

A Night for Nicole

Back in October, one of our best friends Gemma decided she would organise a dance show. Gemma is a dancer and a dance teacher so this was the obvious choice of fundraising for our Gems. Along with Hayley Conway, Lucy May and the incredible performers from the Newcastle Dance Centre, 'A Night for Nicole' dance show was put together and after five months of incredible hard work and dedication, the show was held over the weekend and what a show it was!!

The tears started before the show even began, when we walked into the foyer and saw the room filled with lots of pink beautiful balloons, glittering smiling showgirls and posters of our beautiful girls around the room. To know people had put so much effort into this event and the realisation that this was all for our girls, to support our family was just overwhelming.

Then the show started and so the tears started again. Such emotive music – the opening performance of 'Diamonds' – well, that was Mammy Rich set off!! The thought that had gone into the whole show was clear, especially when they performed a very special song to us: Coldplay's 'Adventure of a Lifetime' (we would sing and act daft dancing around for Nicole, the children would all be laughing at silly Mammy! Nicole loves this song). All I can say is thank goodness we weren't saying a few words until the end, as we couldn't have composed ourselves enough during the first half, it was that emotional. Such beautiful dancers and singers, such love and commitment had gone in and it shone with every dance.

So, thank you Gems so much, thank you Hayley and the dance centre, Lucy, every single person who supported this show. You have touched our hearts and we will never forget it. Oh, and there's the small matter of the fundraising total... over £6,000 was raised for The Nicole Rich Foundation and the BDFa. **Thank you!**

Gail Rich



John Heath, Social Secretary, handing Martin Freeman a cheque for £160

Thank you Plympton

Martin Freeman's hockey club Plympton Grammar School Old Boys (PGSOB) have been collecting player fines and have donated them to the BDFa (for Katie's specific LINCL research fund). These fines were made for numerous reasons – yellow cards, forgetting kit, mistakes on the pitch, and any comic misdemeanour that was thought to be worthy of a fine. **Over £160 was raised... thank you to all involved.**

BDFa Harriet's Marathon



This year I finally got a ballot place for the London Marathon after seven years of applying! I just wish I had done seven years of training for this event. I am running for the BDFa and Joy for Children and Communities, Children with Disabilities Project which I run in Uganda. I am running for these two charities because I see first hand what a huge difference a small amount of money can make.

I also know that sadly a lot of the children and young people I work with both here and in Uganda will never have the chance to run a marathon so I am running for them. I have decided that I will be putting names of the children and young people I work with on my running vest so they will be there running with me. **Thank you all for your support. Let's hope I make it to the finish line.**

<https://mydonate.bt.com/fundraisers/harriettlunnemann2>

Harriet Lunnemann

For Leo

I am raising money for the BDFa as a member of my extended family Leo Olivacce has Batten disease.

I felt I had to do something to help. I enjoy running and always wanted to run a marathon so I set it as a goal to do one and at the same time help raise money for the charity.

I was originally running the Southend marathon with two of my friends but this got cancelled, so we decided to run our own marathon anyway. One of my friends is raising money for Dementia and the other for Little Havens. **Thanks Alex.**

www.justgiving.com/fundraising/Alex-Henshaw



BDFa
BATTEN DISEASE FAMILY ASSOCIATION
Together we WILL make a difference
Registered Charity No. 1084908

ISSUE FIFTEEN • SPRING 2017

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

Batten Bulletin

FUNDRAISING FOCUS FROM THE BDFa

The Batten Disease Family Association Starlight Ball

9th June 2017 - 7pm - Midnight
Warbrook House Hook, Hampshire

Come and join us for dinner, drinks and tunes
All proceeds go to the BDFa
Together we WILL make a difference

£75 per person
Table of 10 - £700

Black Tie/Dark Lounge Suit preferred

Tickets available from
www.bdfa-uk.org.uk or Call 01252 416 323



Starlight Ball 2017

The Starlight Ball will be held on Batten Disease Awareness Day, Friday 9th June at Warbrook House, Eversley. Tickets are £75 per person. Hotel rooms are available for £42.50 per person. Come and join us raise much needed funds and awareness on this special night. Warbrook House is set in acres of gardens, greenery and woodland which come together to form the perfect backdrop for our special evening. Tickets are available online or please call **01252 416323**.

Email: fundraising@bdfa-uk.org.uk Telephone: 01252 416323
For more information see our website at: www.bdfa-uk.org.uk



THANK YOU FOR YOUR SUPPORT!

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01252 416323 fundraising@bdfa-uk.org.uk www.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.

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Hello from your fundraising team...

Well done to everyone who has helped raise funds and awareness. Thank you to all the runners, sky divers, cake makers and many more. We love to hear about your events and are here to help however we can. Give us a call on **01252 416 323** or email us at fundraising@bdfa-uk.org.uk.
Keep up the good work!



Louisa Maddison and a group from The Royal Blind School, Edinburgh took part in the 26 mile Kiltwalk on 18th September in support of the BDFA. The ladies managed to finish the Edinburgh Kiltwalk in memory of Caitlind who passed away from Juvenile Batten disease earlier in the year. The 26 mile walk was tough but they managed to all complete it. They have raised over £950 for the BDFA. **Very well done and thank you from all of us!**



London Marathon Walk



Come and join us in the London Marathon walk on 23rd September 2017. It's a 26.2 mile 'marathon' walk (half-marathon option also available) which takes in famous landmarks and lesser-known corners of the historic capital.

Our route takes us towards the church of St-Mary-le-Bow, centre of London's Cockney heritage, while having fun learning the old cockney rhyming slang (some of which you will have to figure out yourself as you go along!)

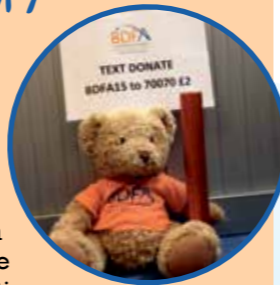
This is a tough challenge and you can expect tired *pins* and *plates of meat*, but there's plenty for you to have a *butcher's* at along the way! With plenty of sights for your *mince pies*, it'll be one of the most memorable things you do this year – you won't *Adam & Eve* it! So *bubble and squeak* to your *china plates* or your *trouble* – and even if you start out on your *Jack Jones* you'll end up with plenty of new friends. Register online or just pick up the *dog and bone*...

Call **01252 416 323** or go online and register. Registration fee is £25 with a fundraising target of £100.



Awareness Day 2017 Friday 9th June

We are ramping up events for Awareness Day this year which will end with our fantastic Starlight Ball. This year we will be running a month long campaign that will kick off on 2nd May. Please keep your eyes peeled for information on social media and do get involved!!



We are 'passing a Baton for Batten'. If you can think of a unique or funny way of passing a baton get in touch and we can send you one. Think rugby scrum, school assembly, underwater, in the air etc...

We will post ideas throughout the campaign, please get in touch if you want to discuss any further with us – **01252 416 323**. You are all so fantastic on Awareness Day so we look forward to seeing lots of photos and posts.



Huge thanks to Tim Martin and Guy Carpenter

On Friday 27th January Tim hosted another fantastic successful event at the City of London Club. We were extremely pleased to have our Patron Andrew Strauss in attendance as well as our Chairman, Mike O'Connor.

STRUTT & PARKER
Strutt & Parker
Having been moved by what was seen at the Lord's lunch last year, Strutt and Parker made a £2,500 donation.
Thank you!

Our former trustee Ellen Bletsoe gave another moving speech and we were thrilled to be able to skype her daughter Laura at Heather House.

Tim's lunch raised over £36,000 which is a massive achievement. Thank you to all involved in this lunch and we look forward to next year's activities. **Thank you.**



Ryan's Rebellion against Batten

Ryan's father Ross has embarked on a mission to lose 10 stone this year, to raise funds for the BDFA. He is doing amazingly well so far. He has lost 3 stone 4lbs and also lost 22 inches!!! What a fabulous achievement! **Keep up the good work Ross!**

The BFF Story

We received Annabelle's diagnosis in August 2016 and kept it a secret. When we received Robbie's diagnosis in January 2017, we told Annabelle that she had Batten disease. She was devastated, but more for her little brother than for herself. We decided as a family that we were going to do everything we could to raise awareness of Batten disease and to raise funds for the BDFA.

Annabelle came up with the name of our campaign, Batten Fighters Forever (BFF). We told the world, we set up a Facebook page and created a JustGiving page. The support we received was amazing and donations came flooding in.

Our first fundraising event was held at the children's school on Rare Disease Day. We held a mufti day and a cake sale and raised £541.93. We also hosted a PartyLite party and raised £66 in commission. Playsportz, the football group that Robbie attends had a superhero week and the donations from that were £227.

To build awareness further, we have had an interview published in a local free magazine, have been interviewed by a local newspaper and have subsequently been contacted by BBC Radio and a national health journalist.

In the six weeks or so since we went public we have raised almost **£14,000** and started a journey to raise awareness that we didn't imagine at the outset. We are currently running an Easter raffle, and in the future we have plans for children's discos, a ball and plenty of sponsorship events.

www.justgiving.com/fundraising/BF4ever



Regular Giving

A gift of £2 each month will help to make a difference to children and young adults affected by Batten disease.



I often hear people saying they would like to help but they don't feel they can run a marathon or jump out of a plane. Regular monthly giving is easy and can help the BDFA plan ahead and ensure funds are available when they are needed the most. You can make a big difference in people's lives by giving just £2 per month. £2 is less than an English breakfast tea at a 'well known' coffee shop.

Could you make a regular gift of £2 each month to help the work of the Batten Disease Family Association supporting families affected by Batten disease? Please visit our website and sign up to a monthly donation, www.bdfa-uk.org.uk

Your gift can help to fund research into Batten disease so that more can be understood about the disease and potential therapies developed. It will help us to bring more awareness to Batten disease in the UK. **Together we can make a difference. Thank you.**



Rio Langford

It's that time of year again, when Holsworthy Short Mat Bowling Club have just finished Rio's competition.

We are pleased to say they raised £612, so £306 will go to Rio's funds and £306 to the BDFA. They have an end of season luncheon on 9th April, which is where they will present me as Rio's Grandma with a cheque for the BDFA. "Thank you for all that you do for this terrible disease".

Sylvia Langford

