

Vein of Galen Malformation

Support Group Newsletter



1 September 2009

Hi there everyone.

A warm welcome to our newsletter! I hope that the cold weather we've been having hasn't impacted too heavily on your family and now that Spring is on its way you are starting to get out and about in the sunshine more.

Since the last newsletter our family has moved from Auckland down to Wellington to live. We felt that it was a good time to move back closer to my family and further away from Starship Hospital which, thankfully we don't need to visit as frequently now. We have settled into life in Wellington and have been enjoying all the things that the Capital has to offer. We have been particularly enjoying all the parks, playgrounds, markets and cafes around the waterfront during the weekends. Make sure you drop me an e-mail if you are ever in Wellington as we are always keen to catch up with other families.

Our website has moved onto a new system and has been given a design makeover during the last month or so. The new colour scheme reflects the colour and style of our logo and the layout is now easier for visitors to navigate. A big thank you to Benedict, our web designer for all his hard work on keeping our site looking fabulous and up to date.

If you have any updates, stories, research, articles or motivational poems that you have found useful or interesting we would love to include them on our site. Please e-mail them through to me and I will organise for them to be put on.

I would also be interested in any new photos of your children or of interesting vein of galen images you may think suitable for the site too so we can keep it looking fresh and up to date.

Have you visited our online forum? Our online forum is a place where we can communicate with each other, share ideas, offer and ask for support, ask questions and get to know each other.

The forum allows us to get together even though we all live miles apart. It would be great to see our forum being used so please drop by and leave a message. You will find the link to the forum on our home page www.veinofgalen.org.nz.

I have been thinking about new pages to add to our website that would be of help to new families. I would like to have a page for families that have just found out they are having a baby with the condition or they have a child who has just been diagnosed. Sometimes all the information on the site can be overwhelming and when you are in the "Just Been Diagnosed" position you want info fast and don't have time to research or wade through entire websites. I am imagining the page will have ideas for where to next for these families. I m looking for someone to put this page together, maybe someone who has recently been through this and can give advice from their experience. Let me know if this is the job for you.



Over the last six months there has been a large increase in the number families sending in requests for information and support from all over the world. I have been sending through general vein of galen information and ideas of where to look for help to these families but sometimes they are asking for information relating to their hospital systems or other information relating to the area in which they live and my knowledge is a little limited when it comes to this.

If you know of any other support groups around the world that I could direct these families to or if you would like to be a support contact for where you live could you please let me know.

Also, if you have any other ideas of ways to help support these families please share them with me.

Best wishes,
Bridgette Wright



New Families

The Vein of Galen Malformation Support Group would like to extend a special welcome to the following new members and their children.

Rachel and Derek Nelson and daughter Rosa

Rosa was born in March this year. She has had a number of embolisations and is currently waiting for what we all hope will be her last one for a long while. She is being treated in Starship Hospital in New Zealand. Rachel and Derek have put together a Caring Bridge website and welcome you to visit to keep up to date with Rosa's progress. Rosa's website is: <http://www.caringbridge.org/visit/rosanelson>.

Sarah Hodnett and her daughter Alyssa

Alyssa is eleven months old and has had two embolisations. Her proud Granny Elaine tells us she is doing well.

Kaylene and Bruce Grigsby and daughter Ebony

Ebony was found to have vein of galen malformation in October 2003. Ebony is now seven years old and is enjoying being at school.

Tina and Carl Doran and daughter Kendal

Kendal was born in March this year. She was diagnosed with vein of galen malformation at 36 weeks gestation. Kendal is scheduled for her first embolisation in August this year, which we all hope, will go well.

A Big Welcome to You All!

New On Our Website

- The website has had a design makeover
- complete with new colours and layout. It not only looks fantastic, it is easier to navigate too.
- An exciting new online forum. This is an excellent tool for communicating, offering and seeking support, asking questions, sharing information and for chatting to get to know each other better. We can't physically get together for a coffee and a chat but now we have the next best thing. Make sure you stop by and leave a message.
- Mason, Danny and Fynn's personal stories have been updated. It is great to read that all three of these boys are doing so well. The updates have been added to their stories so click on the link to view their stories on the "Our Stories" page.
- We now have on line membership, question and feedback forms.
- There are a couple of new inspirational stories from around the world about children with the condition.

Ideas for New Pages


Calling volunteers to put together some new pages!
Let me know if you can help.

Newly diagnosed - Where to from here
Just for Dads - Support and advice in bloke speak
Little Miracle Kids Page - page for our kids
Glossary of Medical Terms - relating to VGM
Explaining Procedures in Kids Speak




Becoming Your Child's Advocate


Once you become a parent you begin to find that there are many roles that you will have to fill. One of the most important roles is to be your child's best and most assertive and effective advocate.




As a parent of a child with vein of galen malformation I have found this role to be quite involved and at times challenging. I wanted to write this article to share with you what I have learned while advocating for my son over the last three years. I hope that it will make your job of advocating that little bit easier.




When my son was discharged from hospital we were put into the care of a very wise home care nurse. On her initial visit she told me that "I would need to become the expert on my child's condition, be able to tell other medical professionals about it and would need to keep information about all his treatments and the different teams working with him". At the time I thought this a little over the top. Looking back now this is the best piece advice I received about becoming my son's best advocate.




After being home for only a few days from NICU with my son he stopped breathing for a minute or so. We called an ambulance and with the words playing in my ear from the home care nurse I picked up our NICU discharge report, my baby and a container of expressed milk in case he would require a nasal gastric tube again and boarded the ambulance.




In the emergency department no one knew us, our history or anything about vein of galen malformation. We asked the staff to call NICU or to look in the computer and we were told "You're not in NICU now." We sat back in our places as the professionals took over as they seemed to know best. Our son was x-rayed and we were told he was in heart failure! We had already told them this on arrival and that it was part of his condition. I started to realise I did know something. I then remembered I had the letter and after I urged the doctor to read it, we started to get somewhere. My first step at advocating, be it a little timidly, and my realisation that a letter from a medical person is worth its weight in gold.




Once home again, I decided to start a folder of any information that we had about his medical history, condition and his doctors names.



After one of the many clinics we attended I received a clinic summary letter. At our next and every clinic after that I requested a copy of the summary letter to be sent to us and I added them to our increasing folder.



I learned that all the doctors working on your child's case don't automatically receive these letters, you have to ask for this to be done. I now have a list now of all the professionals who need a copy in my folder!



You sometimes have to advocate firmly and assertively to get your child the help they really need and these letters can provide the evidence and information in medical terms to get your child seen or picked up by a service when appointments seem like hens teeth. Information is your best key to opening closed doors. Go armed with your folder.

Becoming Your Child's Advocate cont.

Last year I went to a talk about raising boys by parenting expert Ian Grant. In this talk Ian said that, as a parent, you need to realise that you are the builder of your child's life. Everyone else is a sub-contractor on your parenting job. As the builder you have an invested interest, subcontractors work with care but little or no responsibility.

In my son's team there are many medical professionals and educational professionals or sub-contractors and you will probably be the same. It is your job as your child's best advocate or builder to ensure your child has all the sub contractors he or she needs and that they are providing the best possible service for your child. As an advocate you may have to make changes or seek alternatives to your child's team if the best outcomes are not being achieved.

Being an advocate means you sometimes have to stand up for your child and ask professionals to explain, modify or stop what they are doing if you know it isn't going to work or be in the best interest for your child and your family. Sometimes it can be hard to be assertive to a professional but remember you know your child best and no one will care for your child as much as you.

Being an effective advocate means you will have to:

- Be an expert on your child, their condition, their medical, emotional and educational needs.
- Collect, collate and share information about your child, their condition, treatment etc - Make a folder and take it everywhere.
- Communicate respectfully and honestly and speak confidently and assertively.
- Ask questions to clarify and find out more. Don't be afraid to ask for explanations in everyday language if you don't understand.
- Debate and persuade professionals to provide everything your child needs and is entitled too. Don't take no for an answer when you know your child's best interest isn't being taken into consideration.
- Ask for help and support when you need it. Everyone needs help along the way and there are lots of people out there only too willing to help you.
- Make changes or seek alternative professionals if you are unhappy with a service or provider. Do not be afraid to get a second opinion or change providers. Only you have your child's best interest at heart.

Sometimes it is not easy being your child's advocate but with experience and practice it does become easier.

In twenty years time when my son is grown up, I want to look back on my journey with him as a parent and know that I have done my best to be an effective advocator for him. I want to look back with out any regrets of questions not asked or services not pushed for. I want him to be provided with every opportunity and all the help and support he require to grow and develop to his fullest potential. I know you will be the same.

Best of luck!



Little Miracles

The Club for Vein of Galen Kids

Rhyme Time

It is no accident that nursery rhymes, lullabies and children's songs have been passed along for many generations. Both parents and children love them! When you share rhymes and songs with your child you are sharing language and getting to know your child better. Songs and rhymes help your child to learn through repetition, rhythm and rhyme.

Repetition

When words are repeated over and over in a rhyme or song your child learns to expect what is coming and their brain becomes better organised to hear, speak and later on to read. Repetition also helps establish early memory skills.

Rhythm

Babies are born with rhythm! From sucking to banging a spoon on their highchair, many of your child's actions are rhythmic. The rhythm in songs and rhymes can attract a child's attention or calm a child depending on the rhythm. Sharing rhymes and poems with different rhythms helps the brain to begin making pathways and connections which will help mathematic learning when they are older.

Rhyme

The rhyming words in songs and poems help children hear similar sounds. Because rhythm and repetition attract a child's attention they will focus on the words they hear. Learning to recognise similar sounds will help your child develop language and help them learn to read when they are older.

Have Fun

Just have fun sharing rhymes and songs with your child and you will get a big reward for your efforts. When you share rhymes and songs together with your child, you are creating a closeness that will last a lifetime.

Have fun sharing these poems and rhymes with your little one.

*Slowly, Slowly, Quickly,
Quickly*

Slowly, slowly, very slowly,

Creeps the garden snail.

Slowly, slowly, very slowly,

Up the wooden rail.

(Walk fingers over body slowly)

Quickly, quickly, very quickly,

Runs the little mouse,

Quickly, quickly, very quickly,

All around the house.

*HAMMER, HAMMER,
HAMMER!*

Hammer, hammer, hammer.

(Hands in fists, one hammers on top of the other)

Shake, shake, shake.

(Shake hands like shaking water off them)

Twirl, twirl, twirl.

(Move hands around each other like Wheels on the Bus)

Clap, clap, clap!

(Clap three times as saying the words)

Repeat poem and actions faster than clapper, then