

# BDFA MEMBERSHIP APPLICATION/RENEWAL FORM

Please supply the following details so we can ensure our records are accurate and up-to-date:

New member\*  Member renewal\* (please indicate\*) Membership Number (if known) \_\_\_\_\_

Family/Surname:	First Name(s):	Title:
-----------------	----------------	--------

Organisation name and address:
--------------------------------

Town/City:	Postcode:
------------	-----------

Contact telephone number:	Contact email:
---------------------------	----------------

**Are you a:**  Parent  Carer/Friend of Family/Relative (please indicate relationship) \_\_\_\_\_

**or:**  Professional (Area of Work:  Social Care  Health Care  Education  Research)

Job Title:	Key words of area of expertise:
------------	---------------------------------

**In order that we can provide the appropriate support, if applicable, please could you let us know the following details about your child or children/young person affected by Batten disease and their siblings:**

Name(s)	Date of birth	Date of diagnosis	Genetic diagnosis eg CLN1, CLN2 etc

All these details are held confidential to the BDFA.

**We will send you our BDFA membership pack/renewal confirmation. So that we can include in it information relevant to you could you tell us/update us:**

- Would you prefer to just contact us as and when you feel you need support?  Yes  No
- Would you prefer to be contacted for support  By email  By post
- Would you like to receive your members' newsletter?  By post  By email
- Would you like to receive information on the BDFA Batten Disease Professionals' Services?  Yes  No
- Would you like to receive information about how you can fundraise for the BDFA?  By email  By post  
(leave blank if you do want this information)

**I wish to become a member of the Batten Disease Family Association and enclose a cheque/have made arrangements through Standing Order/PAYE/GAYE for payment of £15 for the annual membership subscription.**

If you would like to add a donation to your membership subscription please write the amount here £ ..... If you are a UK tax payer and would like to increase the value of your donation at no extra cost to you please tick here to receive a Gift Aid form

Please note that only UK members have voting rights at the AGM. Your membership subscription entitles one member of your household aged 18 or more to vote at the meeting. If you would like for each member of your household to vote please complete a form for each person.

**Signature**..... **Date**.....

If you would like to change your choices at a later date please call 07876 682589 or email [info@bdfa-uk.org.uk](mailto:info@bdfa-uk.org.uk). If you decide to stay in touch, we will keep you up to date with news about membership, products, our work and services. Your details will be kept safe and secure, only used by us, or those who work for us, and will not be shared with anyone else. We analyse information you provide, and about how you've helped us to decide what communications will be of interest to you, and to help us understand our supporters. We also use this information to run our operations, e.g. if you place an order or make a donation we will need your details to process those. If you would like to know more or understand your data protection rights, please read our privacy policy on the website.

## INFORMATION ON METHODS OF PAYMENT

Please make cheques payable to the BDFA and post to BDFA, 209-211 City Road, London EC1V 1JN  
If you would like to set up a regular payment to cover your membership subscription or to make further contributions to our funds, the most efficient method is to set up a standing order with your bank. The easiest way for you to do this is via your online banking account. If you would like the BDFA account to set this up or if you have any queries please contact us on 07876 682589 or email: [info@bdfa-uk.org.uk](mailto:info@bdfa-uk.org.uk)

## What BDFA membership offers families

We hope that through membership of the BDFA your family will feel supported in finding out more about your child's disease after diagnosis. We hope to work alongside you each step of the way, to give you information and confidence to manage the future and quality of life for your child and your family. We will be able to give you news of opportunities and developments in our understanding of Batten disease and potential therapies for the future.

Discovering that your child has Batten disease will have come as a great shock bringing a mixture of emotions: sadness, confusion, numbness, anger, guilt, isolation or bewilderment. You might be feeling overwhelmed at your lack of knowledge about your child's condition. Perhaps you felt you could cope but now things are just getting too overwhelming.

Whatever your feelings, feel assured that other members of the BDFA have experienced at least some, if not all, of them. We know how much it can help to talk to people who understand what you are going through.

## What the BDFA memberships offers professionals

If you are a professional, we recognise that working with a child or young adult with Batten disease and their family can be an intense and challenging time, but ultimately rewarding both personally and professionally. Being part of the BDFA will help keep you in touch with families and other professionals as an opportunity to share your experiences and learn from one another.

### **You are not alone.**

Please feel free to contact us Monday - Friday, 9am - 5pm. If you have a question, we will do our very best to answer it or point you in the direction of someone who can.

With your support we can bring light to Batten disease. Thank you for helping us to make a difference.

If you register as a member you will be helping other families and professionals. The more members we have, the wider and stronger our network and the louder our voice to raise awareness, seek funding and facilitate research in the hope that one day soon a cure will be found.



BATTEN DISEASE FAMILY ASSOCIATION

*Together we WILL make a difference*

Registered Charity In England and Wales 1084908 - Scotland SC047408

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



Filling in the form gives us your up-to-date details and permissions for data protection and mailings so we can offer you the support and information you would like.

Subscriptions go towards the costs of us keeping in touch. Pay by cheque each year or consider setting up a membership subscription by Standing Order as the most efficient way to renew your membership automatically each year.

If you have any queries or comments about BDFA membership please contact us on 07876 682589 or [info@bdfa-uk.org.uk](mailto:info@bdfa-uk.org.uk).

Your feedback would be much appreciated as it helps us to improve our services.

**Thank you.**