Eventually I was back teaching full-time but needed to rest as soon as I returned home. I discovered that keeping my mind active was helping towards healing. I continued teaching until I retired in 1992.

In 1993 the Support Group in Melbourne was formed by James and Betty Gerrand. I received the INformation newsletter as each issue was printed, looked forward to reading it and then, with my sister's help, was able to attend meetings and meet so many people with the same or similar illness CIDP, as well as their supportive friends or family. The social functions which were organized by the committee were an added bonus. I have found that this has been a great help to me as we always learned something at the meetings from the many guest speakers, as well as hearing of the update with treatment that was being tried. I feel very thankful to James for initiating this group and to all the people who have continued to put so much of their time and effort into keeping the group going.

I began to write some of the experiences that I felt helped me with my recovery. My eldest daughter suggested I could make a small booklet which may help others. She offered to design and have it published to sell as a fundraiser for the Support Group (The 'IN' Group) if that was what I would like. I really enjoyed doing it and found it was great therapy.

During the tenth year after I contracted GBS, I went to Darwin where my daughter lived. She took me to a publisher and we chose the cover, etc. and I came back with 100 copies of the booklet, "**A Road to Recovery**". Since then Ian Clarke generously published extra copies free of charge.

It is now ten years later and I am one of the fortunate people who have made an 80% recovery.

The main attributes towards my recovery would be that I have a loving supportive family and many friends and am able to belong to groups within this small town where we can help others. I follow a healthy diet. There is a water exercise group which I have been able to attend each week for 18 years as well as having physiotherapy. We have an excellent medical centre with a very caring staff. I still have the same doctor who sent me to visit the Neurologist who diagnosed GBS in 1988. I have always listened to relaxation tapes and rest before becoming tired, even when the grandchildren come to stay.

This last 10 years of my life has been very fulfilling as I have been able to lead a moderately normal lifestyle and have been for a number of trips with friends and relatives.

We have been blessed with thirteen grandchildren who give us great pleasure and hear from them and see them at regular intervals, some more than others as our family is scattered.

Recently I was asked if I had any residual effects from GBS. I feel that one learns to live with pain and discomfort from a long term illness. I do still have pain in my arms after using them for a length of time, sometimes more severe than other times depending on the activity. I become breathless from excessive exercise. The tingling in my hands becomes quite severe when under stress. The more stressful the situation the more severe the agitation becomes in my hands and right arm. I have continued to take 'Clonazepam' for the anxiety and 'Dymadon' for pain when necessary.

Although we may have the same symptoms our bodies seem to respond differently to treatments so it is difficult to compare our response to recovery.

I am very grateful to have had the opportunity to belong to this very worthwhile group and thank all of those people who have given many hours of their time with organization of meetings and functions, as well as all others who do things behind the scenes. I value the friendships that I have made.

With best wishes to all,

June.

June Cathcart generously donates the proceeds from the sale of her booklet "A Road to Recovery A-Z" to The 'IN' Group. Copies are available from Melva. Cost \$6.

GBS/CIDP AWARENESS DAY – JUNE 1ST, 2009.

We would ask members to contact their local newspapers to arrange for an article to be published near to the June 1st Awareness Day. This is a wonderful opportunity to make the public aware of what can happen if they contract CIDP or GBS especially, as it is very frightening and not many GP's come in contact with it.

Make the decision today, to play your part in GBS Awareness Day. A sample article will be published in the next issue of INformation.

GEELONG SUPPORT GROUP

The next meeting of this special group will be on Saturday, February 7th, 2p.m. at the home of **John and Margaret Widdicombe**.

The Geelong Members would like to express their sincere appreciation to Margaret and John for generously opening their home for meetings. **Thank you so much.**

President Margaret Lawrence, Treasurer, Doug Lawrence and Committee members, Gwen McInnes and Melva Behr are looking forward to attending the meeting. Geelong and the surrounding district have the highest incidence of GBS and CIDP in the country. This support group is very important.

They are also very generous, recently donating many gifts to the Dutch auction. A heartfelt "Thank you" to all who donated and to Margaret and John Widdicombe for delivering the gifts "door to door".

John, for you especially, we send our warm wishes for an improvement to your health in 2009.

The contact for the Geelong Support Group is: Dee Cooper. Phone: 03 5244 3382

NEWSLETTER MAILING LIST

Occasionally members choose to be deleted from our Newsletter mailing list, for various reasons. Recently two members left the ranks, one because she has reached the wonderful age of 101 and the other because she is travelling indefinitely overseas. We wish them both well in the continuing journey of life.

We will be doing a “stock take” clearance of inactive general memberships prior to the next publication. If you are not a paid up member but you wish to continue receiving the newsletter, please return the Annual Subscription form a.s.a.p. We realise sometimes these things can be overlooked, so if you have not been a paid up member for 2 years your name will be deleted. Support groups with whom we exchange information, members of the medical profession, medical institutions, government bodies, etc., are of course exempt.

SEND ONLY IF UNPAID

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

Annual Subscription

Subscriptions are due on the 1st July of each year.

I am happy to continue helping The ‘IN’ Group by renewing my membership from 1/7/08 – 30/6/09.

Annual Subscription \$ 15.00

Other Items

Booklets- The Road to Recovery A-Z \$6
- Boy, Is This Guy Sick \$2
- CIDP \$2 \$
- GBS \$2 \$

Donation to support medical research \$
(Donations of \$2 or more are tax deductible) _____
(Tick if receipt required)

Total Payable: \$ _____

Enclosed is a cheque/money order (payable to The IN Group)

Membership Details

Name: _____

Address: _____

_____ Postcode _____

Telephone: (Home) _____ (Work) _____

Email Address: _____

Signed: _____ Date: _____

Thank you. Please forward this form along with your payment to:
The Treasurer, The IN Group, 26 Belmont Rd., GLEN WAVERLEY 3150

A special “Thank You”

We are most grateful to both Jenny Murray from the NZ support group and Mary McAlister from the NSW Support Group for their continued assistance.

Having such excellent reciprocal co-operation is very much appreciated by those seeking support.

Good News –Peter Always has had Stem Cell treatment and is taking “steps” in his recovery. Peter was diagnosed with POEMS (really, really, rare). They took some stem cells from his blood (spinning it and taking what was at a certain level) then gave him chemotherapy to “kill off “the remaining cells, then infused his own stem cells back into his blood stream.

Things like taste buds were affected and now everything tastes strongly of its flavour. Something he has to get used to. We all know how taste reduces as age increases so Peter must be experiencing what babies do. No wonder they screw up their faces. Remember the terrible taste of Brussels sprouts – but have you tried them recently?

Peter - We send our best wishes for your ongoing recovery.