

The Daisy Garland

'A journey of hope... for children with epilepsy.'

The Daisy Garland Newsletter

Spring / Summer Issue 2010

To all our readers old and new we wish you a very happy 2010

Welcome to The Daisy Garland Spring and Summer newsletter which is packed with interesting articles as well as details of our forthcoming events and information on how you can help us in 2010.

There's something for everyone so please read on ...



Bookworm

There's nothing better than sharing a book at the end of a busy day so if you are thinking of buying your little ones a book for Easter take a look at the following recommendations all of which received a 5 star thumbs up from parents. All eight books are beautifully illustrated by our very own Nick Maland. Nick, award winning illustrator on both sides of the Atlantic, designed the Daisy logo as well as our pretty notelets and wrapping paper and each year he designs the Daisy Garland Christmas card.

Friends and You've got Dragons both by Kathryn Cave

Brave Whale by Alan Temperley

Imogen & The Ark by William Mayne

And the following all written by Mara Bergman: *Oliver Who Travelled Far & Wide*, *Oliver Who Was Small But Mighty*, *Oliver Who Would Not Sleep* and the engaging *Yum, Yum*.

You can take a look at all these books on Amazon and don't forget to access via The Daisy Garland website. Just click on the Amazon button at the top of the home page - it's as easy as that.

Happy reading ...

Did You Know?

That St. Valentine is the patron saint of people with epilepsy.



Lest We Forget

Daisy, the little girl who gives her name to this committed charity, would have celebrated her 12th birthday on April 11th. She is profoundly missed by all those who knew and loved her.

Thankfully Daisy's strength, courage, determination and grace live on in her parents Sara and David without whom some of the 60,000 children in the UK who suffer from epilepsy would not be given the chance to try for a seizure free future.



Daisy aged 4 and her daddy

Marathon Man



A very big thank you and good luck to Paul Bassett who will be running the 2010 Virgin London Marathon for The Daisy Garland.

Look out for Paul on April 25th he'll be wearing our Daisy logo. If you would like to sponsor Paul, please go to: www.justgiving.com/Paulbassett



Read inside Gillian White's inspirational account of her 2009 half marathon run for The Daisy Garland. If you think you would like to do something similar let us know at info@thedaisygarland.org.uk



Calling All Schools - The Daisy Garland Charity Needs You

With 3 new hospitals waiting for a Ketogenic Dietitian this year we need to work doubly hard to raise the £26,000 needed to fund each Dietitian.

Can you help us reach our goal? We are asking schools if they would adopt The Daisy Garland as their charity of the month or year.

In 2009 Belmont School in Mill Hill held a sponsored swim and raised just under £4,000. If just 5 schools did something similar we would be well on our way to raising the full salary for 1 Daisy Garland Ketogenic Dietitian. Imagine if 20 schools took part in some form of fund raising activity The Daisy Garland would be able to give the three hospitals the dietitians they so badly need. Some ideas

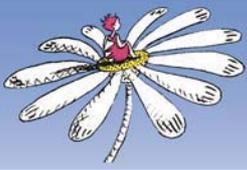
Have a Smarties Party – then fill the empty Smarties tubes with small change. **Pyjama Day** – ask your teacher if you could wear your pyjamas to school for a day. **Don't say a Word** – choose a word you mustn't say for a day, anyone saying that word must pay a fine! **Flower Power** – collect small change and make a daisy flower in the playground.

Can you, will you, help us ease the trauma of epilepsy? Contact us at info@thedaisygarland.org.uk for one of our Schools' Charity Information Packs. **Thank you.**



Donate on-line at www.thedaisygarland.org.uk





The Daisy Garland

'A journey of hope... for children with epilepsy.'

The Daisy Garland Newsletter

Spring / Summer Issue 2010

Daisy Diary Dates

MARCH

Don't miss the launch of the new Daisy Garland website. Your feedback would be greatly appreciated. Comments to: kathryn@thedaisygarland.org.uk

APRIL



On Sunday 25th April Paul Bassett will be running the **Virgin London Marathon** on behalf of The Daisy Garland. If you would like to support Paul please go to: www.justgiving.com/Paulbassett

MAY

Saturday, 8th 6.30pm until midnight



www.warrenhouse.co.uk

The highlight of the Daisy calendar is undoubtedly **The Daisy Garland May Ball**, this year celebrating Daisy's 12th birthday. As in previous years the ball will be held in the elegant surroundings of Warren House, Kingston-upon-Thames, Surrey. Warren House is a 19th century, Grade II listed mansion situated just a 5 minute walk from Richmond Park. Once used as a military convalescent home during the second world war this beautiful house, set in 4 acres of stunning gardens, was frequented by the likes of Queen Mary, George V, Edward VII, Queen Alexandra and Gladstone.

Desperately Seeking ... Raffle & Auction Prizes

We are looking for prizes for The Daisy Garland Ball raffle & auction. Do you have anything to give? Last year a local company donated a 'Handyman for a Day' – I can't tell you how popular that was. If you think you, or someone you know, can help us please e-mail Sara at: info@thedaisygarland.org.uk

The 150 guests will start the evening with pre-dinner drinks followed by dinner and dancing until midnight. During the evening there will be a luxury auction and raffle. Some lucky winner will walk away with a week in a converted barn in south west France or overnight accommodation for two people at Warren House plus a champagne dinner; just two of the many prizes on offer.

JUNE

Saturday, 19th – 10.30am - 5.30pm
Wimbledon Village Fair



Wimbledon Village Fair and Horse Show is a major annual fundraising event run by the Wimbledon Guild. The Daisy Garland will be there with their range of pretty Daisy merchandise including mugs, key rings, organic cotton shoppers, kagools and much more. Be sure to come along and say hello.

JULY

Saturday 3rd
1pm - 5pm
The Daisy Garland Family Day Picnic and Balloon Race.



Holland Gardens, West Wimbledon (5 minute walk from Raynes Park station)
Neatly tucked between Cottenham Park Road and Cambridge Road, Holland Gardens is one of the treasures of West Wimbledon. Bequeathed to the people of Wimbledon by Lady Holland in 1928 the gardens, bordered by cherry trees and dotted with flower beds, are popular with mums, dads and toddlers seeking a peaceful green place to relax. This is the location for our Family Day Picnic and Balloon Race, which is not to be missed.

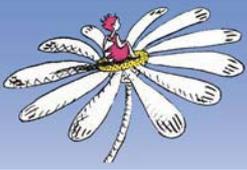
A truly old fashioned day out for all the family with a hurdy-gurdy, coconut shy, bric-a-brac stall, face painting, an organic produce and preserves stall plus mouth watering homemade refreshments and cakes and much, much more. Don't miss the chance to take part in the famous Daisy Balloon Race. This really is a must for all the family so make a note in your diary and come along and share in the fun. Oh, and admission is free!

***NB All dates are correct at time of going to press. Please visit www.thedaisygarland.org.uk in advance of events to check on dates and times. Thank you**



Donate on-line at www.thedaisygarland.org.uk





The Daisy Garland

'A journey of hope... for children with epilepsy.'

The Daisy Garland Newsletter

Spring / Summer Issue 2010

A Big Celebration! by Karen Cronin

On the 3rd October 2009, we had a party to celebrate my 40th birthday



Maddie and her cousin

and Maddie's 10th birthday. It was a great party and instead of presents Maddie and I decided that we would raise funds for The Daisy Garland. We raised over £330 and we were delighted.



Karen, Maddie's mum

The charity meant so much to us because of our own journey living and coping with Maddie's epilepsy. Sara knew what we were going through, she understood and she was a much needed lifeline at one point on that journey.

Sadly, Maddie was never a candidate for the Ketogenic Diet. After many agonising appointments and hospital investigations we found out that Maddie was a possible candidate for surgery. People have



Maddie's OP at GOSH

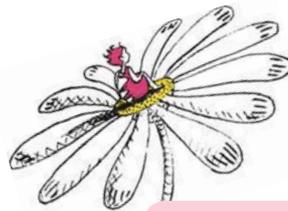
said that it must have been a hard decision to make for your child but actually it wasn't. Her life was so hard with 3 to 4 partial seizures a day,

sometimes lasting up to 15 minutes long. Therefore we decided to go for the surgery. Maddie was so brave, it was a difficult procedure and heartbreaking to watch her go through it. However, her final surgery was on 2nd April 2009 and she has been seizure free ever since! Praise God! I say that because Maddie asked me if she could be baptized so the night before her surgery we were both baptized in St. Christopher's Chapel in Great Ormond Street Hospital.



Santa's Helper

2009 was a truly amazing year and it ended with Maddie winning a local competition to be Santa's helper for the day! We had the best Christmas ever and now we are just having a ball! Thank you Sara for all your kindness, we will never forget Daisy and the wonderful work that you do.



DON'T FORGET ...

... THE 3 FREE WAYS



amazon.com

... give with a click!

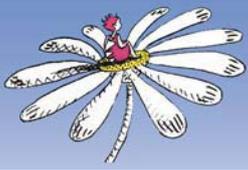
And Last but Not Least

A very big thank you to all those who supported and sponsored us in 2009. To those who donated fabulous prizes for last year's Ball and those who helped set up stalls, blow up balloons, paint faces, make cups of tea and cakes and jars of jam for the Family Day Picnic. To those who asked for donations to the charity in lieu of flowers at the funerals of their loved ones. To those who held coffee mornings and those who swam and ran and sold toys and nick-nacks to raise funds for us, your endless and generous support is greatly appreciated. **Thank you is not enough.**



Donate on-line at www.thedaisygarland.org.uk





The Daisy Garland

'A journey of hope... for children with epilepsy.'

The Daisy Garland Newsletter

Spring / Summer Issue 2010

A Day in the Life ...

of Nicol Clayton 'Daisy Garland Dietitian' at North Bristol NHS Trust.

In our 2009 Autumn/Winter newsletter we introduced you to Nicol Clayton, our 6th Daisy Garland Ketogenic Dietitian. Nicol took up her post at Southmead Hospital in Bristol in July 2009.

As a regional referral centre for neurology, Bristol Consultant Neurologists are keen supporters of the ketogenic diet as a treatment for those children whose epilepsy cannot be adequately controlled with medication. However, previously we had to apply for funding for each individual patient referred, which meant that patients often had to wait a long time before funding was agreed, and some patients ultimately had to be turned away. It was therefore a fantastic boost to receive the Daisy Garland funding last year and I was able to fully take on the role of ketogenic dietitian so that we could develop our service and see more patients much quicker!

My day starts by meeting a recently referred patient with their Consultant Neurologist, where we discuss all the possible treatment options and review the progress made so far. As medication is not adequately controlling the seizures and the family are keen to try using the ketogenic diet, I see the family after the medical consultation and we run through the basics of the diet.

This first meeting with a new patient is often about explaining the foundations of the diet – what is a carbohydrate, where is it found in the diet, and which foods would be restricted alongside how much fat is needed on the ketogenic diet and how it is incorporated into the meals. I show parents pictures of typical meals and we look at the child's current diet and talk through some of the changes



that would be required. As the ketogenic diet involves having high levels of fat, there are a number of tests the child has to undergo before starting the diet to make sure that they are medically safe to commence. We go through these and I also explain how the parents would be able to test for ketones once on the diet, both in their child's blood and urine.

I give the family a starter pack of information and also a book of recipes, containing typical meals and ideas for making ketogenic bread, muffins, pancakes and biscuits. Over the next month the family will be able to try these with their child to find meals and snacks they are happy to eat, which I will build into their individual diet plan.

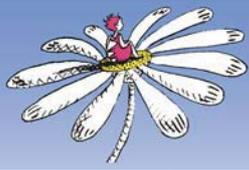
Back at the office, I write to the child's local Paediatrician and GP with details of the tests that need to be done, and asking them the best way to contact them as I expect that I will be speaking with them regularly over the coming months. I also notify Sara at the Daisy Garland (with the patient's consent), who arranges to send the patient a really useful starter pack, containing essential items needed for the diet

such as weighing scales, tupperware containers, carbohydrate free sweetener and information booklets, which the patients really appreciate. It's then on to emails - as we see patients across the region I frequently use email and telephone contact. A patient has sent through to me their blood ketone readings for the week. This patient's seizures have been really changed by the ketogenic diet, going from several violent seizures a day to one small one a week, and their child is now alert and happier, Mum is really concerned when she noticed that her ketone levels had dropped recently and her seizures were starting to increase. We go through the diet with a fine tooth comb, making sure that no extra carbohydrate has crept in from unknown sources, such as new medications. We make a couple of changes to ensure that the diet is still providing enough energy for growth and contains enough fat and agree to review her closely over the next week. My next email contains lovely news from a family who have just started the diet and are finding it easier than anticipated to manage. In fact the celeriac mash, used to replace potato, is a great success with all the family! They have also sent through a ketogenic recipe for cheesecake, for others to try. As a developing centre we are building up our database of resources, so, after a quick lunch stop, I calculate the nutritional content of the recipe and add this to our recipe book for new patients.



Donate on-line at www.thedaisygarland.org.uk





The Daisy Garland

'A journey of hope... for children with epilepsy.'

The Daisy Garland Newsletter

Spring / Summer Issue 2010

Inspired to Run



Gillian White is Head of Dietetics at the Queen's Medical Centre, Nottingham. I started running very reluctantly a few years

ago. I've always loved walking and could walk miles but never seemed to be able to run round the block without being out of breath.

I began slowly, especially up hill, and little by little I found I was going further especially on Saturday mornings in spring when running is a great way to put the week behind me and enjoy

the local countryside. I'd been trying to pluck up the courage to do a half marathon for a while, partly inspired by friends at work and partly just to see whether I could. So, rather anxiously, I put my name down for the 2009 Robin Hood Half Marathon in Nottingham; asking for sponsorship for The Daisy Garland cemented that commitment, now I couldn't let Daisy or the people who were supporting me down!

The Daisy Garland support one of the Dietitians in our department in Nottingham and that means we've been able to provide a regular ketogenic diet service for the first time. We really value David and Sara's personal involvement and concern

for the work we do. I know how hard fund raising can be and this was my chance to give something back. Taking part in the event was inspirational, it was amazing to have the support of so many people whether running or handing out bottles of water or shouting encouragement, and somehow the miles just flew by. I would have been pleased just to have got round the course so I was thrilled when I realised that I had done it in a few seconds under 2 hours, and I was just as delighted to have raised over £300 to support The Daisy Garland's work. I'd recommend it to anyone!

Clever Gift Ideas

With Mothering Sunday, St. Patrick's Day, the first day of spring and Easter just around the corner - plus a whole raft of other days to celebrate throughout the year - it can sometimes be difficult to come up with different gift ideas. That's where The Daisy Garland merchandise can help. Here are a few ideas:

A Daisy mug makes a very pretty temporary plant pot. Line the mug with clingfilm, add a handful of compost and a sprinkling of bulbs, a beautiful flowering hyacinth or some miniature flowering daffodils and you have a perfect gift for Mothers' Day.

Easter is always associated with chocolate but this year why not fill a Daisy mug with packets of seeds such as chocolate cosmos,



Habanero chocolate chilli pepper seeds, chocolate coloured sunflower seeds or a packet of wildflower seeds to attract bees – with a few chocolates tucked into the bottom of the mug for good measure of course! Good for the environment and even better for the waistline.

Did you know you can buy your seeds on-line from Amazon's Garden and Outdoor Department? If you access Amazon via the button on The Daisy Garland website 5% of the cost of your total purchase will automatically be

donated to the charity with no extra charge to you.

Why not use a Daisy organic shopping bag instead of wrapping paper?

Sounds odd ... why not try it? Put your gift inside the shopping bag tuck the handles neatly inside, synch-in the top of the bag and tie with a length of pretty ribbon or coloured string. Two gifts in one and no wasted wrapping paper!

Our note cards make perfect Easter cards and are available on our website.



Donate on-line at www.thedaisygarland.org.uk





The Daisy Garland

'A journey of hope... for children with epilepsy.'

The Daisy Garland Newsletter

Spring / Summer Issue 2010



If you think you could help us fund our next Daisy Garland

Ketogenic Dietitian your donation, no matter how small, would be gratefully received.

Donate on line at:

www.thedaisygarland.org.uk

or send your donation to:

The Daisy Garland, 32 Trewince Road, London SW20 8RD.

Your help counts - Thank you for your support.

How to Donate without Spending any Money

With the credit crunch nipping at our heels and our purses we can't always be as generous as we would like. One charity after another is in competition for our spare pennies so it's a pleasure to announce that The Daisy Garland can benefit from your charitable spirit with no extra cost to you. Interested?

THREE FREE WAYS TO SUPPORT THE DAISY GARLAND ...



Sign up to the search engine EveryClick.

It's free, it's easy and it's a great way to help children with

epilepsy. Sign up at everyclick.com/daisy-garland/670703/1006567/info



Each time you buy from Amazon The Daisy Garland will receive 5% of your total spending with no extra cost to you but only if you access Amazon via The Daisy Garland website. And here's how -

Simply click on the Amazon logo located at the top right hand corner of the Daisy homepage. Wait for the Amazon page to come up. Type the name of the book/item you want into the Search Box and away you go. Amazon has made giving easy - so why not give it a try.

And remember Amazon is not just about books, you can buy anything from gourmet food to a new set of tyres from their website.

Simply click on the Amazon logo located at the top right hand corner of the Daisy homepage. Wait for the Amazon page to come up. Type the name of the book/item you want into the Search Box and away you go. Amazon has made giving easy - so why not give it a try.



Place your order by post, phone or at easy2name.com for name tags and labels to sew, iron or stick onto your child's clothing and we will benefit from a 20% commission. It's simple, when you reach the checkout please quote: Daisy Garland TQ9

Place your order by post, phone or at easy2name.com for name tags and labels to sew, iron or stick onto your child's clothing and we will benefit from a 20% commission. It's simple, when you reach the checkout please quote: Daisy Garland TQ9



Keto Kitchen

Here is a Keto recipe that can be enjoyed by all the family ... perhaps as an Easter treat?

Chocolate Mousse

Green & Blacks organic 70% chocolate

Double cream

Break the chocolate into small pieces and place in a bowl over a pan of hot water. Melt slowly - too fast and the chocolate will go grainy.

Whisk the double cream and add the melted chocolate, mix until thoroughly blended. Pour into bowls or small coffee cups and chill until required. Bon appetit!



IMPORTANT

Before attempting to include this in your child's menu it is essential that you consult your dietitian who will have to calculate appropriate weights and measures in keeping with your child's ratio.

Keto Packs

A reminder for families starting the Ketogenic diet; don't forget to ask your Daisy Garland Ketogenic Dietitian for details on how to apply for your free Daisy Garland Keto Starter Pack which includes electronic scales, silicone scraper, tupperware pots, The Ketogenic Diet Book, a Daisy apron and Liquid Hermesetas.



Donate on-line at www.thedaisygarland.org.uk

