

B DFA 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*)

Family/Surname:	First Name(s):	Title:
House and Street/Organisation:		
Town/City:	Postcode:	
Contact telephone number:	Contact email:	

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

Professional (Area of work: Social Care Health Care Education Research).

Job Title:	Key words of area of expertise:
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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 like to be part of our registered members' family networking group? Yes No
(This gives families the opportunity to make contact with other families that are experiencing the journey of Batten disease, throughout the UK)
- Would you like to receive our registered members' e-bulletin? Yes No
(This is a bulletin with breaking news and other information of interest issued by email)
- How would you like us to send you our biannual members' newsletter? By post By email
- Would you like to receive information on the BDFA Batten Disease Professional Development Group? Yes No

So we know how we are reaching families and professionals and why they join us please could you tell us:

How you found out about the BDFA: Personal contact Website News report BDFA leaflet Info Sheet Other _____

What is your main reason for becoming/continuing to be a member of our Association?

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.

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

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.

INFORMATION ON METHODS OF PAYMENT

Please make cheques payable to the BDFA and post to BDFA, The Old Library, 4 Boundary Road, Farnborough, Hants. GU14 6SF

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 tax efficient method is to set up a standing order with your bank. A form to enable you to do this is enclosed and further forms are available to download from the BDFA website www.bdfa-uk.org.uk. If you have any queries please contact us on 01252 416110 or email: 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 BDFA membership 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 at any time. 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.



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 tax efficient way to renew your membership automatically each year.

If you have any queries or comments about BDFA membership please contact us on 01252 416110 or info@bdfa-uk.org.uk.

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

Thank you.