

The Daisy Garland

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



Welcome to The Daisy Garland Winter Newsletter,
keeping you up-to-date with recent news and fundraising events

Scarlett's Story

by Kirsty and Miles MacKinnon

"In October 2005 our daughter Scarlett suffered the first of many tonic clonic seizures later to be classified as a life threatening neurological genetic mutation 'SMEI' (Severe Myoclonic Epilepsy of Infancy) or Dravet Syndrome.

Like many parents in our position we spent hours trawling the internet for answers, cures, reasons and support. It was on one of our late night research sessions that we discovered the ketogenic diet and first encountered 'The Daisy Garland'.

From my first contact email, Sara sent me a wonderful heartfelt note enclosed with the DVD 'First Do No Harm', completely thoughtful to our position in a way that we have come to know is consistent from 'The Daisy Garland'!

In Nov 2007, we were fortunate enough to start the ketogenic programme sponsored by 'The Daisy Garland' at the Evelina Children's Hospital, Guy's and St. Thomas', London. The experience was amazing. Tara, Mary-Anne and Ruth together with their team were so very dedicated to support us as a family, integrating the diet into family and not family to the diet.

We thought that the package we were given from the team was fabulous, complete with Daisy Garland pins, T-shirts and balloons for the kids and great support information for parents - which you **really can** use for support when you get home.

Although the diet was unsuitable at the time for Scarlett, we do not believe this is an indication that the diet will never work for her and for this reason have remained actively involved with 'The Daisy Garland' and the ketogenic team.

In 2008, Miles and I were really struggling with Scarlett's seizures and after a stint of 2 weeks on life support in the PICU unit at St Thomas' we decided

January is a great time for taking stock. Perhaps one of your New Year's Resolutions is to support a charity?

It's such a brilliant thing to do. Try it and see!

Daisy's charity was set-up just over 4 years ago to support families of children with intractable epilepsy.

As a charity we always promise to do our very best and from the feedback we have received so far, I think we have lived up to this promise.

Helplessly watching your child suffer from

the effects of drug resistant epilepsy, day in, day out, is unimaginable.

It's like living your worst nightmare...



**Donate
with confidence**

www.thedaisygarland.org.uk



only worse... a zillion, trillion times worse; perhaps more than that...

Every penny raised and donated to The Daisy Garland gives children with drug resistant

epilepsy a chance to reach their full potential. Please support us by joining us on 'A journey of hope... for children with epilepsy', in doing so, helping us to continue our important work.

that we really needed an Oxygen Saturations Monitor at home. We desperately needed to have some peace of mind at night. We should have been sleeping when instead we were watching a video monitor with a sound monitor on full volume and getting up every 15-30 mins to check temperatures... Our nerves were so bad and we were both exhausted from lack of sleep and worry. Despite this we really did want to show our support to those that support us and we attended 'The Daisy Garland' Ball with other friends who have a daughter with the same condition who is also on the diet.

During the Ball Sara and David were able to find the time to chat with us and in the days following Sara contacted me to offer some financial support to help us buy a monitor for the house.

I have to say that whilst reading her email I had to get up half way through to get tissues as I could not read through the tears.

This was a generosity we had never experienced nor expected and both of us were completely astonished and overwhelmed!

We now have our monitor and it is thanks to that (I am in the hospital typing this) that we picked up Scarlett's

most recent seizure.

Sara and David have been completely open, honest and real to both of us and so completely approachable, realistic and understanding to our situation in a way that only a couple who have been in our situation could really be. Talking to Sara, who incidentally makes herself available whenever you need her even if you need to chat, is like talking to your best mate or a sister.

We are completely in awe of her strength and courage especially when you take into account hers and David's own ordeal.

We would like to say thank you too to Daisy, an obviously special little girl. It is easy to see where her strength came from."



The MacKinnon family - Kirsty, Harry, Scarlett and Miles (L to R)

You can contact us at:

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32 Trewince Road
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w: www.thedaisygarland.org.uk
Registered Charity Number 1106530
Patron: Emma Thompson



The Daisy Garland

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

Meet our 6 'Daisy Garland Ketogenic Dietitians'

We are hugely proud of our wonderful 'Daisy Garland Ketogenic Dietitians' who are all doing such an amazing job...



Lee-Anne McHarry,
St. Georges Hospital,
SW London



Mary-Anne Leung,
Guy's and St. Thomas',
London



Tara Randall,
Guy's and St. Thomas',
London



Alison Hill,
Derriford Hospital,
Plymouth



Jane Davison,
The Queens Medical
Centre, Nottingham



Coming soon

The Bristol Royal
Hospital for Children,
Bristol

Four and a half years ago when we set up Daisy's charity, our dream was to fund a ketogenic dietitian to work within the NHS treating children with drug resistant epilepsy.

We achieved this dream in March 2006 when we placed Lee-Anne McHarry at St. Georges Hospital in London. As time went by our dream reached new

horizons - our aim was to place six 'Daisy Garland Ketogenic Dietitians' - one for every year of Daisy's little life. We are delighted to say that this dream came true on Christmas Eve 2008, when we provided funds for our sixth 'Daisy Garland Ketogenic Dietitian'. Bristol here we come! And now we would like to double this figure.

If you wish to try this amazing diet, you will require a referral from your GP, Paediatrician or Neurologist.

Further Information

For further information and a free handbook on the ketogenic diet please visit our website or contact us at thedaisygarland@btinternet.com or call our charity line on 020 8247 3614.

The 2009 Daisy Garland Black Tie Ball

Tickets are still available for this fabulous annual event - this year held in celebration of Daisy's 11th Birthday.

Held in the magnificent setting of Warren House, Kingston-Upon-Thames, on Saturday 28th March, from 6.30pm until midnight; fabulous charity Auction and Raffle at midnight.

Tickets are £55 each and can be purchased from our on-line shop at www.thedaisygarland.org.uk. Or they can be reserved by contacting us on 020 8247 3614. You can also email us at thedaisygarland@btinternet.com.

We look forward to welcoming you.

Joint Epilepsy Council

Last year we were invited to join the JEC. The JEC works to unite the efforts of its 26 member organizations to reduce stigma, challenge, discrimination and disadvantage and improve the quality of life for people with epilepsy.



Voted 'Charity of the Year' at Orchard House School, W4

We look forward to working alongside the staff and pupils of this lovely school and thank them very much for their valued support.



Warren House - All proceeds from the evening go directly to Daisy's charity.

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Warren House Mount Snowdon Trek

In a bid to raise money for their favourite children's charity, The Daisy Garland, members of staff from Warren House are planning to accept a fitness challenge and walk up Snowdon on the 4th of May.

General Manager, Carolyn Henderson, will be joined by 5 members of staff all of whom plan to don walking boots and tackle the scenic walk up the Miners Track, returning by the PYG's Track.

The walk is estimated to take around 6-7 hours to complete and will cover 10 miles.

The plan is to raise £6,000 and walkers will look for sponsorship to cover their expenses and raise money.

To assist with sponsorship and for further information please contact Helen Bull at Warren House on 020 8974 7049 or email

her at helenbull@warrenhouse.com. Individual walkers can be sponsored at www.justgiving.com/carolynhenderson-tdg Good luck to you all - we can't wait to see the photos!



One of the walkers - Kathryn Moore, Membership Co-ordinator, Warren House

The Plymouth Coasters Santa Xmas Pud Run

Sunday the 14th of December dawned crisp, blue and bright and 350 runners dressed up as Santas set off on a 5K run in Saltram Park, Plymouth organised by the Plymouth Coasters. All proceeds from the race were donated to The Daisy Garland and every penny of this will go towards funding our 'Daisy Garland Ketogenic Dietitian' at Derriford Hospital in Plymouth.



Nigel Rowe MBE (R), Chairman of the Plymouth Coasters, presenting a cheque for £2,576.02 to David Garland (L)

New Charity Window Display

We have received many lovely comments from the residents of West Wimbledon, complimenting us on our new display board in the window of Frederick Paine. The board will be updated on a regular basis and our merchandise is available during normal opening hours

A huge thank you to Frederick Paine, in particular to Lyn Sanderson, who has supported us from the onset of our journey.

The London Marathon - 26th April 2009

If you wish to sponsor one of our wonderful runners please click on any of the following links:

www.justgiving.com/davidgarland

www.justgiving.com/tracymclean

www.justgiving.com/rboyle

If you have a place in this year's Marathon and don't know who to run for... look no further! Every penny raised will go directly to supporting children with drug resistant epilepsy.

Every Click

It's free, it's easy and it's helping children with epilepsy! Please sign up at <http://charities.everyclick.com/info.xq?id=569091&name=THE-DAISY-GARLAND>

New Year's Day Sponsored Swim!

14 year old Shelley Glasspool braved the freezing waters at Cawsand Bay Cornwall, to raise money for Daisy's charity, scooping First Prize for fancy dress in the process.

We think she deserves a 'warm' round of applause and a massive thank you!



Shelley Glasspool in her Daisy Costume

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The Daisy Garland

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

Fabulous Daisy Garland Merchandise

Bring a little sunshine into your lives with our beautiful Daisy Garland merchandise.

They make fabulous Easter/ Mother's Day/ Any Day gifts!

Why not pop them into one of our organic reusable cotton bags?

Step this way to make your purchase...



www.thedaisygarland.org.uk/shop

Mugs, Bags & Keyrings



Note/ Easter Cards



Support The Daisy Garland website with a homepage link

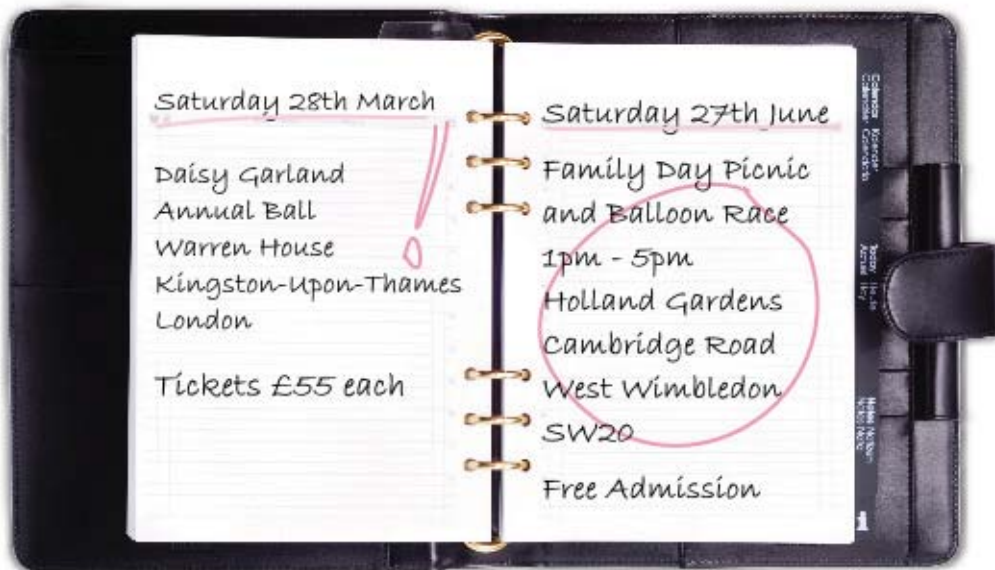
If you own and/or manage a website, why not link to The Daisy Garland website at www.thedaisygarland.org.uk to help spread the word and further the journey of epilepsy through online search engines.

Contact Marcus Link at Link & Co. by email to marcus@link-co.co.uk for more information.



Support The Daisy Garland website by placing a link on your homepage

Daisy's Diary



Saturday 28th March

Daisy Garland Annual Ball
Warren House
Kingston-upon-Thames
London

Tickets £55 each

Saturday 27th June

Family Day Picnic and Balloon Race
1pm - 5pm
Holland Gardens
Cambridge Road
West Wimbledon
SW20

Free Admission

Ball Auction/Raffle Donations

We work extremely hard (and have great fun!) generating the most fabulous raffle/auction prizes that we can for the most glittering night of the year - The Daisy Garland Ball. Each prize is donated by incredibly kind companies/individuals. If you know someone who might like to donate a prize, please contact thedaisygarland@btinternet.com asap. Thank you very much.

*Happy New Year!
With our very best wishes,*

Sara, David, Tracy, Sarah, Carol, Kim and Tony

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