



24 March 2016

Dear Members and Supporters,

We are pleased to invite you to the 2016 BDFFA Family Conference which will be held on:

**Friday 18<sup>th</sup> - Sunday 20<sup>th</sup> November 2016**  
**from 9.30am – 4.00pm**  
**at the Holiday Inn**  
**Bridgefoot Quay, Warwick Road, Stratford-upon-Avon CV37 6YR**

There will be the opportunity to attend talks and workshops and to meet with other families and professionals as well as BDFFA staff and advisors. A more detailed programme will be available in due course. Lunch and refreshments will be provided on both days and there will be an evening meal and social event on the Saturday evening. There will also be a welcome drinks event with a pay bar on the Friday evening at the hotel.

Activities for children will run throughout the weekend with activities at the hotel on Saturday and a trips out on the Sunday. These will support affected children and their siblings giving them all the chance to get involved in fun activities. Support will be provided by fully qualified nursing and care staff from Nurses Plus throughout the weekend, as well as by other volunteers.

We have secured generous sponsorship for this event enabling a limited number of families to attend the conference (including hotel accommodation) free of charge. We therefore hope as many families as possible will attend.

If you would like to attend, please complete and return the enclosed Registration Form with a deposit cheque (see enclosed Terms & Conditions). If you will be bringing children please also contact Lucy Roose directly ([admin@bdfa-uk.org.uk](mailto:admin@bdfa-uk.org.uk) or by phone on 01252 416323) for the relevant paperwork. If children will be attending, please let us know as soon as possible so that we can discuss your child's needs in planning for the trips, even if your requirements change closer to the date.

Batten Disease Family Association  
The Old Library, 4 Boundary Road, Farnborough, Hants GU14 6SF  
For more information on supporting our work visit [www.bdfa-uk.org.uk](http://www.bdfa-uk.org.uk)  
Tel: 01252 416323 Email: [admin@bdfa-uk.org.uk](mailto:admin@bdfa-uk.org.uk)

Registered Charity No 1084908



We do hope you will join us for the weekend. Please return your registration as soon as possible and no later than Friday 14 October. If you are unable to commit early, please contact us anyway to let us know you would like to come, particularly if you will be bringing children who would like to go on the day out. This will be very helpful for our planning.

If you have any further questions at this stage, please do not hesitate to contact us.

With best wishes,

A handwritten signature in black ink that reads 'Andrea West'.

Andrea West  
Chief Executive  
Batten Disease Family Association

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## TERMS & CONDITIONS FOR FAMILY BOOKINGS

Free places to attend the BDFFA Conference are available to families meeting the following criteria. Please read the Terms & Conditions carefully.

- Funding is available on a limited number of places. These will be allocated on a first-come, first-served basis to those who are entitled as detailed below.
- Funding is only available to current Members of the BDFFA. Membership of the BDFFA is free of charge to families but please ensure you have completed and returned a membership form in advance. Membership forms can be downloaded from our website.
- Funding is limited to the “immediate family” of affected children. This includes parents, carers, grandparents and siblings but is limited in number. Please contact us to discuss your booking needs.
- All bookings will be made and paid for by the BDFFA. Bed and Breakfast is available for Friday and Saturday night if required. Lunch will be provided during the conference and an evening meal on the Saturday night. Any other charges will be payable by guests on departure.
- All bookings must include a £100 deposit cheque made payable to “BDFFA”. This will only be cashed after the event in the case of non-attendance when a booking was not cancelled before **midday on Wednesday 16 November** (see below). The actual cost to the BDFFA of accommodation for two adults and two children to attend the weekend with accommodation is in the region of £400 and in the past we have had to cover this cost for families who booked but did not attend or cancel in advance. We are sure you will appreciate that this is not good use of BDFFA funds. Of course we absolutely understand that children get ill and circumstances may change but we ask you to notify us about any changes needed to your booking as soon as possible to avoid costs being incurred.
- All cancellations must be advised in writing to Lucy Roose (admin@bdfa-uk.org.uk) by no later than 12 noon on **Wednesday 16 November** or the deposit paid at the time of booking will be cashed.

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