

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.

OUR ANNUAL CHRISTMAS BREAK-UP this year will be High Tea & Dutch Auction

at Balwyn Library Meeting Room, Whitehorse Road, Balwyn 2.30pm.

SUNDAY, NOVEMBER 16TH, 2014. \$20 PER HEAD

A wrapped gift (with an indication of value for the Auctioneer) would be appreciated.

RSVP to Margaret on 9802 5319 or Melva on 9707 3278 by Monday, 10th November.

Due to a misunderstanding with the new times at the Library, we were unable to have a Luncheon this year. We will have a **cuppa on arrival**, then the **Dutch Auction**, followed by **High Tea**. This is our **main fundraiser for the year and is always enjoyable**. We hope **you can join us for all the fun**.

Annual General Meeting held on the 17th August, 2016.

Firstly, welcome to everybody and thank you for coming and a big welcome to Scott Earle and he has brought his helper, his sister Brooke so thank you for joining us today.

Apologies: John De Ravin, Erma Hannah, Barbara & Tom Rivett and Barbara Clifford.

Minutes: As posted in Newsletter.

Moved: M. Lawrence Seconded: J.Behr Carried

President's Report:

It has been another very good year for The IN Group. Our members are so generous that we have been able to donate a substantial sum towards research. My thanks to a great committee who give much support in so many ways to keep the group going so well.

To Melva and Joe thank you for a well produced Newsletter. We receive many good reports from our members who enjoy reading the interesting articles.

A special "thank you" to Gwen McInnes who every meeting produces sales money from her craft items to be put into research.

This past year we have enjoyed two social gatherings which always are great fun while raising money for research. We have wonderful support from Andreas' family gathering friends to support and money tins in their shops. Normally I don't select anyone but they just go beyond that. They have been fabulous.

The Web site takes many enquiries which is marvellous as we have the on going problem to get doctors and hospitals to pass on the information about our group.

A thank you to CSL for funding the Web site and also another thank you to the Balwyn Library who reduce the hire costs.

Before I close I must say what a marvellous group of people come along to the quarterly meetings. Not always do we have a speaker but they enjoy the company and support from one another.

It is a pleasure to be part of you all. My thanks. (Margaret Lawrence)

Treasurer's Report:

Finance Report for the year ending 30th June, 2014.

Our total income for the year was \$10,335 made up of subscriptions, donations, a State Government Grant, Bank Interest and numerous fund raising activities.

Income was down on last year by \$1,864 which was due to the State grant being split into two payment periods resulting in a timing difference as the balance of the grant is payable in 2014/15. Proceeds from fundraising and the rest of the items were up on last year.

Our expenses, excluding donations were down by \$137 or 7.8%. Donations to the Royal Children's Hospital Foundation via Assoc. Prof. Andrew Kornberg for research into GBS and CIDP was \$10,000 an increase on last year of \$2000. Again, a remarkable result as all monies come from our members plus our hard working and very generous committee.

I would like to again thank CSL for their generous support in funding our website.

Statistically in the seven months to August we have had 114,000 hits with in excess of 14,000 visits and 76,000 pages visited. Interestingly, the top five countries to visit our website were Finland, Brazil, United States, Netherlands and of course Australia.

In closing I would like to thank all our members for their generous financial support allowing us to make these regular annual donations to research of approximately \$10,000 and we all hope that our contributions will greatly assist in the finding of effective treatments and eventually cures for both GBS and CIDP.

Moved: D. Lawrence Seconded: P. McInness Carried

Committee: The committee remains the same with a welcome to Nathan Mittelman who has joined the committee. There were no other nominees. Therefore, the committee remains the same and they are a great group of people, so thank you to everyone for staying on the committee.

Meeting closed. 2.24pm.

Gwen: At the next meeting there will be a beautiful handmade knitted rug. As it is a bigger item than we usually have, we thought we would have a Silent Auction for this item.

Email Mailing List. If you would like to be included on The IN Group email mailing list please send an email to John Burke at the following address: **jburke@contracts.com.au**

If you use *hotmail* or have junk mail filtering software running you will have to include the above email address in your "safe list" otherwise *hotmail* or your junk mail software is very likely to delete our emails.

Talk by Scott Earle. (Author of: **The Wave of Guillain-Barre` Syndrome**)

Firstly, thank you to Doug and Margaret. I received a phone call going back a couple of months now and they asked me to come along one day to meet you all and have a **chat about my experience with GBS. It is coming up to my third anniversary, so this time 3 years ago I was in Caulfield Rehab. Throughout the course of today my story will probably hit home with some of you who have experienced very similar things.** We have all got similar stories unfortunately. We have all been through some pretty tough times and that's what brings everybody here I guess as a group. You will see me tear up. That's part of it. I'm sure we all do from time to time. You will see me laugh and I'll make a joke at my own expense because if you can't laugh in those dire times, then it really gets you down.

Laughter and being around positive people is important. I probably will not look to the back of the room today as Brooke and I went through this journey together. I have a very close family. **Mum and Dad, my sister Brooke and her partner were the rock and foundation that really got me through. Their positive attitudes as I was down and out a couple of times, but I never ever heard from them that they were down. In front of me it was a brave face. I think the strength of family and support groups like this really help each other.**

I will talk a little about me before and then after. **I had a pretty active lifestyle.** I played every different kind of sport at a pretty good level. **At 17 I trained with Richmond** in some of their junior squads and was teetering on becoming an AFL footballer. I chose to divert off and concentrate on my studies; **went to university and did a sports coaching degree** and again trying to remain fairly active. I was really fortunate growing up to be able to travel a lot and do what most people do in their twenties – **backpacked around the World** and I had a pretty charmed life.

I had a hamstring injury playing football, but I very rarely got sick, I very rarely fell ill and I was blessed. **No-one in our family, not even in our extended family had ever been touched by severe illness.**

That all changed 3 years ago. I was a **new father** at the time and I have a beautiful daughter Miller who is now 3 years old. She was 6 months and I was going through the rigors of becoming a new father and the stresses of taking that on. I have my own business in IT, so certainly there **were work stresses, there were stresses of being a new father and certainly at that time I was balancing trying to keep active** and trying to get home and spend time with Miller and obviously work. I fell ill on the Easter getaway. The first week when I was quite sick **I thought I had the flu or a virus** and the doctors gave me some antibiotics and said go back to bed. I went back 3 days later. They gave me more antibiotics and was told go back to bed. So **I was misdiagnosed twice in 5 days and it was only the third time when I went back and I've walked into a packed doctors waiting room on a Friday evening and as I walked in they sort of looked at me. They could see I was unwell and shaky on my legs. They had to help me and sit me down and they rushed me through and at that time the doctor said, "We need to do some further tests. I'm not too sure what it is but you are going downhill and not getting any better."** It was the next morning and my partner at the time called my mum and said **"You need to come and get Scott. He has gone further downhill in the night. Downhill was – I had to walk down the hall holding onto the wall. I was starting to lose the function in my legs.**

I ended up early Saturday morning 14th of May, 2011 (**some of you don't forget those dates**) in at **Cabrini hospital**, straight into emergency and the gentleman who diagnosed me that morning was named Jack Wodack. He is a specialist at Cabrini and fortunately for me **Jack's mother had had GBS. He was a neurologist** and very familiar with GBS and straight away had me diagnosed and said to me **"There is some good news and some bad news."** **When I left home that morning I thought maybe I may have to go into hospital and might stay there a day and a night and I'd be home in a day or two – I didn't think I wouldn't be home for 7 months.**

Jack said to me **"The good thing with GBS it is a neurological syndrome that you can recover from. There are cases where people recover 100%. The bad news is you could be here with us for anything from 6 to 18 months."** So for someone who had never really been sick, never had an illness, to be told you wouldn't be going home for 6 to 18 months was a real eye opener.

Then of course he said, **"You've got Guillain-Barre` Syndrome"**. Mum and I looked at each other and said **"What's that? Never heard of it"**. He wrote it on a piece of paper and I did what most people do. **I Googled Guillain-Barre` Syndrome. I checked Wikipedia** and I think **I read two or three sentences** and then put it down and I didn't want to know anymore. **I would take it on trust of the specialists and just deal with it day to day.** That was the approach I took from day one. At that time I think the seriousness of it hadn't really hit home.

Week 1. I was up on the ward there for a couple of days and **they started the treatment. Ivig. 5 courses** straight away. **I started to plateau then got a little bit worse.** A little bit worse was having to **use a lift to get me out of bed.** I was **starting to get tingles in my fingers** and at this point of time it hadn't made it to my legs. I was just finding I was deteriorating slowly. It was a slow deterioration.

Week 2. **Another 5 day course.** They didn't see improvement. **I didn't plateau** so I was bedridden. It was a lift to get me out to bathe me, shower me. I started to **lose all the function in my hand and really only having my right hand to feed myself.** I was losing weight. I think around then the seriousness of what was going on really started to kick in.

Even at that time, in the early stages, **everyone around me was saying "You will be okay."** **I think that was the key. The positive attitudes of everybody around me really made me feel positive and I didn't get the opportunity to sit there and say "Why me. Why am I in this position?"** **I didn't let that mindset get into my head right from the start.**

Week 3. **Another 5 courses.** 15 now. They thought that perhaps I'd plateau. At this point they were starting to look for some rehab. facilities and they said **"Maybe within a few days you could get out of here"**. I was still **having some problems with my breathing.** They were monitoring it three times a day. I was doing a peak flow meter and they were making sure it was all very stable. It was a really nice time when Mum went to look at a few rehab. facilities and I thought **"Great I'm coming out of it. Rehab is where people get better."** That was also going to be 3 weeks in hospital which is still a long time, but much better than the other option.

It was a Sunday night about 6 o'clock, sitting there with Dad (and again Dad was amazing throughout the whole experience) at my bedside. Between Mum and Dad and Brooke

coming in and bringing my daughter Miller, my days were filled with my loved ones and they would bring in books, magazines and we would watch football. I was being distracted in the best way by family, by people who were really close to me. But then I was sitting there and I said to Dad **“I feel a little bit short of breath”** so **they got the peak flow meter** and I think at that point **200 was the reading** I was consistently hearing. If I hit 200 everyone was pretty happy.

The first one was around about the **100**. That wasn't good. Let's try it again. The next one was **80** and the next one was around **50**. Straight away the nurses were off and in 5 mins. an ICU nurse had come up and said **“We want to take you down for observation. Your breathing is shallow. Don't be alarmed. We just want to keep an eye on you.”** **Don't be alarmed! We are taking you to ICU!**

Again it was the best place for me to be. I was in a bit of trouble. That Sunday night they **inserted some breathing tubes** to try to help me breath. I didn't react very well to them and **from there I was sedated a little bit and from then I have no memory of the next week.** What I am about to tell you is through stories I have heard from Mum and Dad, friends and doctors and the nurses.

My breathing got to the point where I needed ventilation. The decision was made as it had got to the point where **they would put me in an induced coma** to let my body rest and not fight.

Once I was in an inducted coma I was much more at peace, more at rest. They did a **tracheotomy** so I have **a nice scar that reminds me every day of how lucky I am to be here.**

I woke up 5 days later. Of course that was **a pretty rude awakening.** I remember going into ICU and then waking **up being on life support which was a huge shock.** It was something you can never prepare yourself for; you can never really truly explain what it is like but I was very fortunate. **In those 5 days I was revived 3 or 4 times.** The GBS had got to the muscles around my heart. **They tell the story of one particular evening when about 3 or 4 times in a row when they would start my heart, it would stop. They would start it, it would stop. Then the story goes that every 15 to 30 seconds it was going we wondered if it would stop again. So Dad got a call that night to say “You need to come to the hospital as Scott is in a very bad way.”** Of course, he didn't want to alarm Mum. He told me **“Of all things, I didn't want to alarm your mother.”** He didn't say anything. **They told him they would call him back in 15 minutes but get ready to come down.**

So they got there and at that point **it was when I had been revived a couple of times and at the fifth time it kept going. It didn't stop. It just wasn't my time.** So obviously Mum and Dad arrived to the story of just what had happened. **No parent should ever have to go through that, sitting looking at their son or daughter or loved one and be told what had been going on for the last half hour or so. That was the low point.**

I wake up and it's Friday and I'm on life support and at that time I'm completely paralysed. I'd lost function – I couldn't blink. The GBS had got to the muscles around my eyes and the only way they could ensure that my eyeball was lubricated was to **stitch my eye shut.**

So they stitched one of my eyes shut. Picture what I looked like. I was a pretty sad sight laid up in ICU, one eye shut. Couldn't talk, couldn't communicate, couldn't move, yet my hearing was perfect. I could hear everything that was going on around me as my brain wasn't affected. Obviously I was sedated but you become very aware and every doctor, every specialist, every nurse was talking about me and my condition. **I was soaking it all in and really listening to the enormity of the trouble I was in.**

I often say and I have said this to mates over the years, imagine lying in bed even for a couple of hours dead still, not being able to move or communicate; just lying there and see how long you can do it for. I did it for 32 days, so **it was about a month of no communication, being locked in your head to some degree and over that time I started to get some function back in terms of body functions.**

My hands started to come back a little bit. They obviously said that was a positive outcome that I could start to move my hand. I remember when I got to a point on about day 25. **The occupational therapist and physiotherapist spent 5 days teaching me to move one finger. I would sit there with Brooke and Dad and they would do this all day, (he showed us bending his finger) hour after hour and it was just massaging and moving because I couldn't do it on my own.**

People have asked me why I think I have recovered so well. I don't know if there is any medical evidence but I firmly believe that having Mum, Dad, Brooke, everybody beside my bed exercising for me, just sitting there moving my fingers, my wrists, my joints, keeping everything moving, it was probably teaching my brain that this was what it should be doing. I couldn't do it on my own. Others doing it for me, I believe, had a huge impact on my recovery.

In the time since I have recovered, I have been to see a number of patients in hospital and one thing **I tell their loved ones is "Within reason, (check with the physio first) keep them moving. Keep moving like you would every day.**

That was a positive on day 25 that **I could move my finger.** The physio said "Great you've done that one, **now I want you to do the next finger. I thought, "What another 5 days."** Sure enough **it only took 1 day and that's when I knew I was on the path to recovery and I was going to get better.**

You have a lot of time to think when you are lying there and **I came up with a concept and it was the concept of 10%. Every day you can do something 10% better than the day before. It was about winning every day.** There are some really tough days, really bad days, but I looked for the positive in it, so this came back to this positive mindset of winning every day and **thinking "Hang on, I am getting better."** Nothing else is moving. Nothing else is working but I'm able to see some improvement and **that mindset just challenged me.** Some days maybe it wasn't 10%, maybe it was 2% but it wasn't going backwards.

As long as I wasn't going backwards and I was aware that they were slowly weaning me off life support, I knew, even in that dire position, I was getting better. **It was a mental game I played with myself to keep the recovery 10%.** And I put that into practice later on.

Communication was near impossible and **the only sound I could make was like that of a Kangaroo. Click, click with my tongue.** The sisters were quite good at lip reading. They

were trying to understand what I was saying, which is quite difficult when you have facial palsy, which I had. Half my face was dropped and drooped, one eye was shut.

They are amazing people. I'm sure you all know the amazing doctors and specialists you've met over the years and I'm sure we all have a pretty soft spot for the special ones. They are phenomenal in the job they do and they made the effort to help me. They could see the frustration as I was getting towards the end of the 30 day period in ICU, when I couldn't communicate. **All I wanted to do was hug my daughter, talk, ask questions and tell them I was going to be alright.**

The day **the trachea came out** Dad was there. The first thing I said was **"It's good to be back."** And then I didn't shut up for a day. I had so much to say and so much to ask and of course **I wanted to tell the nurses how much I appreciated everything they would do. I had a month of stories; a month of trying times in my head and I wanted to verbalise it.**

That was a pretty big day – coming off Life Support and starting again. It was a pretty harrowing time. ICU was pretty tough. That wasn't the end of it. When you are in ICU you **have specialists around you and you have all the support of the doctors and nurses and they are doing the hard work for you and making sure you are okay.**

Rehabilitation. That's where all the hard work started. **That was all me.** They **wouldn't feed me.** You have to try and do that yourself. I tell a funny story. We laugh about it often. It was in the first couple of days in rehab. Brooke had come out and was going to help me feed this particular night and the nurse had come in and said "Now don't you do it for him. He has to do it for himself." So of course I've got a spoon. We have a photo somewhere. (We looked at a picture of Scott covered with food from his forehead to his chin.) **I got it everywhere but in my mouth.** Again, this was one of the times we laughed. God knows, we cried a lot. To be **able to laugh at me painting my face with this food** was one of those things we still think about.

Rehab. Another show of hands. Anyone been to Rehab? They put the emphasis on you. **However hard you want to work dictates how much better you get, how you recover and how your mental state takes it on is how quickly you'll get out of there. They said I will be there for 6 to 8 months. I told myself I wanted to be out in 4 and I was out in 3.** It was **just through sheer trying.** I got Dad to bring in hand weights and he made these little wrist things so that when I wasn't doing occupational therapy or physiotherapy or in the pool, **when I was just lying in bed resting, I could do something extra** to help one little part of my body recover.

So rehab was pretty difficult. **Again it was 10%. Every day do another 10%.** Eventually I got to the point when I was getting better and I wanted to be **out before Millar's birthday** which was the 28th October. I got out 14 days before then on the 14th October, 2007. It was **exactly 6 months to the day from when I went into Cabrini and I came out of rehab.**

I keep coming back to **the power of the mind. I visualised going in. I was in the back of the ambulance and there was this big tree right in the front in Caulfield and in my head I said, "It is going to October on a nice sunny day and I'm going to walk out of here. Now if I had told anybody they would have said "Now just slow down a bit. You can't move anything below the waist, you can only move one hand, maybe thinking you will walk out is dreaming. Just take it a step at a time."** Sure enough, I walked out of there.

I think it was mainly around the fact that no matter what the specialist said, didn't matter what they told me I couldn't do, **I firmly believe that when Jack Wodack told me that people can recover close to 100% that I was one of those people. In my mind there was no question, I was going to be one of those people. I would work where I could to be that person.**

A tough day, about half way through, a doctor came in and I was with Mum and he said "You are never going to walk again. We don't think your feet are going to recover and you are not showing any signs of recovery, but its okay, people can still have a very fulfilling, meaningful life living out their years in a wheelchair. I thought it was a pretty strange thing to say to someone 24. Of course Mum's broken down and cried and I sat there and in my head I said, "No your wrong. I'm going to walk out of here." Sure enough about a month later we were doing some physiotherapy and there was a machine there that I'll never forget. It is a machine you sit on with a motorized bike. You clip your feet in, push a button and the motor does the work. But again, sending all the right signals. The legs are moving, sending signals to the brain that this is what should be happening. My physio set it to 500 metres which was a short ride and at the end they have a reading as to how much I had contributed out of the 500 metres so I sat there and with all my mind, I knew my legs were weak, they were just along for the ride, I concentrated as hard as I could and I saw this read out at the end which said of 500 metres you contributed 17 metres. So all my effort and all my willing and I got the message that something said I contributed 17 metres. So in my head, my legs are working. I did it a couple of days later and it read 25 metres. We just kept doing it to the point where I could wiggle a toe. Wiggling a toe was the best day of the year.

As soon as you start to know the signals are getting through, again that's the message I needed to say "Well I'm going to get out of here." On the 14th of October, **after 3 months of intensive rehab.**, we had a beautiful day again with the family. It was a sunny day (as I had envisaged) and **we walked out**. It was exactly how I had hoped. I was on crutches, I was still very weak. I went back to live with Mum and Dad because I was unable to care for myself. It probably took me another 3 - 6 months of outpatient work, rehab., gym work. Again sitting at home with Dad, he we would be on the couch doing exercises with me. They were focused on getting me better. Again without that support I don't think I would have got there.

That was the physical of getting out of rehab. As you all know **there is the emotional side which doesn't go away so easily**. Still to today I have bad days. They are few and far between now. I still break down and cry for no reason. I have a day when I am feeling down, my feet still tingle a little bit. **In terms of my recovery, I'm at about 95-96%. I think the nerves in my feet will never come back. But that's okay. 97% for me is fine. The emotional side doesn't go away.** It is not easily seen. Something on any given day, you look fine, you appear happy, but it is still nagging. It is always going to be there. **It is the different ways we deal with it.**

I come back to this theory of 10%. Mum and Dad were support for me while I was in hospital and in rehab. When I came out they started to fall in a heap. So, Brooke, myself, Mum and Dad, we jumped on a plane and **went to Hawaii for 10 days** just to have a family holiday and be together. Be there for support, but not be anywhere near a rehab. centre or a hospital. **That was the start of the healing process for all of us.** We really started to get on with our lives. I would say **it took me about 12 months to have a day when I didn't think**

about GBS or think about my ordeal. It was a long, tough road. But **I came up with this whole idea. If I did the really good things in life 10% more;** 10% more time with family; with friends; with my daughter.

All of the things that contribute to wellbeing I wanted to do 10% more.

The reason I chose 10% is because it is a really easy change to make. If I was exercising 2 hours a week, to go and say I'm going to do 10 hours is a major change. I might do it for a few days but I'm not going to sustain it. 10% is a nice little bite sized chunk. **Anyone can make a 10% change.** So that was the 10% more. The **10% less was worrying about the things that you can't help. You know, there are certain stresses at work. I don't stress about work anymore. That was 10% less. 10% less junk food. By the time you combine that with 10% more healthy food that's a pretty good change. So these balances of 10% more and 10% less, I found for me I was all of a sudden much healthier, much happier and it has got to a point where I'm actually feeling better than I was before I had Guillain-Barre`** and I always thought I was pretty healthy. Maybe I drank 10% too much but not that I have moderated my drinking it made a change and I came up with this idea that **if I keep the 10% in the balance of my life there is nothing stopping me in what I can achieve next.**

At this time I was grappling with returning to work, needing to sleep a lot more, needing to rest and really **still battling the effects of my ordeal, but I wanted to set a challenge.** That was perhaps a little bit unrealistic. I wanted **to set a challenge to do a Half Iron Man.** Mum and Dad said "You are stupid. Please don't put us through this." I thought with the right attitude, with the right approach to it, and when I say **the right approach I mean not doing anything stupid that would get you back making yourself ill, I mean the right rest, the right nutrition, the right advice.** That's a 1.9km swim; followed by a 90km bike ride and a 21km run at the end of it. Anyway, **February this year I did my Half Iron Man.** It took 10 months to prepare for but with everything else, the little changes I made, the 10%'s everywhere, all of a sudden I found it easy. **My training only went up by 10%. I would never try and do anything that was outlandish** like running 5 km one day with 10 the next. I would do 5 and go up to 5-1/2 to 6 so everything was **a little extra every day,** pushing yourself a little bit more, **just a little bit out of your comfort zone,** allowed me to fulfil that dream. I have other goals which I have set myself for the end of this year.

10% more and 10% less is something probably everyone in the room could do. **The big one for me was rest.** I was always rushing to work, rushing out, fortunately now Brooke will tell you I'm home every night (we live next door to one another). I'm **home from work by 6 and in bed by 8.** During the week it's pretty quiet except for my exercise – **but it is all about that rest. You know what you need; rest, diet and we can all improve.**

That's my encounter with GBS and if I really had to hone in on how I recovered or why I recovered, certainly there were factors on my side, my age, I was fairly active when it happened at 36. Without question it is mindset. The mind is the most powerful thing we have and obviously the support of family and friends was of course most important.

Then I got the phone call from Seb Costello that **Alistair Clarkson could have been diagnosed with GBS. We spent about 3 hours together that day doing some interviews.** It was a **really special day** to think that I went to the coffee shop that morning, picked the paper up and **it was one of the crying days. Guillain-Barre` was all over the paper. Something that no-one had ever heard of when I had it 3 years ago. I had a moment**

where on the front page, second page, back page and fourth page there was all this awareness and secretly I sat there thinking this is magnificent. Tens of thousands of people are now going to know what GBS is. It was a positive. Fortunately Alistair got off pretty lightly. When I heard them saying he will be back coaching in 4weeks I was going whoa.....because we all know that can be the best case scenario but quite often it can be a lot longer than that.

Question: When did you stop IVIg? I only had it at Cabrini. I've seen that some people regularly go back and have a top up to boost their immune system. I'll keep informed but I don't think for me there is a need but **I certain wouldn't discount that some time in my life I might need it again. I am not on any medication.** I stopped my medications 6 months after rehab.

Question: Do you still see Jack Wodac? I got a beautiful letter from Jack about a month ago. I wrote a book. (I've got some books here). One of those things that happened in rehab. I wanted to **learn more about GBS so I got my ipad and couldn't find much literature.** So with **4-5 hours per day lying in rehab. I decided to write a book.** The first few chapters were **written by my one finger** on the ipad and then slowly **when I got the other hand back** I completed it that way. I wrote it more as a diary but also a "How To" when things get you down. **It is a summary of the story of how to get through and I did that specifically for people who are members of families of patients with GBS. To learn what they are going through and how to communicate.**

Question: Did you have a lot of pain with this?

Pain in rehab.? Your muscles are seized up and people are rolling you in the bed. It took 4 nurses to do it as **I was in so much pain.** They would give me pain killers before they would roll me. That went on for **about 2 months** then slowly the pain subsided.

The nurses were amazing in ICU. They knew it was very painful for me and so they would come over and **very gently roll me over.** Then one day there was this "**Bank**" nurse and **she wasn't familiar with my condition.** They came over to do a roll and I saw these familiar faces and I had this level of comfort that they knew what they were doing because that was very important. This Bank nurse came in and was asked to help and **grabbed my leg and just moved it fast and I could see it was going to happen but when you can't move and you can't talk it was just**anyway the pain from her doing that, **my heart stopped again. That was the next time they had to revive me. That was the last time they had to revive me.**

Coming back to this 10%. There is **something that I think is critical and that is diet.** I really removed anything that was bad for me so I simplified it. **Fruit and vegies, meat, protein, fish, get rid of sugar – minimize it and go back to whole foods.** Again that was a **pretty big change I made.** Not that I ate terribly, I ate fairly well but **I did get rid of the pastas, rice things and substituted good whole foods like fruit and vegetables.**

Even now **I sometimes slip off** and I find I have a quick fix of a meal but I always feel a bit **sluggish the next day.** As soon as I get back on track I go down to the market and do my big weekly shop and **have my meals all planned** out funnily enough **I feel good again.** There is **a direct correlation with what you eat is what you are. Food is a critical one.** There is always **this excuse that oh it is hard to always eat healthy. It is not hard to eat healthy.** It doesn't mean that you can't have a meal every few days, say a pizza some where, it is not

regimented, **not something that dictates your life, but again 90% makes you feel really good.**

Do you still have a beer or a wine? Yes absolutely. Not very much. I try to keep it to one day a week. Friday night we had a few drinks. Saturday I was a bit sluggish. Do you know what I did? I got up, jumped on the bike. How do you think I felt? The mental endorphins rushed in and I got back on track for the week.

Also **the right exercise. For me it was swimming. Swimming for most people is good as there is no jarring – riding is pretty hard to do, but swimming was always the one.** My father has just recently got into swimming. It is not about how you go it's about how you feel. **You feel good after doing something.** Your body is moving and again **it's that endorphin rush as your body is releasing the right hormones to make you feel good.**

There is a **circle of feeling good, resting, eating, exercise, feeling good and its great.** Obviously you have bad days in there and that's going to happen to all of us.

Peter M: With CIDP you have to maintain your exercise but **sometimes I push myself** too much because in my brain I say "I can do more". **The next day I suffer** I'm a bit down. You have to **find the balance your body copes with.**

Scott: Has anyone looked at alternate therapies? Reflexology, kinesiology or anything left of centre? If I had a choice between a western doctor and an eastern doctor and I had to chose one, I would go with the eastern doctor to start with. Now that's a pretty big statement given all the western medicine that has helped me get to here today, but from here on that's my choice. I see a Kinesiologist who is also my Physiotherapist, if not every week, every second week. I call him my Witch Doctor and I go in for my tune up. I still go.

Kinesiology? Couldn't even explain it. (Member: They touch different parts of your body and they can tell from reactions if they are not right. They touch pressure points really don't they?) In its simplistic form the gentleman I go to would **use my right arm as my indicator.** He would **push my right arm down.** He will say "**How are you feeling today about work?**" Work is good. Now **how are you feeling about your health** and he keeps pushing on my arm and I hold it up. But if he asks a question and **my arm drops, that's the issue and then he hones in on that.**

Recently **I was having headaches** and he asked me a couple of questions and **I had just had two wisdom teeth taken out.** When he asked me about my wisdom teeth and I said "**yeah**" my arm dropped. He said **that may be why I was having headaches and he checked my jaw and it was a little out of place.** Sure enough he fixed it up and asked "**How is your headache now?**" **Gone. My headache was gone.** This gentleman is a wonder. I saw other Kinesiologists, etc. until I found this guy. **He was recommended to me and he is brilliant.** Anyone who wants his name or number I will certainly pass it on but **he is my tune up man.**

(Scott showed videos of his rehabilitation. Walking between the bars. Hydrotherapy.)

Scott: Hydro really helps. The last video was when he left Caulfield Rehab. **At this time I was still on crutches. I bright sunny day as I envisaged it. I walked out but then needed my crutches. I had them for about a month after that.**

There are 10 copies of my book. If you would like one, maybe throw a gold coin in the jar and the money can go back as a donation. I usually have them **on Amazon for \$20.**

Peter M: On behalf of The IN Group, Committee, friends and everybody here. **Your story was inspirational and I hope a lot of people have got a lot out of it with your 10% gain and your positivity. I'm proud of you mate.** Just a little something to show our appreciation.

Scott: I'm certainly going to hang around for the afternoon and if anyone wants to have a chat and wants my details, I am happy to come and speak to anyone else you know who may be struggling with it. Feel free to pass my details onto anyone. The more people who support others, the better.

Visit Scott's website at: www.thewaveofgbs.com

PS: \$80 was donated through sales of Scott's book. Thank you Scott and the members.

Subscriptions were due on the 1st July. If not already paid please use this form. Thank you.
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