GBS Connections

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Guillain – Barré Syndrome Support Group New Zealand Trust

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NEWSLETTER September 2017

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In this Issue

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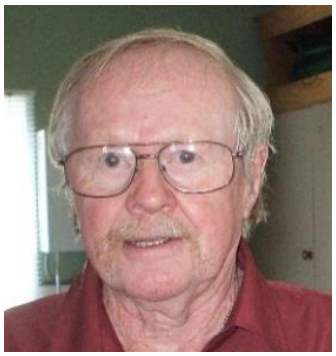

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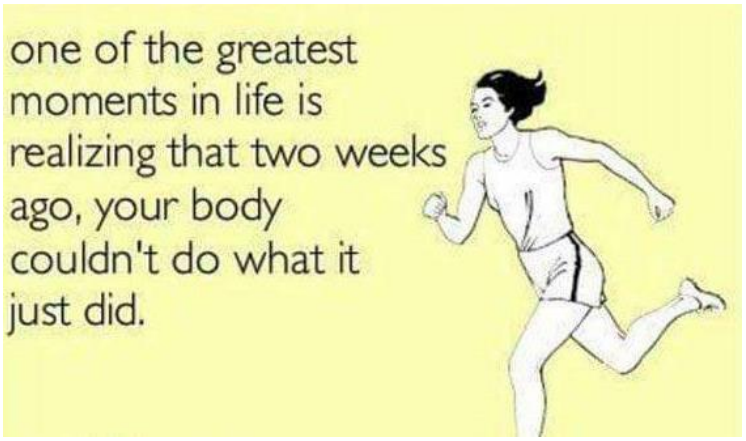


Editor's Note

Spring has sprung and is throwing us up all sorts of weather. Most of it rather crappy in my area Iôm afraid to say. But at least it means I have had to stay inside and get to work on your magazine.

There is no personal story this month as sadly I donôt have any to print. Iôm sure there must be a few of you out there who could knock a few words together and send it in. These stories are what people like the most in the magazine. Especially those new to GBS/CIDP. Helps to give them hope for their own recovery and know they are not alone in what they are going through. So do it for them.

We have had another successful coffee group get together this month. We had 2 new couples attend which was great. I arrived late so only got to say a brief hello to one of them, but was great that they found out about us and popped along. Sadly neither couple were aware of our Support Groups existence when they were first diagnosed and dealing with the illness. Despite our attempts to make all hospitals aware it appears we are still no further ahead in that department. We discussed this at length at our get together and the consensus is still that regular ñcold callingò on the hospitals by our hospital visitors is the only way to make progress. Posters we put up on hospital notice boards are routinely removed to make way for other things so that too is an on - going job. I have to say Meike does a splendid job of this in the Thames and Waikato Hospitals.

Eileen and Sharon have been trying hard to get a coffee group off the ground in the Auckland areas, both west and south but numbers attending still remain small. I realise that Auckland encompasses a very large area but if a meeting is being held near you please try and attend. Their next meeting is 19th November so mark it on your calendar now. Details are on the ñNotice Boardò page.

At the conference in Rotorua this year we were treated to armchair aerobics by the QE Health staff. It was a lot of fun. Andrina Romano from QE Health kindly gave me permission to print this workout in the magazine. Give it a go. As you can see from the picture below most of us attempted it on the day. I was surprised how much energy was expended. Sorry Royce you are out of sync with the rest of us.

Will be checking my mail box for those stories.

Chris

Friendships forged and stories shared at coffee group gathering. Newcomers (top left) Kathy and Robert Boswell were welcomed by regulars, Julia Ardern, Barry and Judy Deed, Fran McKay, Emma Wolfe, Rex and Karen Soppett, Ken Ardern and David and Yvonne Powell

Presidents Report

Welcome to all our readers.

Another quarter year has passed and as it was the winter we appeared to have hibernated a little!

As I have been working in the Auckland area often over the last 4 months I can confirm what a wet winter they seem to have had up there (How the worm has turned this year, now sitting in Invercargill hearing from people living on rural blocks complaining about trucking in water for their house tanks, at this time of year!)

So like the bad weather, our secretary ï Tony Pearson - continues to receive a number of enquiries from new GBS suffers from all over the country.

The web site is working and leading people to us, However we still need theò cold callingò at the hospitals and rehab units to try and stay in touch with the staff so that they know about our organisation, along with this valuable publication of Chrisôs as yet another method of communication.

Our Auckland visitors had been having issues with access to Starship Hospital recently. Tony Pearson has managed to make contact with Starship Hospital management to confirm there is a procedure for us to gain access to GBS sufferers if requested as our visitors were being turned away even though patients & care givers had requested our presence.

I have noted an increasing number of media releases about people who have contracted GBS this year, then found the lack of support for them in various ways. Particularly those with medical insurance policies that donôt cover them for an event like ours. Itôs good to see people are not taking these issues ñlaying downô but are being proactive in exposing the problem publicly in an attempt to effect change for a fairer deal on the money they have put up in good faith, often over a lengthy period.
It would appear that ñincome protection insuranceò is the only one to work for us at present. If only we had known!

Upgrading of the web site to take on the social media aspect under Matt Peacey is well under way and I am looking forward to seeing the end result.

Finally the idea of establishing more area coffee group meetings is reinforced by the success of Chris Hewlett and Meike Schmidtôs gathering in Thames last week, where I understand 16 people turned up for this event. Well done everyone who made the effort to travel to the venue and I hope it was worthwhile.

Regards to you all.

Doug Young
President.

Below is a link to a GBS patients video of their journey. It is very inspirational watch.

https://www.facebook.com/carobeard/posts/10155643057683474

Secretary's Jottings

I am guessing that by the time Chris gets this Newsletter published I shall have ticked off another birthday ï who says 3 score and 10 is our given lot?- lot of mileage left in me I hope ï in spite of CIDP!

Additionally on the same day we shall all have collectively elected (or re-elected) a new government for the next 3 years. I may be cynical but isnôt it amazing how the promises have rolled out over the past few weeks. Of course we need better medical and education services and policing needs to be beefed up but where are all the people and dollars coming from? ï these are not new problems and as anyone in our Group knows our Hospitals are under tremendous pressure which sometimes results in outcomes that are less than satisfactory but why does it take an election to bring out the promise of the ñgoody bagò? Enough ranting Tony ï just find the pin and vote!

Since the Conference last May I have received 17 referrals from new GBSôers (2 re-directed from the USA Support Group) but have not come across any local cases in my visits to Nelson Hospital. More often than not the cases that come to the Groupôs attention are some of the more harrowing situations where initial diagnosis has been incorrect or delayed or the response to the regular treatment regimes has not been positive ï or in some cases caused additional complications. This becomes particularly distressing when the patient is a young person or a child and the parents are desperately seeking the magic bullet that will set their loved one on the path to recovery. Sadly there are not many magic bullets about and whilst I accept that by and large the medics get it right I do find myself frustrated when I hear about a GP or Consultant who ï on the face of it ï doesnôt seem willing to progress things in what is by now a well - documented ï if not publically aware ï system of establishing the likely existence of a GBS condition and the potential remedies that are then available. In such cases there is little the Group can do other than to recommend that the family seek another opinion ï but that is often easier said than achieved.
It is therefore a welcomed event when I get a call from a GBS patient or carer who wants to share their good news story of EXCELLENT medical care throughout their treatment and rehabilitation and to pass on their advice on positive points and experience to others who may be in the ñen routeò phase of their GBS journey. I was particularly struck by one carerôs story that throughout a prolonged period of support for their partner ï which they documented daily - they made a point of finding at least ONE positive development or event in that day to end the diary entry ï a good practice for all of us to adopt. (*I would love to have their story to print in the magazine. Ed)*

The IT sub-committee of the Board have made a proposal for the structure of the new website ï which has been reviewed and approved by the Board and funding allocated. Development is now underway by the web design team that we have contracted with and whilst there is still a lot to do this project is now moving steadily forward led by Matt Peacey.

Our new Brochure library has been well received by those patients I have sent them out to ï and all Hospital visitors have been equipped with a supply along with Flyers and Notices for displaying on Hospital and Doctors Clinic notice boards. If you would like copies for your own use please let me know.

I am becoming more familiar with our Facebook site and the two other (American??) sites that respond to my ñGBSò request. Thanks to everyone that responded to my concern over the Shingles vaccine. There has been a deafening silence from Newsletter readers to my request last quarter for ideas on how we should organise our future gatherings at a Group level so I might just resort to canvasing for input on the Facebook site ï is that OK Meike? On the other hand the Coffee Groups seem to be moving ahead very well ï congrats to those of you behind their organisation.

Well I had better call it a day and get back to studying the political landscape - as its bedtime that should be easy ï either sweet dreams or nightmares!
As always Take Care
Tony

Medical cannabis for treating neuropathic pain. Fact or fancy?

Dr. Gareth Parry

Chronic pain is a major issue in patients who have had GBS or who have CIDP, affecting about 40% of individuals. Available treatments are only partially effective and their use is limited by the adverse effects that occur at the high doses that are typically needed. As a result, and added to by a chorus of positive claims reported in the lay press and individual testimonials from brave and articulate people like Helen Kelly, there is a lot of interest in the use of cannabis for chronic pain. But is it really as safe, well tolerated and effective as claimed? Letôs examine the facts and learn a little about this interesting and controversial weed.

What is cannabis: Cannabis is a blanket term used to cover all of the chemicals derived from the plant, Cannabis sativa. There are over 100 biologically active chemicals known as cannabinoids derived from the plant, most of which have no psycho-active properties. The best known is tetrahydrocannabinol (THC) which is responsible for the ñhighò sought by recreational users. The other major cannabinoid is cannabidiol (CBD) which has no psycho-active effects and, in fact, partly inhibits the effects of THC. There are more than 2000 different strains of the plant which have been extensively hybridized by illicit growers to optimize the amount of THC. The cannabinoids are concentrated in the flower of the plant, contained in small needle-like projections called trichomes which secrete a resin (see figure). A crude extract of the flower can be ingested or inhaled.

Leaf of C. sativa

Flower head of the plant

Trichomes with the resin

A brief history of cannabis: Cannabis has been used medically and recreationally for about 5000 years. It was introduced to Britain in the late 19th century and it was praised by Queen Victoria, hardly a notorious pot-head, as helpful for her dysmenorrhea (period pains). It was widely prescribed in the first third of the 20th century in both the US and Europe for a range of conditions as diverse as anxiety, arthritis, labour pains, migraine, loss of appetite and nausea. In the 1930ôs in the US, at the time of alcohol prohibition when puritanical urges were sweeping across the land, anything that might make you happy was considered evil and therefore heavily regulated or outright banned. This lead to tight regulation of prescription of cannabis and ultimately, following the war, classification as a dangerous drug in the same class as opioids, cocaine and amphetamines. In some US states, people can be jailed for life for three convictions for simple possession for personal use. In 1988, a distinguished panel of experts in the US concluded after extensive study that cannabis was ñone of the safest therapeutic agents known to manò and recommended that it be reclassified but the recommendation was rejected by the Drug Enforcement Agency.

Pharmacology of cannabis: The body has a system of cannabis-like molecules called endo-cannabinoids and receptors in the brain and other tissues with which these molecules interact. The purpose of the endocannabinoid system is not entirely clear and is the subject of intense research. Phytocannabinoids (i.e., plant-derived) hijack the endocannabinoid system to produce a wide range of medical effects. Interestingly, there are cannabinoid receptors on lymphocytes (immune cells) so their effects on autoimmune conditions such as GBS and CIDP is uncertain. Some analgesics such as paracetamol and the aspirin-like medications increase levels of endocannabinoids which may explain their effect. THC and CBD have both been shown to have analgesic properties; remember that CBD has no psycho-active properties and inhibits the effects of THC so a combination of the two has potential for treating pain without producing side effects. The pharmaceutical cannabis products approved in NZ contain equal amounts of THC and CBD.

Medical cannabis for treating neuropathic pain.
Fact or fancy?
Dr. Gareth Parry

Medicinal use of cannabis in the modern era: In 1985 the first cannabis product, dronabinol, a synthetic form of THC, was approved by the FDA for treating anorexia and weight loss in AIDS patient and shortly thereafter expanded to nausea and vomiting in patients receiving cancer chemotherapy. In 1996 California introduced the first medical cannabis program and now 22 states have made it legal to prescribe cannabis for carefully defined conditions, one of which is neuropathic pain. Regulation of the medication and determination of the conditions for which it can be used is determined by individual states; the Federal government still considers it illegal but has not pursued prosecution. Other conditions for which it is approved in Minnesota, where I formerly practiced, include spasticity (muscle stiffness) related to multiple sclerosis, some forms of epilepsy, glaucoma, Tourettes syndrome, motor neuron disease and many others but there is scant evidence of benefit in many of these conditions. In NZ, it is now possible for doctors to prescribe pharmaceutical forms of cannabis in certain situations, including intractable neuropathic pain, but the medication is not funded.

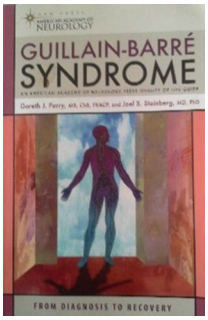
What does the scientific evidence tell us about cannabis for neuropathic pain? High quality clinical trials in which cannabis products are compared to placebo are essential because pain is a subjective experience and trials regularly show that up to 40% of subjects benefit from placebo. Furthermore, if the cannabis product contains some THC there may be subtle euphoria which could provide a perception of benefit independent of any analgesic properties. A few studies of this type have been done so what do they tell us?
Pharmaceutical quality cannabis products:

- Have a modest beneficial effect in relieving neuropathic pain.
- Are extremely well tolerated. There is a range of minor side effects that are rarely disabling and usually abate with continued use. They never produce a ñhighò except in the mind of the consumers who think that all cannabis products are psycho-active.
- Are extremely safe with no evidence of organ damage if used as prescribed.

Recreational use of cannabis has been associated with rare instances of psychosis and cannabinoids do affect the developing brain so pharmaceutical products should not be used therapeutically in adolescents except under the strictest medical supervision. Nor should they be used by pregnant women since they are likely to affect the developing foetal brain.

Based on these studies it is reasonable to conclude that cannabis, probably in an equal mixture of THC and CBD, is worth trying in individuals who have failed to achieve adequate benefit from the more traditional analgesic therapies or who are unable to tolerate the adverse effects. Overall, the beneficial effects are modest but there may be individuals for whom cannabinoids represent an effective therapy. The safety and tolerability of these medications is so extraordinarily good that they may be worth trying before resorting to the much more dangerous opioids (narcotic medications).

All of the forgoing assumes the use of pharmaceutical quality products. Smoking or ingesting home grown or illicitly produced marijuana remains illegal. Also, there is no way of knowing the exact composition of these illicit products. They are, therefore, not recommended.



New Stocks of this easy to read and enlightening book written by Dr Gareth Parry and Dr. Joel S. Steinberg are now available. $30 including P & P.
If you would like to purchase one contact:
Tony Pearson: tonypearson@xtra.co.nz

GBS Coffee Group Report
23.07.17 Hobsonville, West Auckland
30.08.17 Drury, South Auckland

The Auckland Coffee Group is growing.

July meeting welcomed a new attendee whose encounter with GBS was very recent, one of several in Auckland around the end of last year.

At the end of August Kathy and Rob (and their homestay and 2 dogs) welcomed us into their lovely home in rural Drury. No matter that the attendance remains small in number, even if only one person turns up, it is worthwhile as we get to discuss symptoms that remain a mystery to people who have not encountered these conditions and learn from each other.

As well as current state of illness or recovery, we discussed the differences between CIPD and GBS, effect of diet in recovery and viewed Renee Ballôs dance video (itôs on the internet, very eloquent if you havenôt seen it before).

I especially appreciated meeting a lady whose daughter had had GBS as a teenager and was now in her thirties. This meeting was the first that the lady had ever been to about GBS. I well remember how significant it was for me after diagnosis to meet another person who understood the syndrome and had recovered. How important hope is when you are newly diagnosed or still recovering.
So the meetings are not just for people who have had (or still have) CIDP or GBS but also for family and friends, caregivers, professionals, anyone who would like to tell their story and learn more.

Next meeting Sunday 19th November 2pm. 35 DeHavilland Rd, Hobsonville
South Auckland mid-week meeting to be advised.
Contact Sharon Phone: 473 1128 Email: sharon@dixonz.nz
or Eileen Phone 021 1133607 Email: eileenmagnajacobsen@hotmail.com

Eileen Jacobsen
Co-convenor of Auckland Coffee Group

Members chatting at the Conference

Conference Break Out Groups Summary of Comments
Compiled by Tony Pearson

	GBS	CIDP
Length of Time for a Definite Diagnosis	Most Diagnosed within a month of 1st visit to GP	Most diagnosed very quickly especially if the GP had seen GBS before. Carers noticed Partners deterioration quickly. Other Medical issues confused diagnosis in some cases. Most experienced a delay in seeing a consultant after the initial diagnosis.
Hospitalised?	Yes. Most were from 2 days to 11 months	
Satisfactory Treatment	Mostly yes. Pain treatment could be improved. Nursing sometimes fell down at the handover. Beside manner could be improved. Rehab treatment dependant on ability of Physio/OT	Hospital treatment and nursing generally good.
Triggers	Ear/nose/throat infections most common Camplobacter and flu vaccinations minority but most not able to pinpoint the trigger.	
Time for Recovery to Previous Fitness	10% in under a year 15% in 3 years Majority not yet back to previous levels of fitness	Mostly ongoing issues
On Going Pain?	Most to some degree. Fatigue experienced by the majority. Pins and needles common.	All experienced fatigue.
Flu Vaccinations?	Less than a third have this vaccination.	No one has this vaccination
Support from the Group?	Once contact made support was good and useful. Visits from non ï group GBSôers also experienced.	Website important for information source and group support good. Being able to talk to other carers important. Understanding that it was not likely to be fatal was very important.

Conference Break Out Groups Summary of Comments Compiled by Tony Pearson

Other Support		Most carers realised it was important to look after themselves as well. The experienced has strengthened the bond between partners. Additional tolerance for each other was necessary. A break or respite from caring was welcomed.
Other Issues		Travel Insurance complications

BOP/Waikato Coffee Group Enjoys another get together. This time in Thames.

Back Left to Right: *Phil Wolfe, David Powell, Meike Schmidt-Meiburg, Barry Deed, Ken Ardern, Grant McKay*

Seated Left to Right: *Judy Deed, Julia Ardern, Fran McKay, Emma Wolfe, Yvonne Powell, Chris Hewlett, Karen and Rex Soppett*

Absent when Photo Taken: *Michael and Roberta Cameron and Kathy and Robert Boswell*

Vaccinations and Immunisation in GBS & CIDP
A Conference Presentation by
Dr. David Gow
Consultant Neurologist SDHB

Overview:

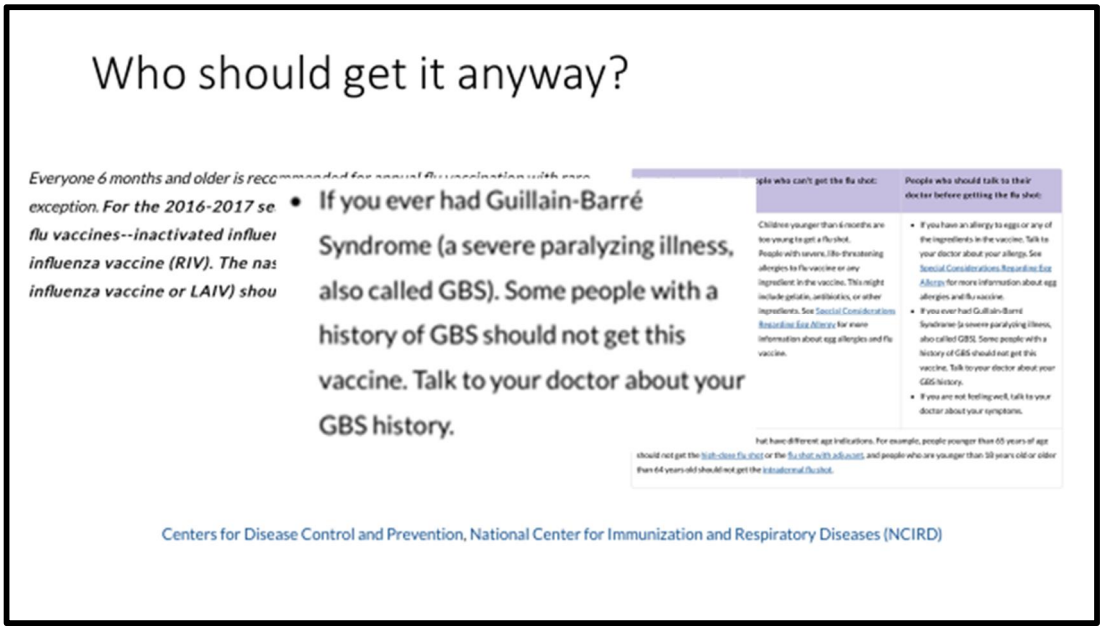
- What are vaccinations and immunisations?
- Why do we vaccinate against flu?
- How do they relate to GBS and CIDP?
- How does influenza infection relate to GBS and CIDP?
- How do they relate to recurrence of GBS and CIDP?
- Should you have the jab?

Definitions:

- **Vaccination** is the administration of antigenic material (a vaccine) to produce immunity to a disease.
- **Immunusation** is the process by which an individualôs immune system becomes fortified or built up against an agent (known as the immunogen). Can be active (antigen) or passive (transfer of immunoglobulins through the blood).

Morbidity/Mortality Influenza/Influenza-like Illnesses: 2009 H1N1 and seasonal flu vaccine data

- Hospitalization rate: 222 patients per 1 million
- Death rate: 9.7 per 1 million
- Slight increased risk for GBS
- Vaccination: most effective method to prevent serious illness/death from influenza infection

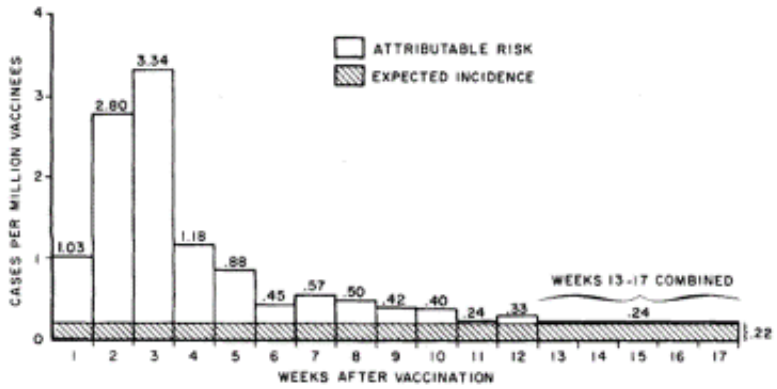


Do vaccinations and immunisations cause GBS?

What causes GBS?

- 2/3 of people get GBS in the days or weeks following diarrhea or a respiratory infection.
- Infection with campylobacter jejuni is one of the most common risk factors for GBS.
- People also can develop GBS after having the flu or other infections (such as cytomegalovirus and Epstein Barr virus).
- On very rare occasions, they may develop GBS in the days or weeks after getting a vaccination.
- How do we know this?

1976 and the swine flu vaccine.....



GBS 9.5 per million vaccines
In following 6/52
V
0.79 per million unvaccinated

Schonberger LB et al. Am J Epidemiology 1979

Surveillance for Guillain-Barré Syndrome Aftyer Influenza Vaccination Among the Medicare Population, 2009 – 2010

Conclusions. Medicare data contributed rapid safety monitoring among millions of 2009-2010 influenza vaccine recipients. Adjustment for claims delay facilitates early detection of potential safety issues. Although limited by lack of medical recored review to confirm cases, this claims-based surveillance did not indicate a statistically significant elevated GBS rate following seasonal or H1N1 influenza vaccination. (*Am J Public Health*. 2012;102:1921-1927. Doi:10.2105/AJPH.2011.300510)

What about flu as a risk factor for GBS?				
	Vaccination Seasons	**Study Location**	**Study Design**	**Outcomes and conclusions**
Sivadon-Tardy et al[76]	1996-2004	Paris, France	Time-series method single-centre study based on reports of influenza-like illnesses by surveillance networks to assess correlation between monthly incidence of GBS	Association between monthly incidence of GBS and influenza-like illnesses. 10 (14%) of 73 GBS patients had serological evidence of recent influenza A and four (5%) of 73 had serological evidence of influenza B
Sivadon-Tardy et al[77]	1996-2001	Paris, France	Single regional reference centre case series	GBS cases after unidentified infections characterized by repiratory disorders and influenza-like syndrones (60%) peaked in winter months
Tam et al[8]	1991-2001	UK	Case-control study of data from the UK General Practice Reasearch Database	18 fold increased risk of GBS after influenza-like illnesses
Tam et al[78]	1993-2002	England	Time-series method to study correlation between weekly incidence of laboratory-confirmed influenza reports and hospital admissions for GBS	Association between weekly numbers of laboratory-confirmed influenza A cases and hospital admissions
Stowe et al[7]	1990-2005	UK	Self-controlled case series method to assess data from primary-care database	Increased relative incidence of GBS within 90 days of influenza-like illnesses, greatest within 30 days.
GBS= Guillain-Barré syndrome				

Table 1: Guillain-Barré syndrome after influenza infection

Guillain-Barré syndrome after exposure to influenza virus
Helmar C Lehmann, Hans-Peter Hartung, Bernd C Kieseier, Richard A C Hughes

Lancet Infect Dis 2010; 10:643-51

Conclusion

- Although Flu vaccine changes year on year the problems of 1976 have not been consistently replicated.
- Flu causes GBS.
- On a population basis balance of risk favours vaccination

So, I have had GBS will having a vaccination make it come back?

Journal of the Peripheral Nervous System 14:310–315 (2009)

RESEARCH REPORT

Recurrences, vaccinations and long-term symptoms in GBS and CIDP

Krista Kuitwaard[1], Martine E. Bos-Eyssen[1], Patricia H. Blomkwist-Markens[2], and Pieter A. van Doorn[1]

[1]Department of Neurology, Erasmus MC, University Medical Center, Rotterdam, The Netherlands; and [2]Vereniging Spierziekten Nederland (VSN), Baarn, The Netherlands

Questionnaire Study, for vaccinations

245 GBS, 76 CIDP patients surveyed

Auto-immune disorders: 9% GBS, 5% CIDP pts

None of the 106 GBS patients, after vaccine: recurrence

5 of 24 CIDP patients, after vaccine: increase symptoms

Pain, fatigue, reduced quality of life reported in 70% patients after GBS and CIDP

Conclusion: Flu vaccinations seem relatively safe for patients with GBS and CIDP.

Recurrent Guillain-Barré Syndrome Following Vaccination

Roger Baxter,[1] Ned Lewis,[1] Naandini Bakshi, [2] Claudia Vellozzi,[3] Nicola P. Klein,[1]and the CISA Network

[1]Kaiser Permanente Vaccine Study Center,[2] The Permanente Medical Group, Oakland California; and [3]Immunization Safety Office, Centers for Disease Control and Prevention Atlanta, Georgia

Background. Guillain-Barré syndrome (GBS) is an acute polyradiculopathy, thought to be autoimmune, which has been reported following vaccinations. The Advisory Committee on Immunization Practices recommends not administering influenza vaccine to individuals who have had a history of GBS within 6 weeks of a prior influenza vaccination if they are not at high risk of severe complications from influenza illness.
Methods. We identified GBS cases from the Kaiser Permanente Northern California databases from 1995 into 2006 using hospital discharge codes; each medical record was neurologist-reviewed and only GBS-confirmed cases were included for follow-up. We followed confirmed cases through 2008n for vaccinations and recurrent GBS.
Results. We identified 550 cases of GBS over 33 million person-years. Following their GBS diagnoses, 989 vaccines were given to 279 of these individuals, including 405 trivalent inactivated influenza vaccines (TIV) administered to 107 individuals with a prior diagnosis of GBS. Among the 550 total cases of GBS, 18 initially had onset within 6 weeks of TIV; of these 2 were revaccinated with TIV without a recurrence of GBS. Only 6 individuals of 550 (1.1%) had a second (recurrent) diagnosis of GBS. Among these 6 individuals, none had any vaccine exposure at all in the 2 months prior to the second onset of GBS.
Conclusions. In our population of over 3 million members, during an 11-year period, risk of GBS recurrence was low. There were no cases of recurrent GBS after influenza vaccination and none within 6 weeks after any vaccine.

Clinical Infectious Diseases 2012;54(6);800-4

Vaccinations and Immunisation in GBS & CIDP continued

Risk of relapse of Guillain-Barré syndrome or chronic inflammatory demyelinating polyradiculoneurapathy following immunisation

J Pritchard, R Mukherjee, R A C Hughes

J Neurol Neurosurg Pyschiatry 2002;**73**: 343-350

11/311 of GBS and 5/65 CIDP patients experienced a recurrence of their symptoms following a vaccination.

Only 1 GBS patient had a functionally significant change.

Tetanus toxoid seemed to confer a higher risk of deterioration in patients with CIDP. (only 2 patients!)

Small numbers hampers CIDP data.

Low rates of re-vaccination in vaccine related cases across all these studies

Recomendations based on this evidence

- In individuals with no history of GBS/CIDP vaccination benefit appears to outweigh the risks.
- In everybody else the decision to vaccinate should be individualized and an attempt to strategise risk made.
    - Did the initial illness occur following a vaccination?
    - Did the illness occur following flu?
    - Are there clear factors to suggest that vaccination would usually be strongly recommended?

Worked Examples.

- Did the initial illness occur following a vaccination? Yes
- Did the illness occur following flu? No
- Are there clear factors to suggest that vaccination would usually be strongly recommended? No

Probably risk too high

- Did the initial illness occur following a vaccination? No
- Did the illness occur following flu? Yes
- Are there clear factors to suggest that vaccination would usually be strongly recommended? Yes

Probably risk justified

Codicil to an existing Will

If you have already made a Will you can still help the Guillain Barré Syndrome Support Group by adding a codicil to your Will.

If you would like further information or would like to talk to a Trustee of the Group about making a bequest to the Charity please contact us on 03 540 3217

We do advise consulting with your legal advisor before completing this codicil form
Please take this form to your legal advisor

I é (Name)

of é

é (Address)

Declare this to be a é é é é é .. (first/second) codicil to my Will dated é é /é é /é é .
In addition to any legacies given in my said Will I give to the Guillain Barré Syndrome Support Group New Zealand Trust, of 30 Higgs Road, Mapua, Nelson 7005 (or any other premises which the Support Group may hereafter occupy) a charity registered in New Zealand No. CC20639,

A share of é é é é é é é ... of my estate or the sum of NZ$ é é é é é . and/or
é .. (a specific sum)
to be used for general purposes and I declare that the receipt of the Treasurer or duly authorized officer shall be full and sufficient discharge. *
In all other aspects I confirm my said Will and all other codicils thereto.
**please complete as required and cross out those options not required.*

Signed é é é é é é é é é é é é é é .

Signed by the above named in our presence and witnessed by us in the presence of him/her and each other

Witnessed by:	***Witnessed by:***
Signatureé é é é é é é é é é é é	Signatureé é é é é é é é é é é é .
Name é é é é é é é é é é é é é .	Nameé é é é é é é é é é é é é ..
Addressé é é é é é é é é é é é ..	Addressé é é é é é é é é é é é ..
é é é é é é é é é é é é é é é	é é é é é é é é é é é é é é ..
é é é é é é é é é é é é é é é	é é é é é é é é é é é é é é ..
Occupationé é é é é é é é é é .	Occupationé é é é é é é é é ...
Dateé ../é ../é é ..	Dateé ../é ../é é ..

Board Members at the 2017 Conference
Left to Right: *John Davies, Doug Young, Tony Pearson, Chris Hewlett, Dr. Matt Peacey, Dr. Pralene Maharaj, Beverley Whittaker, Dr. Gareth Parry, Meike Schmidt-Meiburg and Peter Scott*

NOTICEBOARD

Publicity Officer

The Group **desperately** needs a Publicity Officer ï someone with the experience to help us get our message ï indeed our very existence ï out into the public domain via the media.

Do you have the skills to help us?
The Board has approved the payment of an **Honorarium of up to $1000pa** (depending on the level of skill and experience demonstrated) to encourage someone to step forward ï could it be you!

Contact the President or Secretary if you are interested.

West Auckland Coffee Group Meeting

When: 19th November

Where: 35 De Havilland Road, Hobsonville

Time: 2pm onwards

Confirm with:

Sharon: Ph 473 1128
Email: sharon@dixonz.nz

Eileen: Ph 021 113 3607
Email: eileenmagnajacobsen@hotmail.com

WAIKATO/BAY OF PLENTY COFFEE GROUP XMAS LUNCH

Where: The Cheese Factory Waharoa

When: Thursday 30th November

Time: 11.00am onwards

Please bring a $5 gift for our Secret Santa Bag

Please let Chris know by Wednesday if you are attending so she can confirm numbers with the Café.

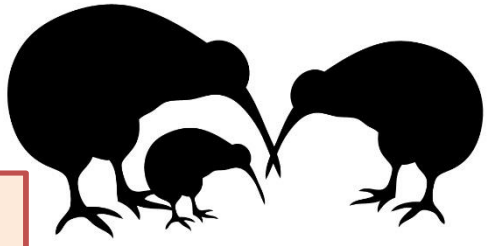
Email: chrispy57@gmail.com
Cell Ph: 027 6113246
Ph: 07 5490931

Everybody welcome.

What's Your Story ?

Urgently needed are your stories to publish in your magazine.

Please take the time to write about your GBS/CIDP (and or other Variants) and post or email to me – your editor. Details on the front of the newsletter.



Want to receive your newsletter in **colour**?
Receive it by email and save a tree.
Please contact the Editor to update your delivery option