

# Agenda



## Living Life with Batten's

Thursday 29th March 2012

Royal Holloway College, London

### BDFFA Training Day for Professionals caring for children and young people with Juvenile Batten disease.

This course is suitable for teachers, nurses, therapists, social workers and all professionals involved in the care of children and young people with Juvenile Batten disease.

#### Morning

10.30 - 10.40am	Introductions and welcome
10.40 - 11.00am	Introduction to Juvenile onset Batten disease (CLN3 disease) – <i>Ruth Williams</i>
11.00 - 11.45am	Educational issues – 15 minute overview then Q&A session – <i>Barbara Cole</i>
11.45 - 12.00pm	Coffee
12.00 - 12.50pm	What are seizures and how are they treated? – 15 minute overview then the demonstration of emergency seizure management, Q&A session – <i>Ruth Williams</i>
12.50 - 1.00pm	The Role of the Batten Disease Family Association (BDFFA) – <i>BDFFA Family Support Officer</i>

**1.00 - 2.00pm**

**Lunch**

#### Afternoon

2.00 - 3.00pm	Talking to the children and other family members – <i>Melinda Edwards</i>
3.00 - 3.15pm	Tea
3.15 - 4.00pm	Preparation for the future – maintaining skills and well-being – <i>Sarah Kenrick and team</i>
4.00pm	Thanks and close of meeting

Organised by the Batten Disease Family Association • Registered Charity No. 1084908

T. 01252 416110 E. [info@bdfa-uk.org.uk](mailto:info@bdfa-uk.org.uk) [www.bdfa-uk.org.uk](http://www.bdfa-uk.org.uk)

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Name: .....

Position/Job Title: .....

Address: .....

Contact telephone number: .....

Email address: .....

Please complete the following to help us tailor this training event to your requirements.

How many children/young people with Batten disease are you currently working with? .....

What are your main aims/objectives for the day? .....

Please list any questions you may have? .....

Please give details of any dietary requirements: .....

## Further Information

- The booking fee of £50 must be paid in full prior to attending the workshop.
- Cancellation up to 14 days before the event will result in a refund of booking fee. A £5 administration fee will be deducted. Booking fees will not be refunded if cancellation is made within 14 days of the workshop taking place.
- In the unlikely event that the BDFA has to cancel the event, a full refund will be given.
- Payment may be made by a cheque made payable to "BDFA"
- Please return the booking form and cheque to **Andrea West, Charity Manager, BDFA, PO BOX 504, Fleet, GU51 9GE.**