

## Would Your Company Help?

### Could we be your adopted charity?

Over the years we have developed some fantastic partnerships with companies who have helped us with matched funding, sponsorship and volunteering, whilst raising awareness of the work we do.

It's been shown that being involved with a charity can increase staff morale, customer loyalty and enhance stakeholder value.

Could a company you own or work for achieve its social responsibility goals by becoming a BDFFA Corporate Partner or Supporter?

### Could we be your "Charity of the Year"?

For more information contact the fundraising team on **07876 682589** or [fundraising@bdfa-uk.org.uk](mailto:fundraising@bdfa-uk.org.uk).



## Recycle 4 Charity

We have signed up as a charity that can now be supported by Recycle4charity – head over to the website and see if you can help.

You can recycle ink cartridges and mobile phones, both of which we all go through lots of!

Now we as a charity can get the rewards for recycling them. Please look on our website to join in!

## Regular Donations

Did you know, for the price of a cup of coffee you could help the BDFFA in a big way.

Making a regular donation of just a few pounds a month means we can plan the funding of essentials such as the **Support Helpline**, **clinical research projects** and the new **Clinical Nurse Specialist**.

We can grow the charity to meet the needs of families and professionals using our service.

Or you can visit the BDFFA website, [www.bdfa-uk.org.uk](http://www.bdfa-uk.org.uk) and follow the links to give monthly.

## BDFFA and Sparks Collaboration – Your Chance to Run, Walk and Ride for the BDFFA!

The BDFFA have teamed up with Sparks, the children's medical research charity, to move forward research into Batten disease.

As part of this partnership, we now have access to some of the most iconic walking, running and cycling events across the country, including the London to Brighton Challenge, the Mudnificent 7, Matt Dawson's Cardiff to London Cycle and even the Berlin Marathon! For a full list visit the BDFFA website. There are minimum fundraising targets to be met, and all money raised will be used to fund research into the NCLs.

If you want to take part in any of these races, just contact Kate and Gaynor by email or on our facebook page.

## BDFFA Stamp Collectors!

Well done to everyone who has been collecting stamps for the BDFFA. Don't forget, you can get your freepost envelopes by searching 'stamps' on our website.

One family who will be needing a lorry rather than an envelope is the Hadmans. Carly and Paul set up boxes around their local area to collect stamps, supporting their 4½ year old daughter Effie who has CLN2. So far they have collected over 10kg of stamps from all around the world. Well done everyone.



# THANK YOU FOR YOUR HELP!

# Batten Bulletin

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



## Norway to the Arctic Circle in 6 days!

A tale of penguins, bears, tandems and two determined, if somewhat crazy, people.

In July 2015, Duncan Brownnutt and his friend Rod Wark will be travelling 500 miles in 6 days from Røros in Norway to the Arctic Circle. By tandem! In response to the question, "So which one's Daisy?" Duncan replied "Rod is Daisy. And I'm half crazy".

They are currently training hard, both physically to build up the required stamina, and by studying the dangers along the route, (including bears, chemical toilets and having to eat reindeer and drink Akavit) and of course, learning how to balance whilst hurtling down hills. They will be ably supported by their 'third man', driver and all round backup, John.



Røros was chosen as the start point because it was here that Batten disease was first recorded, with four siblings from the same family being discovered to have symptoms back in 1826.

Both of Duncan's two children, Ellie-Mae (6) and Caleb (4), have Late Infantile Batten disease. You can read all about them, and Duncan's exploits by visiting his Cycle to the Circle blog page (<https://cycletothecircle.wordpress.com>).

Please help support Duncan and Rod by donating at JustGiving: <https://www.justgiving.com/Duncan-Brownnutt4/>. This is an amazing undertaking and we wish them well. And

penguins? Well, as Rod said when asked about his reasons for doing this challenge... "I've always wanted to see penguins in the wild".



## Great Gnome Giveaway

...as if penguins and bears weren't enough, there are even gnomes getting involved in Duncan's fundraising! Family friend Katie Mclean, who creates baby slings and carriers, is offering the chance to have a unique gnome patterned sling made.

For a donation of at least £2 (which goes to the BDFFA) you can be entered into a draw to win the sling. An ideal present for parents-to-be. To donate and enter, go to Katie's JustGiving page: **Crafty Little Slings Great Gnome Giveaway**.





# Batten Fundraising Focus

## Welcome!

We are your new fundraising team. Call, email or facebook us for any fundraising support or advice you need – we'd love to hear from you.

We job share, so Monday to Wednesday Kate will be available and from Wednesday to Friday Gaynor will be your contact.

Email: [fundraising@bdfa-uk.org.uk](mailto:fundraising@bdfa-uk.org.uk)

Tel: 07876 682589

Search **BDFa Fundraising** on facebook



Kate Shefford



Gaynor Heeson



## Notre Dame School raises €2000

Well done to all the pupils and staff at the Notre Dame School in Cobham, Surrey who have raised the massive sum of £2000. Pupil Hannah Humble was a friend of Ben Pickering, who had Batten disease. She persuaded her school to raise money for the BDFa.

Last November, Ben's mum Julie visited the school to give a talk to the girls and present the school with a framed painting Ben had created of a sunrise, called 'Bringing Light and Hope to a New Day'. Hannah and her fellow pupils and members of staff then handed over the very generous donation. Hannah says "Everyone was adamant that Ben's picture should be placed in a part of the school where everyone would pass it daily so we have placed it in the centre of the school".

Well done to Hannah and everyone at Notre Dame.

## Wear Orange To School Day!

With the summer term coming up, it's the perfect time for your children's schools to hold 'muft' or non-uniform days.

Why not persuade your school to support the BDFa by wearing something orange, for a donation of £1? We can provide information leaflets and even (orange!) wristbands to sell, all to help raise awareness of Batten disease.

Contact the fundraising team if you or your school want more information or resources.



**We still have a couple of spaces left for the 10K. Samantha will be running for the BDFa – here's why:**

"In 2010 I ran the Asics British 10k in London for a charity who had helped my son with the loan of an Eyegaze computer. At that time, after 4 years of illness, we still had no diagnosis – Batten disease had been tested for and ruled out twice.

However, in July of 2014 we did finally get the NCL diagnosis through the DDD study and so as soon as I saw the call for people to run for BDFa, there was not even a second to think about it – I was in! What also makes this significant for me is that 'if you see me running, something scary must be after me'... I don't run! After the 2010 run, I couldn't walk properly for a week!

I can't wait to do this run, with my partner Dean, for BDFa, and for my beautiful, brave son, Lewis Jaynes. Thank you BDFa for giving me this opportunity."

Samantha Tolmie

# Batten Fundraising Focus



## Team Ready Assaulted!

What would you like to be doing these cold winter's days? Curling up in front of a fire, with a good book? Or running hundreds of kilometres through freezing water and mud? That's the challenge that Jenny Shackleton, her husband Marc and friend Jonny have set themselves for 2015.

Jenny's niece Amber is affected by CLN1, and so to raise money for the BDFa, Jenny and the team will be undertaking 15 'muddy runs' over the next 12 months – with names like Spartan Beast, Mudnificent and Zombie Evacuation Race you know they are not going to be a gentle walk in the park.

Already they have completed three races – the Hell Runner, The Eliminator and the Nuts Challenge. Braving all the elements – including ice shards in the water – they have already raised £200, but hope to make this much, much more. Here's Jenny's story.

"I first became aware of the BDFa shortly after my niece Amber was diagnosed with Infantile Batten disease. They have been a source of support to my sister's family and were able to help support them with an understanding of the devastation that Batten disease has had on us all.

I met some of the families last year on an annual walk at

Queen Elizabeth Country Park and I felt that I wanted to help fund the charity and also the research into the disease. I decided that I would set a challenge for 2015 to help raise funds and spread awareness about the BDFa. That challenge being roughly 150km of muddy obstacle races.

I started with a race called Hell Runner. It certainly lived up to its name! The hills were very steep and we had to go through "the bog of doom". I ended up having to swim this as only being 5ft, I couldn't touch the bottom of the ditch. Being in January, this was absolutely freezing and my whole body went numb. I also pushed myself to the finishing line at the Eliminator race after carrying a BDFa flag all the way through freezing bogs and challenging terrain.

I am taking part in many races over the year such as the Spartan Races, Wolf Run, Tough Mudder and the Nuts Challenge. For my last race I am facing the brutal cold in the toughest race of its kind which is Tough Guy in January. Tough Guy claims that my fear of heights, tight spaces, fire, water and electricity will be tested to the max.

When Amber was first diagnosed, I was really overweight and unfit. Amber has been my biggest inspiration to change my life around by always doing the best I can. She has amazed us all with her fighting spirit and that is what I think about throughout my races, especially if I am finding it tough."

Find Jenny's JustGiving page by looking up 'Fighting Batten Disease' at: [www.justgiving.com](http://www.justgiving.com).



**COLLECTION BOX AMNESTY** Do you have a collection box in your local pub, Post Office, school or shop? Have you visited it recently? If not please do! Each box can collect around £150 per year – and we think we have at least 70 out there – that's over £10K. Please send any unused boxes back to us. If you want to reuse your box we can send you new seals. Just get in touch with us. Contact Gaynor or Kate on 07876 682589 for more info. With your help we can make sure that another £10K can be spent supporting those living with Batten disease.



Running a 10K isn't enough for some people. In June, Tom Smith will swim 2.4 miles, cycle 112 miles (including a 5000m ascent) and then run a whole marathon, all against the picturesque backdrop of the Cote d'Azur around Nice, Southern France. He is raising funds for the BDFa, as well as the Jane Tomlinson Appeal. A keen hockey player for Wakefield Hockey Club in Yorkshire, he became aware of Batten disease because his coaches Norman and Pam's daughter Amy was diagnosed with the adult onset form of the disease aged 24.

In Tom's words, "The training is gruelling and taking up all my time, but it is all to make a big difference for two awesome charities both in terms of funding and exposure."

Tom has already held a large event at the hockey club, including a tournament that was graced by England players, and raised £1000 in the process. What is it that keeps Tom going through the lonely hours of training? Says Tom "When the going gets tough I know I will think about Amy, Pam and Norman and be inspired to push on to the end."

Help Tom reach his £3000 target visit his page at <http://uk.virginmoneygiving.com/smithy183>

