

Help us make a difference...



"The BDFA has given me hope, encouragement and support and helped me recognize that good things and happy times can still be accomplished by Jo and James and the rest of the family."

Pauline Muncey, Mum

"We are an enthusiastic and growing group of professionals from a variety of backgrounds and disciplines, sharing a common aim of improving services for children and families affected by Batten Disease. We aim to work closely with the BDFA ... in order to respond to the needs of families and carers."

Dr Ruth Williams, Consultant Paediatric Neurologist and Chair of the UK Batten Disease Professional Interest Group

"The support of the BDFA is invaluable, not just in making it possible for us to do important work, but also giving us a real sense that we are working closely together with everyone affected by Batten Disease."

Dr Jon Cooper, Paediatric Storage Disorders Lab, King's College London and Chair of the BDFA Research Assessment Panel

Become a member

We welcome all affected families, friends and care professionals to register as members to make our national network and voice even stronger. If you think you can help or you need ongoing advice, information or support please contact us.

Become a Friend of the BDFA

Whether you are an individual or a big company have fun raising funds and awareness for a really worthwhile cause! We are a small charity for a rare disease so a little goes a long way. If you would like more information about fundraising in aid of the BDFA please get in touch or check out our website.

Find out more...

- I have a child/young adult with Batten Disease
- I am friend/relative of an affected family
- I am a carer/professional
- I am a company/organisation
- I am a member of the public

I would like to find out more about:

Name: _____

Address: _____

Email: _____

Phone: _____

I am making a donation today of £ _____

Send me information on making a regular donation

Cheques payable to BDFA.

If you are a UK taxpayer, we may be able to reclaim tax on your donation if you fill in your details and sign the declaration below:

gift aid it

I, Title: _____ Forename(s): _____

Family/Surname: _____

I am a UK Taxpayer and would like the **Batten Disease Family Association** (registered charity 1084908) to claim back tax on all donations I have made since 6th April 2000 until further notice, at no extra cost to me.

Signed: _____ Date: _____

NB: you should expect to pay at least as much income tax and/or capital gains tax this year as the BDFA will be reclaiming on your donation(s) (currently 28p for each £1 given).

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. You may inform us at **any** time if you do **not** wish to receive mailings from us about our activities and events.



BATTEN DISEASE FAMILY ASSOCIATION

Bringing light to Batten's

Registered Charity No. 1084908

a supportive, informative, national networking organisation for the families, carers and professionals giving care to children and adults with Batten Disease and for promoting awareness of, and research into, the disease

Batten Disease Family Association

c/o Heather House,
Heather Drive, Tadley,
Hampshire RG26 4QR
0115 965 4815

B DFA.info@btinternet.com
www.bdfa-uk.org.uk



What is Batten Disease?

The group of diseases known as Batten Disease (after the British paediatrician who first described it in 1903) or the neuronal ceroid lipofuscinoses (NCLs) are rare, genetic, progressive neurodegenerative, metabolic diseases that occur in children and adults worldwide. Symptoms include loss of vision, epilepsy and loss of abilities including walking, eating and talking. Our understanding of Batten Disease is improving all the time and work to develop new therapies is progressing well. However at present there is no cure or treatment that makes a significant impact on the progressive decline in bodily functions and inevitable early death.

A number of different forms of Batten Disease, including less common variants and a congenital form, are known. These share similar symptoms but progress at different rates and are all genetically different. It is important to know which gene mutation causes the disease in each individual. The types of Batten Disease are often classified by age of onset:

Infantile – onset between 6 months and 2 years.
Death normally occurs in mid-childhood.

Late infantile – onset between 2 and 4 years.
Death normally occurs between the ages of 5 and 15.

Juvenile – onset between 5 and 9 years.
Death normally occurs at any time from the late teens to the mid-30s.

Adult – onset normally before the age of 40.
Shortened life expectancy.

Who are the BDFA?

The Batten Disease Family Association (BDFA) was formed in 1998 by a small group of parents of children with Batten Disease with the help of seeAbility and Contact-a-Family. Registered charity status for our national support network was granted in 2001.

In 2003 we received grant funding from the Jeans for Genes Campaign to carry out research projects into patient support and clinical assessment to inform our support provision.

In 2006, we employed a part-time Charity Development Officer and restructured our Board of Trustees to support our essential work and ambitious plans for the future...

Our Mission Statement

THE BDFA'S VISION IS TO BRING LIGHT TO BATTEN DISEASE BY BEING THE CENTRAL POINT OF EXCELLENCE IN THE UK FOR SUPPORTING AFFECTED FAMILIES AND TO FACILITATE RESEARCH INTO THE DISEASE



Our main aim is that no family will go through the devastating journey of Batten Disease alone.

What do we do?

- provide a helpline for carers and professionals
- maintain a website
- put affected families in touch with other affected families
- signpost families and professionals to other supportive professionals
- provide educational conferences and supportive resources
- provide updates on research developments
- increase awareness of Batten Disease amongst the public, medical and research world.

What research do we support?

- understanding more about the disease process so that better support can be given to those affected
- identifying the genes and mutations that cause the disease
- understanding the functions of the genes and the effect on their activities of the different mutations
- developing model systems for understanding the biology of the disease and what changes are significant
- understanding exactly how the brain is affected as a first step towards one day slowing Batten Disease or stopping it
- the development of better diagnostic tests
- the development of potential therapies or new methods of treatment.