

In Your Face Batten



In Spring 2015 two of Tina Penn's nephews were diagnosed with CLN3, Juvenile Batten disease, and just a few weeks later one of her nieces had the same devastating diagnosis. Not one to sit around, Tina decided to start fundraising to help the family, and within the space of a few weeks had organised a massive Funday in their local area, complete with bouncy castles, tombolas, local radio and Disney characters. This was a great success, but still Tina wanted to do more.

Another Funday was organised for the summer holidays – even bigger than the first, including a dog show and with a very special event at its heart – a record breaking attempt at the number of 'cakes in faces' she could persuade people to throw at the same time. Nicknamed 'In Your Face, Batten's!' over 125 people squashed cream cakes into their faces in an effort to raise awareness of Batten disease. Tina says "it was a fun way of raising awareness, especially if we do get the record!"

She has definitely caught the fundraising bug – more events, including a Christmas Grotto weekend are coming up over the next few months. Well done to Tina, and all her friends and family for the huge efforts – and fun – they put into both Fundays.

Fundraising Stamps



With Christmas coming, don't forget to save all your stamps from your cards, parcels and letters. Every one you send back makes a few pennies for the BDFA. You can obtain a FREE envelope by searching "Stamps" on our website. **Keep collecting!**

In memory of Dylan



Over the last six months James Sinclair has been working tirelessly arranging fundraising events. Sadly last March his son Dylan, who had CLN2, passed away at the age of 7 and James wanted to raise money and awareness of Batten disease.

He started with a series of Teddy Tombolas, which raised £900, followed by a sponsored walk (accompanied by Boris of course). James surpassed himself in July with a fantastic Funday, organised in less than 4 weeks – this event alone raised more than £1250. He also featured in a double page spread in his local newspaper – great for raising awareness. His JustGiving page stands at over an amazing £3000.

James says "I enjoy giving back to the charity who help support families through what I've been through. Having been in my position and met other people in the same position I understand how difficult it is. It makes me feel positive, and I credit Dylan for his strength and the inspiration he gave me throughout his battle with Batten disease, and I will always give my time to help raise awareness for the cause. Finally, I would like to thank people who have donated, helped or contributed in any way". Well done to James, and to everyone who supported his efforts.



Ben Nevis Batten Challenge

In June 2016 we have a unique fundraising opportunity for those who enjoy the outdoors and want to set themselves a massive challenge – conquering the highest mountain in Britain, Ben Nevis.

We are organising for a group of around 20 people to undertake this 6-9 hour hike up the mountain. The trip will be over a weekend, date to be confirmed.

We will pay your 'entry' fees, which includes all accommodation, food, and experienced first aid trained guides. In return we request you commit to raising a minimum amount of £500 – a large sum we know, but this is an exceptional challenge.

If you are interested in taking on this challenge for the BDFA, and can commit to the fundraising target, please contact Kate or Gaynor on 07876 682589, or at fundraising@bdfa-uk.org.uk

Teddy Bears' Picnic... watch this space...

Next summer we are hoping to hold a teddy bears' picnic in a park local to BDFA HQ. Families are welcome to come along and Boris will be looking forward to meeting lots of new friends. More details in the New Year!



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Please share this bulletin with friends or colleagues to further support our work

Batten Bulletin

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

You've probably heard about the amazing adventure Duncan Brownutt and Rod Wark completed in July. We want to express our enormous gratitude to them for raising in excess of £12,000 for the BDFA.

What We Did Last Summer

For our Summer holiday this year Rod and I decided to cycle the length of Norway. There is a bit more to it than that and I would like to state categorically that the whole project was Rod's stupid idea.

We wanted to do something to raise money for the BDFA but also to raise awareness and spread the story. We both felt that if we did a standard sponsored event as we've done before we would be asking the same people for money. We'd probably make some but we'd be telling the same people the same things so we needed something different. It needed to be challenging and it needed a connection with the BDFA to enable us to talk about them as much as possible.

In the south of Norway is a small town called Roros. It's a very pretty place and acknowledged as a place of interest as it's achieved UNESCO World Heritage Site status. But more importantly for all of us it's the town where the first case of Batten disease was diagnosed. In a family with four children, two showed signs of the disease. The other two children were sent away as it was feared something in the environment was causing the illness. When those two also developed the same symptoms the town doctor, Christian Stengels diagnosed the same condition for all. It was later that the disease was named after Dr Batten.

In Roros we were able to find both Dr Stengels' house and his grave in the town churchyard and we had agreed this would be our start point. From there we cycled 500 miles over five days, stopping at campsites in our motorhome and eventually arrived at the Arctic Circle centre. The line of latitude on the globe which marks the start of the Arctic actually passes through its gift shop!

We did say we wanted it to be a challenge so to make it a little bit harder we cycled the whole thing on a tandem. Anyone who is interested in challenging themselves should consider staring at Rod's bottom for five days. It's really not very easy.



Completing the ride in this way did allow us to create contacts with lots of different people over social media.

We had retweets and personal donations from a number of big names in the cycling world and lots of free support with the bike from our local bike shops. The country itself was lovely and we were aided in all our preparations and in some post-ride recovery by Bengt and Anne-Grethe Elmerskog, who you may remember from last year's BDFA conference.



We took Boris the bear with us and he had a wonderful time, so much so that he decided to stay in Norway a little longer, hoping to get in touch with some of the local bears.

We hit our fundraising target before starting the trip but more importantly we managed to arrange a number of interviews for local and

national press and radio. We were even interviewed whilst on a lunch break over Facetime whilst logged into the free Wi-Fi at a Norwegian garden centre!

Overall it was a very difficult ride but very enjoyable. The Arctic is a very strange place to reach and we weren't sure what to expect. Of course it had the usual gift shop selling "I've been to the Arctic" t-shirts! Norway was a lovely country and well worth a visit, although perhaps not on the back of a bike. Everyone we met was very interested in our story and in supporting as much as they could.

Please feel free to keep sharing the social media pages which explain the trip and will give you some photos of the area. cycletothecircle@wordpress.com

A Souvenir of Norway



As if all the money raised by Duncan and Rod wasn't enough, local artist Nikki Corker painted and then donated a stunning original picture to commemorate the Cycle to the Circle ride. We held a raffle and the lucky winner was Emma Schoon. It doesn't stop there though as Emma donated it back to the Brownutt family as a souvenir of the trip. Thank you for such a wonderful gesture Emma. Nikki has also produced notelet cards featuring the painting, which can be bought at the BDFA online shop - £5 for 5 cards and envelopes. Just visit www.bdfa-uk.org.uk. Huge thanks to Nikki for everything she has done, and thank you to everyone who bought raffle tickets.

THANK YOU FOR YOUR SUPPORT!

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01252 416323 fundraising@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.



Email: fundraising@bdfa-uk.org.uk Telephone: 07876 682589
For more information see our website at: www.bdfa-uk.org.uk



Batten Fundraising Focus



Welcome!

Welcome to the Autumn edition of the Batten Bulletin. It's been a very busy six months, with so many of you challenging yourselves to raise money for the BDFA. We hope you feel inspired by some of the stories we feature here. If you're coming to the conference, please come along to our Fundraising Workshop on the Saturday afternoon for more ideas. If you have an event coming up, please get in touch if we can help in any way. Be sure to take lots of photos and let us know all about it – we love hearing from our fundraisers!

Happy 60th Birthday, Sir Ian

July saw a huge party to celebrate Sir Ian Botham's 60th birthday. As one of his Beefy's Foundation charities, the BDFA were invited to come along and support the event. Our trustees Ellen and Pauline represented the charity and both had a fantastic time celebrity spotting and listening to Eric Clapton!



Hello from Boris!



Would you like me to attend your fundraising event? I love getting out and about and meeting new people and seeing what fun you are having raising money for the BDFA. Please contact me at my very own email address, boristhebear@bdfa-uk.org.uk, tweet me @Mr_Boris_Bear, or call my PAs Kate and Gaynor on 07876 682589.



Raising for Amy

Our daughter Amy Hughes was diagnosed way back in 2005 in her early 20s with adult onset Batten disease. She had been a very active young lady, playing hockey, golf, tennis, swimming, etc. Our family has been encouraged considerably by the fundraising activities of people in the Wakefield area. The variety of fundraising has been very wide. We are humbled by the range of activities and the effort which people have made to support the BDFA.

- Our annual club dinner has been a great occasion for raffles, the standup-sitdown bingo and other semi-drunken games
- Junior training sessions on Sundays have brought out the bakers in force and we have a great reputation for cakes and buns to feed the spectators
- One of our members, David Johnson and a university friend, tackled the Land's End to John O'Groats cycle ride
- The club links with Muiderberg Hockey Club in Holland and does a reciprocal exchange annually. Over the last few years when they come to England they have made a very substantial donation. They raise funds by sponsored hockey skills, training runs and selling mini waffles (and that's a shed load of waffles, I can assure you)
- Amy was games captain at Wakefield Girls' High School. They had a mass balloon release at school which involved all the girls and raised a huge amount of money
- Coffee morning in May to support the fundraising below.



This summer, Tom Smith, a club member, undertook the Nice Ironman – Nice as in the French city, not a description of the challenge! So far he has raised a magnificent £9,400 for the BDFA and another charity.

You can continue to pledge via Tom's Virgin Money Giving page. There are lots of lovely messages from a whole host of people including many from Amy's former school mates. These messages have been invaluable to us. As we all know, Batten disease makes it very hard for people to have a normal social life so knowing that Amy is in the thoughts of her old school friends is wonderful. It helps to spread the word of the BDFA.

As members of Wakefield Hockey Club, Norman and I are immensely proud of the generosity of so many people over such a long time. They have given their time and energy in so many ways and no words can really express the gratitude we feel for this teamwork and support over many years, by so many members, in so many ways.

Pam Hughes

London 10K



A huge thank you to everyone who took part in the London 10k this year. Over 20,000 people took part in the iconic 15th Anniversary London 10k on 12th July this year, and 17 of those were running for the BDFA.

We ran past Piccadilly Circus with Eros as a backdrop (three times), Oxford Circus, St. James's Palace (twice), the Theatre Royal and Her Majesty's Theatre.

We also ran on the UK's premier shopping street Regent Street.

Other landmarks we passed included Trafalgar Square (three times!), Big Ben and Houses of Parliament, the historic Westminster Abbey, Parliament Square, and Downing Street before finishing at Royal Horse Guards and Banqueting House.

Well done to Samantha, Dean and Gareth – they couldn't make it down to London for the 10k in the end – so they did it in Doncaster instead.

A fantastic experience, ending in the pub for a well deserved pint. Same time next year everyone?

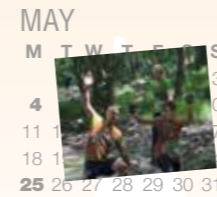
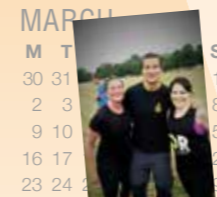
If you would like to run next year please get in touch with Kate or Gaynor at fundraising@bdfa-uk.org.uk.



Batten Fundraising Focus

The Mud Queen

Jenny's Year of Obstacles – and TV Fame!



Last January, Jenny Shackleton took on the challenge of 15 obstacle and mud runs over 12 months, covering over 150km, all to raise awareness of Batten disease and money for the BDFA. Since then, she's really caught the muddy bug and has added even more races to her schedule, even carrying on into 2016. Not only that but she was chosen to be one of Good Morning Britain's 'Tough Mums' and appeared on the programme in September. We caught up with her after her latest race, Lake Fear...

Why the BDFA?

My niece Amber was diagnosed with infantile Batten disease in 2013. The diagnosis has shattered all of our hearts and it has been tough to watch the effects of Batten disease take hold of my sister's family. I decided that I wanted to raise awareness and fundraise for the BDFA.

Why did you choose this activity?

I chose to set myself the challenge of running over 150km of obstacle course races over 2015. Sometimes I actually question myself as to why when I am crawling through pits of mud whilst being electrocuted! But my inspiration for doing these challenges comes from my niece Amber.

How have you found the experience?

I have found the whole experience so far totally amazing. I have met so many new people (who all now know about Batten disease). And their encouragement and support has been really humbling.

What was the most difficult part - did you ever feel like giving up?

I would say the hardest part of my challenge was in the Tough Guy Nettle Warrior event. I actually cried in this race from pure fear and from being so cold. I really felt like giving up but carried on as I didn't want to let everyone down that has supported me.

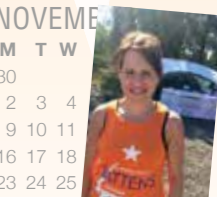
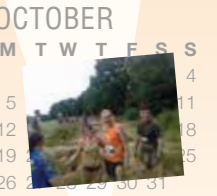
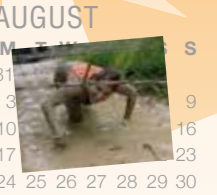
What was the most fun?

They all have their unique quirks about them but what I have enjoyed the most is meeting the different, amazing people who are all racing for their own reasons and different amazing causes.

Any words for anyone who might be considering doing anything similar?

So far I have been in skips of ice, jumped through fire, crawled through mud, been shot at with paint balls, swum in freezing waters, been electrocuted, climbed walls and conquered some real fears which has all been down to my inspirational niece. Her strength and fighting spirit, along with the support and encouragement I have received, is what has kept me going.

You can still support Jenny by visiting her JustGiving page, www.justgiving.com/fightingbattendisease. Please give generously to support this amazing fundraiser. Keep it going Jenny!



Silly Santa



With Christmas approaching, for the month of December



we'd love to see your silly Santa photos posted to our Facebook page. The photos can be anything Christmassy and fun, but please include some BDFA orange in there to help raise awareness. Don't worry – we'll remind you nearer the time!

Fundraising the Dunford Way

Paul and Marilyn Dunford from Leeds were devastated to learn their little granddaughter Yanna had been diagnosed with CLN2 in June 2014. Furthermore, she was to be enrolled in the trial taking place in Rome, and so Yanna moved to Italy with her parents Neil and Dida, a thousand miles away from her grandparents.

Marilyn and Paul threw themselves into fundraising for the BDFA, holding a bake sale at their local Tesco, a tombola, a gala stall and placing collecting boxes in local shops and pubs. With lots of help from very good friends including Eileen Naylor, to date they have raised over £1000, and had plenty of fun in the process.

Says Marilyn, "It's been harder work than we expected, but well worth the effort. We are really pleased with the results of all our events, and everyone had a great time!"

