

INFORMATION

STICK WITH IT SLOW BUT SURE

NEWSLETTER OF THE IN GROUP: THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC.
Supporting sufferers from acute Guillain-Barre Syndrome(GBS) & Chronic Inflammatory Demyelinating Polyneuropathy(CIDP)

**NEXT MEETING: SUNDAY, MAY 17TH 2009, AT 1.30PM
BALWYN LIBRARY MEETING ROOM, WHITEHORSE ROAD, BALWYN
GBS INFORMATION DVD – ANNA MELVILLE, CONCERT, VIDEO**

DATES FOR 2009 MEETINGS AT BALWYN LIBRARY MEETING ROOM.

Annual General Meeting 16th August Guest Speaker Bill Stevens on Hydrotherapy
Christmas Luncheon 29th November

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

Winter Luncheon 26th July

AWARENESS DAY, JUNE 1ST.

On the back of your address sleeve is a suggested article for your local newspaper. The committee will be endeavouring to have articles in major newspapers and community notices on radio.

Early diagnosis is imperative. Please help to make it a reality.

NOTES FROM THE FEBRUARY MEETING

(We hold a brief general meeting prior to our guest speaker's address.) Dr. Russell Gibbs was unable to be our guest speaker due to breathing problems from the smoke covering Melbourne and sent his apologies. Apologies were also received from June Cathcart, John Burke, Bernie and Jan Pettit and Barbara Clifford.

President, Margaret Lawrence, told how with her husband Doug, Joe and Melva Behr, she travelled on what is now known as "Black Saturday," to meet some of the Geelong group. They are a very good group and very interested. About 20 attended at Margaret & John Widdicombe's home and had a lovely afternoon. Unfortunately John was in hospital where he was recently diagnosed with a severe case of gout.

Margaret showed us their Whiz Bang toilet. It had balance bars on the side and a bidet attached to the original toilet. Some plumbing and electrical works had been required. They found it in the "Seniors" magazine and it may be accessed at www.australianbidet.com.au. All present agreed it was a very worthwhile addition.

New members **Graeme and Dianne Medlyn** travelled from St. Arnaud. Graeme has quite severe pain at the moment and has been in hospital. He has been given no definite diagnosis. It's a small world - he found the group because he was a friend of Margaret Widdicombe's next door neighbour. Graeme was so happy to be able to talk with people who could relate to his problems.

One of their members made marmalade, others brought rhubarb and nectaries which were sold and raised \$42.50. They are an excellent group giving each other wonderful support. **Congratulations Geelong!!**

Margaret told how member **Brian Boyd** is involved with bike riding which has helped his muscles enormously. He has been written up in **Bicycles Victoria**. Brian stated that it has helped him with circulation, well being and stress as well as improving his muscles.

Brian said he also had had gout and local anaesthetic couldn't do anything to help it. The doctor asked if he had been eating seafood, and he said he had a passion for marinated muscles. He stopped eating them and the gout went away. Another member said she had to stop eating sardines because of gout.

We welcomed new members **Peter and Susan Paterson**. It was great to see long time member **Robert Every** and his wife who had travelled from Bendigo.

Margaret then asked members to introduce themselves. This is what expired:-

Dorothy Brennan. I had GBS 17 years ago. I'm 75-80% recovered. I was treated with plasma pheresis.

Noel Petheridge.. CIDP 2000. I'm having no treatment at the moment but seeing neurologist in May. Treated with Plasma exchange, (no improvement) 'Intragam', (no improvement) then 'Imuran' but ended up on 'Prednisolone'. I was in a wheelchair but now walking unaided.

Jan Petheridge. I'm Noel's wife. He is good now, but it was difficult when he was in the wheelchair.

Questions from new member Susan Paterson whose husband Peter was recently diagnosed with GBS.

How did it first strike you? Noel –Generally being unwell and hard to explain the problem. GP sent me to a neurologist, who diagnosed GBS then sent me to Austin Hospital.

Do you all get tired? Is that a big thing? Do you have to have a rest when you feel tired, even after the smallest of exercise or walking around the block? Do you feel you need to have a solid sleep?

One member said he fights it. Others said don't fight it – have a rest. Another member said he picks up after a **Vitamin B12** injection.

Do you feel better after a rest? All said Yes. **This is real fatigue.** A member said it is like chronic fatigue syndrome. **Yes, it's very similar.**

Peter Males. I work for a couple of days doing something around the house and then the next day I'm very listless. I don't do anything. I go to the pool every Friday where I do **warm water pool exercises**. I use dumbbells and work my upper body as well as the rest of the body. **I love it as it makes me feel great.** (Others agreed **that warm water exercises improved them.**)

Another member said her husband had CIDP and overworked and then was completely exhausted and his muscles become very weak. **Just do what you can and recognise when to stop. Pace yourself.**

John DeRavin. I had a faulty valve at aged 15 but years ago I was still able to row in the Head of the River. I have always been tired but don't think it has anything to do with my CIDP. I have a 4 wheeled trolley and can only walk about 150 yards before getting pains in the back but that probably is from another condition too. **If I get hold of a trolley at the supermarket I can walk around quite good for a long time.**

(It was agreed that shopping trolleys are easier to walk with and keep your back straighter and people don't notice you are handicapped.)

I have been on 'Intragam' for 3 year, monthly for 2 days and I think its helping. If I can do more exercise like bike riding, I think I'd feel a lot fitter and psychologically think maybe I am getting over it. I don't have any tingling in the hands at all (I am getting close to 80) and **'Intragam' is helping a lot** as I am feeling much better with it.

Brian Boyd. I'm nearly 74, CIDP 10 years, last 6 going to hospital every 4 weeks for 2 days and get 6 big bottles of 'Intragam' pumped into me. Afterwards I have to force myself to do things for 2 or 3 days and I find the best way is to go to my local therapeutic pool and do some vigorous **water therapy** and ½ to ¾ of an hour in the sauna. Then I lay down for ½ an hour to recover. I feel good for 3 days. **Somehow thinning the blood**

gets it pumping through. I have checked with my Dr and he says that's fine as long as you don't have low blood pressure. The next day I cycle.

I hadn't cycled for 55 years but I find you don't need your sense of balance. My doctors and neurologist comment that my calf muscles are very well developed. (Many patients with CIDP lose a lot of condition.) That leaves the top half of the body which cycling doesn't do much for so **I have been doing a course of physio, gym and water therapy at Rehab. That has been excellent in developing the rest of my body. It also helps blood circulation and stress relief."**

Margaret. With all these things you do, do you pay for those privately as that can be a problem for some members or can you claim them, like going to the pool, the sauna etc?

Brian. With Vic. Rehab., Medibank Private pays for 100 half hour sessions, whether physio or gym. I had a referral from my neurologist to the rehab. centre and they claim it straight from Medibank Private. At our local pool, **Hydrotherapy** is \$3 for a senior. If you want the sauna as well it's about \$7. **The relief I get after it is worth every penny."**

Peter Males. I buy a book of 25 tickets for the hydrotherapy pool for \$92 for the year.

Susan . How did you get to go to St.Vincent's? **Brian.** I was in a private hospital in Blackburn where I caught one of the "super bugs" in a wound. Eventually after being transferred to other hospitals I was put at the Mercy. I now have my treatment for CIDP at St. Vincent's Private. I feel the available resources are far greater at St. Vincent's Private. I also went to St. Vincent's for skin cancer treatment.

Susan. When my husband couldn't walk and the GP said he didn't know what it was, I said we wanted to go to St. Vincent's Public because it was an emergency. The service was excellent.

Peter Paterson. Emergency diagnosed me overnight, taking spinal fluid and doing a conductivity test on the nerves and from those two results they diagnosed straight away GBS. My condition was sufficiently severe that I had to be kept in and put on 'Intragam' straight away. I couldn't be sent home and stayed for 10 days.

Susan Paterson. Shortly before my husband came down with GBS he had treatment at St. Vincents for his skin.

Peter Paterson. Yes that's right. I went to St. Vincents Dermatology Department with scaling of the skin on my scalp. They said we have an excellent product Aldara. It is a cream which doesn't cure any conditions but triggers the immune system of the patient to look for what's wrong and in my case it went to the scaling. Now it started to work very well, (as it's an excellent product) but in the published literature Aldara says patients may be susceptible to side effects. There are 10 side effects and I was getting three of them; pains in the lower back, pains in the legs and tingling. I accepted these three conditions as being normal for Aldara so continued using the cream each day. However, these symptoms got progressively worse and **over 9 days from being a perfectly happy bloke with just scaling on my scalp, I was virtually crippled.**

Now it's a dilemma as to whether I was developing GBS independently of the cream. The Professor in Dermatology, when I put this suggestion to him said, "No way, I won't accept that. You have to look for another source for your condition (GBS)". Of course, as you all know, **it's almost impossible to nail down what triggers GBS.** So that's the little side effect story.

Brian. Like most of us I've searched for a cause and the only things I can think of is Agent Orange which I could have had contact with or severe scarlet fever for which I was in hospital for 2 months. That's my thoughts.

John DeRavin said he met Brian at the hospital and that's how he joined our group. **Brian** said "Whenever I go for my treatment I always ask, "Who is on 'Intragam' regardless of what it is for and I usually find the time to go visit those who are having it."

Brian and **Peter** told the group "**There are also half price taxi tickets.** You must have a Doctors Certificate and it must say "**Chronic**" on it. This helps with visits to the hospital as it would be very difficult to get there any other way. Both men have treatment over 2 or 3 days, returning home between treatments.

Peter Males. I have CIDP. I noticed it because **my big toe was going numb**. The doctor said my circulation was fine and I'd be okay. At the time I was seeing a physio for a **crook leg** and he suggested I go back to my doctor and get a nerve conduction test. He said, you don't need that, but I said I wanted it so I had it and they discovered I had nerve damage in my legs, feet and hands. I asked to see a specialist. **He diagnosed CIDP**. He said it was an auto immune disorder where the outside of the nerve is being attacked and **I asked will it kill me and he said, no, but it will make you uncomfortable**.

Since then I get 'Intragam' every 3 months. The first couple of times they put me into hospital for 3 nights but now I go in at 9 am and get home by about 1pm. I have 3 large bottles and a small each day for the three days.

I have tingling in my hands and they are weak. The worst thing is trying to do up a nut and it keeps dropping. You get very frustrated. (All the men related to this. Discussion took place about a new screwdriver that holds the screws on.)

I don't know how I got this thing, but at the time my job was very **stressful**. I also had a chest **infection** which I couldn't shake.

Another member said they were in the Austin Hospital for 3 weeks and as you know it's a training hospital and every day a **tutor would come in and say he'd like his class to look at me. I said yes because I asked my GP did he know about CIDP and he said he remembered reading about it in university but never had contact with it since**. Every time the students came they asked me what did I think caused it. Was it herbicides, insecticides, stress? Nobody ever knows. It may also be a virus.

Margaret. Andrew Kornberg says one of the things they look at is **stress**. Stress plays a big part in a lot of things.+

Kerrie. You have to stay positive. **I am getting closer to waking up one day saying, "What was CIDP?" I feel mine is disappearing**. I go bush walking. Okay I get really tired. I talked with Dr. Russell Gibbs when he visited as I was very concerned about my work and my long hours. He said it was ridiculous and I needed to cut back. 5 hours is plenty as I'm on my feet. I eventually cut down to 5 hrs. I change my shoes three times during my shifts. This helps my feet. **It is to know your limit and try and live a normal life, stay positive, be happy, go about your business but don't overdo it**. I have to mow my own lawns, so I do only half each time. Be sensible.

I go to exercise classes for an hour each week for the over 55's and I do **water exercise** and afterwards I feel really good.

I am getting a larger dose of 'Intragam' than I normally get. I am getting higher than for my weight. I feel fantastic.

Peter asked **Kerrie** about her special sandals. She said she wears them for bush walking and has found because they are lighter she can manage well. She lifts her feet higher but they make her use her toes and she can feel the nerves in her toes returning.

Some of the members had a discussion on "hot" feet. It seemed to be a problem for most.

Gwen McInnes. I have had CIDP for about 10 years but I have a variety of symptoms. I had a **back problem** with the same symptoms as CIDP and I had surgery about 14 years ago. At the time I was told there had been damage to the nerves and that maybe in 5 or 10 years I may need more surgery because the bone tries to make up – but my neurologist Dr. Richard Starke was able to say I was beginning CIDP then. Instead of my brain telling my feet what to do, my feet tell the brain they have already done it. I have 'Intragam' every 4 weeks.

My question is: How do you tell if it's doing anything. I don't want to go off it and find out the hard way as some people have. I go to the Alfred Hospital. I keep a "hypochondriac diary" because I have very peculiar other things, so I write these down because you think "Did I imagine that". I am very fortunate; I have close contact with my neurologist as his wife is our GP. I try to keep up with everything and **I preach about it as so many people don't know about CIDP**.

I went as a guinea pig into the **Alfred for doctors who were working in industry** and they were coming in for further testing, because they might think that something is wrong with a person that is work related, but it

might actually be CIDP or something else. **Not one of them found I had CIDP.** First of all they asked did I have diabetes, then a heavy drinker, had I been exposed to chemicals, not one over the 2 years, **seeing 25 doctors**, so I preach to everyone. Dr. Russell Gibbs said always ask your GP, "What else could it be" and I do.

Peter McInness. My only claim to fame is I have been married to Gwen for 57 years. **Gwen said he does all the housework** which makes him pretty important.

Doug Lawrence said his main objective is to **help spread the word.** We are working towards getting our own Website. Nothing much on as yet except past newsletters. We will have direct access rather than through vicnet. We are also having links through it back to other groups and overseas which we hope will help people searching for more information.

Finances - We have deposited \$1976, of which just over \$1000 was from the Christmas Luncheon and Auction, more subs. and donations and jewellery sales of \$60, with book sales making up the remainder. Our expenditure was \$587 for which we purchased new recording equipment to record speakers and transfer to Newsletters. Sum total in bank as at the end of December \$13,105. We are ready to give Andrew Kornberg another donation (**thanks to the fabulous generosity of our members**) and we hope he will attend a meeting to tell of progress in his research.

We did get a grant from the Department of Human Services of \$1500. This money is not for donation but used towards spreading information, Newsletters, booklets, notices in hospitals, etc.

Gwen. I would like to thank everybody who supported the Jewellery Drive. I don't know how much we made. **Doug** said \$5-600. **Thanks Gwen for your generosity.**

Robert Every. I had no symptoms until 2000 when I had a **hip replaced**, came out and the bicep in my arm got weaker and weaker. The GP said you have pinched a nerve. Then I started getting tingling in my toes and left hand and in the end he referred me to a neurosurgeon that visits Bendigo and he said it was from a **vertebrae** in my neck which is where those nerves come out and he said I might refer you to my mate in Melbourne. I went down to see Mark Cook at St. Vincents who is an epilepsy expert. He examined me and started tapping and said "you haven't got any reflexes." Oh, previously I'd been to the Royal Melbourne for a lumbar puncture and got very sick. St. V's did another lumbar puncture test and a nerve conduction test etc. and determined that I had this CIDP and put me on Prednisolone which kept me wide awake for a month – a huge dose – it didn't do any good, so he put me on 'Intragam' for 5 days. I came back home good as gold.

It's like a barometer of how I am going **this arm**, and gradually I became worse until eventually the hand started clawing up and getting weaker. After 6 months I went down for another burst and 6 months later yet another one.

There was a fellow visiting from Tasmania who said we can't let you go down this far every time and put me straight on fortnightly 'Intragam' now administered in Bendigo and consequently I don't have any big side effects apart from weakness in that arm and clumsiness and tangled foot, and tiredness, which I didn't associate with my CIDP until I came here today. . I go for a walk every day and get desperately tired. I work full time.

My biggest gripe is coming up to retirement I will not be able to get away from Bendigo. Recently my daughter had a baby in Noosa and I needed my treatment so had to go through a specialist up there, and it was quite a nuisance. Eventually I did have it and everything was quite satisfactory. I have 600mls. 3 bottles. I need it more often than others I know, but I went for a holiday for 3 weeks and by the end of the third week, it took me another couple of treatments before I came back up again.

Peter Males. I get it as per my weight. Others said they too received 'Intragam' per their weight.

Melva. Dr. Kornberg has said they are looking at different doses now, not necessarily governed by weight as is the case with Kerrie. Everyone is different. Some people can go for months, others only weeks.

Don't think you can't travel. One of our members had treatment at Guy's Hospital in London.

Robert. Did Australia send it over? No, it can be accessed throughout the world.

Barbara Rivett told how her husband Tom has his treatments in Brisbane. The appointments are made by Monash Hospital in Melbourne and when we arrive in Brisbane we give them our letter and they say just come in on the day. No hassles whatsoever.

Peter. Do you get this letter from your GP? **Barbara.** No we get it from the hospital, stating 2 days in a row and Brisbane now have it on their computer and say, anytime you are coming up just bring your letter with you.

Peter Paterson. Is it Red Cross who produce this product? **Joe.** Red Cross collect the blood and CSL produce the product. **Peter.** This makes it an Australian product. It was explained that other countries also make similar product.

Peter. When I was given it they were so concerned about batch numbers. Two nurses, cross checking it, tags off the bottles, etc.

Joe Behr. I have had CIDP for about 21 years now. The reasons for it I don't know, but I've had them all. I had **stress** at the time, contact with **chemicals** at work, a **flu injection** which I had a bad reaction to and I was on two **medications** which are now not given together. I had **golden staff** and I also had **an injury to the base of the spine**. It was a few weeks after that I began to have tingling in my toes and my legs became weak. They did a spinal tap and confirmed the CIDP and gave me plasma pheresis but it made no difference. They put me on 'Imuran' which was good but because I was diabetic there were problems with my feet so eventually I was put on 'Intragam'. I had it every 3 months over 3 days and did that for approximately 9 years.

Once I was given 1-1/2 times my dosage in error and it was amazing. I could walk up a flight of stairs easily when I came out of hospital. I felt it stabilized me and eventually I didn't feel I was getting any benefit any more and my arteries and veins would collapse during infusions and it became just too difficult, so I stopped treatment. At the time it was very hard to get, and there were people who needed it more than me, (especially those with GBS) and since then I have had no medication at all for the CIDP and I have gradually got more strength in my hands and feet. I feel I have been stable for 5 years.

Just after my last treatment though I also had a **bowel operation** after which (while in ICU) I had a **heart attack**. As soon as possible after that I have a **quin triple bypass** and during these two operations **I had 8 full blood transfusions**. It was after I stopped the treatment but **I think the CIDP just said "I'm out of here"**. I feel I'm just plodding along. It's not getting any better or any worse. I used to be on a walking stick and now I just use Melva's arm for a bit of support when walking in unfamiliar territory. I call her my two legged tripod. Crowds are bad as you can't react to get out of peoples way.

My worst thing is **I had foot drop from the beginning**. I have learnt to live with it. I don't notice it as much and I don't fall over as much. I used to trip over my own shadow. I'm just getting used to it. You change your style of walking. I can't lift my toes up at all. Some years ago just the slightest drag on the carpet and I'd be straight down but now I can actually lift my leg up and catch myself, so **feel I have some reflexes back**.

Melva told how she watched him recently stand in a queue in the middle of a room. Usually he would have leant on a wall but now he can stand quite still. Also when we had our daughter he wasn't able to pick her up or carry her but now with the grandchildren he can carry them to the car. **Joe** said he only does it when he feels he can and doesn't like it when they run at him.

Brian had recently arranged for **Joe** to try out on a child's bike. **Brian.** You don't lose your balance do you Joe?" **Joe.** No you get it back quickly. **I didn't think I would be able to ride** but I could do. It was fine except I couldn't stop. I thought if I stopped I'd fall off. It was such freedom to be able to ride away after not being able to walk other than at snails pace for over 20 years. No balance difficulties. Fantastic!" After riding the bike I did have pains in my muscles. I hope it's not my hips going as I do get pain there. I can't walk up slopes these days. I'm fine on flat ground but my hips ache very quickly otherwise.

Question: How do you get on a bike if you can't lift your leg high enough to clear the pedals?

Answer: You lay the bike down and step one leg over the pedals, then stand the bike up. We were in a dilemma until we were shown this trick.

Susan Paterson. Joe you said you went to Austria? **Joe.** Yes. I wanted to visit relatives. We had to go because I was so bad and told I would be in a wheelchair very soon. This was before 'Intragam'.

Susan: How did you go with Insurance? They accepted you? **Joe.** Yes. It was in 1989 and maybe they are stricter now. I was on 'Imuran' then. The doctors in Austria conducted all the required blood tests, etc.

Peter Males told how he recently went to America and was accepted to travel but was not covered for CIDP. They wouldn't give you 'Intragam' on it. You have to plan ahead. But everything else was no trouble.

John. I think you have heard my story all the way around the floor today. **In 1997** when I was 67, I got very sick and my hands and feet went. **I couldn't get diagnosed.** I came back from England and I got sick bodily too and they thought it was my spine and they tested me like the rest of you and eventually I got too sick and a neurologist lady diagnosed me straight away with GBS.

I was in the Alfred some months before I was diagnosed. I had the plasma exchanges – 5 of them, and slowly got better.

I have been left with what I describe as "tautness" in the feet. It doesn't stop me from walking as I just keep going, painting, etc. I went to the Northern Territory and walked around Ayres Rock, Kings Canyon, Alice, Darwin and Arnhem Land. It's a long walk from wherever you park the car.

I have made a good recovery if that gives hope to anyone here. It took 3 or 4 years but I do hear the length of time before getting diagnosed is a problem. I hear it from everybody and it's a wonder it hasn't been enlightened to doctors.

I met a GP when in repatriation. He went through the same amount of time before he was diagnosed. In fact he was so sick they sent him out to the contagious disease hospital at Heidelberg and eventually he was diagnosed with GBS. I can't speak highly enough of the neurologists. The lady I went to said straight away I had Guillain-Barre` as quickly as that. Her name was Hilary Hunt and her rooms are at Epworth.

Brian said he rang a friend who said "nowadays I'm retired and I'm in a wheelchair". I said "did you break your leg or something?" He said, "No I've got a rare disease and I'm probably the only one in the country with it." I asked "What do they call it?" He replied "CIDP." I laughed and said "I've got it too". He told me "the doctors say there is nothing that can be done for it". I said, "Change your doctor." He said, "I can't he's my best friend and I used to play golf with him and he's a neighbour." I sent him papers on CIDP and he went on 'Intragam' and he's now out of his wheelchair.

Margaret said **Brian** was in the same Probus club as **Doug** and herself and she said to him "You've got problems with your legs?" Brian said "but you won't know what it is." She said you had better come along to the group I'm involved with. There is another lady they both know who went to a neurologist who was so blunt with her she won't go to another neurologist and she won't come to the group.

Another member said his neurologist told him not to go to a support group as he didn't believe it helps. Now he attends our group and says it is a wonderful thing having others who know how you feel.

Peter Paterson. I am a simple case only 7 weeks in though. I developed this condition where I truly couldn't walk so Sue helped me into emergency at St. V's and overnight they diagnosed GBS and my status as mild. I am unsure what medium and severe is. After 4 days of 'Intragam' and 12 days in hospital they said "your ongoing treatment is rehab. I'm now at Caulfield Rehab 2 or 3 times a week for exercises and hydro.

I left hospital with great enthusiasm and confidence. I thought by golly I'm going to be back on my feet in a month. But I was quite wrong and I'm surprised that my recovery is so slow.

Another item that intrigues me is when the rogue cells attack the myelin. As I understand it, until the insulation (myelin) has covered the nerve there is a short circuit. I was an electrical engineer so when they speak about shorting out I understand perfectly. This is what I have been asking the neurologists. If my sensation starts to decrease, does it mean that the myelin is repairing? None of them will really make a statement.

The conductivity test does measure the time taken. They know exactly how long a natural nerve signal takes to move. They measure the damaged system and if it takes three times as long to get to the source, it means that the signal keeps shorting out at the destruction points. So that's quite logical to me. Now **John** beside me here still has the sensation in his feet. Does this mean the myelin hasn't fully repaired there?

Noel? The specialist told me that it is a break down of the nerve and it takes a long time to repair and they are not sure if it does repair, and the arm being closer to the brain will repair quicker than the leg. I am not complaining about my feet. After what I went through, if we all have a little numbness in our feet it doesn't worry us that much. It doesn't stop you painting a roof or something.

John DeRavin. My feet feel like two lumps of lead. (All said. Yeh.) A funny thing is, when I walk with bare feet on the polished floor and if I haven't vacuumed for a couple of days, I can feel the dust. Now there must be two different types of nerves. **My doctor doesn't say goodbye to me anymore, he says "Watch Your Step". He is filling me up with Calcium etc. because he thinks I'm going to trip one day and break a bone.**

Susan P. We went to Paris after which we spent 4 weeks cleaning up our garden and **Peter was on a ladder and within 24 hours he couldn't walk.** When the taxi driver helped me take Peter into the hospital he was laughing. I said, "He's not drunk – he cannot walk". Peter would walk 8 kms. twice a week as his regular workout and he was fit and we walked all over Europe.

Peter. Since this happened to me my wife has become very anxious. We were hoping to hear Dr. Gibbs speak about anxiety.

Barbara Rivett. I am my husband's carer. We have travelled. I have learned to tow a caravan. I didn't think I could do it, but now I can. When Tom was diagnosed we wanted to visit the Kimberleys and Western Australia. After 6 months, the neurologist said "Go do it."

Tom Rivett. I have had CIDP 14 years. It started with tingling in my fingers and toes and it took two weeks to diagnose. As I see it CIDP manifests itself in many ways. My fingers don't do what I want them to do. (Tom is a radio Ham and told how Barbara helps with soldering.) **The worst thing in my case is my feet which are absolutely red hot.** I walk to collect the mail which is at the gate (suburban block) and I have to rest before I go back to the house. I recently had another nerve conduction test and asked if the voltage had dropped. The doctor said it was 0 last time and 0 this time, so you can't get lower than nil.

Barbara, I wouldn't let him on a bike as he would fall off.

Fred Hooton. I have had CIDP for 17 years and am treated with 'Intragam'. **I am very dependent on it and go to The Alfred every 5 weeks for 30 grams. After 4 weeks (with 1 week to go) I can tell because my balance starts to go off and my walking is not steady.** I go again next Tuesday, so today (Sunday) I have to be very careful I don't fall over.

After I was diagnosed I asked my GP did he know about CIDP and he said he'd never heard of it. I believe its different now with the majority of GPs knowing what CIDP is. In those days some neurologists wouldn't have heard of it.

When I went to rehabilitation my daughter asked if she could bring my dog to see me. They told her she could. Every time she came to my ward, (which was 2 minutes from the entry) it took 15 to 20 mins. for her to get to me. All the patients said bring the dog in. In the end I wrote a little note to Donvale saying they should seriously have a dog. It is very good therapy.

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Melva. I apologize to those members whose voices I could not recognise. I hope all who are unable to attend meetings relate to the stories relayed. This may be a little long winded but is an indication of what goes on at our support meetings.

Of course we also have our "afternoon tea" and the committee would like to thank all members who bring along the tasty "plates". Thank you.

Disclaimer Information presented in "INformation" the Newsletter of the Inflammatory Neuropathy Support Group of Victoria Inc., is intended for information only and should not be considered as advising or diagnosing or treatment of Guillain-Barre Syndrome, CIDP or any other medical condition.

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