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Guillain – Barré Syndrome Support Group New Zealand Trust

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NEWSLETTER JUNE 2015



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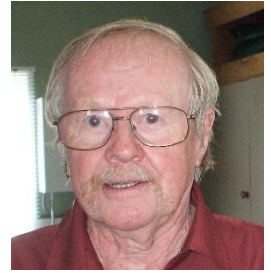
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Editor's Note

The conference is done and dusted and I believe it was the best one yet. So a huge thank you to the organisers and the members of the Medical Advisory Board who appeared as presenters. We have all benefited from your knowledge and expertise which you so readily shared with us all over the course of the weekend. For those of you who were unable to attend I hope to be able to reproduce these power point presentations over the next couple of magazines.

Again I have to apologise for the lateness of the magazine. Life has been very hectic here in Katikati since the conference and compiling this newsletter sadly had to go to the bottom of the pile.

I am in desperate need of your stories to print. I have none in reserve so please put pen to paper over the next few weeks and send me in your journey through GBS. It doesn't have to be super long and the odd photo to accompany it is always welcome. So hopefully when I make the long trek to the mailbox over the coming weeks I will be taking out something other than junk mail and bills. Emailed versions are happily accepted.

This month's personal story is told by Anna O'Reilly on how GBS affected her family when their young daughter Emily got GBS (*her story was in the last newsletter*). Anna spoke at the conference and I don't think there was a dry eye in the house when she finished. She kindly gave me permission to reprint this moving story.

Dr. Gareth Parry is still seeking participants for his study into the benefits of hospital visitors. More on this is on the 'Bits and Pieces' page. Your support here is crucial to the study going ahead.

Thank you all for your continuing support of our group.

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Presidents Report:



There can only be one topic that dominates this article and probably this newsletter. The Rotorua Conference! Held at the Sudima hotel in May the conference was for me and the board one of the best that we have had. Our thanks go to all those who helped organise it. Gareth Parry showed his gentle persuasion in gathering the medical advisory board together to give some truly informative and interesting presentations including an insight into new research, papers on pain and fatigue as well as a look inside the workings of an intensive care unit. Our grateful thanks to all those who presented the papers. It wasn't just the medics who held the audience's attention. As in previous years personal accounts of the effect of G.B.S. and C.I.D.P. on the individual as well as on their families proved to be a popular session before the panel discussion. For those who were able to attend the conference dinner there was continued sharing of experiences and the forming of new friendships. While it is often seen as bad form to choose some people for special mention we are all particularly grateful to our Secretary and new National Coordinator Tony Pearson, our Treasurer and venue organiser Peter Scott and Board member and past President Bob Stothart and his wife Margaret for all the work they did. Finally we were sorry to accept the apologies of Jenny Murray who because of ill health was prevented from attending this conference. There were many tributes paid to Jenny for the years of dedication that she has showed our group since its formation. A special thank you to you Jenny. I am now looking forward to the summer and the next conference!

Ken Daniels

A message from Jenny



I wish to thank everyone for their messages on the card signed at the conference in Rotorua. A lovely card and lovely messages and I appreciate each and every one of them. GBS is in very good hands today and a huge thank you to all executive and board members (past and present) who have done a fantastic job in keeping the group growing. Special thanks to Dr Parry and his MAB for their input, without which we would have struggled.

I believe there are new members, and some of the signatures on the card I do not know. Welcome to all new members and 'hi' to those I do remember, All the best for a continuing increase in membership, and long may the group flourish.

Thank you all,
Jenny



President's Annual Report of the Guillain-Barre Support Group New Zealand Trust 2015

I am pleased to report that the affairs of the Support Group are in good hands with last year passing without any great dramas. We have continued our support throughout the year to those affected by G.B.S. and its variants. Membership of our group stands at approximately 130 but there are some G.B.S. families who remain outside official membership. Hospital visits have encouraged members, non-members and their families; regular news letters put together by our dedicated editor Chris Hewlett have kept us all entertained and informed and coffee groups have supported the contact with members in some regional areas. The first point of contact with our group for many has been our website. People from all over the world search for information about this often puzzling illness and thanks to Lil Morgan work on our website has resulted in a great and well used portal for people wanting to know more about G.B.S. and our group.

The Medical Advisory Board chaired by our champion and benefactor Gareth Parry has remained in support providing assistance and advice to individual members and medics working in the area of G.B.S. Without the medical expertise provided by this advisory board our group would lack a very valuable resource and our thanks go out to all its members who have helped during the year.

Particular recognition needs to be recorded of the help given to the group by our National Co-ordinator Jenny Murray, Q.S.M. whose dedication to our organisation and its members has exceeded all that could ever have been asked of her. Without Jenny's long-time assistance our support group would never have been able to achieve the help that it has given over the years to so many people. Jenny is not able to be present at this conference due to ill health and has decided to stand down as National co-ordinator. Our secretary Tony Pearson has volunteered to take over this role for the coming year.

True grit and determination have also marked the continued service of our secretary Tony Pearson over the last 12 months. Tony's correspondence, organisation and precise documentation has been of the highest standard that I have seen in a voluntary organisation. Our sincere thanks also goes to our Treasurer Peter Scott. Without his delivering financial order from chaos we wouldn't have any idea of membership numbers or finance. I can't ignore also the background work done by Bob Stothart and other members of the Board. Their degree of support and assistance to our members is pretty extraordinary. We also acknowledge the help that spouses and family members have given to the board and also in helping with the setting up for the conference. Thanks to all of you.

As with most Charitable organisations we rely heavily on donations and subscriptions to continue our work with those affected by G.B.S., C.I.D.P. and similar variants. This year we must thank all of those who have contributed fees for both annual subscriptions and this conference. We are also extremely grateful for the support of a donation from the ARA Lodge No. 348 IC Charitable Trust. Support from this trust has been present for some years and the donations are very much appreciated and put to good use.

Finally may I invite you to participate as much as you can in supporting each other and your families? G.B.S. can have life changing effects on those who are touched by it. Active support could consist in visiting other sufferers, setting up a coffee group in your area or helping with fund raising. But support can be less active but just as helpful. It may include for example donating funds or making a bequest that can be used for education and support for G.B.S. sufferers. You may know of a potential sponsor or benefactor. Let us know.

It has been a privilege to act as your President during the last year, but, as the board will know, my contribution to the group has been supported immensely by the work that others have put in. Thanks to all of you.

Ken Daniels



Secretary's Jottings

Rotorua can be a ðsmellyö place ó especially when you are based at Sulphur Point as we were for the Conference But it's surprising how quickly you get used to the smell and it no longer bothers. Now this could be due to the nose adapting to its environment OR because one's senses are otherwise distracted by what's going on around you ó and for me that's the explanation! I think I can honestly say that - with the exception of the inaugural

Conference which will always be special for me having recently arrived in my new Country - Rotorua was the best Conference I have attended. From a Secretary's perspective Conferences and AGMs mean a lot of hustle and bustle making sure things ðflowö as planned but this time thanks to Ken's and Peter's organisation I was able to take in a lot of the presentations and although I guess I am classed as a ðregularö I learnt a LOT. Roll on the next one when you get the chance to learn from the best medical advice on our ðsubjectö in the country and have the opportunity for ðone on onesö about your particular concern ó without a large Consultants bill coming in the next post.

So life goes on. At the Conference and in the stories I read in our Newsletter and the UK one, which I still receive, I appreciate I got off lightly in terms of residuals but one thing I do have in common with pretty much all of those stories ó and re-affirmed by those I met at the Conference ó is a POSITIVE ðCup half fullö attitude ó a determination not to let this ðBö thing beat us. Anna's speech at the Conference telling us about the trials and tribulations of coping with little Emily's journey was something nobody would wish on their worst enemy and yet Anna ended by **thanking** GBS ófor making my family closer and strongerö If that ain't positive thinking I don't know what is!

AGMs are thrilling things are they not! ó I have reported elsewhere in this Newsletter on the proceedings but perhaps need to add that the significant number of new faces at the AGM made for a lively and sometimes thought provoking discussion. As Board members we do not have a monopoly on good ideas ó if you think we have got it wrong ó or think there is a better way - then for goodness sake say so and be prepared to follow it up with help and advice.

Most of you will know by now that Jenny has had to bow out of her day to day role as National Co-ordinator due to her ongoing health issues. In putting my hand up to take on this role I know I can never replicate the work that Jenny has done nor have her caring and personal approach to new contacts nor would I wish toó I'm a Bloke! ó but I do need help to continue to Group's work and in practice that means members who are prepared to visit and re-assure new GBS'ers that life does go on after ICU, Rehab etc. In the front line are our approved Hospital Visitors ó we have 25 already approved and as a result of the Workshop in Rotorua 9 new applicants who have put their hand up to help. It's a start but we need more ó there are 60 plus Hospitals in New Zealand that we need to be able to cover with a locally recognised contact that Hospitals and their staff have confidence in calling on to comfort a new sufferer and their families.

Is anyone in NZ on ðsubcutö yet (subcutaneously supplied immunoglobulin treatment) if so PLEASE report via Chris our Editor on how you are getting on ó this could be a VERY important development for regular IvIg users.

I was interested to read in the UK magazine about a new piece of equipment used to measure the recovery progress of GBS'ers called the Martin Vigorimeter ó a rubber bulb attached to a pressure gauge that GBS'er in Rehab squeeze on a regular basis to measure how their strength of grip is progressing and I had to smile to myself ó I started with a soft tennis ball which I could barely flatten with TWO hands via a rubber kids ball and now use a sprung ðgymö grip that I squeeze 40 times every day to ensure my grip is strong and the CIDP ain't returning! ó Good old NZ No 8 wire alternative to a high tech UK device!!

Perhaps more significantly for us CIDP'ers was a recent small but properly controlled trial comparing a group of moderately ðresidually affectedö CIDP patients ó half of whom were given IvIg regularly for a period and the other half Steroids. Most on IvIg'ers showed good improvement compared to only half on Steroids BUT within 6 months nearly half of the IvIg'ers were worse off whilst all of the Steroid'ers continued at their improved level. If it works then using Steroids is a ðwin winö ó it's easy for the patient and cheap for the DHB.

As always ó take care

Tomy

Report on the proceedings of the 2015 Annual General Meeting in Rotorua

Bright and early at 0900hrs on Sunday morning 10th May 29 members sat down to commence the AGM of the Group ó a significantly larger number than previous years AND the many of those attending had come to the Conference for the first time and likewise the AGM. Some 24 members who were not able to attend had taken the trouble to complete and send in their Proxy Forms ó thank you. A full complement of Board members were present with the exception of Dr. Pralene Maharaj who apologised for being unable to attend as she was in the middle of some very important career exams. Pralene's apologies and those of 8 other members were accepted by the meeting.

Referring to Matter Arising from last year's AGM Tony was able to report on a successful Hospital Visitors Workshop on the preceding Friday afternoon, attended by 32 members of which 15 were new members and following which he had received 9 applications for consideration by the Board to become Approved Hospital Visitors representing the Group.

President's Report

Ken presented his report to the meeting. A copy of the Report appears in full elsewhere in this Newsletter but in summary Ken recognised the growing importance of our website maintained by Lil Morgan which, increasingly is becoming the point of first contact for new sufferers. Jenny's continuing poor health has led her to step down from the role of National Co-ordinator ó Tony will now take on that role in addition to his Secretarial duties. Chris Hewlett produces a great Newsletter and with members opting to receive this by Email the costs of producing it have significantly reduced. Subs and Donations are the backbone of our financial strength and Ken acknowledged the ongoing support from the ARA Lodge as well as significant private donations.

Financial and Legal matters

Peter's Accounts showed a strong financial position for the Group and the efficacy of our Treasurer's efforts are reflected in an unqualified Audit Report ó something of a rarity in Charities circles where accounting tends to be the poor relation of the focus of many organisations. Reflecting the robust financial situation of the Group Peter was able to recommend to the meeting that no changes in subscription levels were needed. The meeting agreed with this proposal and also supported his recommendation that the Group membership category be discontinued as there had been no take up over the past few years.

Whilst there have been no allocations of grants from the Memorial Fund, now standing at about \$108,000 Dr. Parry assured us that his colleagues in the Medical Advisory Board are continuing to review potential projects in their respective fields of medical expertise.

As there were no new nominations for Board positions the retiring Trustees, John Podd, Chris Hewlett and Meike Schmidt-Meiburg, all of whom had indicated their willingness to continue to serve, were re-elected to the Board for another term.

General Business

Following the success of the Bay of Plenty Coffee Group an Auckland member and first time attendee has volunteered to set up an Auckland Group (see details elsewhere in the Newsletter) and Lil Morgan will try and arrange a similar Group in Hawkes Bay.

Maurice Vickers urged the Group to continue to attend the Neurological Society's Brain Days around the country as it was an excellent shop window for the Group. Ken confirmed we will seek volunteers to man stands when the next event is announced.

Ken thanked members for their input and attendance and for making the Conference such a great success.



2015 Conference in Pictures



Past and Present Presidents
Left to Right: Terry Watton, Bob Stothart
and Ken Daniels



Hon Steve Chadwick opens
the proceedings



Anna & Sam O'Reilly gave a heart
wrenching talk on their families
brush with GBS



Attendees enjoying the
Saturday programme



Below: Saturday night's dinner. A great chance to make new friendships





GBS – A Very Personal Encounter – Anna O'Reilly

Hello I am Anna O'Reilly and I am a mum of a G.B.S. child. Emily was 2 years 10 months at diagnosis and became paralyzed from her cheeks down and spent 2 months on a ventilator and got a trachy, at Starship. She spent a further 2 and a bit months at The Wilson Centre on the North Shore (a rehab facility for children).

When Ken rang and asked if I could talk for 3-4 minutes about our story with the focus on the perspective of how it affected the family unit. I thought how do I actually do this and represent each affected party justly?

I decided that because there are 5 different perspectives of this situation I needed to talk about how I saw the different personalities at different stages of life (and therefore different understandings of what was happening individually).

I am sure you all read the newsletter and have read Emily's recount of her personal encounter with the dreaded G.B.S. So I won't go into the details of her story. *(This was printed in the last newsletter. Ed)*

The major issue after Emily came home was crafting/ creating a family unit again. We had in all intents and purposes 3 only children and 2 only parents, at the start and we had to slowly create the cohesive family unit again.

The other issue was the struggle to get people (close family members included) to appreciate that although Emily could walk and run she couldn't sustain a whole family soccer game that lasted for an hour. And that yes she does have to go to bed early every night. Not because I am an anal mother but because her body and mind need that time to recoup, repair and reenergize for the next day.

I have decided to write a letter to G.B.S. highlighting briefly the affect it has had on our family.

To You

I am writing this letter to inform you of your impact that you have had on our family.

Two years ago you threw our happy healthy farming family into an emotional, mental and uncontrollable rollercoaster, which we had no way of stopping, we just had to ride.

You caused a 1-year-old baby to be separated from both of her parents and siblings for 5 months as she was cared for fortnightly swapping between grandparents - one in North Otago and the other set in Matamata.

You caused an already sensitive and protective big sister aged 7 to be without her family unit for 5 months only allowing her to visit during weekends for her next weekly dose of Mum hugs and sisterly love. You let her stay in her bedroom at her home with no one but her worried, emotionally wrought, busy dairy farming, - in the middle of calving father.

You made a loving husband and doting dad be separated from his support crew of girls. His only chance to get refueled on love and therefore strength to go another week was in the weekends, where he would arrive at 4 pm on a Friday and leave at 4.30am on a Monday. You removed his ability to protect his family without consultation. You made a Mum, who would do anything for her children or family, have to go against her maternal instinct and believe in a system, which had let her down, - knowledge is power. You made her have to focus on the sick child and therefore made her release the primary care of her other two children, she cherished and agonized over leaving. You made her sleep away from her house, her friends, her family, her life for 5 months, without consideration of what it might do to her marriage, mental state or life.

I guess though you can see that you picked the wrong family unit if you were wanting to break us. We are now a more loving, accepting of each other and our abilities, tolerant strong family unit.

We got to this point by; communicating to each other, either by phone, email or text message. By recording everyday a journal of Emily's day, allowing for reflection and noticing progress which enabled us to stay positive about the rollercoaster ride we were on.

We learnt to cherish the moments we did have together.

And by having the most caring support, sensitive talented professionals ó primarily for Emily but also for us along the way from P.I.C.U. in Starship to community based care at home.

Thank you for giving us as a family the chance to see what we can do as a team; look out the years to come.

QUESTIONS AND ANSWERS FROM THE "ASK THE EXPERTS" SESSION AT THE CONFERENCE.

The following notes were typed from a recording and there may be some risk of mishearing or inaccurately crediting an "Expert" with another's advice or spelling a medication incorrectly – apologies where due are offered.

This represents the essence of about half of the 40 minutes Q and A session – more to follow. – Tony

Q. Is there any evidence of seasonal increases in GBS incidence?

A. Dr. Dean Kilfoyle: Not that I am aware of although a bout of a virus in a community may lead to a clutch of GBS cases but this is random.

Dr. Gareth Parry: The only recognised regular GBS surge is in China when in the spring flood the village streets are awash with Chicken poo and this leads to a regular surge in the incidence of the AMAN (axonal damage) strain of GBS.

Q. Are hallucinations common in ICU?

A. Dr. Annette Forest: Yes they are a regular occurrence brought on by fever, lack of sleep and the medications we use. We can see it developing and try to break it but it's very difficult.

Dr. Dean Kilfoyle: Delirium is commonly seen in Hospitals in the geriatric or older persons ward and also in the acute wards where people are very sick or become agitated. It's not just related to GBS.

Q. Is Restless Legs common after GBS?

A. Dr. Chris Lynch: Yes Restless Legs Syndrome is associated with a Neuropathy and that is what GBS is but it's strange that GBS is a Motor neuropathy whereas Restless Legs is a sensory one. In truth Restless Legs after GBS is not Restless Legs Syndrome (which can be treated quite successfully with medication) but rather a TYPE of restless legs that is much more difficult to resolve as it does not respond as well to the drugs used to treat the Syndrome version.

Q. Is there any relationship between Food Allergies and GBS

A. Dr. Dean Kilfoyle: Not that we are aware of. Food allergies are a different form of autoimmune disease so there is no proven statistical relationship.

Dr. Gareth Parry: It is important to distinguish between a Food Allergy (eat shrimps and your face swells up) and Food Intolerance (eat cheese or milk and get diarrhoea). The widely touted Gluten Intolerance is a global Allergy with not a shred of evidence to support the things it's claimed to cause.

Q. Can IVIg be used in later stages of GBS to aid/speed up recovery?

A. Dr. Gareth Parry: No that's not what IVIg does. We use it to treat (modulate) the immune system not to induce recovery. In the USA you can find clinics that offer ongoing IVIg treatment claiming to stimulate new nerve growth. There is no evidence at all that this is the case but it does provide a good income for these clinics.

Q. What is the general treatment for Neuropathic Pain?

A. Dr. Chris Lynch: I find that pain often goes hand in hand with sleep loss and so I choose as a first response Nortriptyline. It's taken in a single daily dose at night and immediately helps with sleep but assists with pain control throughout the following day. If the condition is non-responsive to this drug I would move to Gabapentin so not because it is any better or worse than Nortriptyline but simply it requires more paperwork to gain access to it.

It is important that when commencing a medication regime it is taken consistently over a period of time so a single dose or two is unlikely to produce the desired result. The level of dosage will vary from patient to patient so there is no norm. If neither of these two drugs brings relief then I move on to the others listed in one of my slides in my earlier presentation.

Dr. Gareth Parry: As a general rule the over the counter pain relievers such as Paracetamol, Ibuprofen, Nurofen etc that you can get from the Pharmacy do absolutely nothing to relieve Neuropathic pain so and you should not continue taking them just because your GP prescribes them.

Dr. Dean Kilfoyle: People tend to have an unrealistic expectation of what pain relief medication can do. It is very uncommon to be pain free from Neuropathic pain but hopefully the medication will improve the patient's quality of life. Additionally it is unrealistic not to expect there will be some degree of side effects of taking the medication. When prescribing these pain relief medications it is generally a compromise between getting some control over the pain without creating too many unpleasant side effects. There is no magic bullet!

Penny Spender: When we discuss pain with patients we counsel them about this over expectation aspect of pain relief.

Bits and Pieces

YOUR HELP IS STILL URGENTLY REQUIRED.

PLEASE TAKE PART IN THIS STUDY

A study of the impact of a hospital visit on the quality of life during and after recovery for patients with GBS.

Dr. G Parry and J Podd would like to conduct a study on the above topic and need your help. Initially they would like you to answer these simple questions:

1. Did you receive a visit from a member of the GBS Support Group N.Z. at any time during your initial hospital visit?
2. Regardless of whether you received such a visit or not, would you be willing to participate in a research study? The study will entail answering a series of questions about your in-hospital experience.
3. If you are interested in participating please contact Dr. Gareth Parry at the following e-mail address: gareth.parry@ccdhb.org.nz

Link between GBS and campylobacter in the UK

This article was received via email from Dr. Bob Gregory as a point of Interest only.

362 people fell ill with campylobacter food poisoning last year in Plymouth. It's one of the most common types of food poisoning and is mostly found lurking on raw chicken. You can't see it, smell it or even taste it on food, but if it affects you, you won't forget it. At its worst, campylobacter can kill or paralyse you. Now Plymouth City Council has joined other councils across the country as part of this year's Food Standards Agency (FSA), Food Safety Week. Campylobacter food poisoning usually develops a few days after eating contaminated or undercooked food and leads to symptoms that include abdominal pain, severe diarrhoea and, sometimes, vomiting. Some can have lasting effects for example irritable bowel syndrome, reactive arthritis and, in rare cases, Guillain-Barre syndrome - a serious condition of the nervous system. The FSA wants to cut the number of cases of campylobacter poisoning in half by the end of 2015. It could mean that over a hundred thousand fewer people would get sick next year. If everyone does their bit including industry and consumers this can happen. Cabinet member for the Environment Councillor Brian Vincent said: "Campylobacter is a nasty little germ that's the most common cause of food poisoning. The good news is it's very easy to kill; you simply need to make sure any chicken you eat is thoroughly cooked. "It's also important to remember that despite what your granny may have said you don't need to wash your chicken before you cook it. Some of the worst culprits for making us feel un-well are things like undercooked chicken liver pate, eating chicken goujons raw, thinking they were already cooked and simply not washing your hands after preparing chicken dishes." To try and raise awareness the FSA is asking people to take the chicken challenge.

Not confirmed information!

Did you know that NZ still has one of the highest rates of campylobacter in the world?

We all need to take extra care when preparing and cooking chicken.



NOTICEBOARD

Live in Auckland? Want to meet other GBS'ers? This could be the answer:-

Any Auckland area members and supporters who would be interested in forming an "Auckland Coffee and Chat" group to get together fairly regularly and swap experiences and ideas"

please contact Grant and Sharon Dixon 09 473 1128 sharondixon@orcon.net

What's Your Story ?

Urgently needed are your stories to publish in your magazine.

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

There were lots of new faces at the conference so I know there are many stories out there. I look forward to receiving them.

Chris

WAIKATO/BAY OF PLENTY COFFEE GROUP

July 2015

Where:

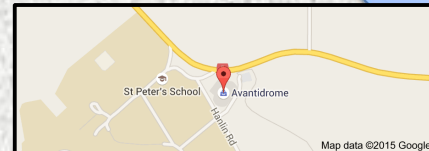
Revolve Café
The Avantidrome
St. Peters School Road, CAMBRIDGE

When:

Wednesday 8th July

Time:

11 am onwards



Give a Little

We received an email recently from an ex member whose daughter is in Starship Hospital. Here is a small excerpt. If you feel you would like to donate just follow the link provided. We wish the family well and hope that a diagnosis is not far away.

For those of you who do know me very well, you will be aware I have spent the last year and a half with my new daughter (now 2) in the Starship hospital intensive care unit!

Here is a link to a TV3 article about her 2nd birthday last week

<http://www.3news.co.nz/nznews/toddler-with-rare-unnamed-condition-turns-2-2015050318#axzz3Z9Jevyx7>

She has an undiagnosed condition involving inflammation in her peripheral nerves, likely to be unique, and despite extensive testing and international consultation, we have no real diagnosis or treatment. She is basically paralysed with her motor nerves not functioning over most of her body. This means she can't move her limbs or diaphragm, but her face seems fine, she can look around, smile and communicate and is generally very happy. The diaphragm movement is key, because without it she needs to be attached to a ventilator to breath. This has become the critical issue!

She has been stable for over a year and is in no pain (most of the time, she has had 4 teeth come through recently and had to have some Pamol during this period, but no more than any normal child) and enjoys busy days with varied activities. However, this is not a service

Our nursing team have suggested we set up a Givealittle fundraising cause to help, which is the purpose of this email. It is always difficult to ask for money from people, but NZ people are generous and the health of children is always a great cause. Whatever happens we will be helping pioneer medicine in NZ for the future of children to come, as well as the future of our child. For those outside New Zealand a YouCaring page has also been created.

Givealittle: www.givealittle.co.nz/cause/AnaCarolina

YouCaring: www.youcaring.com/ana-carolina-de-moraes-lobo-bircham-358781