

Legacy giving

If you or your family have been helped by the BDFA, have you thought about leaving a gift in your will, for us to continue the work we do supporting families, raising awareness and funding research. If you'd like further information on how to do this, contact your local solicitor, or give Kate or Gaynor a call, or drop them an email at fundraising@bdfa-uk.org.uk

THE GREAT BATTEN BAKE OFF

BioMarin bakers

The team at pharmaceutical company BioMarin, who are running the BMN-190 trial at Great Ormond Street, recently held their own Bake-Off competition to find who was the best baker in their London office – congratulations joint winners Denis and Raivo! Thanks to Alex Inake for organising – so far they have raised nearly £500 for their Tough Mudder fund (visit www.justgiving.com/biomarkers to donate)



Sweet valentine

Inspired by Effie Hadman's story, Joanne Bowes held a Valentine's cake sale at the Royal London Hospital where she works.

She also sold ceramic red roses. Colleagues and friends flocked to snap up some tasty treats, and Jo raised the brilliant sum of £250 for the BDFA. Thank you Jo for all your hard work.



If you would like to hold a bake sale, head to our website for our fundraising toolkit to start you on your way.

Happy 80th Birthday Mr Bletsoe

We've had cake sales, marathons and quiz nights, but never before a bullock sold to raise money for the BDFA. That's what Christopher Bletsoe has done for his 80th birthday celebrations. Christopher runs the livestock auctioneers at Thrapston Livestock Market, and at the Thrapston and District Fatstock Show Society sold a bullock for £1720. His daughter-in-law Ellen was also presented with a cheque for £3500 by the society Chairman James Bennie. Together with other generous donations the grand total was £5,820. Thank you to all who attended the auction, and many happy returns to Christopher.



Russ Windle's fundraising year

Russ Windle has organised his colleagues at RAF Waddington to take part in various challenges over the coming year. We wish them all the best! Visit Russ's JustGiving page at www.justgiving.com/55qn-Engineering-2016



Bowled over

For the third year running Sylvia Langford has raised money for the BDFA via her short mat bowls club in Holsworthy, Devon, in honour of her grandson Rio. This year an amazing £667 was raised – and Rio even got to have a go at bowling! Thank you to all at Holsworthy bowls club.



Fundraising stamps

We're still collecting so 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!**



THANK YOU FOR YOUR SUPPORT!

BDFA, The Old Library, 4 Boundary Road, Farnborough, Hants GU14 6SF
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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Please share this bulletin with friends or colleagues to further support our work

Batten Bulletin

FUNDRAISING FOCUS FROM THE BDFA

BDFA to be Aldermore Bank's Charity of the Year



2016 has kicked off with the fantastic news that Aldermore Bank have chosen the BDFA to be their Charity of the Year. Up and down the UK, employees will be holding events in their branches, as well as supporting the BDFA by attending our events at Ben Nevis and in the London 10K.

James Radford, Director, Group Operations at Aldermore, said: "Along with all my colleagues in the Aldermore Community Team, I am delighted to welcome the Batten Disease Family Association as Aldermore's new charity partner for 2016. The charity does a great deal of excellent work to support those impacted by the disease. We are really excited about supporting BDFA's activities with our fundraising initiatives throughout the year and hope to raise a lot of money for them."

We spoke to one of the Aldermore Community Team (ACT) Champions to find out more about the bank and its activities. Courtney Bowles is based at the Wilmslow office.



Q: Who are Aldermore, what do you do?

A: Founded in 2009, Aldermore is a modern specialist lender and savings bank which challenges the established view of what banking should be. We deliver award-winning commercial finance, mortgages and savings to Britain's small and medium-sized enterprises (SMEs), homeowners and savers. Over 850 employees work across our 11 offices.

Q: Why have a Charity of the Year?

A: In 2015 Aldermore created the 'Aldermore Community Team' (ACT). As an organisation we are committed to helping the communities where we operate and raising funds for national charities close to our employees' hearts.

Q: Why the BDFA?

A: Two of Aldermore's employees have friends whose children are suffering from Batten disease. In February 2015 the family was given the devastating news that their little boy had Batten disease and whilst processing this, they discovered that their daughter, aged two, was also affected. Batten disease is something many of us had never heard of and we as well as raising money to support those impacted

by the condition, we are also keen to raise awareness.

Q: What was the process? Was it a popular choice?

A: We chose our Charity of the Year via an organisation-wide nomination and voting process. The process involves members of the Aldermore Community Team sending a form to each of our offices to allow employees to choose a charity they would like Aldermore to raise money for during the coming year. The ACT champions then compile all of the nominations and select the top five charities with the most votes. At this point, all our employees are invited to vote for their favoured charity from this list. The charity that receives the most votes wins. BDFA was definitely a clear winner!

Q: What events have you planned?

A: We have a lot of events which are currently in the pipeline. The first major event will be our 'Big Quiz' in April. We will be holding regular fundraisers throughout the year for BDFA, including four main events, preferably per quarter. In between these events we have other activities going on, such as tuck shops, cake sales, bake-offs and a charity collection every Friday in our Wilmslow office.

Q: Is there lots of competition between branches?

A: Our offices do enjoy a bit of friendly competition, although some are much larger than others meaning they tend to raise more. We receive frequent updates showing how much each office has raised, which keeps the competition going and also helps to inspire ideas for fundraising activities when we see the different events that the other offices have held.

Q: How much are you hoping to raise?

A: We have a target of £15,000, although we would like to think that we will be able to exceed this!

Q: What are you most looking forward to?

A: We are most looking forward to getting started with our events at Aldermore but also starting to work with the BDFA team. We want to help raise money to enable the charity to hold events and invest in the resources they require to carry out their activities. We are very much looking forward to working alongside such a special charity and to help raise awareness for this life limiting disease.

Thanks so much to all at Aldermore Bank – we look forward to working in partnership with you this year.

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



Hello from your fundraising team...



It's been a busy six months on the fundraising front, as you can see from this latest copy of the Batten Bulletin. Our partnership with Aldermore Bank is very exciting – perhaps your company could make us their Charity of the Year? We have an action-packed summer to look forward to, with our Ben Nevis trek, the London 10K and Batting for Batten coming up. For the sporty amongst you, get inspired by stories from marathon runners, cyclists and obstacle course participants. And don't forget to turn the world orange on June 3rd for Batten Disease Awareness Day. Contact us for advice, resources and encouragement at fundraising@bdfa-uk.org.uk or on 07876 682589, or visit our facebook page and website for more ideas. We love photos! Please send us pics of you having fun raising money for the BDFA.

Have a great summer, Kate and Gaynor

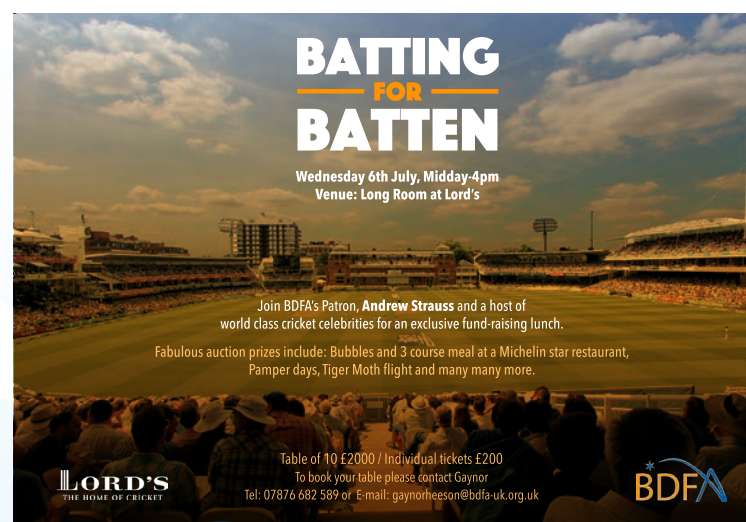
LORD'S THE HOME OF CRICKET

Batting for Batten

We are excited to announce that the BDFA is hosting a fundraising lunch in the Long Room at Lord's, on Wednesday 6th July.

Our Patron Andrew Strauss will be in attendance, and we hope many other cricket celebrities.

A table of 10 costs £2000 and individual tickets are £200. For more information please contact Gaynor at Gaynorheeson@bdfa-uk.org.uk



Hey Charlie The Voice of Batten

Don't forget you can still buy your physical copy of the wonderful song written by Ian Frazer Smith, and recorded at Abbey Road Studios with renowned choir Cantate. Visit the BDFA website and click on 'Shop' – only £5

Awareness Day June 3rd 2016

Spread the word and turn the world orange with Boris.

Watch out for information on our social media and our website.



Cabin Crew's fundraising takes off

Huge thanks to the people at British Airways. The Cabin Crew Entertainment Society (BACCES) chose the BDFA to be one of the recipients of their annual pantomime receipts – oh yes they did! Here's the cast of 'Sleeping Beauty' looking suitably glamorous.

Running all over the land...

So many of our supporters are getting fit whilst raising funds for the BDFA. Marathons, 10Ks, muddy runs, colour runs – you name it they've done it. Leading the way with her amazing programme of obstacle runs is Jenny Shackleton, who competes to raise awareness and money in honour of her niece Amber, who sadly passed away in February. We featured Jenny in the last Batten Bulletin – this year an obstacle race community group inspired by her will feature the BDFA as their charity of the year, and hopefully raise even more money! Thanks to Daniel from OCR Solomudders for choosing us. Also getting in on the mud race act are a team from BioMarin, the pharmaceutical company who already have a great relationship with the BDFA. They are running their Tough Mudder race this May, and we wish them luck.

Half marathons are all the rage too, with Tom Bletsoe, James Smith and Louisa Dimmick running in Bath, Surrey and Plymouth respectively this Spring. Ben Christofides ran a half marathon one day, then got on his bike and rode 112 miles through the Welsh countryside the next. Says Ben "the weather was great which made a big difference". So far Ben has raised over £1400; visit his JustGiving page to support him further.

Humanware Triathlon

The team at Humanware in Northampton, who specialise in equipment for the visually impaired, have 25 teams of people doing the London Triathlon in August – all for the BDFA! Keep an eye on our website and social media for more details.



Tom, Ellen and Laura



Ben

Francis is at it again!

Francis Mills was inspired to run the London Marathon for the BDFA after reading a local paper article about an affected family. Here's his story.



"I read about Harry having Batten disease, and after hearing how rare it is decided to fundraise for the BDFA, who helped me out with a lovely orange running vest. I thought, if I'm going to do it, I may as well do some good at the same time. The day itself dawned, getting up at 4am wasn't great, but the best bit was the crowd – it was a wall of noise all the way round. I saw family members around the route, in their bright orange t-shirts, but unfortunately missed Harry and his family who had also made the trip up to London. It was strangely emotional – I had a lump in my throat and watery eyes at times! I never felt like giving up, never once thought 'why am I doing this'. I was very proud of my achievement, getting a huge personal best time, and even sneaked onto BBC TV.

Since then I have done Bournemouth and Ipswich half marathons, the BUPA 10K and the Valencia marathon. And this summer I will be taking on a challenge on two wheels not two legs when I cycle from London to Paris. I get to have a great experience, and even see the end of 'Le Tour' the day after I finish! Everyone's a winner in my book (except my poor behind which may be a tad tender!)



When organising fundraising I have met some great people who go through so much in their daily lives, gained new friends and achieved – and hope to achieve – so much. So go for it, grab the opportunities by the hand – you never know who you may meet, or what you can achieve. But most importantly do it with a smile on your face!"

You can support Francis's London to Paris ride by visiting his JustGiving page – just search Francis Mills

Over to you!

You too can join in the running revolution! The BDFA has a few places left in the Vitality London 10K on July 10th. This race takes place over parts of the iconic London Marathon course taking in many historic landmarks as you run. We pay for your place, we ask that you raise a minimum of £250 in sponsorship. To register, or for further details, please contact Kate or Gaynor.



Thank you Tim



A very special thanks to Tim Martin for hosting a lunch to raise funds for the BDFA. Over the years our trustee Ellen Bletsoe has built up a great relationship with Tim and his colleagues, and this lunch has become an annual event.

This year, Ellen's daughter Laura, who is affected by Batten disease, attended, making a speech with her mum and even entertaining everyone by singing over coffee. The magnificent sum of £32,000 was raised, which is an incredible effort by all those who attended. Once more, thank you Tim!