**GBS ……..CIDP** **Issue No: 90. March, 2015.**

**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) 26 Belmont Road, Glen Waverley, 3150. Victoria, Australia.
www.ingroup.org.au email: info@ingroup.org.au.

**NEXT MEETING**
**SUNDAY, 17TH MAY, 2015 FROM 2.00PM TO 4.00PM**
**Balwyn Library Meeting Room, Whitehorse Road, Balwyn**
**GUEST SPEAKER: RALPH BAILEY, BARRISTER AND SOLICITOR (Retired)**
Re: Wills, Power of Attorney, Probate, Legal/Medical documents.
Questions welcomed.
A small plate to share would be appreciated. Thank you.

**Dates to Remember**

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| Sunday, 29th June. | Mid Year Function – Time, etc. to be advised. |
| Sunday, 16th | August 2.00pm ANNUAL GENERAL MEETING |
| | Guest Speaker: Associate Professor Tim Day, Neurologist. |
| Sunday, 15th November 12.00 noon | End of year Luncheon and Dutch auction. |

**Notes from February meeting**. (A small group met on what was a very hot day.)

President Margaret: It is lovely to welcome new member Joy and her husband Geoff who have travelled from Wodonga to be with us today. There are apologies from Barbara, John B., Barb and Len and Dorothy.

**Treasurers Report** - Doug: October-December Quarter $4158. Our Christmas function raised $1101 which included **money from tins on the counter at the Batikas' shop**. Subs. were $335 and donations $1200 which is representative of the tremendous support we receive from our members. There was also a State Grant of $1458 for Self Help Groups. Since December, there has been more come in via subs and donations. Expenses incurred were for printing of the newsletter, postage, etc.

**Correspondence: The Children's Hospital booklet, "The Impact of Giving**" has our name in it. You can look at that later.

Also I would like to say it is lovely to have Margaret here. You may or may not know but **Russell** passed away. His funeral was musical and lovely for a lovely man. It is great to have Margaret join us today.

I had a phone call last Thursday from a man in Brisbane. He was concerned for his partner and wanted to know **if any of our members go overseas for second opinions or treatments**.

I didn't know of anyone who had and he said he would save his money and instead will come to Melbourne to one of our meetings.

I also had a letter with **a donation from a Sister with the Sisters of the Poor** saying how much she **enjoyed reading our newsletter.**

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**We received the following letter which I would like to read:-**

Dear Margaret and all your other committee members,

I greatly **enjoy your newsletter and really admire the work you do for members and their friends and families with GBS and CIDP through The IN Group.**

Back **in 1993, aged just 21, my son Thomas came down with a very severe case of GBS; ICU, ventilation, lung collapses, paralyses up to eyes,** etc. He was **a patient at the Alfred** in Melbourne for some months and his **neurologist was Richard Stark**.

**Tom made a complete recovery** in **no small part due to the hospital and the medical staff**. However**, the best thing the hospital did for me was very early on to contact The IN Group and within days a very tall man, James Gerrand came to the hospital and spoke very reassuringly to both of us. I have never forgotten his kindness and the difference his knowledge made to how I got through that time.**

**Reading Richard Stark and Andrew Kornberg's talks in your most recent Newsletter brought back a lot of memories.**

Once again, my congratulations on **the fine work you do, especially fund-raising at the grass roots level.**

This letter was from **Margaretta O'Hara**.

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**Margaret: It was great to receive this lovely letter**.
(Ed: We still have members who **visit patients in hospitals**. They are our unsung heroes. Please **let the hospital you attend know of this service.** Thank you to the ICU **staff members** and Rehab centres who **contact us following discussions with family and friends of GBS patients**. This is an **important** part of our **support**.)

**I have spoken again to Maria Batakis about her son who is 7 and has CIDP and just had three weeks in hospital.** He is coming along quite well. When he is tired he has to be in a wheelchair as his legs get exhausted and I sent him a book and a puzzle from The IN Group.

**Her main conversation was, while she was at the hospital she got on line and eventually got on to a lady whose daughter had exactly the same problems as her son. The lady said treatment was given a different way. Now this lady is saying her child is cured. It is now 7 years since her daughter had any problem.**

**In Australia we tend to help after a relapse has happened but in America they are doing a treatment where they never let it come to a crisis. Maria was hoping she could come today to read us the information.** She said she felt it was a lot **more progressive in America** as to what they are trying to do, but of course the other thing is that if the government don't go with it, they just don't go with it.

I think the **treatment is the same sort of medication, but they keep giving it to you in small quantities every week** instead of going along every so often. Member: They might be doing it subcutaneously.

**** Maria was unable to come but sent an email which is at the end of the newsletter.**

**Margaret to Joy: Would like us to go around the room and say about ourselves as that is what we do when we have no speaker. Joy: This is what inspired us to come down. We saw a newsletter where this took place. Margaret: Okay. We'll start with Joe.**

**Joe**: **I have had CIDP for 26 years**. It was a lot worse in the beginning. I tried lots of things. Plasma pheresis, 'Imuran' then eventually **'Intragam' and I stayed on it for 12 years** until I **reached a plateau**. I got to the stage where I couldn't see the benefit of having it. I was having reactions, headaches after the treatment; my hands were peeling, etc. I would have **24grams for 3 days every three months**. I found my arteries didn't hold up that long and it was quite uncomfortable and painful. I couldn't notice improvement or deterioration afterwards so **I thought I would stop it** altogether and for the last 13 years I haven't had any medication for CIDP at all and I have **found progressively my legs have improved. I still have foot drop** but I can now get

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up ladders, so I can still do things. I'm painting the house at the moment. It is just **difficult in a crowd**. You are walking and you never know when you will lose your balance but I have my wife to hold on to. The only thing is **balance is a bit of a problem** but you learn to live with that and I certainly have. Life's good.

**Tom**: It took over 12 months for the neurologist to say what it was and I have now been **having treatment with 'Intragam' for 18 y**ears. **I have tried cutting back but I would deteriorate**. Now if I try cutting back I don't deteriorate as much as I did years ago but I still do deteriorate a bit. I go in for **two days every 4 weeks**.

**Barbara**: No I haven't got it. **I just take Tom for his treatments**.

**Melva**: **Tom**, we should say you **are one of the people who suffer from pain**. **Joe** suffers from **tingling** which he refers to as "another inconvenience" but **you** actually have quite a bit of pain. **Tom**: **I constantly have pain and tremors,** some of which they are not sure is related to this, but **I do have consistent pain**. **Melva**: **Do you still have the same dose of 'Intragam' as you did? Tom**: It has been changed. **It has gone up and it has gone down**. They have **tried all sorts of things. I have tried every new drug** that has come on the market **but nine out of ten times they have an adverse affect** on me so they take me off again **I have 'Prednisolone' and 'Intragam' at the same time**.

**Margaret.W**: Well, in 2002, when he was **85, my dad Russell** was dancing around at his nieces wedding and he sat down on a chair and was **complaining about sore legs**. A week later he was **diagnosed with GBS**. Eventually he went into Rehab. **The paralyses only came to his elbows and up to his knees.** He couldn't hold anything but his brain was like a firecracker so **he hated being so helpless**. Anyway **he worked hard**. He didn't want to. He thought the physiotherapist was so hard on him. But he did it and eventually he was ready to leave and he **went into a Retirement Village on his own** as mum had passed away a few years before. Someone mentioned to him that he would probably go to the nursing home section because he couldn't look after himself, but he said "no way". **He elected to go into the low care section and he worked jolly hard at the physiotherapy for 2 years. He went every week. He would be exhausted.**

Then **after 2 years he said, "This is it. This is where I'm at."** Well he went from someone who couldn't feed himself, someone who couldn't do anything, to being able to walk with a frame, then to a wheelie and eventually a walking stick. **He had a little weakness but he got another 12 years out of life. He did really, really well and I just had great admiration for him.** He was cheesed off about it all. **I persuaded him to come to The IN Group** and he saw a couple of people around his age with similar problems and thought "That's alright" and he had a chat with them and **he found out life goes on.**

At the very time when he was at his weakest, he could still phone me or my sister and say to bring in something from a cupboard, on the left hand side. He was right on the ball. When I read the last newsletter I was contemplating the difference in what is generally **now** known particularly about **GBS** which was our focus and I suspect **CIDP**, compared to when we first came here and **there is much more knowledge about treatments**. **We were very grateful for the support of this group.**

**Melva**: We must say that **Russell made the most wonderful Pickled Onions**. He used to bring them and put them on our trading table and the committee used to snavel them. He was **one of nature's gentlemen**. He was (as you find GBS and CIDP patients) a person that doesn't want to put anyone out; a person with a very good brain; a person who is quiet and respectful, which brings us back to our founder **James Gerrand** who was all these things as well.

As most of you would know, I am Joe's wife. At one stage **they did give Joe 1-1/2 times his usual dose of 'Intragam' and we came out that day and he walked up a flight of steps with absolutely no hesitation or strain.** I have said this many times to neurologists over the years but they just stick to measuring **the dose by weight** and no matter what you say or do they won't change it, but to me, I feel they should **experiment a bit and see whether an increased amount stops it** as following this episode Joe felt he didn't benefit from further doses and **was able to stop treatment. It is a very touchy subject.**

**Joy**: **How did you get this 1-1/2 dose? Was it a mistake?**

**Joe**: I was in hospital and a young chappie administered it. We always went to a Private Hospital and this time I thought I'd go as a public patient. This young chap came in and said, "I've never done this before. This will be interesting". And he said, "I'll tell you what. The lady who picks this up from the blood bank is on holidays, so we have extra. We picked up double **and I'm going to give you double today**". …/4

**Melva**: He **was given 1-1/2 times his usual dose**. **My brother who is a medical scientist came to visit** and Joe said "**I've had 1-1/2 times my dose." My brother disappeared and very soon** after that the young doctor came in and said, "**I can't give you any more" and turned it off**. All we know is that when we left Joe could go up the steepest steps without assistance and at full pace.

We have **never known if that was what stopped Joe's CIDP** because after this he had **bowel surgery and was given 4 units of full blood**. Within weeks he had **a quin-triple bypass and again received another 4 units of full blood. Was it the increased dose, the full blood or better circulation through the body? Who knows? Some patients who have been treated for many years now sometimes get a booster dose over 5 days which would probably be similar.**

I think circulation is very important because the blood flow through the body surely would help keep muscles healthy. Joe used to have freezing cold feet. About 4 years after his by-pass surgery he got to a stage **where he couldn't walk very far at one time.** He would have to wait for a while and then go on. A friend of ours said she thought he had **blockages in the arteries** as they separate and go down the legs. He went to the doctor who sent him to a specialist who said "Yes, that's right. We are going **to put stents in where it separates." They did and he can now walk much further and he has the warmest feet.**

**Peter McI:** Don't be deceived by the walking stick. **I don't have GBS or CIDP**, I have **arthritis** in my legs and shoulders. I have three problems: a**rthritis, balance and I'm very very old.** My purpose for coming is to **drive Gwen**.

**Gwen**: To Margaret W., do you have Russell's pickled onion recipe?
Margaret W: I do. Gwen: I was thinking that would be good for our placemats for the end of year function. Margaret W: Oh yes. I'll make some. Margaret: My mum used to sleep with her hands under her pillow for weeks after she made her pickled onions because she said she could still smell it. Melva: Rub your hands on stainless steel. Margaret W: Put mustard on them and they won't smell. Doug: You could put these solutions to stop smelly hands on the recipe sheet. Laughter.

**Gwen**: I'm 82 so very old too. If I don't have to tell my age, I say I was a child bride.
**I have had CIDP for about 15 years**. It was a complicated diagnosis because I had a back condition which had the same symptoms and it took a while to sort out that I actually had both. I have **'Intragam' every four weeks** and just in the last couple of year I have noticed I am **not as good for the week before my infusion and it takes another week after to catch up again.** This is probably my age because you can't expect to go on the same all the time.

Talking about symptoms, I would say **the pain is like something similar to sticking needles through the flesh. It's very painful. I have been on 'Trammel' for most of the time and that works a treat.** Every now and then I still get a stabbing. I have **permission to increase the 'Trammel' at any time if I really need it** and it is a long lasting one and a shorter term one so I get by without extra most of the time.

About 5 years back I was having more troubles. **I thought it was CIDP but actually it was restless legs.** There is no blood test or anything, there is just a list of questions and if you answer them all in such a way it indicates you have restless legs. I don't know if anyone else has it. **It is very common**. It just drives you nuts. It is not painful. **You just can't keep them still, particularly when you go to bed. There is a drug (which is also used for Parkinson's disease) called 'Sifrol'. It's for restless legs too and it works like a charm.** I just go along with my regular 'Intragam' and all my pills and I have had various other medical issues along the way which had nothing to do with CIDP. If there is something weird then that's what I get.

I have been a Guinea Pig for **Richard Stark** a couple of times at the **Alfred** and **doctors came in during an exam** for them to try and find what was wrong with me and **not one of them did**. Most of them came to the **conclusion that either I had diabetes or I was an alcoholic**! Well I do have diabetes now, but **it just shows how difficult it is to diagnose CIDP,** particularly when we are all different and you don't know what's related to it and what is not.

I say "I'm well". I don't have heart problems, liver, or anything like that**. I have a weird Blood Pressure to the extent where I collapse sometimes. My blood pressure can vary between 250/120 (which is very high)**

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**and 80/40, within 20 minutes. I don't know when it is high as it doesn't affect me, but I know when it's low and occasionally I pass out because it is just so sudden.** I have had every medication for that and when I would go to a doctor and they found a pretty normal reading they would say "just keep doing what you are doing." Now I am **under a regime with a doctor who is doing her PhD on peculiar blood pressures.** She doesn't have many Guinea Pigs. At present I am still having the lows but not as bad. I haven't had a really high one for quite a while but **it is a matter of changing the medication and when you take it** and **taking your blood pressure 6 times a day**. I have had a resting cardiogram and my heart is so good she hopes hers is as good at my age. So my blood pressure has affected me, but I am well.

**Joy**: I have been **diagnosed since April last year with CIDP**. I had **symptoms** we are now aware of, **dating back to 2007**. It was silly things that nobody associated with anything in particular. **A lot of separate symptoms that occurred at different times and because nobody really thought they were a collective thing, it was kind of brushed aside.**

The **first thing I had was numbness on the left side of my foot and two toes that wouldn't move at all.** I mentioned that in passing to a nurse. (I must mention that Geoff and I spent 10 years in the Territory working in remote communities so health care there is not as good as it could be.) The nurses just tended to go "Oh really" then talk about something else. The **next symptom was having pins and needless between my groin and my knees on both of my legs. I didn't realise that they were pins and needles. To me it felt like somebody had got steel wool and was rubbing really hard on my skin. It probably took two years until I realized that it was pins and needles. The after affect of that was a great loss of sensation when I touch the tops of my legs.** The backs of my legs I can feel, but I have not much touch sensation at the tops of my legs. When I mentioned that to a doctor, I also had a cough at the same time. They said "Oh Gosh. That doesn't sound normal." They **took the pulse on top of both my feet to see if there was some sort of a blockage then said, "No. The pulse is normal."** They then continued on to treat the cough, so **I thought maybe this toe business is not that important**.

Have you all got bucket lists of things you would like to do if you had the opportunity? One of the things **on my bucket list was to learn how to ride a motorbike**. That was only 5 years ago. I was going to surprise Geoff because Geoff rides a motorbike and instead of being the pillion passenger, I was going to ride alongside him or ride his big bike. So I turn up to get my L's, passed the theory – that was fine. I had to turn around **on the Saturday to put in a day doing some practical stuff before they give you your L's. I got on the bike; knew the principles of it; you know what I mean about pressing it down to change gear, then having to swing your foot around and up to change gears, well my ankle wouldn't allow me to do it**. **(CIDP members all related to this. They can't move their feet upwards.)**

Half way through the day the trainer came up to me and said "**Look Lady, I really just think you need to resign yourself that you can't do this." I was devastated.** I went home and wiped that off the bucket list, but **didn't realise again what the problem was. I thought it was mainly co-ordination.** So then I got **to the stage where I started to walk funny**. **Joe:** Foot drop? **Geoff**: Yes! You could hear it. **Joy**: Clomp. Clomp. I just **thought it gave me an interesting wobble when I walked.**

When we came down from the Territory **my seductiveness got worse and my hips were saying "You'd better get that looked at".** Last April I was having x-rays to see if there was something wrong with my hips and they ruled that out then **referred me through to a neurologist in Albury. He just took one look at me before he did any tests and said, "You have CIDP but we are going to do all the tests to confirm it".**

So we did the **nerve conduction studies and found I have very little nerve reaction, particularly in my left leg.** I've had heaps and heaps of blood tests to rule things out, then a **lumbar puncture to confirm** it. Now I have **'Intragam' every 4 weeks**. **Initially I had 5 days, going into the hospital each day for 5 days then I had 'Intragam' four weekly. We took it out to 7 weeks because within 24 hours of the infusion I broke out with a skin irritation which felt like my hands were bursting all on the top of my hands. We stopped the treatment until it cleared up.** I wasn't allowed to put any creams on to clear it up. I had **another treatment in January**. I have **another next week**. After the one in January I had no reaction. **My condition hasn't improved. It has degenerated a bit. I am starting to get tremors in my hands.**

One of the **problems Geoff and I are both having is getting information from our neurologist**. He is, I think, very clever to have diagnosed so quickly.

**Melva**: He has had a previous patient. **Joy**: Is that Jill? **Melva**: No Vilma was his patient. …/6

**Joy**: He is very good, but when I go to ask him questions about it I feel he is patronising. When **I went to see him about the tremors in my hands** he said "You're not just nervous about what's happening to you?" I said, "No. **I'm not nervous. It comes and goes. Is it part of the condition? Is it something we should be looking at?"** So those things concern me and I don't know what's ahead. Because **I'm not getting better** and my neurologist said it **is because I have had it so long**. He just keeps shaking his head and saying "**Why didn't you do something about it before this?" I said, "I tried but nobody ever put all the pieces together to get the right picture".**

**You don't get your own doctor in the Northern Territory**. All the trainee doctors go to the Territory to get their experience, so you go to see a doctor today, you go **back to the same surgery in 6 weeks time and there is another doctor. There is no consistency in the Territory.** It is **very hard to get somebody to put symptoms together** unless they know to ask the right questions.

So, we are a **little bit frustrated and a little bit confused**. **I'm a little bit scared and we have just found the information on your site is terrific**. I also need to say as I finish that **Joe really was up on the ladder painting last week or the week before when I rang** you Melva and you were telling me about Joe and what he was doing at the current time. On telling Geoff he said, **"Well what are you doing sitting there?"**

**Margaret**: Do you go to the **Albury hospital** for your treatment? **Joy**: **I go to the Wodonga hospital to the Day Procedure Unit** there. One of the things that concerns me, listening to **a couple of people talking about the medications you are on, is you are having 'Intragam' and other medication.** My neurologist has organised the 'Intragam' infusions and does the follow up on that. I am **having the nerve conduction studies done in another couple of months to compare what they were like 12 months ago**. Then I have my family doctor who doesn't know anything about CIDP. **I am not on any medication**. **I still have severe pins and needles in my thighs.** I have probably, **in the last two months,** gone **from walking to walking with a walking stick** which has become my best friend. I have **a walking stick in my right hand and my other walking stick in my left**. **Melva**: Joe calls me **his two legged tripod**. Laughter.

**Joy**: **I feel I am going down hill a little bit**, but I haven't a family doctor that knows. **Melva**: But **your family doctor should be able to find out the information from your neurologist.**

**Joy**: He's very good. He has organised a disabled sticker for the car. I can't drive anymore because I can't feel what I am doing with my foot anymore, so I've lost a bit of independence. **Melva**: You might get that back. **If you keep getting your infusions every 4 weeks and you don't have go down before you get your infusion, it hopefully is stopping further damage to the nerves, so you might find that you improve over time and be able to drive again. Joy**: I've lost my confidence as I can't feel my foot on the pedal so I don't know if it is the clutch or the brake. **Joe**: It is best to have an automatic. I've had an automatic for many years.

**Joy**: Joe, **can you stand on your tiptoes**? **Joe**: **Yes, but I can't stand on my heels.** I can balance and stand up like this. **Joy**: I can't do that. The other day I was walking outside with bare feet (I don't know why I was doing that) but I got a piece of glass in my foot and I didn't realize. I had to walk to the chair to sit down to be able to remove the glass. Every footstep I pushed the glass further into my foot because I couldn't walk on my toes. **Joe**: My feet are hypersensitive. I can't walk bare-footed. The slightest little grain of anything hurts. **Gwen**: I can't wear sandals. If I go shopping and **hit my toes on the trolley – ouch, it takes a long time to stop hurting. Melva**: Joy I wouldn't be too worried about taking other medications with your 'Intragam'. I think it is only given when someone is deteriorating significantly. Do you think so Gwen? **Gwen**: Yes.

**Melva:** Joe has the **tremor and they found that 'Inderal' which is for high blood pressure has another affect of stopping tremor, so he takes it for the tremor and it works well.** It allows him to do things like painting. He is a toolmaker by trade and likes to do very fine things which he couldn't do before 'Inderal'.

**Peter McI**: **25 years ago Richard Stark diagnosed a non essential tremor** which was very slight but I had it **when I played the piano. I take 'Inderal' only for that purpose**. **Gwen**: Another thing that works is alcohol. That steadies it down.

**Peter McI**: Could I just make another comment. **You were saying about your ankles and not being able to control the pedals in the car. Some three years ago I had a number of falls and I put my full weight on my right knee and the tendons were torn and the quad muscle and I spent 4 days in hospital while they were sewn up and then 8 days in rehab. One of the exercises the physio gave me there was a length of**

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**rubber about that wide and about two metres long with a tied loop in the end and he told me to lie on my bed with that on my foot and hold it and stretch and I do that everyday, three times a day to each leg and I believe it has improved the flexibility in my ankles.**

**Melva**: Joy, have they suggested a calliper? Some of our members wear plastic callipers. **Joe**: I had them. Then I had ones that had a spring loaded hinge so that you could actually bend it because the others are fixed. They are moulded, they come around here and go around there and hold your foot up. You don't notice the foot drop. You look like you are walking normally. The first thing I do when I get new shoes is to grind the thick soles off at the front to make them so I can't trip. (Joe showed his thick rubber soled shoes with Velcro straps with the soles shaved at the front.) If I didn't do this, I'd trip over my own shadow.

**Joy**: Sometimes **people ask "Does it hurt**". I say "**It is like having an artificial leg and you have to walk like a walking doll. You have to swing your hip to shoot your leg out there to be able to take a step"**. That gives me that stunning waddle when I walk.

**Melva**: A good **orthotic might help. They are also for balance. They are called AFO's. Look at our newsletters. One of our members sent us information about buying them from the US. There are some without heels. I think you can get them on the PBS through your doctor. Margaret: I know Vilma had private cover and she was able to claim for her special shoes.**

**Geoff**: I'm glad we came down. It has been interesting listening to the stories. Joy basically said everything **but we were unsure what to expect coming down here, but you are all quite normal. (Laughter) It is good and we will get a lot out of it.**

**Margaret**: Thank you. Well Genevieve it is your turn.

**Genevieve**: I've learnt a lot. Regarding the neuropathy, I went to my doctor, a wonderful man. He's just retired. He sent me to see Dr. Gilligan and no sooner had I gone to seen him than I had a phone call. I thought it was a change of appointment but it was to say the doctor had dropped dead. So we did a search and came up with **Dr. Stark and he has been terrific**. I stagger. **I can't move my feet and I have the numbness in my legs and in my feet**. I don't have problems with my hands but it is so hard when people ask what's wrong with you. We can't describe the feeling. **It's not really pain. It's just the numbness**.

**John:** Genevieve has numbness and burning but it's no good taking an aspirin. This **new tablet 'Lyrica' which is for nerve pain is excellent. It was originally for epilepsy then eventually they agreed to approve it for CIDP. They put it on the PBS which was a boom for us as the price went down from $80 to about $35**.

**Gwen**: I now have it up my arms to the elbow. There is '**Tegretol'** but it gave me headaches. I take the '**Trammel'** now. **Genevieve**: Dr Stark makes me walk down the hallway to see how I walk. **Gwen**: I found that if I stood at the bench and relaxed a bit this leg would shoot out. That lasted about 2 or 3 months. I think the myelin has changed in some way.

**Geoff: When you go for your treatments of 'Intragam' you said it takes a few days for you to get back to normal. Gwen**: Yes I go down. **I'm very fatigued**. **Melva**: Do you find that Joy? **Joy**: **I am exhausted**. I come **home from hospital and then sleep, get up to have dinner, then go back to sleep. Geoff**: **But she doesn't come good**.

**Peter**: Gwen, you didn't mention that **you had chronic fatigue**. Gwen goes to bed **after lunch every day for two or three hours**. Why, because **I hear her tell people on the phone that her energy runs out and if she hasn't done something in the morning then it won't get done**.

**Melva**: One of the things that **people with GBS say about is their continuing fatigue**. Joe works outside most days from 8.30 to 4.00 but if he does something strenuous he loses his voice. I know when he's overdone it. Then he sits in the chair and he's out like a light and will sleep for hours. The following day he usually stays inside. **With GBS and CIDP you have to know your limits**. **Margaret**: **The body needs to rejuvenate.**

**Joy**: **I think it has been a learning curve the last 12 months realising that life goes on. Things will wait for you.** **…/8**

**John**: I'm the carer. **After Gen has an infusion we try to work out whether the infusion has made a difference.** It's like Gwen says, **it takes a week before she starts to get better and it last for a couple of weeks and then she goes down again.**

**Margaret**: It makes you **wonder if it should be administered more often like in America and then people don't go up and down.** With other medications you take them everyday. **Melva**: Maybe with **subcutaneous it might be better for a lot of people**. **Joe**: They may be able to just do a little bit everyday.

**Margaret**: **One of the neurologists has said that Medibank are going to stop paying if you have two infusions within a 28 days period. They will not pay the second amount.** I went to Medibank and they didn't know anything about it. I thought about it and with Blood Products that's government so I went to Medicare and they said we have to quote a number and then they would look it up. Just talking about it she couldn't go into the system to look for it.

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The following is Maria's email: "Hi Doug and Margaret,

I am absolutely delighted to be sharing my information with The IN Group. I have the attached copies of the conversations made and I would be more than happy to share my experience on the Forum as a positive one. I have read a few different success stories, that the mothers like to share regarding their children's process."

**Maria Toras Batikas** January 26 at 8:12pm · Melbourne
Hi has anyone every been sent home after a relapse because the space between infusion was too short? I have been sent home with my child wonky! The Neurologists are saying that his last IVIG was only 18days ago and at this present time it would be harmful more than effective. I am unable to see him like this. His next IVIG is supposed to be in 12 days and feels too far away.. by then he might be wheelchair bound. Seriously this is toucher!!! Has anyone looked or received stem cells? I am really getting over this sentence. I need to hear something positive like remission stories! My boy has had this for more than four years was doing well with diet earlier in 2014 for quite some time. I am not sure but for some reason the progress of the illness is worsening and becoming more aggressive??? We are extremely frustrated.

**Frédérique** Hello, We encountered the same problem, the time between infusions was getting really too short (less than 3 weeks). So, doctors have added some steroids every day, which allowed us to extend the period of 6 weeks. The risk of IVIG too close is that first it is useless, and then the body can be immunized.
Cheer Up.(sorry for my english, I am writing from France and Google takes care of the translation lol)

**Maria Toras Batikas** Thanks for the quick response. I really appreciate it. I never knew that. I always thought with CIDP if your getting worse your suppose to go to the hospital quickly not be sent home. They told me his life's not in danger so if I saw him with difficulty breathing then to take him back. He is on an immune suppressant he has been on Imuran the dose has been increased to 10ml. I think it's just not working.

**Ron** With my daughter she would get ivig weekly. After that stopped working we did plasma exchange. That no doubt saved her life.I have to disagree with your neurologist about saying his life is not in danger plus the damage it could be doing to his nerve endings. Go with your gut, get another neurologist or go to a different Children's hospital....fyi the same thing happen to us once. They said go home, nothing, we can do. I went to another hospital where she was admitted for 2weeks. Turned out the other hospital wasn't giving her the right brand of ivig. I know it sounds silly but for whatever reason it made a difference.January 26 at 9:12pm · Unlike · 3

**Maria Toras Batikas** Exactly this what I am trying to tell them! I am going back to hospital tomorrow definitely this what I know and have understood about this disease you have to catch it early for less damage!

**Christina** Some people get Ivig on a weekly basis. I've never been told that Ivig can be dangerous at close intervals. The life of the IG is only 21 days. There are other therapies besides Ivig that may help even better than it.
Is it possible for you to find a new neuro? Have you gone on the GBS-CIDP website to look for Centers of Excellency? You can also call them, they may be able to help you. I completely disagree w your doctor about this not endangering his life. This could seriously affect his breathing. Are you able to go to a children's hospital if you aren't at one already? And as for stem cells, I think for kids they can do a bone marrow transplant. But as for stem cells done by HSCT they have to be 18.

**Kelly** My daughter used to get IVIG 2-3 times a week. Over 7 years we spaced her infusions out & she has been off of all meds for over a year & a half. Studies show that frequency is more important than volume, so perhaps you could Google & share that info with the drs. Are you near a major hospital like a Children's hospital, Mayo Clinic, or Johns Hopkins? The drs there would know how to treat CIDP. January 26 at 11:02pm · Like · 2

…/9

**Frédérique** Waow here in france the life of the ivig is 4 weeks...

**Christina** I agree w Kelly . Frequency is important. You want to stop the relapse before it starts again. You want to create a stacking effect with these meds to keep all symptoms at bay. January 26 at 11:31pm · Like

**Nikki** We do weekly, my son relapsed when they spaced it out. He is now getting better and has reflexes in his ankles! Going to be going to biweekly infusions soon. Our neuro said if you space them out too quickly you run the risk of relapse. January 27 at 12:49am · Edited · Like · 1

**Kasia** So sorry you are dealing with this with your child. I am an adult with CIDP and had been on IVIG for years. I was getting IVIG every 3 weeks, then 2 then 1. But at every week it wasn't better then every 2. The half like of IVIG is only 3 weeks so ideally he should receive every 3 weeks or it does wear off. I went into remission for about 8 years with prednisone and IVIG. But then it came back and nothing was working but I had stem cell transplant back in July and it seems to be stopped now. I am slowly recovering from the damage left behind. In the US you have to be about 18 for stem cell transplant. Doctors could use smaller doses of chemo but would be carefully assessed with a child. Best of luck! You'll be in my thoughts. January 27 at 12:55am · Like

**Maria Toras Batikas** Can you pleae give me your neurologists number Kelly or a number I could call for another doctors I tried to find the centre of excellence and there number is disconnected from the website :(( January 27 at 4:15am · Edited · Like

**Christina** Where are you located? I bring my daughter to Hopkins all the way from NYC but she gets treated at a local infusion center. If you can take a road trip it may be worth it for you to visit one of the big children's hospitals.
Oh wait you're in Australia? Nevermind about American hospitals then. Sorry lol

**Kelly** Maria Toras Batikas - My daughter's neurologist trained under Dr. Peter Dyck at Mayo Clinic in Minnesota, USA. I feel he is one of the leading experts in treating CIDP. Perhaps you could see if the drs there would be willing to conference with him. I know he works with drs across the US.

**Maria Toras Batikas** We just went to a different hospital and they done with the previous neurologists and they also sent us home and he is now wheelchair bound this really sucks! January 27 at 4:50pm · Like

**Maria Toras Batikas** After loosing sleep feeling extremely frustrated with the hospital situation. We have come back to the children's hospital and I have insisted that he gets a form of therapy and they have decided to do steroid pulse treatment over 3 days looks like the first day back to school for the year is out of the question! CIDP I hate you! Fingers crossed everyone January 27 at 10:39pm · Edited · Like · 1

**Christina** This is crazy....I honestly can't believe they are pretty much refusing him treatment. I'm sorry you're going through this. January 27 at 11:25pm · Like

**Maria Toras Batikas** They are saying his not responding he had two doses of ivig on the 8th Jan so this should be still working..it's only been almost 20days usually he can go upto 4 weeks plus within two weeks I saw symptoms :(( this disease feels like we are sitting on a roller coaster blindfolded! January 28 at 1:01am · Like

**Kelly** If he didnt respond with the last dose then he probably had a relapse starting. I would advise at least one 5 day loading dose of 2grams per kg. You could also Google IVIG dosing for CIDP, contact the GBS/CIDP Foundation of info, and contact the pharmaceutical company that makes his IVIG for dosing information. January 28 at 8:51am · Like

**Christina** I remember at one point my daughter wasn't even making it to 2 weeks between needing treatment. Adding solumedrol really made all the difference for her. January 28 at 9:14am · Like

**Maria Toras Batikas** His doing ok, walking a bit better just finished his last day of steroids, still not walking 100%. Since yesterday his standing and still trying his best to walk. he needs to stay in hospital another week to do Physio because his having problems liftin...See More January 29 at 10:00pm · Like

**Rebecca** Hi, just read this post. Where abouts in Australia are you? We are on the Gold Coast & our neuro team is in Brisbane. My daughter is 4 with cidp. Diagnosed at 3 yrs. originally had gbs at 18mths old.February 22 at 10:04pm · Like

**Maria Toras Batikas** Melbourne we took him to the Childrens Hospital it undoubtably they have a huge department under Neurology. I'm really surprised with CIDP in Gold Coast that's even rarer. How does your little girl cope with the heat? The heat bothers Andreas. February 22 at 11:21pm · Like

- **Rebecca** She feels the heat more and gets more uncomfortable, but everywhere has air con up here. The cold & wind is what sets off her cidp symptoms. She is 6 months without treatment & no relapse 15 hrs · Like
- **Maria Toras Batikas** That's great I hope can get to that stage. How were they doing her treatment?14 hrs · Like
- 
- **Rebecca** She was having ivig every 4 weeks, though after her big relapse at Xmas 2013 She had IV steroids & prednisone for couple months along with the ivig monthly. Recovered so well, got all her reflexes back so they stopped the ivig.

**Maria Toras Batikas** That's great news! I hope that's happenx to Andreas, I'm weaning him off the steroids this week I'm not shut if it's help. Fingers crossed. It's great hear positive news.14 hrs · Like

**Marci** I am so sorry for all you are going thru!!! My heart just aches for you!! Here is our experience- I hope to encourage you. Started with solumedrol 600mg a week my picc line after 6 weeks she was horrible (being 4yrs old). We said no more we want to go to the IVIG - then we had 22 mg of IVIG every week for 3 weeks then every other week for 3x's - followed that pattern thru 6 weeks. Took 2years. Praising God for His healing touch & our doctor! We also went vegan a year ago January. Diagnosed September 11,2011 doctor said our sweet baby was in remission on August 14,2014!!!! Praying for a continued miracle!!! Our last treatment was 12/3/13. Maci is not on any meds since that date. She does get some bad days but she is doing great! I say all this to encourage you! Hopefully this is positive you want to hear. Praying for all our children!

**Maria Toras Batikas** Thats great news I am praying so hard that we will also do the same. Andreas was diagnosed with GBS on 25/1/2011. Andreas responded well to IVIG however he weakness returned and four months later he was Diagnosed with CIDP. Andreas has had 58 Admissions in Hospital. During this time he has also been close to getting better. He has had a lot relapses but nothing like this one recently. About 9 months ago Andreas was on a Organic Food Diet he wasn't on a Vegan Diet, However he was not having any Saturated Fats. I had him taken to a doctor where he also helped me by doing a food study test this test cost me a lot of money..but hey there was no price that I wouldn't pay for my boys health. It was called the IGG 98 Food Groups Test were they tested his blood and found any intolences. Eggs and Cows Milk were definitely a must go! He mostly ate Organic Lean Chicken, Vegetables, Qunioa Pasta, Gluten Free Bread. He would walk into his infusions for 1 year and look like he was a normal healthy boy he was playing soccer and was doing swimming. Yes he had the illness but he pretty much had a normal life. 4 weekly infusions seemed like they were not even required.
I promised my boy that when he is doing better I would take him to Disneyland. Unfortunately since then 1 week before we flew out to LA he was stuck with tonsillitis. It was a relapse but nothing IVIG didn't fix.. Andreas was devastated and so were we having cancelled our family Vacation we rebooked and managed to go to LA and Las Vages and Hawaii before the next scheduled infusion date and of course we all needed to get away. Andreas was doing so well 1 year no replaces was huge for us. Doctor started to span his treatment to five weekly. It was then when everything went down hill. I found myself on our family Vacation in a Hawaii Hospital and then the next flight home. Since then the infusions have been brought forward. Unfortunately at the moment it seems CIDP keeps winning. I am back on the dieting for Andreas and its is mostly on a Vegan sort of diet. I definitely believe diet is everything. It brings me so much happiness hearing these success stories remissions. Andreas hasn't been lasting up to 3 weeks but IVIG is still in 4 week blocks and If I don't make it to the infusion day. I end up in Emergency Department explaining my situation from the beginning every time until he is admitted and then seen by his neurologist. They themselves thought that Andreas wouldn't take long to into remission as they have helped our children do this in the past. I don't know how long the road will be..but i am hoping we will be getting close. I have recently made an order for some camel milk? has anyone ever tired giving there children Camel Milk? I am hoping it can help my boys autoimmunity. I will definitely keep you all posted. At the moment he is back at school and doing regular Physio twice a week. and I have had to hire a wheel chair since his last relapse because he fatigues. However he had bounced back to normal and walking. After his IV Steriods I believed they didn't do much only the IVIG made his legs move after the last relapse. At the moment. (He has a bit of a drop foot). Physio said that its improved since out 1month in hospital recently. He is walking and sometimes running. Today I actually took him to his first Chiro adjustment also. So hoping that we are getting closer to the end of the tunnel. Will definitely keep you all posted on our progress. 6 mins · Edited · Like · 1

**Maria Toras Batikas** We did well In Physio today

**Matt**
February 4 at 3:22am
Hi parents! Would like to bounce a few questions off you all since we are all going through the same thing.
My daughter has been on prednisone since she was diagnosed in June 2012. She does the every Friday and Saturday prednisone doses. I REALLY want to get her off presnisone completely if possible, or at least get her off as much as possible. However, I know that would make her relapse so I'm wondering about IVIG. I know some people have IVIG every 3 weeks or once a month. My questions are, how did the dr come up with how often to give the IVIG? Is it basically just trial and error - like you give an INIG treatment and then when your child shows signs of relapse, you get another and then time it that way?
And those of your kids that do IVIG, do they have to take prednisone as well? The problem with IVIG in our situation is my daughter is absolutely completely terrified of needles and if she would need it every 3 weeks or something, the trauma of the needle might be worse than her being on prednisone all the time. Thoughts? thank you! Like · …/11

**Kasia** The half life of IVIG is typically 3'weeks so that's where the docs usually start and adjust based on how well the child is doing.

**Kelly** My daughter was on IVIG for 7 years. She currently is off any treatment & is symptom free. She was put on steroids for a brief time 1 year into her illness but it made her symptoms worse.
As far as her schedule, its really trial & error. I kept track on a calendar when she got an infusion & when she relapsed. I did this for a few months (she relapsed often in the beginning). Once the dr realized there was a pattern he agreed to a treatment plan which was tailored to my daughter.
Every time there was a relapse she would get a 5 day loading dose. That was very important to her recovery. The key is to get ahead of the disease. We very slowly spaced her treatments apart & we would sometimes push too hard & she would relapse.
My advice would be to start off with a 5 day loading dose then schedule an infusion every 2 weeks for a few months. If she does well then schedule the infusion for every 2 1/2 weeks for a few treatments then move to every 3 weeks & so on. The longest my daughter spent at a time frame was between 2 & 3 weeks. If she relapses before the initial 2 weeks, do a loading dose then try a weekly schedule for awhile. Keep in mind that IVIG has a half life of about 21 days.

**Christina** We started out w Ivig every 4 weeks-That did not work so we went to every 3 weeks. For us it was Trial and error in the beginning. She was diagnosed the same time as your daughter. You pretty much don't want a relapse so it's best to get the Ivig before a relapse to totally prevent it in the first place, hence why most doctors prescribe it before the life wears off. The life of Ivig is only 21 days so typically people need it that much....at least in the beginning. My daughter gets a dose of solumedrol (iv steroids) w the Ivig every 3 weeks. This made all the difference for her and the iv steroids (and pulse dose steroids) apparently don't have the same effect as daily prednisone. She has a port bc the meds make the veins mush. It was the best thing we ever did. February 4 at 4:15am · Edited · Like · 1
**Matt** Thank you ladies - I did not know the life of ivig is 21 days. it makes sense now!.

**Kelly** I agree with getting a port. My daughter had one for 4 years when she outgrew it. We decided to then do IV's.
I called Gammaguard & asked them what the full life of IVIG is. I was told the full life is around 42 days & the half life is 21 days.

**Polly** My daughter is 13 and has been on pulse dose prednisone Sat/Sun since 2011. It helped big time. I too wanted her off prednisone and so we tried a weaning trial from Aug 2013 til April 2014 and slowly dropped from 125 to 100 I believe. She had a relapse and got weaker and so we upped her to 150 last july and she regained her lost strength, etc. I think she had her 7th grade Tdap shot also during this time which could have caused the relapse too. She is steroid dependent. We also just started IVIG two weeks ago for the first time ever. (first had symptoms at age 3). After everything my daughter's endured during 10 years in search of a diagnosis, she doesn't think anything of the IV needle.....compared to spinal taps and EMG's at least. We don't have a port but that might help the fear factor. It's too early to tell if the IVIG added to the prednisone will help but I think it will. I hope she doesn't have to be on prednisone forever. It's not fun but ya gotta do what works and just be thankful something works. So to clarify we added the IVIG to the prednisone and are now doing both. For some reason we only do the IVIG every 4 weeks for a 6 month trial. February 4 at 5:02am · Edited · Like · 1

**Michelle** HI! I think you already know this but my Grace does both. She started with the IVIG every 4 weeks and pred on the weekends only. After three months of that and no recurrences we spread the IVIG to 8 weeks. After 6 months of that, we're currently going to try to spread to 12 weeks. If we can do that for 6 months with no recurrence we will drop the IVIG and stick with only the pred for some period of time before trying to reduce that. Gracie is not having recurrences is she? If she is not, are they willing to try to start reducing it to see if she can hold steady? Oh and also, it's pretty clear the goal is to get Grace of the IVIG first, then the pred. If Gracie's doing ok on the pred, not sure they will switch to/add the IVIG?

**Matt** No Michelle she is not having any problems. I am just wanting her weaned off pred. Just hate that she has to take it and gracie is just so so so difficult on the weekends .. Which is when we spend the most time together as a family and events !

**Michelle** Matt yes that is hard to be sure. Mine is definitely wiped out at the end of the day. It always varies from week to week, some are just harder than others. Also, it's somewhat hard for me to accurately assess how much is the pred and how much is being 7...you know? They're kids, sometimes they're going to be challenging.

**Matt** That's exactly what I am thinking too Michelle !

**Cindy** Hi - my daughter is 13, diagnosed in 2012 with CIDP, IVIG x3 weeks, no steroids ever. IVIG is her neuro's first line of defense for CIDP. Steroids are a distant second choice, especially for girls. when I started seeing how many

…12

folks on here are using steroids, I was surprised, but then I realized how varied the cases are And how some people have reactions to IVIG. Some here started with GBS. Some, like my Jess, are just CIDPers. I think that enters into the equation heavily when a treatment program is made. The dosing follows what clinical trials have shown as effective to keep on top if the symptoms. IVIG does not cure anything, it simply confuses the immune system so it stops attacking the nerves. Remission comes hen the immune system finally forgets that it was attacking the nerves and starts to behave "normally" again. Our neuro explains no medicine will make that happen. IVIG confuses, steroids suppresses. Only the body can "cure" CIDP and this happens - our dr. refers to it as it burning itself out. The timing of it is different for everyone.

**Michelle** I think it is important to remember that all medicines/treatments have their own risks and side effects, and every case is different. I, too, feel the pull of wanting her off the pred, and yet, when I read up on IVIG I am reminded of the serious risks of that as well. I wish they didn't need ANY of this, but here we are.

**Cindy** " I wish they didn't need ANY of this..." Amen to that Michelle

**Maria Toras Batikas** Kelly Guilds this what I've realised with my boy his relapsing too quickly and doctors are not staying on top of the disease. When you say a 5 day loading dose what do you mean? February 6 at 2:31pm · Like

**Kelly** A loading dose, for CIDP, is typically 2 grams per kilograms given over a course of 5 days. My daughter always had 20 grams at each infusion (from the time she was 35lbs up until her last infusion at 105lbs). When she had a loading dose she had 20 grams every day for 5 days for a total of 100 grams.
Some drs want to do a loading dose over 10 days with each infusion every other day. We tried both ways & the every day for 5 day loading dose worked quicker for my daughter. By dose 3, she would be back to normal.

**Maria Toras Batikas** Thankyou so much about your advice and information. As I will show this to his neurologist and see if we can try this method to help him go into a remission. We have spent over a week in hospital since his relapse last week and they only did the 1 of I...See More

**Michelle** Maria Toras Batikas the goal always should be to stop the recurrences before they start. You have to get to a treatment protocol that does that. They can't heal if they're continuing to have damage. Several of us on here are treated at St. Louis Children's Hospital in the neuromuscular division. Dr. Connelly is the head (although I think someone said she couldn't consult without seeing the patient?). Sorry to hear your son had a set back. That has to be very upsetting. Good luck!

**Kelly** My daughter no longer sees her neuro because she has been off of treatments for almost 2 years. I would recommend contacting Dr. Dyck, who works at Mayo Clinic in Minnesota, USA. He has consulted with neurologists around the USA.

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