

# How can you help?

## Your gift to bring light to Batten's

The Batten Disease Family Association supports families affected by Batten Disease through training days, our Batten Disease helpline and family networking scheme. We work to bring awareness to Batten Disease in the UK and each year hold a Batten Disease awareness weekend. We fund research into understanding more about Batten Disease in the hope that potential therapies can be found. Your gift will help to bring light to Batten Disease.

### YOUR GIFT TO BATTEN DISEASE

- I would like to make a donation of £ \_\_\_\_\_  
(cheques made payable to the BDFA)
- I would like to make a regular donation to help the BDFA.  
Please send me a standing order form.

### GIFT AID YOUR DONATION

To qualify for Gift Aid, you must pay an amount of UK Income Tax and/or Capital Gains Tax at least equal to the tax the charity reclaims on your donations in the appropriate tax year (currently 25p for each £1 given).

I, Title: \_\_\_\_\_ Forename(s): \_\_\_\_\_

Surname: \_\_\_\_\_

Address: \_\_\_\_\_

Would like to Gift Aid this donation of £ \_\_\_\_\_

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

### YOUR HELP AND SUPPORT FOR BATTEN DISEASE

- Yes, please send me information on the 2012 London 10K Run
- Yes, please send me information about the 2012 Sponsored Walk
- Yes, please send me information about volunteering

I would like further copies of the Batten Bulletin. Number of copies requested \_\_\_\_\_

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 Charity Manager: 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.

## A huge thanks to all our fantastic supporters!

We would like to thank the following people and groups who have recently donated to the BDFA:

Jazz on The Lawn, The Rotary Club of Thrapston and Raounds, Barking for Batten's, Madge Boxall, Elspeth Anderson, Sandie Mander, Algis Kuliukas, John Parkinson, Mr and Mrs David Graves, CHP Consulting, The Wilson family, Severn Trent Water Ltd, Richard Rayner, Mill Road Leisure and Cafe, Wendy Talbot, Laxton Junior School, Maurice and June Newbold, Brenda and Leo Sharp, Anna Pickering, Lucy Mackie, Sophie, Lucy and Henry Jenkinson, Charlotte Fisher, Cameron Brown, Frankie Brown, Alison Clough, Moore Stephens, Marion Bayliss, Neal Cumming, Stephen Harris, Ellen Bletsoe, Sara Whitwell, Sandra King and friends, Vicky Gettings and staff at Rainbow International, Chelsea Building Society, Coombe Infant School, Waitrose Community Matters Norwich, The Lynn Foundation, Richard, Ann and Mary Heathcote, Debbie Monks, Mr Howard, ISS-Shipping Sky Dive Team, Ben Marlow, Inken Whitehouse, Amy Lazenby, The Quentin Blake Award, Dr and Mrs O'Connor, Stephen Parkinson, Stanley Primary School, Oundle School, Heather Sickelmore, Holly Winder, Martin, Karen and Holly Freeman, E M Storer-Hamm, 1st Gedney Hill Guides, Shaun Andrews, Brian and Rachel Lake, Charlotte Maisey, Nicole Sandey, Company of Actuaries Charitable Trust Fund, Kieron Brace, Julie Arnold, Sheila Janman, Ray Scrivens, Nicky Rawlinson, Joss Dare, Landulph School, Landulph Under Fives Group, Hugo Chelton, Justin Whitehead, Mia Dailey, Jayne Lennon, Helen Gough and Mary Ioannou.  
Everyone who took part in Batting for Batten's: The Second Innings  
Everyone who took part in Our Baking for Batten's month  
Everyone who purchased Christmas Cards in 2011.

**Thank you! Your support makes such a difference.**

### A spare 10 minutes...

Often volunteering for a charity can seem like a massive chore. Well it doesn't need to be! With just 10 minutes of your time you can help to bring light to Batten Disease. Visit our website: [www.bdfa-uk.org.uk/volunteer](http://www.bdfa-uk.org.uk/volunteer) to find out ways that you can help us from updating Facebook, getting involved with Twitter to writing to MP's. Just 10 minutes of your time can help to bring a difference to Batten's today. **What can you do to help?**

### Diary Dates 2012

28th - 31st March: NCL 2012 Patient Organisation Conference  
22nd April: London Marathon  
19th May: Sponsored Walk for Batten's  
May: Ebay for Batten's month  
1st - 2nd June: Batten Disease Awareness Weekend  
8th July: London 10K Run (please note change of date)  
October: Baking for Batten's month



Please share this newsletter with friends or colleagues to further help support Batten Disease.

# Batten Bulletin

Bringing light to Batten Disease, the main paediatric neurodegenerative disorder in the UK



## I am Ashleigh and Alisha's Mum and always will be

On the 30th of April 2008 I learned that my daughter Ashleigh had Late Infantile Batten Disease. Until this day I had never heard of Batten Disease, after being told the prognosis of this disease came the news that as it is genetic that my youngest daughter Alisha had a 1 in 4 chance of also having Batten Disease.

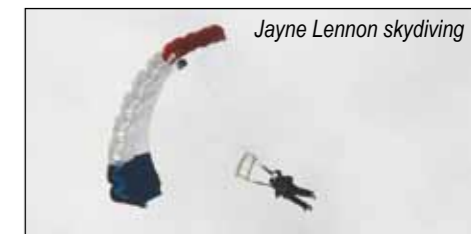
Ashleigh was born on the 15th May 2003 she weighed 8lb 2oz and was a very healthy little baby. It became obvious to me in the first few weeks that something wasn't quite right with Ashleigh, I couldn't even say what it was, but this is my second baby (Lucy is 16 years old) and it was just different. As time went by it was becoming more and more obvious that Ashleigh had learning difficulties, her speech wasn't developing, her understanding was poor and she was very obsessive and ritualistic. She didn't play like other children or with other children and I began to think she was on the autistic spectrum.

On the 5th of May 2006 just ten days before Ashleigh's 3rd birthday Alisha came into the world weighing a very healthy 8lb 13oz. Ashleigh was a little scared of her at first

but soon accepted her and adored her and nicknamed her "turtle". Alisha was very different to Ashleigh and I had no initial concerns about her like I had had with Ashleigh, she was very bright and was developing like any other child.

On the 30th of November 2006 Ashleigh had her first seizure, within that week she had three seizures and was put on an anti-convulsant drug. In the weeks and months that followed her epilepsy got progressively worse until she was having some kind of seizure activity every few minutes. She was referred for further tests which included a skin biopsy and 9 months after having the skin biopsy came the result which showed she had Late Infantile Batten Disease.

I don't really remember much about the days that followed Ashleigh's diagnosis. I was in complete shock. I remember I felt like my heart had been torn out and that feeling was worsened six months later on the 5th of November 2008 when our little "turtle" was also diagnosed with Late Infantile Batten Disease. She was just two years old and although her speech wasn't quite as it should have been for her age she was just like any other little girl.



So we have been living with Batten Disease for over three years now. Ashleigh is now 8 years old and this cruel horrible disease has taken almost everything from her; her mobility, her vision, her ability to eat or drink and her voice, however her personality and the sparkle in her eyes remain strong. Alisha is now 5 she has seizures but on the whole they are well controlled, it is becoming more difficult for her to swallow and she has been referred for a feeding tube. Her balance is deteriorating but she still runs, jumps and plays just like any other child, she helps Ashleigh by bringing her toys and helping her play with them, they have a very strong bond, they are "best friends".

I did a parachute jump with my friend Helen on the 18th September to raise money for the Batten Disease Family Association (BDFA). The BDFA for me are a wonderful support and have put me in contact with other Batten's families. They have supported the girls doctors, therapist and teachers, many of whom had never heard of Batten's. With this advice from the BDFA they are able to give my girls the best care possible.

I'm a single mum and although looking after the girls can be physically and emotionally draining I feel blessed and very proud to say that whatever happens and wherever we are "I am Ashleigh and Alisha's mum and I always will be".

If you would like to help families affected by Batten Disease why not look at [www.bdfa-uk.org.uk/sponsorship](http://www.bdfa-uk.org.uk/sponsorship) and you may find yourself enjoying the thrill of jumping out of a plane for Batten's!



# About Batten Disease and the BDFA

## From the Chairperson



Sam, James and Pauline

As I write this, in mid November, the weather is still mild (no snow - yet!), Christmas is approaching (far too fast - again!) and I can look back at yet another very successful year. The amazing fundraising efforts have continued to result in a steady stream of income. At any time, this would be seen as impressive but given the current recession, it is nothing short of a miracle and I have to thank you for all the things you are prepared to do to raise funds.

But the thing is, we need your help more than ever. Children continue to be diagnosed with this, one of the most devastating of diseases and they, and their families, need and deserve the best of support, just as the already diagnosed families do. We also need a better understanding of the disease and of course, improved treatment and ultimately, a cure.

We, at the BDFA want to ensure that all the great work that is currently happening goes on taking place – in fact as you would expect, we want more – even more research and to expand our support services.

A key part of our strategy is to recruit a Research Officer in 2012. This is a much needed role that will help us to fully investigate potential research and clinical projects that the BDFA should fund. There are many areas we would like to get involved in and to do that we need you all to keep on doing what you are already doing so well.

And if this is the first time you have heard of us – well, I hope you feel motivated by everything that you read in our Batten Bulletin and if you can donate, raise funds, volunteer, spread the word – please do!! **THANK YOU!!**

Pauline Docherty

## Batten Disease International Alliance News

In June, the BDFA hosted a number of international Batten Disease Support and Research organisations at the second meeting of its kind in London. In attendance were Beat Batten - Netherlands, Bee for Battens - Ireland, BDSRA - USA, Beyond Batten Disease Foundation - USA, Asociación Española de Familias afectadas por Lipofuscinosis - Spain, ContactPuntNCL - Belgium, Norwegian NCL Family Association - Norway, NCL Stiftung - Germany and BDFA - UK.

The meeting saw the formation of the Batten Disease International Alliance (BDIA), a newly formed group of Batten Disease Patient Organisations and Research Foundations. It was felt that working collaboratively would enable us to promote awareness, and share good practice in support resources for affected families. Collaboration will also enable us all to make the best use of research resources and opportunities to reach our goals of effective therapies and ultimately a cure. The BDIA will be formally launched and have its inaugural meeting at NCL2012 at the Royal Holloway, in March 2012.

You can follow the work of the BDIA on Facebook and on Twitter @BattenDisease. The new BDIA website is currently under construction.



## New Support and Fundraising Telephone Numbers:

Please keep an eye on our website for the new support and fundraising telephone numbers. And, don't forget you can also keep up to date about our work through our Facebook page: Batten Disease Family Association or by through our tweets @BattenDiseaseUK.

## 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 in communities across the country. We provide information, support and friendship. We seek to raise awareness of the disease and to facilitate research so that one day a cure will be found.

## Where your money is already helping

In October we held our Families Networking Lunch with AGM at Keech Hospice, Luton. Families from across the UK joined together to hear how hospices can support families living with Batten Disease as well as learning more about the scientific research taking place into Batten Disease and the start of the BDFA's PhD studentship. It is amazing how the work of the Batten Disease Family Association has grown since it first began in 1999.

This May the BDFA are subsidising family places at the first UK Batten Disease Conference (NCL 2012) bringing researchers and families together from across the world. It's going to be an exciting event and we look forward to updating you in the next issue.

## We DO need your funds to enable our work to grow.

# Batten Fundraising Focus



Walk for Batten's 2012

This year's Sponsored Walk for Batten's will take place on Saturday 19th May at Cannock Chase, Staffordshire. It is a beautiful location and our volunteers have chosen some fantastic walking routes to enjoy. As a walker you can choose to walk either the morning 5 mile walk or the full day 9 mile walk. The morning walk is fully accessible for wheelchairs and pushchairs. The day doesn't have to stop with the walk. The BDFA will be staying at a local hotel where we will enjoy an evening meal together with a quiz – it's a great social event and a good way to become involved in the Batten's family. To receive your 2012 Sponsored Walk for Batten's pack just email your details to: [fundraising@bdfa-uk.org.uk](mailto:fundraising@bdfa-uk.org.uk) or download the pack from: [www.bdfa-uk.org.uk/sponsorship](http://www.bdfa-uk.org.uk/sponsorship). **Why not encourage your work colleagues, friends and family to join in this great event and help to bring light to Batten's in 2012.**



Team Batten's in the London 10K

## Run for Batten's in the London 10K

We have 18 charity spaces in the London 10K Run which takes place on Sunday 8th July at 9.35am. It's a well organised running event where the route passes all the main London attractions. So if you would like the goal of running a new distance or would like to help bring light to Batten's by being part of Team Batten's just register your interest by emailing:

[fundraising@bdfa-uk.org.uk](mailto:fundraising@bdfa-uk.org.uk). We ask that each runner that takes part in Team Batten's raises a minimum of £250 per person and we can help you by offering fundraising advice as well as one of our lovely t-shirts to run in!

## Cycling through France

It sounds very gentle doesn't it... a nice cycle ride through France? Well not for Justin Whitehead and Hugo Chelton who have cycled 856 miles to help raise a massive £16,000 for the BDFA's work. Justin writes "We never saw a drop or hint of rain and were blessed by glorious sunshine. However best of all is that we have raised close to £16,000 and hoping for more towards Batten's. Thank you to all who sponsored us. And a big thank you to my long suffering family who deserve special mention!" **It's not too late to sponsor Justin and Hugo at: <http://www.justgiving.com/hugochelton>**



Justin Whitehead

## Can your company help Batten's?

Many companies enjoy supporting charities in a variety of ways from practical support of sharing their knowledge by becoming trustees or donating their time to volunteer for us through to funding our work. One of the best ways for a charity to be nominated for support is through an employee. Does your company offer a scheme like this? And, if it does, would you be able to suggest the Batten Disease Family Association to them? We can help you with any applications or information that may be needed. It's a really easy way to make a big difference to Batten Disease. Thank you.



## Batting for Batten's: The Second Innings

On Tuesday 29th November at The Embankment Gardens organisers put together a fabulous evening to help raise funds for the Batten Disease Clinical Nurse Specialist project. The evening was a great success with auction items, pledges and table bookings helping to raise over £80,000 to support this project. On the evening Ellen Bletsoe, BDFA Trustee, gave a moving talk about living with Batten Disease and Andrew Strauss with Allan Lamb spoke about the highs of the England Cricket Team in 2011. **Thank you to everyone who organised this event – in particular to Mike and Alex O'Connor. Thank you.**



Ellen Bletsoe

## Regional Press Club supports Batten's

Each year the Regional Press Club ([www.regionalpressclub.co.uk](http://www.regionalpressclub.co.uk)) supports a children's charity. This year the Batten Disease Family Association was fortunate enough to be their charity for 2011. In December Ellen Bletsoe, Fundraising Trustee, spoke about the BDFA's work at their Regional Press Club Dinner. This then began the evening's fundraising activities which raised an impressive £4,500 to help support the Batten Disease Clinical Nurse Specialist role.