

The Daisy Garland

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

The Daisy Garland Newsletter

Autumn / Winter Issue 2010

Welcome to our autumn and winter newsletter

Full of interesting news, heart-warming stories and inspirational children. As you will see we, and our kind supporters, have been very busy over the spring and summer raising funds to support children with drug resistant epilepsy. We would like to say a very big thank you to everyone who has so generously donated their time, energy, ideas and money. Our Daisy Garland Ketogenic Dietitians are dotted around the country successfully treating children with difficult to control epilepsy. But at the time of writing, there are three more hospitals in desperate need of our help and we would very much like to provide each of them with a Ketogenic Dietitian by the summer of 2011. Each dietitian costs £26,000 per annum. Can you help us raise the much needed funds to do this? You don't have to commit to running a marathon you could simply buy some of our new range of Daisy merchandise or place an order for our 2010 Christmas cards. A selection of our new merchandise is featured inside and is available to buy in our online [SHOP](#). **We very much hope you enjoy our latest newsletter and that it will inspire you to do something for The Daisy Garland this autumn and winter.**



Daisy in Mummy's Earrings

How the ketogenic diet transformed Liam's life by Susan Killoughery

Our son Liam developed epilepsy in March 2009. He changed from being a happy independent 2 year old, to a child whose life was dominated by epilepsy. We truly believed that once he was prescribed an anti-convulsant drug, his epilepsy would be controlled and family life would carry on. We could not have been more wrong.



Liam before the diet

Liam did not respond well to his first drug, so a second was added; throughout this time his seizures worsened and became more frequent. What started as a handful of absence seizures a day, rapidly escalated to hundreds a day. He soon developed drop seizures, jerk seizures, and night-time convulsions.

He had a 'status' episode (a seizure lasting over 5 minutes) and spent a week in hospital where a further two drugs were tried. The benefits were very short lived and the side effects were frightening. Whilst Liam was in hospital I mentioned the ketogenic diet, but the medical team explained that it was early days and we should try a few more drugs. We were also told that the ketogenic diet was difficult, and Liam's dairy and egg allergy would complicate things.

By August, Liam's drop seizures were so unpredictable and violent that he was walking with reins and had to be strapped in a high chair, buggy or car seat. He was

having up to 30 drops a day, plus jerk seizures, absences and nightly convulsions, resulting in a third drug being added. Again, this seemed to have little to no effect, increasing tiredness and making Liam more unstable on his feet.

As a mother, I was feeling completely helpless, frustrated and exhausted knowing there was nothing I could do to help Liam. Our family life was non-existent, our days were consumed by uncontrolled epilepsy. At this point I contacted The Daisy Garland and was given some much needed support, advice and guidance.

Our hospital had just received ketogenic funding and after much persuasion on my part followed by various medical tests, Liam was found to be a suitable candidate for the MCT version of the ketogenic diet. Liam started the diet at the end of November 2009 and prior to commencement was weaned off one of his drugs (Epilim).

For the first six weeks on the diet, Liam's day-time seizures worsened - some days he could not even speak. At this point I wondered if we had made the right decision, but my gut feeling told me that we had to persevere.

In January 2010, after six weeks on the diet, our dietitian made some adjustments to his meal plan, increasing his calories. The following day Liam's drop seizures stopped. We thought this was just a coincidence, but the next day he had just a few absences, with a short convulsion at night. After 4 days Liam's seizures stopped completely.

After six seizure-free weeks we started to wean Liam of his second drug (Clobazam). Still no seizures. When the Clobazam had been completely weaned his co-ordination and balance returned to normal and Liam was able to run, walk, play and climb freely. It felt as if a miracle had happened. Liam was weaned off his final drug (Keppra) at the end

of June, and has so far remained seizure free. Words cannot express how incredibly lucky we feel that the diet has worked so well.



Liam after the diet

We have now reached seven seizure-free months and it is all thanks to the ketogenic diet. It has totally transformed Liam's life and our life as a family, as he is now able to enjoy life to the full, with his older brother Aidan (6) and big sister Grace (7). Liam is still on the ketogenic diet and enjoys his food very much - particularly his delicious keto pancakes that he has for breakfast!

Throughout the last year The Daisy Garland has been a beacon of light, during some of our darkest moments. We met Sara and David Garland in May of this year when we attended The Daisy Garland May Ball with friends and family. It was lovely to be able to thank them in person for the work that they do for children like Liam.



Dulwich College, South London

Thank you so much for your support.

Every penny you raise will go towards helping children with drug resistant epilepsy.



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





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Our 2010 fundraising events were a great success

The Daisy May Ball, held in the exquisite setting of Warren House, Kingston-Upon-Thames was a huge success. Friends, family and loyal supporters gathered together in celebration of Daisy's 12th birthday. Thank



The Banks Family from Argentina

you to everyone who donated auction and raffle prizes and a big thank you to Daniel Sandler for providing a complimentary make-up service for our mums attending the Ball. Special thanks to one of our parents, Maria Hambley-Allen for her heartfelt presentation. Maria shared with us the moving story of her 2 year old daughter Scarlett, who suffers from drug resistant epilepsy. You can read more about this on the **STORIES** section of our website.



Grace and Rebecca - Daisy's sister and best friend

The evening raised just under £15,000 and we hope you are able to join us again next year. **Our 2011 Ball** will be held on Saturday the 7th of May at Warren House Tickets are £65 each - to reserve yours please contact us at info@thedaisygarland.org.uk.

Our **Daisy Family Day Picnic and Balloon Race** was huge fun. The gates of Holland Gardens, West Wimbledon opened at 1pm and soon the park was a patchwork of picnic rugs and smiling faces. Little ones ran around in the sunshine with their faces painted, and the air was filled with the jolly music from the Barrel Organ. At 2pm, families settled down with their cream teas to listen to the harmonious voices of the Ursuline High Wimbledon Junior Choir.

It was lovely to see so many of our regular supporters and families enjoying themselves, particularly the Williams family from Wales, the Oldham family from Derbyshire and the Killoughery family from Cambridgeshire. Thanks to the generosity of all those who joined us that day we raised £3,500.

A special thank you to Frederick Paine, Coughlan Evans Estate Agents and Tomkins for their sponsorship and Mary and

John of Solution Designs for their poster artwork and footwork! Also to Hannah and Yasmin Collins for their Picnic pocket money donation. What would we do without you all? **Balloon Race Winner** Congratulations to the winner of our Balloon Race - Nicola Bradford from Surrey. Her balloon travelled 108.4 miles and was found on New Buckenham Common, Norwich.



Craig and Rachel Williams pictured here at our 2010 Family Day Picnic with their two boys Bailey and Ross. The Williams family recently took part in a Channel 4 programme called 'Living with Epilepsy'. You can see a 5 minute video clip from this programme in the **STORIES** section on our website.



Visit www.thedaisygarland.org.uk for more on our 2010/11 events.

Glorious Garden raises funds for The Daisy Garland

Garden Open Day by Claire Miller

On Christmas day 2007, Margot our baby girl was born. She was beautiful and everything we had ever hoped for. We left hospital the following day with the hopes and dreams of every new parent.

In February 2008 our lives were shattered by the agonizing news that Margot had a very rare and severe form of epilepsy, which to date remains undiagnosed.

Margot's first year of life was filled with hospital visits, tests, drugs and endless hours of tears, pain and uncertainty. How were we ever going to get through this in one piece? One afternoon my friend Charlotte came to tea, bringing with her some exciting news! She had received a pamphlet in a bouquet of flowers delivered to her by Season's Florist's, West Wimbledon. The pamphlet was from a children's epilepsy charity called 'The Daisy Garland'. By sheer coincidence I had just got in touch with Sara Garland myself who has

since been a tower of strength to our family. As Margot had been on a huge cocktail of drugs that failed to control her seizures, we asked to be put forward to start the ketogenic diet. Although the diet didn't make Margot completely seizure free, it did give her a whole new lease of life and it gave us an amazing opportunity to reduce her ever increasing drug load. Margot's vocal sounds and wonderful little smile were soon to become an every day occurrence and life suddenly became worthwhile. This is how it has been ever since starting the diet and Margot is now a very happy little girl.

Earlier this year Charlotte told me that she was going to open her parents Yellow Book Garden to raise money for the local church and 'The Daisy Garland'.

The open garden was held at Charlotte's parent's Kentish farmhouse on Sunday, 13th June. Whatever I write will not do this magical place justice. It was as if we had

entered the world of 'Alice in Wonderland'. The vegetable garden, herb garden, lawns, borders, cutting garden, woodland, topiary garden, three ponds and half acre lake were a breathtaking sight - Mrs Eker's garden truly was a little slice of heaven. Everyone who came along had a wonderful time.

Margot too had a fabulous day surrounded by her wonderful friends, her amazing godmother and uncle, and most importantly her grandmother.

Through her hard work and immaculate planning Charlotte raised £2,000 for The Daisy Garland from open the day. We thank her from the bottom of our hearts for her continued loveliness and support.



Margot



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Amazing Grace

One of our younger supporters, Grace Killoughery, whose little brother Liam features on the front page, recently sent us a donation Here is what she had to say...

MY name is Grace I am 7 years old.
I have lost 8 OF my teeth and the
tooth Fairy left me £1 for each tooth.
I have decided to give this money to
Charity. MY little brother Liam is on a special
to help his epilepsy. so I would like to
send the money to your charity.
From Grace



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.

SLEEP-SAFE PILLOW Designed by a UK pharmacist whose son has epilepsy, the Sleep-Safe pillow is recommended for children over the age of 3 years. If you think Sleep-Safe would be suitable for your child take a look at the website www.sleep-safe.co.uk and discuss it with your doctor/health professional.

Keto Kitchen

Ketogenic Scotch Pancakes
a delicious recipe all the family can share
45 grams of egg yolk
75 grams of marscapone cheese
52 grams of ground almonds
(Makes 7 pancakes)

Beat together the egg yolks and marscapone cheese and mix in the ground almonds. Add salt, herbs, spices or liquid sweetener if desired. Grease a frying pan or omelette pan with oil and a small amount of butter. Place on a low heat for a few minutes. Drop a spoonful of the mixture onto the pan and carefully spread it out to the size of a scotch pancake. Continue to heat gently until the mixture starts to solidify and you can lift the pancake with a spatula (take care as they do burn really quickly!). Flip the pancake over and heat until the second side is cooked. Carefully remove from the pan and cool on a wire tray. To serve, melt some butter in a pan, add a squeeze of lemon and pour over the pancake.

Delicious!



IMPORTANT
Before attempting to include this in your child's diet it is **ESSENTIAL** that you consult your ketogenic dietitian who will calculate this into your child's ratio.



Bookworm

Books are an important link between us and our children. We think you will enjoy the following recommendations.

MY FIRST SIGNS

illustrated by Annie Kubler

This signing guide to over 40 key words comes highly recommended. The BSL signs in this book are compatible with those used in the Makaton Language Programme, which uses signs and symbols with speech to encourage communication and language development.

DAY BY DAY BY ME

The idea of Caroline Muir, this seizure diary for children aged 5 to 10 was recently launched by NCYPE. Believed to be one of the first of its kind in the UK, the diary is filled with information and encouragement in a very accessible and attractive format.

Email info@ncype.org.uk for your **FREE copy STARTING SCHOOL**

by Janet and Allan Ahlberg

'Funny, sympathetic and realistic, this is a must for nervous beginners, whether child or adult' - Independent.

YOU CHOOSE

by Nick Sharratt and Pippa Goodhard

A bright interactive picture book which is perfect for sharing. Readers have the power to decide how the story should unfold. With over 40 colourful stickers it's hours of fun!

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...

KETO TIP

Always weigh out the following day's menu the night before.



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Schools raise funds for The Daisy Garland

A huge thank you to Mia and all in Year 7K at **Nottingham Girls' High School**. Earlier this year Mia and her classmates kindly chose to support us and this is what Mia has to say about her fundraising experience:

'I just wanted to say how much I enjoyed raising money for the Daisy Garland charity this year.

It was an exciting and busy experience and one that I will always remember. After Form discussions we came up with a variety of ways to raise funds - ranging from a tricky sponsored silence to an ever popular cake sale. Whilst walking home from school one afternoon, I decided to pop into our local quaint confectioners (Chocolate Box) and told them all about the Daisy Garland charity. They were

most interested and incredibly willing to help. They very kindly donated a MASSIVE chocolate egg (the biggest one in the shop!) When I got it home I decided to put it into a big decorated basket and it was used for the game of 'name the chicken that laid the egg', which as you can imagine, proved very popular!

Our Daisy Garland t-shirts were a great incentive for the Form to raise funds and we were delighted to send you a cheque for £503 to help children with drug resistant epilepsy. The whole experience of supporting a children's charity was a very enjoyable one and we wish you lots of success for the future.

*With best wishes
Mia'*



Mia (bottom centre) & Year 7K

Some of the other schools who have supported us are: Wimbledon College for Girls, Ursuline High School, Belmont School, Orchard House School, Mrs Ethelston's Primary School, Westminster School and South Hampstead High School.

If you've been inspired by Mia's story and would like to do something similar at your school, please contact us at info@thedaisygarland.org.uk. In doing so you will make a difference to the lives of children with drug resistant epilepsy.

Rohan's Story

I was introduced to 'The Daisy Garland Charity' just before Rohan's first birthday. A mother of a little boy with epilepsy who I had befriended had highly recommended Sara Garland to me for her advice and support with regards to epilepsy, medications and the ketogenic diet. Rohan had been diagnosed with Congenital Bilateral Perisylvian Syndrome when he presented with a seizure at 7 weeks old. It meant that 80% of Rohan's brain had wide spread damage and he would suffer from an array of problems and the most difficult being uncontrollable epilepsy. To watch my son go through hours of seizures on a daily basis where he would scream from the pain has been unbearable.

When I contacted Sara Garland I was amazed at how somebody who had been through such an horrific experience could give so much helping others. Sara gave me tremendous amounts of help and advice and when there were times when I felt that I couldn't carry on she would send me the most up-lifting emails which would give me the strength to carry on. She always reiterated that tomorrow was another day. Sara's equally amazing husband David ran the London Marathon to raise money for oxygen saturation monitors which monitor



Rohan

children at night who have epilepsy. If a seizure affects the child's breathing the monitor will raise an alarm which alerts the parents. Rohan received one of these monitors from the Daisy Garland Charity and we are eternally grateful for it. Not only has it given us peace of mind at night but during times when Rohan is 'not himself' we can connect him up to the monitor and it gives us his heart rate and his oxygen levels and we know immediately whether he needs to be taken to hospital or not.

Rohan started the ketogenic diet in November 2009, the effect has been incredible, he's a different little boy and at long last part of the family. Gone are the seizures which made him scream. He now

smiles and makes little noises and he is beginning to use his vision. He has a 4 year old sister Lily and a 1 year old sister Rose-Erin who just adore him and we can tell that he loves them too.

The Daisy Garland Charity have been an extremely important part of our life, we as a family are extremely grateful to them.

The Dhond Family

DID YOU KNOW?

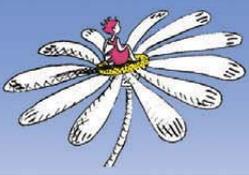
£800 is the cost of a SATS monitor machine, which measures the level of oxygen in the blood, thus reducing the risk of SUDEP (sudden unexpected death in epilepsy patients).

Waitrose A very big thank you to Waitrose, Croydon who chose The Daisy Garland to benefit from their Community Matters Scheme and forwarded us a cheque for £440.



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Daisy Diary Dates

2010

AUGUST

27/28 **Richard Weeks cycle ride** - it's not too late to sponsor him via our website

SEPTEMBER

9th September **Phillip Carling** sponsored swim to Bestival on the Isle of Wight. You can still sponsor him via our website.

Daisy Garland 2010 Christmas cards on sale £4.50 for a pack of 8, +80p per pack P&P, OR collect direct from West Wimbledon. (See order form on back page).

Don't forget to shop early for a Daisy Christmas with our daisy decorated Rice products, Little Mann stocking fillers and books and gifts from Amazon via our website.

OCTOBER

10th October **Colin Brown Leicester Half Marathon** sponsor him now on our website.

NOVEMBER

Hold a coffee and mince pie morning and sell Daisy Garland Christmas cards to work colleagues, friends and family.

DECEMBER

Decorate your tree with daisy baubles and give them as Christmas gifts.

2011

MAY

Saturday, 7th Daisy Garland May Ball at Warren House, Kingston-upon-Thames, tickets £65 each. Tickets are already selling well, so reserve yours now by emailing info@thedaisygarland.org.uk to avoid disappointment.

JUNE

Saturday, 25th Daisy Garland Family Day Picnic and Balloon Race, Holland Gardens, West Wimbledon



The Ursuline High Wimbledon Junior Choir singing at this year's Family Day Picnic

Please check our website for regular updates on events.

WOULD YOUR SCHOOL CHOIR LIKE TO COME ALONG AND SING AT OUR PICNIC? Contact us on our website.

Have we got news for you With the season of giving rapidly approaching we have expanded our Daisy merchandise offer by linking up with two very interesting and exciting companies.



We are delighted to be able to offer you an extended range of daisy printed merchandise thanks to Rice. A Danish company set up in 1998, Rice supports the Global Compact which is a commitment from businesses around the world to eliminate starvation and poverty. Rice products are designed and developed in Denmark and produced in the Third World with respect for people. So you can buy with a clear conscience.

Our Rice daisy merchandise includes pretty wrapping paper and bows in a range of colours, delightful daisy Christmas baubles (a must), melamine mugs in Daisy pink or Daisy blue and more.



Photos © Rice



Why not order some Daisy products today and help us help them help us! Visit our website **SHOP** to see the full daisy decorated range.

party bags and stocking fillers ...

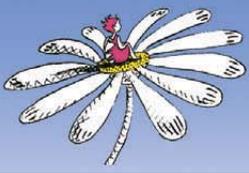


Little Mann Classics will be donating 10% to the Daisy Garland on all party bag and stocking filler sales made via OUR website. To place your order directly with Little Mann simply click on their web address on the **SHOP** page of our website.



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





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Special Treasure by Susan Hill

My grandson Daniel, our 'special treasure', was born on July, 2nd 2001. Sadly, like thousands of children in this country, Daniel suffers from a severe form of epilepsy. This year we celebrated Daniel's 9th birthday at the Daisy Garland Family Day Picnic and Balloon Race in Wimbledon. As well as celebrating Daniel's life, this year, we celebrated the new life he is experiencing on the ketogenic diet. The ketogenic diet is very different to a regular diet due to the high fat content. Our daughter Rosalind, Daniel's mum, researched the diet at great length before she decided it was suitable. We are so proud

of Rosalind - how many mums go to such lengths to find suitable recipes, acceptable treats and are willing to carry a set of electronic scales wherever they go? We saw a difference in Daniel within weeks of him starting the diet, and his medication is now greatly reduced. Daniel has always been a wonderful little grandson - now he is a wonderful little grandson who, thanks to the ketogenic diet, has taken up riding lessons, enjoys swimming and talks in 'Daniel' language. He is just so amazing! This year we opened our garden to the public and raised £413.70 for The Daisy Garland.

A huge THANK YOU to Daisy's family for being so supportive and caring.



Daniel and his family



Each pack contains 8 A5 sized cards.

Please send me _____ packs of cards @ £4.50 per pack PLUS 80p P&P per pack.

I enclose a cheque payable to: 'The Daisy Garland' for £ _____ (incl P&P)

Your Name: _____

Address: _____

Post Code: _____

Email: _____

Please post your order to:
The Daisy Garland, 2 Stoyle House, 7 South Street, Totnes, Devon TQ9 5DZ.

If you live in the London area and would prefer to collect the cards, please include your telephone number below so that we can arrange this for you.

Phone: _____

REMINDER

Don't forget to order your Christmas books and gifts from Amazon via The Daisy Garland website thereby earning the charity valuable commission with no extra charge to you.
... give with a click!

And last but not least our grateful thanks goes to ...

all those who have contributed stories to this newsletter and our website **STORIES** section, to everyone who has bought from Amazon via our website - please continue - it really does make a difference. To Warren House for their endless generous support and professionalism and to Nick Maland for another fabulous Christmas Card. To the families who travelled hundreds of miles to join us at our May Ball and Family Day Picnic. To those of you who sent donations in lieu of wedding/birthday/anniversary presents. To Helen Brown for her incredible continued support. And to all those too numerous to mention - your generous support and sponsorship is greatly appreciated. **Thank you.**



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

