

RECOVERY



From the Editor



Chairman Mark & Shirley



Shirley & Mary



Mary, Mark and Arthur

Special Interest Articles:

- Did President Roosevelt have GBS?
- GBS vaccination no risk

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Meeting dates for 2014

- Saturday February 1st
- Saturday April 5th
- Saturday July 5th
- Saturday November 1st

What constitutes a lifetime? I pondered this question whilst preparing the editorial for this Recovery.

Welcome to December 2013, it is a pleasure to be with you again.

The reason for being pensive about this subject came from the recent ceremony we held to bestow Lifetime Membership upon Mary McAlister, Shirley Cooke and their husband's Arthur and the late Ed.

The Association has been blessed to have Mary and Shirley as perpetual driving forces since it's inception in 1989 when it was formed alongside Professors James G McLeod AO FAA; John Pollard AO; Patricia Armati; and Clinical Sister Claudia Charlton of the Department of Neurology, University of Sydney.

Whilst it was not officially incorporated as a support group until 1991, without the dedication and commitment of these amazing women, supported by their loving husbands, the Association would not be where we are today.

Both women have raised families during their time with the Association and had to deal with, and manage, their own residual GBS symptoms as well as other personal trials and tribulations that come along in one's life journey. It is to their enormous credit that they

have been able to keep up the passion and enthusiasm for their volunteer roles throughout the passing years.

We cannot thank them enough and there is not enough that can be said, but we do hope the small gesture may go some way to show our deep appreciation and gratitude, from the Committee, but more importantly also on behalf of all those people who have benefited from their kindness.

So yes, we feel that more than 20 years qualifies as a lifetime. For we know that those 20 years have changed the lives of many GBS and related disorder patients through the caring and supportive work of two highly spirited ladies.

Well jingle bells if it isn't that time again! The silly season is drawing closer and by the time you get this we will be well and truly into it.

We at the Association would like to wish you all a very Merry Christmas and a Happy New Year.

May 2014 bring abundant health and happiness to you and your families.

Christine S-M

Why not attend a meeting next year?? There is much we want to achieve in 2014 and many hands make light and enjoyable work.

Please join us if you:-

- ♦ have a little time to spare
- ♦ would like to share your story
- ♦ are interested to know what we do
- ♦ want to meet a great bunch of people
- ♦ have the desire to make a difference in your lifetime! (refer page 7 for details)

From the Chair

Christmas is here and our thoughts turn to those who have lost their houses in the recent bushfires. As we know recovery means different things to different people.

For some the trauma will be raw for some time and others will see the opportunity for a new start.

Personally for me this month will see 6 months with no signs or symptoms of Ulcerative Colitis. Also, my MMN (Multi Focal Motor Neuropathy) is seemingly better and I am unsure whether this is a result of the monthly IVIG or the fact I am not battling UC and MMN at the same time. As you may recall just before last Christmas I was hospitalised with a C.Diff infection, a UC flare and my MMN caused significant issues with my arms and legs. Now 10 months down the track I feel very well, in fact I would say 10 years younger. Sure the UC is still there but in remission and the MMN is also still there and every now and then reminds me it is. However, I now have the opportunity for a new start. Perhaps not the life I envisaged 10 years ago when I first acquired MMN nor 3 years ago when I acquired UC but we never know what challenges will cross our path.

Acquiring not 1 but 2 auto immune conditions was a shock to the system, physically and mentally. But, both have thrown their best at me and I have come through.

Also, I now have the knowledge and experience and know what strategies I might employ should these conditions re-emerge acutely. There are no guarantees they will work however the potential shock and trauma will be significantly reduced.



“joining the Association has helped me get on with my life.”

This is where the GBS Association has been such a help to me. It took 7 years to get a diagnosis of MMN and like many felt lost and alone, struggling to come to terms with a strange illness and seeking answers. I had lots of specific questions but the answers came back broad and uncertain most of the time. Sure there are no absolutes when it comes to GBS/CIDP, some get better, some get worse and for some there is often no discernible change. Whatever the outcome you have to get on with life. Both Mary and Shirley acquired GBS at an early age and went to raise loving families and are still going decades later. If they can do it, so can I.

Joining the Association has helped me get on with life. Meeting fellow sufferers who have had similar experiences, strange sensations and a myriad of tests and opinions have removed the isolation I previously felt.

Further, when we get new sufferers attending a meeting and telling their story such as “Robert” who has Miller-Fisher Syndrome I take great joy when they say coming to the meetings and telling their story and talking to other fellow sufferers has been such a help to them coming to terms with their condition.

When we the Association and I as the Chair receive thanks for directly contributing to someone’s ongoing recovery I think that is exactly why this Association was set up more than 20 years ago. It was relevant then and it is relevant now and will go on being relevant until a cure is found and beyond.

Seasons Greetings Mark

Franklin Delano Roosevelt probably didn't have Polio after all

President Franklin Delano Roosevelt ended Prohibition, pulled the United States out of the Great Depression, and bolstered Allied Forces during World War II. He also suffered from paralysis, which was widely believed to have been caused by polio.

After his death, physicians argued that he actually suffered from Guillain-Barre Syndrome. It could be the most famous misdiagnosis in history

The Accident

On an early August day in 1921, a 39 year-old Roosevelt summered with his immediate family at a retreat in Canada. Roosevelt dove (or fell, depending on the account) into the Bay of Fundy while boating. Over the next two weeks, he experienced paralysis that began in his legs and extended to his chest, resulting in a lack of movement and bowel control.

This came at a pivotal point in his political career. Roosevelt would have been Vice President under James Cox if the Democrats won the 1920. But he'd retreated to private life after the Democratic ticket lost the election in a landslide.

Did FDR Have Polio?

Roosevelt visited a Boy Scout Camp two weeks before onset of his paralysis. Roosevelt's presence at this gathering played a major role in his diagnosis, because the gathering of youth provided a likely origin for the polio virus. The physician who diagnosed FDR, Robert Lovett, had an expertise in the field of polio, possibly lending additional bias to the diagnosis.

Physicians and scientists have struggled with the diagnosis of polio in the decades after Roosevelt's death, as Roosevelt's advanced age



made him an unlikely candidate for the disease. Roosevelt also experienced paralysis in both legs, while polio usually affects only one side of the body. Polio does not often affect the intestinal tract, yet the events of August 9th left FDR without control of his bowels. The future president continued to experience pain and other sensations in his legs. Confounding the diagnosis, Roosevelt exhibited a fever, a key diagnostic criteria for polio.

There are notes of clinical cases of Guillain-Barre Syndrome from this time period, with two soldiers diagnosed with the disease in 1916 using samples of spinal fluid. Testing of spinal fluid for increased protein levels without a concomitant increase in white blood cell count continues to be a key factor in the diagnosis of Guillain-Barre Syndrome. Whether any of FDR's physicians knew of the then-obscure Guillain-Barre Syndrome is completely unknown.

A 2012 study published in the Journal of Medical Biography conducted a probability analysis based on Roosevelt's symptoms, with the outcome suggesting Roosevelt likely suffered from Guillain-Barre Syndrome instead of polio.

(Continued on page 4)

Roosevelt - Polio or GBS?

Continued from previous page

Treating Guillain-Barre Syndrome in FDR

If a physician did diagnose Roosevelt with Guillain-Barre Syndrome, his prognosis would have strayed little. Guillain-Barre Syndrome is a viral infection of the body without a specific cure. The disease causes cells to attack other cells, leading to an eventual wasting away of the myelin sheath that surrounds nerves.

Guillain-Barre is currently treated with doses of immunoglobulins in the hopes that the body's immune system will attack these foreign proteins instead of itself. Immunoglobulin therapy did not exist in Roosevelt's time, but if it did, it would have been prohibitively expensive.

Guillain-Barre is also treated through the difficult process of plasma exchange. Plasma exchange removes blood and sequesters white and red blood cells before re-introducing the cells to the body. For a short time, plasma exchange lowers the patient's blood plasma volume with the hope of removing antibodies that are causing the body to attack itself. If available, this treatment would have exposed FDR to infection at the site of blood withdrawal as well as complications involving blood clots and calcium deficiencies.

An FDR diagnosed with Guillain-Barre would have little to gain over one diagnosed with polio due to a deficit in possible treatments.

The Misdiagnosis that Saved Lives

Roosevelt did not hide his diagnosis, forming a polio rehabilitation center Georgia before running

for president. He did downplay the affliction's role in his life, hiding the weakness of his legs behind sturdy podiums, relying on an aide or his son to help him remain standing at public events, and ordering a swift secret service detail to cover any shots of him in a wheelchair.

As president, Roosevelt founded the National Foundation for Infantile Paralysis in 1937, a organization headed by polio victim and Roosevelt's former law partner, Basil O'Connor. In time the National Foundation for Infantile Paralysis would become known as the March of Dimes, with donations going to fund research grants at a number of universities searching for a cure and setting the table for Jonas Salk's successful development and implementation of a vaccine against the virus in 1952.

A final verdict on whether FDR suffered from Polio or Guillain-Barre Syndrome is impossible, and will continue to be. The only method to accurately diagnose the former president with Guillain-Barre Syndrome involves testing spinal fluid. No matter the degree of scientific curiosity, we are unlikely to exhume the body of one of our greatest presidents to test for proteins that have long since degraded.

While we will never truly know if Roosevelt suffered from polio, the attention Roosevelt brought to the illness ended the most rampant cause of death and paralysis in human history, a disease dating to Ancient Egypt.

Not a bad outcome for a possible misdiagnosis.

Your new website is coming soon.....

The Committee have been at work since September developing our new website and we hope to un-veil it early 2014.

We recently gathered at Mary and Arthur's home on a Saturday afternoon to review the work done so far and to give everyone an opportunity to contribute and provide their feedback.



The team gather at Mary and Arthur's to have their first look at the new website

As we told you in our last edition of Recovery we feel a new, user friendly and modern website is one of the most important tools we have to support people and their families when searching for information.

Stay tuned for our announcement, we will notify you of the details when we are ready to go live soon.

Guillain-Barré Unlikely After Vaccination

Published: Jun 24, 2013

By Todd Neale, Senior Staff Writer, MedPage Today

Reviewed by F. Perry Wilson, MD, MSCE; Instructor of Medicine, Perelman School of Medicine at the University of Pennsylvania and Dorothy Caputo, MA, BSN, RN, Nurse Planner

Guillain-Barré syndrome (GBS) does not appear to be a risk following administration of several common vaccines, including seasonal trivalent inactivated influenza vaccines, researchers found.

Over a 13-year period, there was no significant increase in the odds of developing GBS within 6 weeks of receiving any vaccine (odds ratio 1.3, 95% CI 0.8-2.3), according to Roger Baxter, MD, of the Kaiser Permanente Vaccine Study Centre in Oakland, Calif., and colleagues.

The findings from this retrospective study were consistent for the individual vaccines examined, including trivalent influenza vaccine (OR 1.1, 95% CI 0.4-3.1), the researchers reported online in *Clinical Infectious Diseases*.

"Although we had limited power to fully assess the risk of GBS following vaccination due the rarity of the outcome, the low numbers of GBS cases that were temporally associated with vaccination, coupled with our results, provide reassurance that the risk of GBS following any vaccine, including influenza vaccines, is extremely low," they wrote.

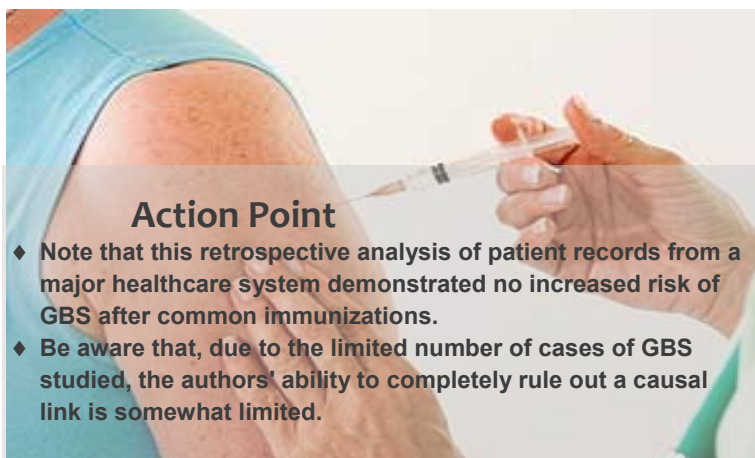
GBS occurs at a rate of about one to two cases per 100,000 person [per] year around the world. Cases have been reported after administration of various vaccines, but causal connections are unclear.

A 1976 vaccination campaign for the H1N1 swine flu was halted after an increased risk of GBS became apparent, but most studies of seasonal flu vaccines since then have not demonstrated a similar relationship. A few have found a small increased risk of about one excess GBS case per million doses.

To further explore the potential risk of GBS after vaccination, the researchers analyzed data from patients who were hospitalized with GBS within the Kaiser Permanente Northern California system from 1994 through 2006. A neurologist confirmed the diagnoses through a review of medical records.

Through about 32.7 million person-years of follow-up, there were 415 incident cases of GBS covering Brighton levels 1, 2, and 3 identified. The average age of the patients was 48.5.

The researchers used a case-centred analysis, comparing the odds of vaccination within the 6- or 10-week period before the onset of GBS with the odds of vaccination during the same risk intervals for all vaccinated individuals in the health system population. The approach controls for the fact that more GBS cases were seen in the winter months.



Action Point

- ◆ Note that this retrospective analysis of patient records from a major healthcare system demonstrated no increased risk of GBS after common immunizations.
- ◆ Be aware that, due to the limited number of cases of GBS studied, the authors' ability to completely rule out a causal link is somewhat limited.

Of the 415 GBS cases, only 25 were associated with vaccination in the 6 weeks before onset, most commonly with trivalent influenza vaccine (18 cases).

The odds of developing GBS were not increased in the 6 weeks following the use of any vaccine, including inactivated polio, tetanus, reduced diphtheria, and acellular pertussis (Tdap), 23-valent pneumococcal polysaccharide, injectable typhoid, hepatitis A, hepatitis B, combination tetanus and reduced diphtheria, or all of them combined.

Even if the five cases of GBS that occurred after flu vaccination and were not associated with a respiratory or gastrointestinal illness were considered to be caused by the vaccination, the upper limit of the 95% confidence interval would exclude a risk greater than one extra case of GBS per 585,000 doses.

Applying the same criteria to any non-influenza vaccination would exclude a risk greater than one extra case of GBS per 3.8 million doses.

Despite millions of doses delivered, there were no GBS cases observed in the 6 weeks following administration of any of the vaccines typically given to children, including oral polio, measles-mumps-rubella, conjugated pneumococcal, live-attenuated influenza, diphtheria-tetanus-acellular pertussis, varicella, *Haemophilus*-diphtheria-tetanus-pertussis, and *Haemophilus* B.

The authors acknowledged that the study could not exclude any possible association between vaccines and GBS and might have been limited by the fact that the reviewer of the medical records knew about the purpose of the study, and was able to see whether treating physicians considered GBS to be related to vaccination.

The study was supported by a subcontract with America's Health Insurance Plans (AHIP) under a contract from the CDC, as a part of the Vaccine Safety Datalink (VSD).

Baxter and one of his co-authors have received research grants from Merck & Company, Pfizer, Sanofi Pasteur, Novartis Vaccines, GlaxoSmithKline, and MedImmune.

Call a Friend



Calling a friend...

I really believe that as we are drawing to a close for 2013 to dedicate this page to the unsung, under-estimated and perhaps largely taken for granted 'Carers' in the lives of both GBS and CIDP persons. We truly may owe them the quality of life which we enjoy as either the new patient or a longer term recovered person. They share to an extent our problems, sometimes quietly in the background other times with a strong "voice" or a ready arm, to resolve issues which might arise. They act as an advocate on our behalf, determining conflicts and issues if that is needed, whilst we ourselves might be at our most vulnerable state.

Most carers initially feel helpless, shocked, where to turn, what to do for the best? how long will this be? do I need to leave work? who will look after the children? how can I run the house alone? and still be there for the patient, to solve if possible and always with fortitude and emotional strength, and one might add love, all I need to do.

Carers come in all shapes and sizes, all ages, male or female, wives, husbands, brothers, sisters, friends. There are no guide lines for their role, they are thrown in to this position just as quickly and immediately as we ourselves have been, we coping ourselves as a helpless dependant patient with GBS or CIDP. Some persons become carer's late in their lives, some have travelled the path with their GBS or CIDP partners for many years, in my own case, fifty-eight years of our marriage as my husband has, — to the other extreme, concerning a recent telephone call from the gentleman about the same age as my husband who has been newly thrown into this role for his wife, who was diagnosed with GBS a few weeks ago. The tables in this case being reversed instead of he being cared for, he is now in the carer role. The mantle seems to drop into place quite naturally, I think showing the tenacity, determination and strength of the human spirit.

Of course carers are not only men, women equally seem to acquire that particular strength and resilience and downright dogged

determination and empathy to understand what is needed, to support knowing when to encourage, when to stand back, when to recognise when help is needed, whether it be emotional or purely physical support. In my experience women often have that innate sensibility to recognise that need.

Independence for most patients can be hard won and this independence needs nurturing and fostering with encouragement and understanding. Recognising where and when care is required but to stand back when independence is so important for our recovery.

Never the less, it is also always important to realise the rippling effects of either condition has and will have on the lives of not only our immediate family, but those of our wider connections, friends, your work place colleges, your social group — the effect is wide spread. So it is important to realise as patients we do not have either GBS or CIDP in isolation, their effects are pervasive. It is often the Carer who is left powerless, devastated and feeling useless in not being able to help their loved one more. Where to turn? the hospital is too busy to answer my questions.

It is in this capacity that *Calling a Friend* may just help in the smallest way. Yes, our support group does have that facility, to call a friend, but also just speaking and voicing your concerns to a friend, or family member, just helps to unload the tension and fears and anguish that you as a carer are likely to be so overwhelmed by. It is understood that you as the Carer should be strong, to know exactly all about these conditions, to always know the right way or the correct answers, when you also may need support and answers yourself

A human voice who has been there and understands exactly what you are speaking about, and willing to listen and to give support even though only a voice on the end telephone line, actually can and does help.

So to all those unsung heroines and heroes I salute you one and all on behalf of all those you have "Cared" for.

till next time... Mary

Bits n Pieces

GBS Association of NSW

A NON-PROFIT VOLUNTEER ORGANISATION

Registered Charity No. CWD295

Incorporation No. Y13693-18

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Committee Meetings

All are welcome to attend the GBS Association of NSW Committee meetings.

Newly diagnosed and people recovering from GBS and CIDP will appreciate the contact, encouragement and support from fellow members.

MEETING VENUE

Ryde Eastwood Leagues Club

117 Ryedale Road, West Ryde NSW 2114

the club is on the Eastern side of the rail line – it is walkable from West Ryde Station, which has lifts. We will be in the “Hawks Room” on the lower ground floor which has a lift to the floor plus lifts from all levels of car park underneath the club building. The room is booked in the name of the GBS Association.

Administration Section of Meeting commences at 9.30 am – 11 am

Open Forum/ Guest Speaker 11.00 am to 12.30 pm

Visitors are welcome to both sessions, or the Open Forum if preferred

Meeting dates scheduled for 2014

⇒ **February 1st 2014**

⇒ **May 3rd 2014**

⇒ **August 2nd 2014**

⇒ **November 1st 2014**

Important Note: we may be moving our meetings back to Ryde Rehabilitation Centre from May however we will confirm in our March 2014 Newsletter, including details.

Financial Year 2014

Members are reminded the Association's financial year is

1st January 2014 to 31st December 2014

GBS NSW would appreciate your continued support.

Disclaimer

Information presented in “Recovery”, GBS Newsletter is intended for information sharing and general educational purposes and should not be considered as advising or diagnosing or treatment of the Guillain-Barre Syndrome or any other medical condition. Views expressed in articles and letters printed in Recovery are those of the authors and do not necessarily reflect the opinions or Policy of the GBS Association of NSW Inc.

Public Risk

The Guillain-Barre Association of NSW would like to inform all members, friends, guests and readers that the Association no longer has Public Risk insurance covering association meetings or association functions. We regret that due to spiralling insurance costs we were unable to renew our Public Risk Insurance.

Contact the Editor

Do you have an interesting story to share with your fellow members?

Perhaps you would like to share your experience with GBS/CIDP with us by writing your story for ‘Recovery’. Maybe you just need some more information on an article appearing in the Newsletter? Whatever it may be you can contact me,

Christine Simpson-Morgan:-

**What lies behind us and what lies before us are tiny matters
compared to what lies within us.
- Henry Stanley Haskins -**

ANNUAL SUBSCRIPTION / DONATIONS

Financial year from 1 January 2014 to 31 December 2014

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*PLEASE TICK THE BOX IF THIS IS YOUR PREFERENCE

☐ ANNUAL SUBSCRIPTION / MEMBERSHIP RENEWAL (for 2014) \$ 20.00 (includes GST)

DONATION

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NOTE: Donations of \$2.00 or more are tax deductible. Registered Charity CWD295.

(Please tick the appropriate box) ☐ GBS ☐ CIDP ☐ DOCTOR/MEDICAL ☐ RELATIVE

Please indicate below how you think you may be able to help:

☐ Hospital or home visits to new sufferers (REMEMBER how you felt)

Preferred areas:

☐ Telephone contact (Be a GBS or CIDP friend-by-phone)

Preferred areas:

Or send us YOUR STORY for the newsletter. How about doing all three?

We need your help to really make our Group supportive and effective.

We are here for you - all on a volunteer basis.

Can you be there for those who are going through what you did, or are still going through?

NAME

ADDRESS

ADDRESS

PHONE /MOBILE PHONE email.....

With thanks to Smartprint for printing, labelling of our Newsletter and also to the Sitemanager
for the generous donation and management of the GBS NSW website