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Batten Bulletin

Bringing light to Batten disease, the main paediatric neurodegenerative disease in the UK



Battenfest 2013

On a scorching weekend people gathered in a field in Northampton for what proved to be an outstanding weekend organised by Ellen Bletsoe and her committee, special thanks to Louise Marden and Cath Sermon.

It was packed full of good food, great company and excellent music that lasted into the early hours of the morning only to be stopped due to the necessity of sleep! However only a few hours later bacon butties kicked off the next round of singing on an equally beautiful day. There was all sorts of entertainment during the day including auctions, a fantastic caricaturist, face painting, a kids' zone, graffiti wall and a well stocked bar!

The event managed to raise over a staggering **£21,500** – a massive well done to all who were involved.



Battenfest 2013

Fundraising for Jenson



Since Jenson was diagnosed with Batten disease we have set up a fund in his name to raise money for equipment and family memories. We have also raised money for the BDFFA, it is also a great way to raise awareness of this awful disease. I have found when people hear about Jenson's condition and meet him they can see despite everything what a happy and determined little boy he is and it inspires people to want to do something. Our events are always very well supported, to

date we have held a couple of race nights and had a pig roast, these alone raised around £4000 for his fund. Jenson was also nominated for the in-store Asda collections and received £200. We have also received numerous donations from an article about Jenson in our local paper.

Our first fundraiser for the BDFFA was my most memorable, a four hour spinnathon organised by one of our neighbours. We raised about £800 which was a great amount. I remember thinking 'four hours spinning, no problem I can do that!' but on the day ten minutes in I had to stop... what hard work! I never realised how hard spinning was, my coordination; or lack of it I should say, meant as everyone else was following the instructor I had to go at my own pace. I was amazed at the stamina of the people that did the four hours.

Jenson's older sister's secondary school heard about Jenson through Lauren and they chose the BDFFA to receive a third of the money they raised during charity week, which amounted to £571. Lauren received a community award at school for all of her fundraising efforts, which was great recognition for her. There was a golf day in July, which our local window cleaner organises annually for two charities and he added Jenson's fund to it for this year which was brilliant.

We had a fun run on the 27th July which was split between Jenson's fund and the BDFFA. So we have lots of ideas for raising money and will continue to do so. Organising all these events gives me something to focus on and helps to spread awareness.

About Batten Disease and the BDFA

From Fundraising



Dear Supporters,

What a fabulous summer we have had! We continue to be impressed with all the fundraising ideas that you come up with from a regular car booter to the massive Battenfest weekend.

As we head into the winter we have to start thinking of ways we can fundraise that are not weather dependent. The BDFA's need for funds continues to grow as we make contact with more families who need our support and the ever present research funding requirement.

Dinner 4 Good, barn dances, balls, hog roasts, wine tasting and quiz nights are all popular ideas but if you have some new ones please let us know and we can share them amongst our ever-growing family of supporters.

Nikki Radcliffe, 07584 300086



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Marathon des Sables 2013

Early in 2012 Paul Barker (aka Bakester) decided to do something extraordinary and registered for the Sahara Marathon, running over 100 miles in searing heat over sand and rocks in under 6 days – all for the BDFA. Paul set about fundraising with his friends and family and decided upon a hog roast – a hog roast with a difference, it was a black tie event with 300 guests!

On the night guests arrived to a massive marquee set up in a friend's garden, fire pits kept everyone warm for arrival drinks, torches blazed, it looked very atmospheric. Inside the marquee was a dance floor and formally laid tables – this was the smartest hog roast ever. After a game of head & tails dinner was served, followed by a raffle and an auction with fabulous prizes. The evening had raised over £45,000 and everyone continued dancing the night away. For weeks after the event money continued to pour in until the final figure was reached – £70,000!

Paul completed the marathon in April 2013 and we heard on the grapevine that shortly after returning home he went skiing with his family – most people would have struggled to walk properly for a few weeks. **Well done Bakester** from all of us and thank you to your amazing support committee who included your wife Alexandra, Mike and his wife Alexandra but most of all to Lily for inspiring Paul in the first place.

Well done Margaret!

Margaret Endersby has been working hard fundraising all summer – she's managed to raise over £1200 from the sponsored walk and nearly £700 from having stalls at car boot sales. This is a brilliant amount in just a few months! **Well done Margaret and thank you for your time and hard work.**

What is Batten disease?

Batten disease is a group of rare inherited genetic neurodegenerative diseases that occur in children and young adults worldwide. Symptoms include loss of vision, epilepsy, dementia and loss of abilities including walking, eating and talking. At present there is no cure. Those with the disease suffer from a progressive deterioration of the brain and nervous system becoming increasingly dependent on others until an early death in childhood or early adulthood.

Who are the BDFA and what do we do?

The Batten Disease Family Association (BDFA) is the UK's only dedicated Batten disease support, awareness and research charity. We work to support families and professionals giving care to children and young adults with Batten disease across the country. We provide information and support. We seek to raise awareness of the disease and to facilitate research so that one day a cure will be found.

Projects your fundraising could pay for

The BDFA have numerous projects to fund during the coming year and your fundraising efforts can help us to make them a reality.

- **Research** is ongoing and we will continue to put as much money as possible into discovering a cure.
- A **Free Phone Helpline Service** will ensure that every parent can access the service as often and for as long as required, regardless of costs.
- **New support packs** will provide families and healthcare professionals with up to date information on each stage of the disease.
- New this year is a **Small Grants to Individuals Scheme** which will allow families to apply for an essential item grant which we hope will reduce some of the stress of caring for a child or young person with Batten's.
- Families coping with Batten's can feel isolated and alone so we propose to hold a **Family Activity Weekend** during the year. We hope this will encourage greater peer support between children and families as well as giving everyone some much needed fun and laughter.
- A full time **Family Support Officer**, we have seen an increasing need for this vital role which is currently part time.

Batten Fundraising Focus

Music for a Summer's Evening



A truly magical evening was held on June 15th to raise money for the BDFA. Despite the awful weather during the day, the rain stopped, the sun came out as the first guests arrived with exquisite picnics, tables, chairs, even a candelabra was spotted, gazebos were set up and black tie the dress code.

A glass of Veuve Cliquot welcomed everyone in the beautiful gardens of Shepwood House, Lord Wandsworth College – a thoroughly English scene. Guests were then entranced by the operatic trio performing a wonderful selection of light opera, starting off with 'Tonight' from West Side Story. The audience enjoyed pieces by Mozart, Gerschwin and Verdi to name but a few. In the interval, delicious picnics were set out. As the sun set the sound of opera could be heard across the grounds, a wonderful memory and a delightful way to raise money for a much needed cause.



BDFA's annual sponsored walk was a winner this year, with 130 people attending. The only thing that out shone the great atmosphere was the weather! Day one eased the party into walking with the first short route, it was then back to base for a BBQ, drinks, games and a quiz involving lots of ABBA singing. Well done to team Bletsoe for winning the tough quiz! Anna Pickering celebrated her 14th birthday in style with an enormous 4 letter name cake, enjoyed by all! On the second day everyone's sponsors got their money's worth out of them with a long trek to Uppark House in Harting for a picnic lunch.

Alex Clothier - Race to the Stones

The stunning weather that we had all been praying for this summer was cursed by those competing in the Race to the Stones. Alex Clothier pushed through the 32 degrees heat, walking from Oxfordshire and arriving in Wiltshire at 4.40am in an amazing 20 hours and 9 minutes. How did he fare after the race? "Utterly exhausted at the end although in great spirits and rather a lot of blisters!" He has managed to raise a brilliant **£1437.17** for the research of Batten's disease. Alex found out about Batten's after a friend's daughter was diagnosed and felt compelled to help.

British London 10k

A group of 18 supporters ran the London 10K for BDFA on 14th July. It's a great course set among the famous landmarks but was a tough one thanks to the heat. We need to make a special shout out to **Raymond Kipps** – he was the official veteran of the team, a self confessed non runner and on top of that the weather was roasting! So it was especially well done to him for completing the run in good time. **We are now recruiting for the 2014 London 10K, there are 18 places again. If you feel up for the challenge please give us a call on 07584 300086 if you would like more information.**



Jail & Bail, Winchester

On the 10th May 2013 a group of very game business men and women agreed to take part in this event. Working with Hampshire Constabulary and a local Town Crier we launched the BDFA on the city of Winchester, arresting some of their leading business people. Handcuffing MDs in front of their staff and customers really causes a stir. Twitter went crazy with staff from Knight Frank and Denplan keeping everyone up-to-date. A total of £7600 in bail money was raised from our prisoners. It was a lot of fun for all and resulted in some very positive radio coverage and reports in all the local papers. **Look out Exeter, we will be coming there next.**



Dragon Boat Racing

by competitor Neil Mann, Moore Stephens Financial Services

The first thing I should mention about this year's dragon boat race is the weather...it was a scorcher which was a welcome change compared to the last time we participated in this event and got soaked! The troops gathered for an early start at 9.00am on Sunday 1st September 2013, and after getting settled were eagerly awaiting our first race. Our first achievement was the fact that we made it to the start line without capsizing. After our first race we were a little disappointed because we didn't win – little did we know that the team who had won were seasoned pros and went on to win the overall tournament. After our 3 races we just missed out on making it to the semi finals by a second. Overall it was a fantastic day and we managed to raise some money for a great charity but most importantly we raised awareness about Batten's.

Your gift to bring light to Batten's

YOUR GIFT TO BATTEN DISEASE

- I would like to make a donation of £ _____ (cheques made payable to the BDFA)
- A monthly donation helps the BDFA to plan its work with confidence, please send me more details on how to make a monthly donation
- I would like to become a member of the BDFA, please send me an application form (annual membership fee £10)

GIFT AID YOUR DONATION

If you are a UK tax payer, you can increase your donation to the BDFA by nearly one third with no further cost to you. For every £1 you donate we can claim 25p from HMRC. To qualify for Gift Aid the income tax or capital gains tax you pay must at least equal the amount we will claim in the tax year.

I, Title: _____ Forename(s): _____

Surname: _____

Address: _____

Would like to Gift Aid this donation of £ _____

Signed: _____ Date: _____

INFORMATION

If you are receiving the Batten Bulletin you are already one of our valuable supporters so thank you but did you realise that you might be missing out on information and news because we do not have all your contact details on our system. We are slowly changing our methods of communication to electronic which will save us approximately £15,000 each year so please take a moment to send an email to fundraising@bdfa-uk.org.uk with names, address including postcode, phone (landline and mobile if possible) and email address.

Full Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

Please return this to: BDFA, PO Box 504, Fleet, Hampshire GU51 9GE

To send items to the BDFA please post to:

BDFA, PO Box 504, Fleet, Hampshire, GU51 9GE Charity Manager: 01252 416110 info@bdfa-uk.org.uk

Registered Charity No. 1084908

BDFA Data Protection Statement:

The Batten Disease Family Association complies with the Data Protection Act 1998 which regulates our processing of information and provision of services. Your details will be added to our confidential database. It would be helpful if you could inform us of any change of address or other details. Please inform us at any time if you do not wish to receive mailings from us about our activities and events.

Thank you

Thank you to everyone, without your continuing support we would not be able to provide help to all our families.



Laurie, the BDFA Lorry

BIG NEWS!!!! Thanks to Lawrence Marshall of Lawrence David Ltd and Jack Richards the BDFA are to be displayed on a massive lorry for at least one year.

Laurie, as we have christened the lorry will be travelling daily from Fakenham in Norfolk to Nantwich, Cheshire displaying a fantastic new livery of the BDFA logo and branding as well as 2000 supporter names. **If you would like to add your name please visit our website at: www.bdfa-uk.org.uk and click on the lorry at the top of the page.**

Katies Cougars



Martin Freeman, who lost his daughter to Batten disease, made a heartfelt plea to local people to help fundraise and Katies Cougars were born.



This fantastic collection of women decided to enter for the Rock Solid event, a gruelling cross country run involving a lot of mud and water.



As you can see from the before and after pictures they certainly got 'stuck in'.

Thank you Katies Cougars for raising over £4000 for the BDFA research programme.



www.bdfa-uk.org.uk