

September, 2012  
Volume 2; Issue 21

# RECOVERY



## From the 'Guest Editor'

### Special Interest

#### Articles:

- Fampridine
- Trial for CIDP

### Individual

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Greetings to you all.

The spring edition Recovery reminds us the year is well and truly drawing to a close and the Christmas Season is fast approaching.

Just for this issue of Recovery Christine has asked me to take on the Editorial because of my involvement with the topics at hand. I do feel a little like the fledgling understudy, however Christine will be back as usual by the next issue, at her Editor's desk.

May I then quickly introduce myself, my name is Mary McAlister. Perhaps I might be better known to Recovery's readers, in my more usual role as the listener and support person at the end of the telephone line for GBS/CIDP calls.

Our GBS/CIDP Association's telephone number (02) 9869 1839 has remained constant for almost twenty years, reluctantly circumstances have recently occurred whereby that contact number needed to be changed. The new contact telephone number of the GBS/CIDP Association of NSW is to be **(02) 9617 0883**, I will still be the listener at the other end of the telephone line that will remain unchanged.

It is with regret that this alteration has been necessary, of course it will take time for many folk to become familiar and accustomed to the new number. Unfortunately many of our booklets, literature and related websites already in circulation will not reflect the new contact number. Future publications and our web sites, will of course correct this situation from about the middle of September 2012. Might I ask you all to note down the new GBS/NSW contact telephone number, it will not be a listed telephone number in any Telephone Directory. The telephone number is only published through our web-site and our printed GBS/CIDP material.

If in any further doubt as to how to contact our GBS/CIDP Association, the email address will remain as before, [info@gbnsnw.org.au](mailto:info@gbnsnw.org.au).

We really hope the transition from one telephone number to another, will not greatly inconvenience anyone.

At our August Meeting of GBS/CIDP Assoc. we were privileged to have two members of a Research Team from the University of New South Wales, and the Prince of Wales Hospital, A/Prof. Arun Krishnan and Miss Hannah Pickering come to our meeting to outline their team's present research trials into the effectiveness of the medication, **Fampridine** for patients with CIDP.

The Research team are looking for additional CIDP persons who might be willing to be involved with these trials. The trials are currently underway, however only for a limited period, (two years). Further details are outlined in this edition of Recovery. If anyone might be interested, Application Forms are available on-line from A/Prof. Krishnan's web site, and from the Association as well.

Fampridine has been trialled and approved for use for MS patients. As there are some correlations between the conditions of MS, and GBS and CIDP, the conjecture was that it might also be of potential value for CIDP patients to improve their overall responses. Fampridine does not cure MS, however it does promote increased improvements in walking and fatigue symptoms in MS. Without adequate trialling positive or otherwise conclusions would not be known whether it might also help CIDP patients with similar conditions.

For those of our members who may wish to hear and see exactly what was said at the meeting by A/Prof Krishnan, and Hannah Pickering, we have a video of the event. One of our CIDP members Mr Russell Hosken, has videoed the entire meeting.

The Association wishes to thank Russell for his generosity in donating several copies of the video for the Association's use. For those who may wish to have the audio alone, we also have audio tape of the meeting as well.

Just to conclude, please note that new telephone number, **(02) 9617 0883**. I will be at the end of the line as usual, now handing my temporary role back to Christine our Editor --- Mary McAlister for Christine...

## From the Chair

As I pen this article, the sun is shining and there is some real warmth in the air a boon for all peripheral neuropathy sufferers thawing out their frozen hands and feet. I always feel better when it is sunny and I can get out, even for brief period, to enjoy it. Sometimes the simple things can have huge benefit.

This then brings me to one of the core reasons I am a member of the GBS Association and why I accepted the nomination to be Chair; the opportunity to improve the quality of life of sufferers and all those impacted by GBS/CIDP.



*"Yes, stress can be good but it is how we manage it that is important"*

For some time we have advocated for 'someone' to conduct GBS/CIDP research in Australia and indeed some years ago Prof Pollard indicated there was a need for CIDP research, particularly a long term impact study.

In this regard, it is with great anticipation we invited A/Prof Arun Krishnan and one of his research assistants Hannah Pickering to attend our meeting at the Ryde Eastwood Leagues Club on Saturday 25 August 2012 and give a talk about their trial to determine if Fampridine, a drug used to help MS sufferers, might also assist CIDP sufferers with fatigue. The talk was very informative with attendees able to ask many questions about suitability for trial participants and how the drug works.

The trial is funded by the makers of Fampridine and as such those participating in the trial will be provided with the drug at no cost and should they wish they will also be provided with the drug after the trial at no cost. A huge saving! Further, this is world leading research and nowhere else in the world is anyone doing this type of trial, so we are privileged to have this occurring right on our doorstep in Sydney at the Prince of Wales Hospital. Numbers are limited. See inside for more details.

Improving the quality of life of sufferers, family and friends can come in many guises. New medical procedures, new drugs, physical aids etc. However, we often neglect our mental wellbeing.

Stress can creep up on all of us and before we know it, becomes a major contributing factor to how bad or good we feel. Yes, stress can be good but it is how we manage it that is important. Suffering from a chronic condition can further complicate the mix, placing stresses on your body in excess of what would normally be expected if you were fit and healthy. So, you need to take time out and do something for yourself and recharge the batteries, mental and physical.

Some of you may recall Peter Tregear, a previous chair of the Association. Peter was in hospital for many, many months with GBS and now some years on he runs a successful B&B Whale Cove at Eden on the south coast of NSW with his partner Terry Anne. When I recently contacted Peter he said, "We would love to have GBS/CIDP people stay with us. Just remember that we have stairs to negotiate to get to the rooms. We are very happy to do 'mates rates' of \$125 per night per room and that includes afternoon tea on arrival and a gourmet breakfast. However, we are sure you will understand these rates do not apply during holiday periods. Our check-in is from 3.30pm and check-out is 10.30am. Phone: 02 6496 2324 Mobile: 0411 809 963 Email: [4tregear@tpg.com.au](mailto:4tregear@tpg.com.au), Web: [www.whale-cove.com.au](http://www.whale-cove.com.au).

Peter has indicated he is more than happy to talk about all things GBS if you would like and/or you can just enjoy this fabulous location. So if you are thinking of taking a break, consider giving Peter a call.

As an end note; What about the Paralympics!!!! Everyone is different, some profoundly so but, what about the effort and achievement. No arms, no legs, some arms, some legs, no eyesight, minimal government/corporate support yet look at the medal tally of our team vis-à-vis the 'normal' Olympics.

Many people living with disability are overachievers and Government and Industry need to recognise this and harness this under funded resource.

Kind Regards  
Mark.

In this edition we feature Jane Rothman, one of our valued committee who takes care of our email and whose willingness to help others inspires us all.



### ***Jane's profile***

***What is your role on the Committee and what does it entail?***

Supported by Mary McAlister (from whom I have recently taken over), I answer email correspondence that comes to the GBS/CIDP email address [info@gbsnsw.org.au](mailto:info@gbsnsw.org.au). Sometimes the answers are quite easy to provide, other emails are quite heartbreaking. We do our best to provide support and/ or useful information and contacts.

### ***Can you briefly share your GBS/CIDP experience?***

My journey into the unknown territory of GBS began in February 2006. I felt a tingling under my thumb and forefinger nails on my left (dominant) hand but thought no more about it. Sleep was restless that night and in the morning I could no longer raise my left arm and my right arm was starting to go weak. We immediately called our GP and meet at his office. He looked me over, found I had no reflexes and sent me to have a CAT scan of my brain (I could still walk at this stage) and wait to collect the results. The results were good, he said, no tumour and no stroke. But I still could not move my hands and arms. He said (although he had never actually seen a case before; only read about it) that he thought I might have Guillain-Barré Syndrome or GBS. I was told to go to RNSH immediately, not even stopping for clothes or toiletries, as the disease could affect my lungs and require being put on a ventilator. When I was finally stabilized, after a month in ICU, I was moved to the Royal Ryde Rehabilitation Hospital. This was bliss compared to my former surroundings and my home for the next 4 months. I still had to be 'hoisted' from bed to chair or shower or wheelchair but there I was dressed and given access to an electric wheelchair almost immediately. I had just enough strength in my right wrist to push the control throttle. The road to recovery in the last 6 years has been slow and thankfully steady - with my hands being the last to recover. I had just assumed that I would be fully recovered before I left rehab. It was a shock that I was not.



Jane, Max and grandson

Returning home again was initially very scary. What bliss it was when I could toilet myself independently again. I now take pride in doing many mundane things I used to take for granted like washing up, using the washing machine, hanging out clothes, and doing some limited cooking (happily more each day). I passed my driving test several years ago and now drive a slightly modified vehicle. I am no longer afraid to walk alone in the street, for fear of falling or being knocked over. In fact, I go bush walking! I can again dress myself and wear 'normal' clothes - but generally still no zips or buttons. The other day I did up the zipper of a jacket I had on for the first time. I haven't given up on having close to full recovery. Who knows how my journey and this story will end.

### ***What was the toughest challenge you faced during your recovery?***

The toughest challenge was leaving rehab still in a wheelchair, being told I might never walk freely again. My hands remain a challenge.

### ***How did you overcome it?***

With the help of great physiotherapists and OT's with their can do attitude. While doctors said 'never', they said 'you can't do it yet'. They never gave up and that gave me determination.

We were a team!

### ***What inspires you everyday?***

Life... my husband, grandchildren, family and friends. My regained abilities, I don't take any of the things I can do again like walking, going independently to a public toilet, holding a cup, etc. for granted.

### ***Do you have anything else you would like to share?***

The support and friendship of GBDS/CIDPNSW has been one of the pegs that has helped me on my road to recovery. Also, a thought about rehab services which need our support. No one thinks about these services until they need them and no one wants to think they'll ever need them. I know I never did.



**THE UNIVERSITY OF NEW SOUTH WALES: DEPARTMENT OF NEUROLOGY. THE PRINCE OF WALES HOSPITAL**

**Effects of fampridine treatment in demyelinating disorders (CIDP)**  
**PARTICIPANT CONSENT INFORMATION SHEET**

- ◆ Dr Arun Krishnan (Department of Neurology, Prince of Wales Hospital)
- ◆ Prof Matthew Kiernan (Department of Neurology, Prince of Wales Hospital)
- ◆ Dr Cindy Lin (University of New South Wales)
- ◆ Ms Christine Cormack (University of New South Wales)
- ◆ Ms Jenna Murray (University of New South Wales)
- ◆ Ms Hannah Pickering (University of New South Wales)
- ◆ Dr Andrew Martin (NHMRC Clinical Trials Centre)

**Invitation**

You are invited to participate in a research study that concerns a potential new treatment for nerve dysfunction in patients who have chronic inflammatory demyelinating polyneuropathy (CIDP).

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

**1. 'What is the purpose of this study?'**

The purpose is to investigate whether treatment with the medication, fampridine, can help improve the ability to function in patients who have chronic inflammatory demyelinating polyneuropathy (CIDP).

**2. 'Why have I been invited to participate in this study?'**

You are eligible to participate in this study because you have CIDP.

**3. 'What if I don't want to take part in this study, or if I want to withdraw later?'**

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

New information about the treatment being studied may become available during the course of the study. You will be kept informed of any significant new findings that may affect your willingness to continue in the study.

If wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

**4. 'What does this study involve?'**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form.

This study will be conducted over 2 years and each participant will be enrolled in the study for approximately 7 months. At present there are no specific medications that help CIDP patients undertake daily tasks, such as walking, doing up buttons or using a fork. This study investigates whether this medication may help walking ability and hand function in patients who have these conditions. While this drug does not represent a cure for CIDP, it may assist with symptoms such as fatigue, walking ability and hand strength.

The study is a randomised "double-blind" trial. In this type of study, participants are put into groups and given different treatments, and the results are compared to see whether one treatment is better. To ensure the groups are similar to start with, a computer allocates each study participant into a group randomly, like the flip of a coin. Neither the doctor nor the study participant can decide which treatment the participant receives.

Furthermore, neither the doctor nor the study participant will know which treatment the participant is receiving (although, if the doctor needs to find out, he/she can do so).

In this study, participants will receive fampridine (the active drug) for 12 weeks and a placebo, which is a dummy treatment that looks like the genuine medicine but contains no active ingredient, for another 12 weeks. However, the participants and the investigators will not know the order in which the participants will receive these treatments. Between these two 12-week phases, there will be a period of 4 weeks in which you will receive neither treatment.

During the treatment phase of the study, you will be asked to take one 10 mg tablet of fampridine twice a day.

If you agree to participate in this trial, you will then be asked to undergo the following procedures, which will take about one hour in total to complete:

- A routine physical examination
- Walking tests which test how quickly you can walk over a short distance of 7.5 metres and how far you can walk over a period of 6 minutes.
- Nine-hole pegboard test which tests how quickly you can place nine pegs into nine holes on a wooden or plastic block.
- Nerve tests: This involves having electrodes taped to your skin over a nerve or muscle. No needles will be involved. You will then be asked to sit still while a series of small electrical stimuli are delivered. This feels like the sensation of zap from an electric impulse. The whole procedure will last between 10 and 15 minutes. During the recording, we may ask you to contract your thumb for 60 seconds to assess how muscle activity alters nerve function
- We will ask you to complete questionnaires that inform us of the symptoms you are experiencing and how they affect your ability to function.

### **5. 'How is this study being paid for?'**

The study is being undertaken using equipment that is already available.

### **6. 'Are there risks to me in taking part in this study?'**

All medical procedures involve some risk of injury. In addition, there may be risks associated with this study that are presently unknown or unforeseeable. In spite of all reasonable precautions, you might develop medical complications from participating in this study. The known risks of this study are:

(1) With respect to nerve tests, you may experience mild discomfort during the procedure. No side effects have been previously encountered using these tests on healthy volunteers and none are anticipated.

Fampridine is a well tolerated drug, with minimal side effects. It has recently been approved by the Therapeutic Goods Administration for use in Australia to help physical function in multiple sclerosis. In this trial we will investigate whether it is beneficial in CIDP.

The only serious side effect of Fampridine is seizures. This is very uncommon but if it does occur, emergency medical review will be organized with your neurologist. Other possible side effects include tiredness and a change in balance. Occasionally, patients may experience an increase in urinary frequency, nausea, vomiting, stomach pain, back pain, difficulty sleeping, pins and needles and headache. There may also be risks associated with this trial that are presently unknown or unforeseeable.

It is important that women participating in this study are not pregnant and do not become pregnant during the study as the study drugs may damage an unborn baby. If necessary, you should use reliable contraception (such as oral or implanted contraception, an IUD or have had a tubal ligation if you are female, or condoms if you are the male partner of a study participant) during the course of the study. If at any time you think you, or your sexual partner, may be pregnant it is important to let the researchers know immediately.

### **7. 'What happens if I suffer injury or complications as a result of the study?'**

If you suffer any injuries or complications as a result of this study, you should contact the study doctor as soon as possible, who will assist you in arranging appropriate medical treatment.

You may have a right to take legal action to obtain compensation for any injuries or complications resulting from the study. Compensation may be available if your injury or complication is caused by the drugs or procedures, or by the negligence of any of the parties involved in the study. If you receive compensation that includes an amount for medical expenses, you will be required to pay for your medical treatment from those compensation monies.

If you are not eligible for compensation for your injury or complication under the law, but are eligible for Medicare, then you can receive any medical treatment required for your injury or complication free of charge as a public patient in any Australian public hospital.

### **8. 'Will I benefit from the study?'**

This study aims to further medical knowledge and may improve future treatment of CIDP, however it may not directly benefit you.

### **9. 'Will taking part in this study cost me anything, and will I be paid?'**

Participation in this study will not cost you anything. You will not be paid to participate.

#### 10. 'How will my confidentiality be protected?'

Of the people treating you, only those named above or necessary others e.g. all nursing staff involved in your care will know whether or not you are participating in this study. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above have access to your details and results that will be held securely at the University of New South Wales and Prince of Wales Hospital.

#### 11. 'What happens with the results?'

If you give us your permission by signing the consent document, we plan to discuss/publish the results at professional forums and in peer-reviewed journals. In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

#### 12. 'What happens to my treatment when the study is finished?'

Fampridine may be available for you to continue, once you have completed the study. . If you have experienced benefits during the course of the study, ongoing compassionate supply will be provided by Biogen Idec. This decision will be made in consultation with your treating doctor. If you do receive ongoing fampridine treatment, your doctor may require 3 monthly assessments to ensure that you are still responding to the medication.

#### 13. 'What should I do if I want to discuss this study further before I decide?'

When you have read this information, Dr Krishnan (Ph: 938422413), or Professor Kiernan (Ph: 93822422) will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact them.

#### 14. 'Who should I contact if I have concerns about the conduct of this study?'

This study has been approved by the South Eastern Sydney and Illawarra Area Health Service - Northern Hospital Network Human Research Ethics Committee.

Any person with concerns or complaints about the conduct of this study should contact the Research Office which is nominated to receive complaints from research participants. You should contact them on 02-9382 3587, email [ethicsnhn@sesiahs.health.nsw.gov.au](mailto:ethicsnhn@sesiahs.health.nsw.gov.au) and quote HREC ref number 1 01237.

Thank you for taking the time to consider this study.

***Anyone interested in entering trials might contact A/Prof. K directly or ring GBSNSW and we will forward the Participant Consent form to you.***

Meeting 26th August at Ryde Eastwood Leagues Club. presentation by A/Prof Krishnan about the Fampridine Trial.



Mary opens proceedings



Chairman Mark thanks A/Prof Krishnan & Hannah Pickering

# Bits n Pieces

## GBS Association of NSW

**A NON-PROFIT VOLUNTEER  
ORGANISATION**

Registered Charity No. CWD295  
Incorporation No. Y13693-18

### COMMITTEE

**PATRON: URSULA CARLILE**

**CHAIRMAN:** Mark Kunach

**DEPUTY CHAIR:**

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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

We are still looking for a permanent home,  
until we do let's get together at

**Ryde Eastwood Leagues Club**

**28th October 2012 at 11:00am**

**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 “Hawk’s Room” on the lower ground floor which has a lift to this floor plus lifts from the 2 level car park underneath the club. The room is booked in the name of the GBS Association.

• **Saturday 28th October 2012**

Meetings commence at 10.30 am - to 1.30 pm

Help support your Association, get involved, come to a meeting, share your experiences, help others like they helped you.....reward yourself !!!

## Financial Year 2012

Members are reminded the Association's financial year is

1<sup>st</sup> January 2012 to 31<sup>st</sup> December 2012

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:-

**Mail:** 8 /36 Mobbs Lane EPPING NSW 2121

**Email:** smorgan8@bigpond.net.au



**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 .....

**ANNUAL SUBSCRIPTION / DONATIONS**

Financial year from 1 January 2012 to 31 December 2012

NAME: .....

ADDRESS: .....

ADDRESS: .....

PHONE / MOBILE PHONE ..... email: .....

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

DONATIONS \$ .....

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**The GBS ASSOCIATION of NSW Inc"**

PO Box 572, Epping, NSW 1710

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

☐GBS ☐CIDP ☐DOCTOR/MEDICAL ☐RELATIVE

*(Please tick the appropriate box)*

Publication of name in newsletter ☐YES ☐NO

IF YOU WOULD PREFER TO HAVE YOUR "RECOVERY" FORWARDED PER AN ATTACHMENT TO YOUR PERSONAL EMAIL ADDRESS; PLEASE TICK THE BOX AND PROVIDE YOUR EMAIL ADDRESS BELOW

email address: .....

**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**