



Thank you Dulwich College



This pretty daisy flower is made up entirely of coins - a staggering £544.74 worth - collected by Dulwich College Junior School boys. A very big thank you goes to everyone who contributed. Our heartfelt thanks also goes to the Friends of Dulwich for raising £527 by running a quiz night and to the Friends of Dulwich College Kindergarten & Infants School (DUCKS) who donated a whopping

£1,100 from their Christmas Fair. We have also received generous donations from members of staff, proceeds of the Christmas Carol Service collection, a Chaplain collection and the sale of old Rugby shirts. Thank you also to pupils - Tim Makower and Sam Milne - who raised £139.73 from a Sweet Sale.

Well done everyone at Dulwich... you're an inspiration!

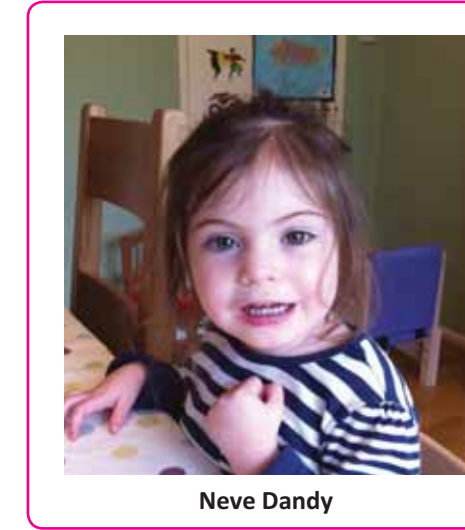
If your school or college would like to support us please contact us at info@thedaisygarland.org.uk for further information and a fundraising pack. Every penny raised will make a real difference to the lives of children with drug resistant epilepsy.

Neve's story

When Sara asked me to write a piece for the latest newsletter about Neve's first year on the diet I thought, 'no problem at all.' But now that I try and put into words just how wonderful Sara and David have been I find I'm almost lost for words.

My daughter, Neve, is nearly three-years-old and has Dravet Syndrome - the same catastrophic form of epilepsy that Daisy had. She had her first seizure at the age of 4-months and since then has had hundreds of seizures and has spent several months of her short life in hospital. Living with Dravet Syndrome has been simply horrendous and a very dark time for our family. When Neve was about 18-months-old and we really were at our lowest ebb, we heard about the ketogenic diet and a small, family-run charity called The Daisy Garland.

Just before Neve's 2nd birthday, and with invaluable assistance from Sara, Neve started the ketogenic diet with a wonderful Daisy Dietician called Nicol - much sooner than might have otherwise been possible. She has now been on the diet for a year and although we have had breakthrough seizures, she is now walking and talking and is a happy and cheeky little girl whose smile could melt the polar icecaps.



Neve Dandy

We have had some tricky patches over the last year but Sara and David have both shown endless patience and understanding chatting on the telephone and via email, day and night, as we come to terms with everything Dravet. They always give the soundest of advice and share their memories of Daisy and all that they went through even though I'm quite sure it must be very painful for them at times.

The Daisy Garland charity was born out of tragedy and the work that Sara and David do so tirelessly is nothing short of amazing - we will be firm supporters of theirs for



Daisy flower of coins

many years to come, whether Neve is on the diet or not. We just can't thank you enough, Sara and David, for the hand of friendship that you gave so selflessly when we really felt like our world was falling apart. We feel like we know Daisy even though we never met her and believe that her spirit and bravery lives on in our little Neve.

The Ketogenic Diet

The ketogenic diet is high in fat, adequate in protein (to allow for growth) and low in carbohydrate. The diet is carefully calculated for each individual child by a trained ketogenic dietician. Studies have shown that half of all children who have failed to respond to multiple medications will have more than a 50% decrease in their seizures on the ketogenic diet. Around one third will have a greater than 90% improvement, and 10% become seizure and medication free.

Due to lack of NHS funding this diet is not widely available in the UK and increased awareness and interest in the diet means that demand is outstripping resources. In the last six years we have funded six dietitians and are currently raising money to fund at least 2 more by the end of 2011. **Each dietician costs c.£26K p.a.**

Blisse Mellen's keto diary



Blisse Mellens

Week 1 Feeling excited and scared in equal measures. Weighing exact food quantities is daunting but confidence growing daily. Seizures reducing - can this be due to the diet?

Week 2 In full ketosis and feeling more confident. Energy levels low but seeing a huge difference in seizure activity. Early days so trying not to get too excited.

Week 3 Low energy levels and she's not interested in playing, but no partials - 2-4 a day pre-diet.

Week 4 Blisse had an operation. Diet worked fine around the surgery and Daisy Dietitian, Nicol, was at hand to help. Blisse back to her normal self and we have only had 2 seizures this week. Still don't want to get our hopes up!

Week 5 An amazing week. Ketones stable and Blisse more active and happier in herself. 13 days with no tonic clonics - unheard of! Feeling positive and hope this is a turning point for us all.

Week 6 Great day yesterday. With the reduction in fits, Laura (mum) felt confident to take Blisse for a walk in her new pram - something we've not felt comfortable doing since last summer - she loved it. She picked up her big sister from school who was over the moon and incredibly proud to show her off to her friends and teachers. Life is really looking up and it's all thanks to the ketogenic diet.

Ashley Mellens, Blisse's dad, says;

"The Daisy Garland changed our lives when they gave us a grant for a SATs Monitor. The monitor has picked up numerous night time seizures and without it I'm not sure she'd be here today. When we were told there were no more medications for Blisse to try and she was still having tons of seizures every day, we felt that it was the end of the road. But this was not so! Once again The Daisy Garland came up trumps when they helped us to access their Bristol based ketogenic dietician as an out of area patient. The ketogenic diet has

given our daughter the wonderful chance of improving her quality of life and, as a family, ours too. The Daisy Garland has touched our hearts with their continuing support and we are blessed to know such wonderful people who really care about our daughter. I don't think we'll ever do enough to thank them."

We're delighted to be able to help and our thanks goes to the Mellens family who have been busy fundraising for us, with a purple cup-cake day, a quiz evening and a sponsored head shave. Ashley's employers, British Gas, got involved too and Blisse's sister Nevaeh organised an event at school.



KETO TIP
Check nutritional values on sides of packets, cartons, tins and jars from time to time as they can change.

Flora's keto journey

6-year-old Flora from Somerset, started the ketogenic diet earlier this year, under the care of Daisy Garland Ketogenic Dietitian, Nicol Clayton, at Southmead Hospital, Bristol. Flora's mum, Charlie, said;

"Ever since discovering The Daisy Garland charity, Sara and David have inspired me to raise awareness about the ketogenic diet and the important work that they do for children with epilepsy. I am particularly keen to help them raise the much needed awareness about the diet and also the funds to place more of their ketogenic dietitians countrywide.

Flora has been on drugs for most of her life - the most important early learning years. She is presently on two different drugs - two of the many possible side effects are speech delay and aggression. I have never

set of scales and a selection of perfectly sized little tubs which I use for Flora's keto packed lunches.

It's such early days, but Flora is doing so well on the diet and has not had a seizure for several weeks which is a record! I truly believe that every parent should be given the choice of diet over drugs when their child is first diagnosed with epilepsy.

Flora's parents live and work at Cothay Manor. The house and gardens are open to the public from April until the end of September and they have kindly offered to display our charity pamphlets and collection pots in their tea-room and shop. www.cothaymanor.co.uk



Flora eating keto waffles

known Flora free from drugs apart from when she was tiny so I hope that the diet will afford us the opportunity to discover whether the drugs have caused her speech delay, stutter, aggression and learning delay, and if so, whether the diet will reverse this. The ketogenic diet has given me so much hope for Flora's future".

Flora's parents live and work at Cothay Manor. The house and gardens are open to the public from April until the end of September and they have kindly offered to display our charity pamphlets and collection pots in their tea-room and shop. www.cothaymanor.co.uk

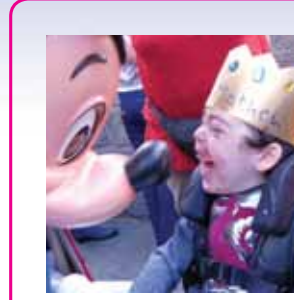
Mathew's thoughts

In September 2010 Mathew Hoadley's parents received a grant for an Oxygen Saturation (SATS) monitor. His mum sent us this letter:

Dear Sara

I thought I would let you know what Mathew thinks of the SATs monitor you provided for us. We are taking part in a Sleep Research Trial for children with Cerebral Palsy and we were asked to take photos of things that Mathew liked or disliked in his bedroom. I took a photo of his SATs monitor and thought it would be one of the things he disliked as it was a piece of equipment relating to his seizures. I was wrong! When he was interviewed by the researcher using his communication book he said that he liked it as it helped mummy know when he was having his 'fuzzy head' and so she could help him. I was in tears when he said that as I didn't realise he knew how much it helps us help him. I thought you'd like to know just how much your monitor means to a non-verbal child.

Best wishes, Jackie, East Sussex



Mathew Hoadley

DID YOU KNOW?
£800 is the cost of a SATS monitor. This measures the level of oxygen in the blood, thus reducing the risk of SUDEP (sudden unexpected death in epilepsy patients).



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 online www.thedaisygarland.org.uk or send your donation to: The Daisy Garland, 2 Stoyle House, 7 South Street, Totnes, Devon TQ9 5DZ

Keto Kitchen

Naan Bread

A delicious recipe all the family can share, sent to us by keto mum Rosalind Oldham of Derby.

- 10g Plain Ketocal
- 10g Coconut milk powder
- 2g Plain flour
- 2g Garlic paste (Gia brand)
- ¼ of a medium egg yolk (beaten)
- ¼ of a medium egg white (whisked)
- 5g MCT oil
- Fresh coriander leaves roughly chopped (optional)

Pre-heat the oven to 150C Gas Mark 2
Beat the ¼ egg yolk in one bowl and whisk the ¼ egg white in another, and set aside. Weigh the dry ingredients into a bowl (cereal bowl size) and then add the garlic paste, egg and oil and mix well to combine everything. Add the fresh coriander (optional) and stir in. Using a spatula spread the mixture onto a silicone baking sheet or non-stick baking parchment into a small Naan bread shape about 3" diameter. Bake in the middle of the oven for 5-10 minutes until light brown. Cool on a wire rack.

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



Bookworm

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

GOOD DAYS BAD DAYS

by Laurence & Catherine Arnholt
This classic picture book illustrates the ups and downs of family life. Full of joyful energy.

THAT'S NOT MY PUPPY

by Fiona Watt and Rachel Wells
Bright, bold and very robust with a different texture waiting to be discovered on every page.

SUNNY BUNNY

by Penny Little
A heart-warming tale - perfect for sharing with daddy!

VICTORIA'S DAY

by Maria de Fatima Campos
Beautifully photographed and simply scripted, this book makes a positive statement about the inclusion of children with learning difficulties in mainstream schools.

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...

Keep on running...

"My husband Vincent, and his brother Andrew Phillips ran the Brighton Marathon on 10th April (the day before Daisy's birthday), to raise money for The Daisy Garland. I had been researching a little about the ketogenic diet as a possible option for our daughter Libby after her seizures returned with a vengeance after a long period of being seizure free. I asked for some support from the charity online and from there I met Sara and more importantly learned about Daisy. We were so touched by Daisy that we wanted to help raise some money to help Sara continue the excellent work that she is doing in the form of the charity."

Katie Phillips, Bedfordshire.
You can still sponsor Vincent and Andrew on JustGiving or via our website.





Daisy Diary Dates

2011

APRIL

Saturday 16th Claire and Alex Miller's Windmill Ball, Kent. Sharon Tozer's sponsored Headshave! Visit our website to sponsor her and see her new hairstyle!

Sunday 17th Rob Ward running The London Marathon. Sponsor him via JustGiving.

MAY

Saturday 7th Daisy Garland May Ball in celebration of Daisy's 13th Birthday, at Warren House, Kingston-upon-Thames, Surrey. All tickets have been sold.

Sunday 29th Tracy, Sharon, Colin, Neil and Bob running The Plymouth Half Marathon. Sponsor them now via our homepage.

Please check our website for regular updates on events.
www.thedaisygarland.org.uk

Ethan's story

by Chris Macey, Gwent, Wales

Our son Ethan developed epilepsy when he was 2½-years-old. Within 2 months his seizures increased to 6 a day - each lasting 5 or 6 minutes - and he was sleeping for up to 16 hours a day. Our happy, active, inquisitive little boy turned into a tired, scared one - too frightened to leave our side even to play with his brother.



Ethan before the diet

Ethan's first anticonvulsant medication was administered in hospital but following an adverse reaction he ended up being transferred to a specialist unit in another hospital. It was here that Ethan was diagnosed with Myoclonic Absence Attacks. Over the next 4 years we were prescribed combinations of Epilim, Lamotrigine, Keppra and Ethosuximide. They worked for a short time, but the positive effects soon wore off, leaving

behind a trail of unwanted side effects. Ethan's co-ordination was terrible, he needed help dressing and eating - we were left with a changed boy. One week after taking Keppra his teacher asked us where Ethan had gone. She said that the child in her class was unrecognisable in all but appearance. He was asked to leave all his clubs and school and was referred to a psychiatrist for suspected autism. We were broken hearted.

Then we discovered the ketogenic diet. But it came as a huge shock when we were told that there were no dietitians in Wales so we couldn't try it. Our neurologist put us forward for a referral to see a Daisy Garland Ketogenic Dietitian at Southmead Hospital in Bristol. We were accepted on the diet as an out of area referral and were so excited to be given this wonderful opportunity.

Some of Ethan's medication was changed prior to commencement of the diet and within a week of starting the diet his seizures stopped. A month later Ethan was riding a bike unaided, he joined Beaver Club and after two months went to summer camp for a week, enjoying archery, climbing and numerous other activities.



Thank you to all those who have shopped with Amazon via our website - we are earning around £100.00 per month in commission so please keep up the good work ... and pass it on.

Remember, each time you buy from Amazon The Daisy Garland will receive 5% of your total spend 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 item you want into the Search Box and away you go!



Rohan's smile

In our last newsletter we featured a story about a little boy called Rohan Dhond, who suffers from epilepsy. We received the following letter from his aunt along with a donation;

*Dear Mr and Mrs Garland
I am Georgina Dhond's cousin and came along to your Ball at Warren House back in May. I saw Georgina and Rohan last week,*

having not seen Rohan since he started the ketogenic diet. I was amazed and delighted by his transformation and could not believe the change in him. Of all the drugs and medical interventions that Georgina and Girish have tried from all across the world nothing seems to have had the impact on Rohan that the ketogenic diet has achieved. Since Rohan's diagnosis over 2 years ago, Georgina's hopes and expectations for Rohan

have decreased and decreased - she once said her only hope was that Rohan would one day smile at her - I couldn't believe the smiling, bright and alert, beautiful boy I saw last week. I hope the enclosed goes a little way in supporting the incredible work you and your charity is achieving by providing the support to other parents that I know Georgina holds invaluable. Best wishes, Shiobhaun and Alex Watt

The Daisy Garland charity



In April 2004 our daughter Daisy died of SUDEP (sudden and unexpected death in epilepsy patients), she was just 6-years-old. In November of that year we set up a charity in her memory to support children with epilepsy and their families/carers. Our main project is to provide funding for Daisy Garland Ketogenic Dietitians to work in NHS hospitals in the UK treating children who suffer from drug resistant epilepsy. (Daisy was on the ketogenic diet for 4½-years and it gave her good seizure control - something which anticonvulsant medication failed to do). We also give grants for SATs monitors. In the last year and a half we have provided 18 grants for SATs Monitors. A SATs monitor alerts parents by way of an alarm, when there are changes in a child's breathing pattern reducing the risk of SUDEP. Each monitor costs £800. **We have a number of parents desperately waiting for a grant.**

I would like to make a donation to support the work of The Daisy Garland.

Enclosed is my gift of £10 £30 £50 £80 £100 £.....

If you are a UK tax payer and would like The Daisy Garland to treat the enclosed donation as a Gift Aid Donation please tick

Name

Address

Postcode

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

You can also visit our website www.thedaisygarland.org.uk to make a donation.

Please help us to help more children. Every donation, no matter how small, goes a long way.

Behind every great charity is great support

Our Newsletter wouldn't be complete without many, many thank yous and as usual the list is long ... To the saddle sore, the slimmers, swimmers and the marathon runners, to our cyclists and footballers and those who have already shaved - and those about to shave - their heads to raise money for us, our profound and heartfelt thanks. To Keto mum Rebecca Dandy who, in spite of having an extremely busy life, put together this newsletter. Thank you to those who have organised coffee mornings - especially the purple cupcakes - and tombolas, quiz evenings and the Windmill Ball. To Michael Collins for his continued support and to everyone else who has donated fabulous raffle/auction prizes for our May Ball, and to Warren House for so many things... To the schools who raised money in lieu of sending Christmas cards, having mufti days, cake sales and sold rugby shirts. To Eleanor and Paul Hyde for spreading the word about Daisy's charity and the ketogenic diet. We are proud to count you among our supporters ... where would we be without you? And finally our grateful thanks goes to Graham Faulkner whose wealth of experience, knowledge and encouraging support will help us go forward and do so much more. *Thank you. SARA and DAVID*



Look what I can do on the diet!



We have a goal - can you help? Two Daisy Garland ketogenic dietitians urgently needed!

Over the last six months I have received many letters and emails from parents of children who are doing so well on the ketogenic diet. The diet helps many children who suffer from drug resistant epilepsy. This year our goal is to place two more dietitians in hospitals on our waiting list. Will you help us raise the £52,000 we need to fund them? Please contact us for one of our fundraising packs if you, your family/friends or your school can help us.

You can support us by visiting our on-line **SHOP** where you will find a new range of pretty daisy jewellery - great for party bags. I hope the Newsletter will inspire you to do something for us in 2011.

Happy reading! SARA

Introducing our new Trustee

We are delighted to announce that Graham Faulkner has joined The Daisy Garland as Trustee.

Graham has worked for disability charities for over 20 years and is Chief Executive of the Epilepsy Society. He is also vice Chairman of the Joint Epilepsy Council, Governor of the UCLH NHS Foundation



Graham Faulkner

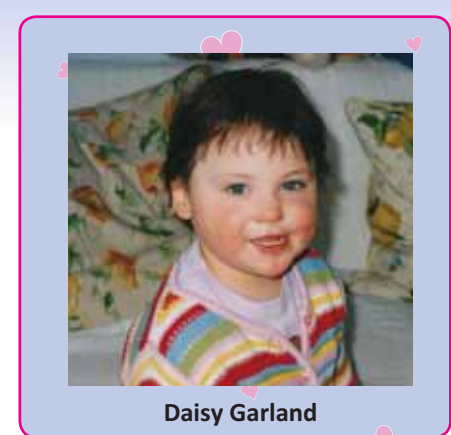
Trust (which has the National Hospital for Neurology & Neurosurgery in its portfolio) and was recently appointed Chairman of the charitable company Queen Squires Enterprises. Graham is also a member of the Benevolent Committee at the Royal College of Nursing.

Graham has first-hand knowledge of epilepsy as his son, Gareth, was diagnosed

with epilepsy when he was a teenager. "I well remember the day that he had his first seizure or at least the first time that we were aware of his seizures. I was terrified and thought he was dying. I can still remember the feeling in the pit of my stomach as I followed the ambulance to the local hospital and the shock when his epilepsy was diagnosed. It was a condition that I knew nothing about at the time and so I can appreciate how parents feel when they receive that diagnosis".

On his appointment as Trustee, Graham said; "I am delighted to have been invited to join the Board of the Daisy Garland. I heard David give a talk at a conference about 18 months ago and I was transfixed by the passion and vision that he conveyed - passion for Daisy and for the new charity that he and Sara had founded in her memory and vision for what it could achieve to help others with the condition. I was intrigued by the work of the charity and by the ketogenic diet. I have long been fascinated by the diet and have wondered why it works so well for some children. I was impressed with the way the charity was going about publicising it and the very practical ways in which it was contributing to provide dietitians and other specialists in hospitals. I hope that I can help in some small way to spread the word and enable The Daisy Garland to grow and to take its message far and wide to bring hope to parents with children who have epilepsy."

To read more about Graham, go to our website www.thedaisygarland.org.uk



Daisy Garland

BBC Breakfast News

In January, The Daisy Garland was asked by the BBC, to comment on the sad case of the mum of a special needs child who posted a message on MUMSNET saying that she felt she had to put her daughter in care due to lack of support. We took part in a live telephone interview on BBC's Breakfast programme where Sara was asked to comment on caring for a special needs child and what she thought the government could do to help.



Three cheers for the ketogenic diet!

16-month-old Blisse Mellens from Barry in South Wales suffers from a rare brain disorder, Periventricular Nodular Heterotopia and has seizures every single day.

Happily we have been able to help this adorable little girl by providing her family with a grant for a SATs Monitor. Blisse is also on the ketogenic diet and her parents have very kindly allowed us to share in the first 6 weeks of her keto journey.

See page 3 inside...



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



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