



Vein of Galen Support Group July Newsletter

20th July 2008

Hi there everyone.

I hope that you are all well and are keeping warm on these cold winter days and nights. It has been a while since our last e-newsletter but lots has been happening with new families joining and new items being developed for our website. If you haven't had a chance to visit the website lately make sure you pay a visit soon to check out all updates and new pages.

The following children, Fynn Wright-Coyle, Danny Gilbert and Levi Kingi have embolisation procedures coming up in the next few months. I know that we will be keeping these children and their families in our thoughts and prayers as they prepare and go into hospital and have their procedures.

I have just put together a blog type website about our son Fynn which we are using to keep family and friends up to date with Fynn's progress. Family and friends can subscribe to the site and then it will notify them via e-mail of any updates. The site is free and you can set it up so only people you want to visit can access the site. We are hoping it will save us time on the phone updating people when we need to be with Fynn while he is in hospital. The website is <http://www.caringbridge.org/visit/fynn> if you want to check it out.

Let me know if you decide to make a site for your child and perhaps we could add the links to a page on the VOGM website or with the family stories to help keep us all up to date with each others progress.

Love to you all and your family,

Bridgette Wright

Special Welcome to New Families

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

Danielle and Dan Gilbert and their son Danny

The Gilbert Family hail from Ohio USA and Danny is 2 and half years old. Read Danny's story in the Our Stories section of our website.

Caroline Steele and her daughter Jessica

Jessica is 8 years old and lives in New Zealand. Jessica's story is also available in the Our Stories section of our website.

Catherine Lane and her son Charlie

Charlie lives with his twin brother and his family in England. Read a recent newspaper article about Charlie on our website on the family stories page under the heading "Other Stories from Around the World" and his story is "Super Glue Surgery Saved Ingleby Barwick Boy".

Happy Birthday to:

Charlie Happy 2nd Birthday for the 30th Jan
Levi Happy 1st Birthday for the 23rd April
Fynn Happy 2nd Birthday for the 24th April
Jessica Happy 8th Birthday for the 31st May
Mason Happy 1st Birthday for the 12th June

And Congratulations to:

All of their parents for another year of fantastic parenting !

*If you have some photos you would like to share in the newsletter of your child celebrating a birthday or an achievement please e-mail them to me:
bridgette.wright@paradise.net.nz*



Here is Mason at his 1st birthday party. Mason's Mum organised a fantastic party complete with a Tigger cake and a magician! From the photos we received it looked like he loved every minute of it!



Here is Fynn celebrating his 2nd birthday. Fynn had a "Bunny" themed party inspired by his favourite toy which you can see replicated on his cake. He had a lovely time playing with his family and friends at the park to celebrate his big day.

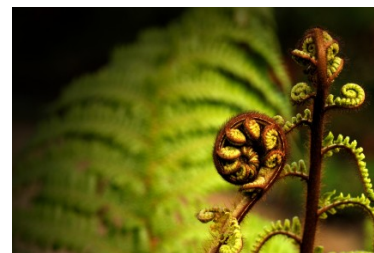


New Images For our Support Group

I have been working with Benedict Chapman who is our wonderful web designer on our new Support Group Logo. I am sure you will agree that Benedict has done a fantastic job with the design.



The koru pattern was chosen for its Maori symbolism of new life and for the symbolism between the coils that are used to treat VOG. The two korus joined at the bottom symbolize the interconnections of the veins in the malformation and where the two korus meet it forms a "V" for vein. The larger and smaller koru have been used to symbolize support and or family. The overall shape is similar to that of a heart, symbolizing love, caring, support and the relationship between the malformation and the heart. The colours were chosen to symbolize new life and renewal.



On the website you will see a Punga fern photo which is on the right hand side of each page. The Punga has been chosen as our Native plant and this image had been purchased for our use. The Punga fern is native to New Zealand and a natural symbol of new life and support which is fitting for our group.

I hope you like the new images and I'm sure you will agree they make the website look really professional.

New On Our Website?

On the Research page we have included a research paper from the Neurovascular Research and Education Fund in the UK

We have a new Questions Page containing question commonly asked by parents. The questions have been answered by Meg Seow (Radiology Nurse) in consultation with Drs Ayton Hope and Maurice Morriarty, Interventional Neuroradiologists (Auckland, New Zealand). If you have further questions that you would like answered there is a link on this page to do so.

Meg Seow is the Nurse who has allowed us to use her presentation on our Medical presentation page. With Meg's help I have put together a profile about Meg which you can access through the questions and the medical presentation pages.

We have two new stories on our family stories page. Make sure you visit to read Jessica and Danny's stories. Both stories are very interesting reading. Thank you to their families for writing their stories for us to share.

We have some new images on the information about VOG pages courtesy of Dr. Laughlin Dawes, MB, BS. The 3D image of the inside of the skull with VOG is amazing. His website is www.radpod.org if you are interested in having a look at some of his other images.

Coming To Our Website?

More photos
Membership joining page with a form to complete
A page with info for parents who have just had a child diagnosed (pre and post natal)
Forum
Dad's Page
Little Miracles Kids Page
Going to hospital page, what to take and what to expect, explaining procedures in children's language and more...

I would love any other ideas, suggestions and information for the website.

Welcome To Holland

by Emily Perl Kingsley ©1987 All rights reserved.

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands, the stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very, very significant loss.

But, if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things, about Holland.

A poem that we both found had some meaning.

Bridgette and Simon

If you have any poems or stories that you have found helpful or insightful on your parenting journey we would love to share them in the newsletter.

Little Miracles

The Club for Vein of Galen Kids

Play Dough for Fun and Learning

Lots of really simple materials can help young children to be creative and express themselves. One material that's easy to make is play dough - it offers a great opportunity for creativity. Young children can spend hours having fun with play dough. Play dough is a simple pliable material that helps young children learn to create objects and at the same time helps to develop their muscles and coordination in their fingers.

Using play dough to express creativity

Children are ready to use play dough when they have stopped putting everything into their mouth - often when they are around 15 months old. At this stage your child is most likely to be using their hands - squeezing, poking and pinching, picking up and putting down. They don't need any tools yet. Just give them the play dough and a space that you can clean up easily.

The play dough experience is much more fun if you are not worrying about the mess. Put down a sheet of plastic or newspaper on the floor or table so that the dough doesn't stick to the carpet.

If you are worrying about your young child eating the dough, sit them on your lap and keep a close eye on them.

Play dough for older children

- As children get older they can roll the play dough out into shapes – snakes, balls and worms. A lot of pretend and imaginary play develops as your child creates things.
- Show them how to do the rolling.
- Talk about the shapes and link them to other experiences EG a worm in the garden or a snake in a book.
- You can ask some questions – for example, “What happens when you drop the ball?”
- Children love to use kitchen tools to work on dough. All sorts of things in the kitchen are really useful with dough.
- Try any small containers or biscuit cutters to make shapes.
- A garlic press makes really exciting streams of ‘spaghetti’.
- Muffin tins are good too, as they can form the basis of all sorts of imaginary cake-making, singing ‘Happy Birthday’, and blowing out candles.

More ideas for play dough

- Expand on the kinds of other materials they use with it.
- Encourage pretend play and support it with a range of things to stick into the dough, including sticks, shells, leaves, glitter, feathers and buttons.
- Make patterns and designs.
- Make several batches of dough in different colours and focus on blending and mixing the colours.

Uncooked Play Dough Recipe

Mix together the first five ingredients, and then knead in the food coloring:

- ½ Cup salt
- 1 Cup flour
- 1 Tablespoon cream of tartar
- 1 Tablespoon cooking oil
- 1 Cup water
- A few drops of food coloring (colour of your choice).

Have fun!