

# 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](mailto: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 01252 416110 [info@bdfa-uk.org.uk](mailto: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.

## 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.



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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



Anyone that joined us for the walk last year will tell you that a wonderful time was had by all, with a little help from the excellent weather. For the first time we held the walk over a weekend and had two fun filled days of walking, camping, eating and relaxing.

This year's annual walk is on **27th/28th/29th June** at the beautiful Queen Elizabeth Country Park, Hampshire. There will be 17 miles of carefully selected walking routes over both days, all being wheelchair and pushchair accessible. Two days camping - £30. Two days no camping - £25. One day - £15. Under 16's FOC. Spaces are limited to 200 and last year was a sell out! **Book your place by visiting <http://www.bdfa-uk.org.uk/events/9th-bdfa-annual-walk>**



## Collecting Box Amnesty!

Have you got a collecting box hidden away in a cupboard collecting dust? If so, we would like to offer May as Collecting Box Amnesty month. Each collecting box can be worth £150 or more each year.



We know we have 60 boxes in various places so potentially they should be earning the **BDFA £9000 EACH YEAR**.

Can you please help us to locate each one? Do you have one in your local shop? If so please make sure it is emptied and the money sent to us or call for a pay in slip. If you have one at home please let us know and either send it in or perhaps you can ask your local shop, pub or post office if they can collect for us.

Either way please call or email to let us know where it is. **Nikki 01489 877319 / 07584 300086 [fundraising@bdfa-uk.org.uk](mailto:fundraising@bdfa-uk.org.uk)** With your help we can make sure that another £9000 can be spent on supporting those affected by Batten disease.



[www.bdfa-uk.org.uk](http://www.bdfa-uk.org.uk)

Batten Disease Family Association, the UK's only dedicated Batten Disease support and research charity

General: 01252 416110 Fundraising: 07584 300086 For more information see our website at: [www.bdfa-uk.org.uk](http://www.bdfa-uk.org.uk)

# Batten Fundraising Focus

## Welcome to Spring!



You will see from the Bulletin that we have lots happening during the next few months. Running, walking, cycling – there is something for everyone, so please make sure you ask all your friends, family and colleagues to choose BDFA this year.

If you are pressed for time, perhaps you can place a collecting box in one of your local shops. They only need emptying once every three months.

Our Spring message is **'Just do one thing for the BDFA this year'** and help to raise more money to support additional research into this terrible disease. **You can contact Nikki, James, Bel or Emma on 01489 877 139 / 07584 300086 to discuss ideas. We would love to hear from you!**

 Follow us on facebook and twitter 

## Who do you work for?

Most companies these days want to help charities in some small way. For every donation they make to a charity they are able to reduce the amount of tax they pay at the end of the year. Much better to give the money to the BDFA than the tax man.

**How can you help I hear you ask?** Simple. Wherever you live have a look around and see which companies are there. We are not a big charity, we do not serve thousands of people so we can't approach the big supermarkets or chains but for companies that only have twenty employees we are a brilliant partner choice. If we can find just 20 companies that would be willing to support us by holding some small events like bake sales, dress down or dress up days, sponsored walk or runs we could raise **£50,000!**

Please look in your local papers, see which companies are doing something charitable or next time you are out make a note of some of the companies near you. You can drop us an email: [fundraising@bdfa-uk.org.uk](mailto:fundraising@bdfa-uk.org.uk) with a list or cut out any press you see that might help us to gather information and post it to us at the usual address. **We really need you to help us TODAY.**

## Schools

**Does your school have non uniform days? Do you think you might be able to persuade them to hold one for us? Mufti days can raise anything from £100 to £1000 depending on the size of the school. Please ask your children's school if they will hold one day for us before the end of the summer term.**



## Bringing Light to Batten's Charity Ball

**Andrea Jessop organised a charity ball in October that raised an amazing £4500!** If the photographs were anything to go by then it looks like everyone enjoyed themselves and the night was a complete success.

Thank you to Andrea for doing such a great job organising the night and to all that attended and gave so generously to be able to raise such a fantastic sum.

## No beer, for a year!

Researcher and supporter Jon Cooper, has set himself a challenge to raise funds for BDFA... no beer for a year! Jon has taken a brave vow of sobriety for a whole year, which will be no mean feat for this Campaign for Real Ale (CAMRA) member and beer connoisseur. He will have a helping hand, with other researchers joining him for one month at a time.

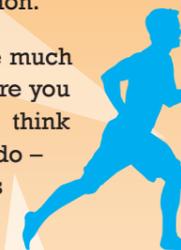
If you would like to sponsor Jon and his team, and send them some words of encouragement to help them fight temptation, you can visit their Just Giving page: [www.justgiving.com/Jon-Cooper-nobeerforayear](http://www.justgiving.com/Jon-Cooper-nobeerforayear).

# Batten Fundraising Focus

## British London 10k

Once again the BDFA have bought eighteen places in the British London 10k on the 13th July 2014. This is the largest untelevised run in the capital and takes you past the greatest landmarks in Central London.

We need a team to take part and raise much needed funds for us again this year. Are you a runner? Never attempted 10k but think you might like to? This is the event to do – thousands of spectators line the streets cheering you on, and it's a fantastic atmosphere.



**Sign up today by calling to reserve your place. 01489 877319 / 07584 30086 [fundraising@bdfa-uk.org.uk](mailto:fundraising@bdfa-uk.org.uk)**

Please tell all your friends and work mates and help us to have a full team flying the flag for the BDFA.

## Thank you

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



This unique night cycle event takes place on the **7th & 8th June 2014** and takes you on a 100km ride past some of the most iconic landmarks in London. Usual cost is £99, fundraise for BDFA and pay just £39.

We only have 7 places left, so don't delay! Enter online at the link below:

<http://www.nightrider.org.uk/>

Our team of ten riders will be a small group amongst the 2,000 people already registered for the event, so it will be quite a spectacle.

Our fundraising team will be on hand overnight to cheer and support so please use the link and sign up now to be a part of something special.

## Spring/Summer Fundraising Tips and Ideas:

Here are some ideas on how to raise some extra money, whether it's sponsorship for your personal challenge or just a little bit extra for BDFA:

### EASTER EGG HUNT

Why not invite friends and family to take part in an Easter egg hunt in your local park or forest? Be as creative as you like from finding lots of decorated chicken eggs to winning a giant chocolate egg or make it an Easter themed treasure hunt. Just ask everyone to pay £5 to take part in the chocolate quest!

### PARTIES AND PICNICS

Spring and summer present the perfect opportunity to enjoy food and fun with friends and family. Cook up a storm and invite people to join you for a BBQ, picnic or a themed party and ask them for a donation.

### MATCHED FUNDING

Many companies will match fund employees' fundraising. Don't forget to check with your employer to see if they will make a contribution to your fundraising, or even match it £1 for £1!

### TALK ABOUT IT!

Ordinary people do extraordinary things for BDFA. Please do share your story and your fundraising challenge/event with your local newspaper or magazine and ask people to contribute to your online fundraising. Writing a blog about your experience, why you are fundraising for BDFA or your personal journey in training for a gruelling event is a great way to inspire people to donate to your cause and social media is another great tool to get the word out.

**If you would like any other tips or ideas to help maximise your fundraising efforts, please do contact the fundraising team. We are more than happy to help you with some inspiration for raising that little bit extra.**

