



INvoice

Newsletter of the Council of GBS/CIDP Support Group of Australia
Supporting those with acute Guillain-Barre Syndrome (GBS) and Chronic Inflammatory
Demyelinating Polyneuropathy (CIDP)

President:

Vilma Clarke

7 Nolan Street Wangaratta 3677

Tel:+613 5722 1183

Email: kclarke@netc.net.au

Secretary:

Melva Behr

44 Mavis Avenue Beaconsfield Victoria 3807

Tel:+613 9707 3278



The President's Message

At the beginning of my second term the Council looks forward to a year of continued support for those with GBS or CIDP. The assistance given by the voluntary committees of all the affiliated Council members is gratefully acknowledged. The past year has been an organisational time for some States. Now new committees, websites etc are up and running and therefore people who

require support can access it more readily. We were pleased to welcome Teri Guest, as the representative for Western Australia, and recently support has been given to set-up an ACT group. We are being recognised as an Australian group overseas as you will note from articles received for this issue. We acknowledge the ongoing financial support given by CSL to the Council for which we are most grateful, and with their new technology, and the Category A rating for GBS/CIDP patients we look with optimism at 'Intragam' being available in the recommended dosages. As always the goal of increasing blood donors across Australia is high on our agenda.

I wish you all good health and ask you all to keep up the good work, as everyone can play a role in support and awareness of GBS and CIDP.

WE ARE SO LUCKY

Except from a letter received from a CIDP patient in America

"In Sept. of 2000 I got very weak and had to go for a series of IVs (IVIGG). Then again in March 2001 more IVIGG. The IVIGG helps me to get over extremely weak spells but does not improve my overall condition. They make me very nauseous and have a bad headache. The bill for two days outpatient and two IVIGG treatments is fifty thousand dollars/US, Luckily I have Medicare, but my portion that I have to pay is five thousand dollars. I have to just make small payments to the Hospital because I don't have that much money, The Hospitals are very understanding as long as I send them some money every month they don't pressure me for the balance. I send one hundred per month."

A Snap Shot of Activity in Tasmania

From Grant Buchan & John Stanley

In April 2002 the Tasmanian group launched their website on the Internet. This was the culmination of 8 months work from start to finish. This included the time to set the group up as an official business with the ATO to gain DGR status to issue funds that were donated from the local Government and local business in Tasmania. Our site is currently enjoying anywhere up to 10 visits a day from Australia and the UK. Due to search engine registration delays we are not having any visits from the USA at this stage. Our address is www.gbstanmania.asn.au please visit and sign our guest book.

John Stanley (pictured right) founded the Guillain-Barre Syndrome Support Group of Tasmania in May 1994. John, a former GBS sufferer, went on to form the support network in Tasmania after identifying a need for an organised community resource for sufferers, their families and friends.

Support was available before this, although not formally in place. The group has been formed to provide support for recovering and recovered patients of GBS and CIDP, to assist their families and friends and the general community in understanding the conditions and their effects.

The GBS Support Group of Tasmania is a non-profit organisation and is registered as a charitable institution and has been issued with official ATO DGR status.

Our business details can be found on the Australian Business Register site. Grant Buchan (pictured above) is our southern contact and also a former GBS sufferer, who joined the group in February 2000.

The GBS Support Group of Tasmania is also associated with the IN Group of Victoria. The GBS Association of New South Wales, the Queensland GBS associations, UK and American GBS Groups. The Tasmanian GBS Support Group is also a member of the National network – the Council of GBS/CIDP Support Group of Australia. John Stanley from the Tasmanian Group currently sits on the National Committee as Vice President.



John Stanley



Grant Buchan

Grant Buchan's Story

I was born in Brisbane in 1955 and grew up in a typical suburban environment. At the end of High School, I started work as an apprentice electrician with the local distribution company. After 10 years working there, I felt it was time for a life style change. Even though I was born in Queensland, I had trouble coping with the humidity in the summer. I have travelled overseas a few times and to every state in Australia except Tasmania, so that is where I ended up. It was a real leap of faith and it was the correct move as I am still here more than 20 years later. I won a job with the then Hydro Electric Commission as a sub station operator.

I met my future wife Rosemary while living on the rugged west coast of Tasmania and after we were married, we transferred to the central highlands where I worked as a power station operator. We were blessed with a daughter during the two years we spent there.

Next move was to Flinders Island in 1985 where I ran the diesel station

....first it was a real mystery as to what was happening to me. He sent me for tests to Launceston but they were inconclusive so I was sent home. Shortly afterwards, my condition deteriorated and it was back to Launceston for more tests. The specialists confirmed GBS and I found myself in hospital for two weeks. I consider myself very lucky as I did not have an extreme case and once my condition stabilised, I started the long road to recovery. It has been almost complete and I now live a full and most rewarding life.

While on Flinders Island, we had two more daughters (one before and one after GBS). We then moved to New Norfolk in 1988 where we had another daughter. We all now live in Hobart with the exception of our eldest daughter who has completed the circle by recently moving to Queensland. Ironically, it seems it was too cold for her here.

"Hi" from the NZ Support Group

Hi, my name is Jenny and I am the Secretary of the Guillain Barré Syndrome Support Group New Zealand. We are a relatively new group in that we began in 1997 after my sister Dulcie was diagnosed with GBS. We hadn't a clue what GBS was, how it would affect Dulcie, or what her long term prognosis was. Fear plays a major part in any illness with which one is not familiar, and trying to get information was not all that easy. Eventually I put a small paragraph in the 'Help' pages of the Womans Day, (a local magazine) and the letters started to flow. Within no time at all I had 37 replies, without exception all saying they had been so alone and confused when their illness was diagnosed, and even years later not fully understanding it, or knowing anyone else who had suffered with it and it was at this point I decided something needed to be done.

Printing and postage was already getting expensive for me so I applied for Lottery funding. To get this, I needed the help of two others so asked Dr Robert Gregory (he is a GBS sufferer and lecturer in psychology at Massey University in Palmerston North) and Terry Watton (also GBS sufferer). They both agreed and we informally got on with it.

Applications for continuing funding were made - we got more and more contacts from sufferers - and today have 342 past or present sufferers in our membership. I must add at this stage that a proportion of these sufferers have CIDP, and are included in our membership as are those with Miller Fisher Syndrome. As time went on, and more and more people contacted us, we decided to form a Registered Charity with a Board of Trustees and were fortunate enough to have

Sir William Birch (ex MP and Minister of Finance and also GBS sufferer) consent to being our Patron. More help arrived when Dr Gareth Parry Neurologist with Auckland hospital who is specialising in Neuropathies, offered his help to our group.

We initially had help from USA with booklets and handbooks, and from UK with their booklets. With the help of Dr Joel Steinberg, Vice President and member of the Medical Advisory Board of the GBS Foundation International, we were able to print our own handbook and make it available to all sufferers or interested parties.

We do not have a website yet, but it is in the pipeline. We have mentions on other websites though, namely www.nzhealth.co.nz and www.everybody.co.nz.

Our Trust Board meets annually, and we are at this moment organising the first ever National GBS meeting in Wellington in May 2003. We send out quarterly newsletters and invite our members to contribute with stories of their personal experiences with GBS. The hardest part of all this is getting the hospitals and doctors to acknowledge that we can help. While one or two are great at passing on this knowledge, we still fall far short of the hope that one day, at diagnosis, a sufferer will be instantly told we exist.

We do not offer medical advice as that is the realm of the doctors and neurologists, but do offer support and help where we can. The best offer we can make is to have a recovered GBS sufferer visit a recently diagnosed sufferer and answer any questions, and offer the support to sufferer and family during the initial stages of the illness. The feeling of not being alone is very valuable, and of having answers and contacts at the end of a phone or e-mail can be very reassuring.

The initial stages were messy, and we floundered a little for a while, but the end result I think was well worth the effort. So, any group out there considering setting up a group such as ours gets our full support and we wish you all the best.

Jenny Murray,
Secretary GBS Support Group New Zealand.
ph/fax NZ - 06-7511014
e-mail: jenny.gbs.nz@clear.net.nz

"Hello" from the UK Support Group

The Guillain-Barré Syndrome Support Group covers the United Kingdom and Ireland. On 20th April 2002 we celebrated our 18th Annual Conference at Gateshead, Tyne & Wear in the north of England.

During the last year we have continued our awareness campaign to achieved 36 awareness presentations to university students studying physiotherapy, occupational therapy as well as to medical professionals in hospitals. These include physiotherapists, occupational therapists, intensive care nurses as well as neuro and medical nurses. They are very well received. At present we show the video about GBS and then include a talk from the patient/s experience of GBS and the Support Group's work.

These presentations will become more professional in future as we have acquired a match-giving donation of £30,000 to upgrade our presentation equipment to include 3 new laptops for PowerPoint and a projector. The donation also helps to cover some of the travel costs. The Support Group continues to display their awareness stands at medical professionals' conferences - the Royal College of Nursing,

British Association of Neurological Nurses, GPs, Occupational Therapists and Physiotherapists. These are very beneficial and are a great way of creating more interest in the illness. We have just purchased some new display boards that provide a professional impression - which is important when displaying alongside other larger charities and pharmaceutical companies. The research fellow, Susan Halsted, who has now been employed by us for eighteen months, continues her study of "Motor Nerve Injury in GBS". We hope for interesting results in another 18 months when she completes her study. This costs the Support Group £65,000 over the 3 years. We are excited to pledge £89,000 to employ another research fellow at Glasgow University for 3 years to "Develop a model of GBS" starting in October 2002. "Reaching Out" continues to be our flagship and we are very proud of its production. Our membership is down on previous years as the Internet is a threat. Patients and their families now have access to our information without having to financially commit to joining the Support Group. Our website www.gbs.org.uk is respected worldwide and the chat room is used globally. It is a very worthwhile resource.

Our achievements could not be made without the voluntary, hard working National Executive Committee and the support we receive from those who fund raise; our local contacts who visit those currently suffering from GBS; other helpers and members of the Support Group to whom we are very grateful.

Glennys Sanders MBE,
 Founder and Hon President

AROUND THE STATES:

Queensland – Ro Harre

Members meet at different locations sometimes travelling 2 to 3 hours. Support by members visiting hospitals, phone, e-mail, booklets, newsletter. A small but friendly/supportive group.

- Kevin Shorrocks

Sadly lost co-worker Alf Reardon. Small group supporting with hospital visits, e-mail, phone, and looking to eventually have web-site. Rayna Donnelly now assisting – thanks Rayna.

Tasmania – John Stanley/Grant Buchan.

Brochure is now complete thanks to funding from Devonport Community Health and has been distributed to hospitals and GP's. Grant's idea of Web-site, www.gbstasmania.asn.au now operational. Linked to U.K. group. Thanks to Aurora Energy for assistance and James Gerrand from Victoria for his help and permission to copy overviews.

New South Wales - Wendy Burg.

New committee elected. Working well with E-mail: guillain@bigpond.net.au operational. Hospital visits, brochures, e-mail and web-site together with phone contact for both GBS and CIDP all offer support. Thanks to all those who lend their support.

Western Australia - Teri Guest.

Have made visits to Charles Gardiner hospital to support GBS patients. They gave the information booklet to the Charles Gardiner Hospital and now when a case of GBS or CIDP presents they photocopy the booklet for the patient and it has her information as a contact. 25 contacts and looking to hold first meeting.

Thanks to the Neurological Council, The Charles Gardiner hospital and Danial Tait for their assistance.

Victoria – James and Betty Gerrand.

Continued support through hospital visits, booklets, meetings, newsletter, e-mail, telephone, web-page and an excellent committee and willing members. Fundraising has been successful with donations to research. Thanks to all helpers.

General: Orthotics – There are new carbon orthotic available.

They go on the front of the leg. They have proved very successful for some patients.

COUNCIL OF GBS/CIDP SUPPORT GROUPS OF AUSTRALIA

Correspondence to:

Secretary, 44 Mavis Avenue, Beaconsfield, 3807. (03 9707 3278)

Members of the Council

The Inflammatory Neuropathy Support Group of Victoria, Inc.

138B Princess St., KEW, Vic. 3101

Telephone: 03 9853 6443 Fax: 03 9853 4150

Email – ingroup@vicnet.net.au

Home Page –

<http://home.vicnet.net.au/~ingroup/>

The GBS Association of NSW Inc.,

P.O. Box 572, EPPING, N.S.W., 2710.

Telephone: 02 9869 1839

Email – guillain@bigpond.net.au

Home Page –

<http://www.ozemail.com.au/~guillain/>

The GBS Support Group of North Queensland

P.O. Box 321, MALANDA, 4885.

Telephone: 07 4095 1311

Email – rohar@austarnet.com.au

The GBS Support Group of South-East Queensland

7 Lamorna Court, FERNY HILLS, Q'ld.,

Telephone: 07 3851 1145 Fax: 07 3851 3744

Email – lamorna@bigpond.net.au

The GBS Support Group of Tasmania

(Nth)

P.O. Box 393, DEVONPORT, Tas. 7310

Telephone: 03 6427 9133

Email – stanley89@ozemail.com.au

(Sth)

Telephone: 03 6272 9352

Email – grant.buchan@aurora.energy.com.au

Web-site - www.gbstasmania.asn.au

Western Australia

5 Oberon Grove, MT. NASUA, 6112.

Telephone: 08 9497 4483

Email – admin@perthacc.com.au

**restricted use

Office Bearers of the Council

President: Vilma Clarke

Vice-President: Grant Buchan

Secretary/Treasurer: Melva Behr

Delegates to the Council

New South Wales: Wendy Burg

North Queensland: Ro Harre

South-East Queensland: Kevin Shorrocks

Tasmania: John Stanley

Grant Buchan

Victoria: Betty Gerrand

James Gerrand

Western Australia: Teri Guest

International Contacts

Guillain-Barre Syndrome Foundation

International <http://www.gbs.org/support/foundations/>

Guillain-Barre Syndrome Support Group of the

United Kingdom <http://www.users.globalnet.co.uk/~gbs/>

“Greetings from Canada”

The GBS Support Group is now operating under the Muscular Dystrophy Association of Canada. I resigned as President as of September, 2001. The Muscular Dystrophy Association has a webpage www.mdac.ca where you will find information in French and English on Guillain-Barre Syndrome. Our GBS Research doctors in Canada wrote the information for our pamphlet in 1985 and it has been upgraded several times with the bi-lingual version in the year 2000. MDAC has created a 'PEER SUPPORT' for all persons willing to support their peers in over 40 neuro-muscular disorders including GBS and CIDP. Our GBS support persons are still supporting GBS families and friends of gbs patients. In 1985, our top neurologist, now deceased, felt we should be a chapter of MDAC.

ALL OUR MEDICAL ADVISORS FELT THE SAME.

MDAC has each GBS/CIDP patient register with it and in turn may obtain, free of charge, the loan of medical aids such as wheelchairs, walkers, toilet risers, ramps, at any time during their life. Canada is a very large country and support has grown quickly with chapters being created in each province.

I have been fortunate to work as a volunteer for seventeen years. Now that the office work is being done by MDAC, the level of stress has been reduced considerably. Since 1997, I have enjoyed supporting gbs families from around the world by way of the internet. By volunteering, I have not only given hope to people but received tremendous support myself. I do not walk very well and have to use a wheelchair to shop. I am able to walk in my house and do some housework. I now have a cleaning lady and give lots of jobs to my grandchildren. I got sick in 1983 when I was 53 years old. I spent one year in a hospital bed paralysed to my brain. Was told I would never walk. I spent the second year in Day Hospital as a quadriplegic in a wheelchair. I received pool therapy for one year which allowed me to stand with a walker. The third year, I struggled to walk with the walker and went out on wheeltrans to visit GBS patients in hospital. Because I did not receive any treatment such as plasmapheresis, I have residual disabilities such as stiff fingers (I type with two fingers); I cannot kneel in church; since July 2001 I have not been able to drive my car; I have a scooter for the summer months; I cannot play the piano BUT I am grateful for the life I have been able to enjoy with my husband, seven children, 12 grandchildren and one great grandson. In October, 1999, I chose to get a flu shot. I had a mild recurrence of gbs which has left me much weaker to this day. I recommend that gbs persons not receive a flu shot. I want gbs families to continue supporting their loved one by giving care 24/7 which entails, turning the patient, giving passive physiotherapy, wiping the patients face and brow, telling him/her that he/she will get well.

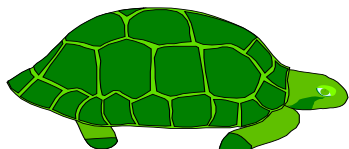
I want all gbs/cidp patients to tell himself/herself "every day in every way I am getting better and better". VISUALIZE AND SEND THE MESSAGE FROM THE BRAIN.

Give the patient a gift of a Doctor of Psychology visit every day for at least two months. I was fortunate to have this therapy and highly recommend it.

I can be reached by e-mail clarksmith@ptbo.igs.net and welcome all requests. YOU WILL GET WELL.

To all support persons, carry on your good work.

Barbara Clark Smith, MSM
Founder; Charter President



Newsletter sponsored by:



Ground Floor, 499 St Kilda Road, Melbourne, Victoria, 3004
Telephone: + 61 3 9620 4550 Facsimile: + 61 3 9620 4554
Email: melb@kildard@snapprinting.com.au
Web: www.melb@kildard@snapprinting.com.au
www.snapprinting.com.au

TOM'S STORY

My first brush with Guillain-Barré Syndrome was when a mate of mine, Fred Porter, got it and was put in intensive care in Cairns base hospital for four months. I can remember thinking 'My god! What sort of disease is this.?It flattened and almost killed one of the fittest men I have ever known.

It was about four years later; I woke one morning with my legs feeling a bit shaky. I didn't think much of it and went on with work on my property. By lunch time my legs were getting wobbly and I thought it was an old football injury coming back but by that afternoon I thought "I'll give them something to be shaky about," and I went to the pub for a few beers. (This was Friday) I was only there a short time before my wife came to tell me our property was on fire. By the time I got there it was well ablaze. I had to catch a horse and get the cattle out of the paddock but I couldn't get on the horse. I had to put him in a drain in order to get on him. By the time I organised a grader and water cart, my legs were getting very weak.

My wife and I fought the fire until 2am but it got the better of us. By this time my legs were like two tree stumps. By the next morning I could just walk and that's when I thought, 'this is not going to go away'. As this was the first time I had visited Dr Power's Surgery when I told her that I thought I had GBS, she looked at me and I think she thought she had a ripe one here! When I told her about Fred she ran some tests and organised for me to go to the base hospital where they ran more tests and diagnosed me with GBS. From there it was off to the Princess Alexandra Hospital in Brisbane. After three days the use of my legs had completely gone and my arm had started to lose power. It was the most frightening time of my life as every day I could feel myself going down the shute and knowing what Fred had gone through. Fred had died twice but it was his will to live that got him through. I didn't know if I could muster up the courage for this.

My wife would come up every day and try to keep me in a positive attitude. It was after the sixth plasma pheresis treatment that I could not handle any more pain. Five out of the six treatments caused extreme pain to the point where even my hair was feeling like it was on fire. After this I thought I would try natural products and vitamins to boost my immune system which I believe to this day helped me to overcome this terrible disease. Before this illness I thought I was bullet proof and did not appreciate the beautiful things that are all around us. After eight months in hospital I returned back to my property and I refused to ever get back in that wheelchair. My stint in the wheelchair taught me to appreciate how strong willed are the people that are confined to wheelies for the rest of their lives. This illness not only changes our life but the lives of our carers and family. For some the pressure and changes are too much. So we must be considerate to the carers as their lives are turned upside down as well.

It has been eight years since I got crook and I have learnt so much.

1. Never to take life for granted as we don't know what is ahead.
2. Admire all the beautiful things around us. There are so many things that interest me now that I never noticed before.
3. I always try to keep my immune system strong with natural products and vitamin B12 supplements. I came out of all this with one leg that doesn't work very well but I believe that is a small price to pay because I am still alive and enjoying the hell out of life.

Old saying;

"Live every day like it is your last and one day you'll be right".

Tom Johnson