

BDFA Family Networking weekend

Crown Plaza, Stratford Upon Avon



Friday 18th November 2016

Welcome reception 7.00pm we have exclusive use of G's Bar to meet with friends and catch up with special mystery guests.

Saturday 19th November 2016

During the weekend the "Reflection" room will be a quiet place containing the BDFA memorial.

Times	Main Programme	
9.30am	Registration and coffee	
10.00am	Introduction to BDFA Family Conference Weekend and AGM	
- 11.00am	BDFA AGM	
11.00am - 12pm	Care and symptom management for children with all forms of the NCLs (excluding CLN3) TBC	Exploring coping mechanisms in loss and bereavement: open session for everyone including ways of accessing local resources and support. Sally Flatteau-Taylor from Maypole Project http://www.themaypoleproject.co.uk/
12pm- 1.00pm	Diet options for children and young people with an NCL diagnosis. Emma Williams from Matthew's friends gives a session on how the charity supports families and the value of the	Batten disease research - updates on current projects (12.00-1.30) Dr Brenda Williams will provide and update on the current status of research with leading UK researchers presenting work on all forms of the NCLs. This session will be followed by breakout sessions with the researchers at their posters and will continue over the lunch break.

	ketogenic diet. There will be the opportunity to share your experiences and questions		
1pm-2pm	Lunch		
2pm-3.00pm	Education for young people with CLN3 (juvenile Batten disease) in collaboration with SENSE Barbara Cole, the BDFA education advisor, and her colleagues from SENSE (Ginny Matthew and Barbara Moore) will offer advice and strategies for families and for education professionals.	Diet options for children and young people with an NCL diagnosis. Suzanne Brown, Children’s nurse and member of the care team at Children’s Hospice South West in Devon explains blended food for enteral feeding via gastrostomy	2pm-4pm Bereavement reflection group A reflection group for parents who have lost a child, with space to talk through their experiences and feelings with others in a similar situation. Pre-booking at registration is required Sally Flatteau-Taylor from the Maypole project.
3.00pm - 3.30pm	Coffee Break		
3.30pm – 4.30pm	Education for young people with other forms of the NCLs in collaboration with SENSE Barbara Cole, the BDFA education advisor, and her colleagues from SENSE (Ginny Matthew and Barbara Moore) will offer advice and strategies for families and for education professionals.	“Rising to the Challenge of a Personal Health Budget for a child diagnosed with Batten disease” James Jeynes is the proud father of Lewis Jeynes who is a very brave 12 year old boy living in Doncaster who was diagnosed with Neuronal Ceroid Lipofuscinosis (Batten disease) on the KCTD7 gene in July 2014. Lewis’s parents have been rising to the challenge of creating the first Personal Health Budget for a child in the Doncaster region. This is their story and how to avoid some of the pitfalls to ensure your child receives the best possible outcome.”	Music therapy and children with an NCL Diagnosis The latest research has shown the importance and value of music for children and young people with Batten disease.. This hands-on workshop with Adam Ockleford demonstrates techniques for using music with affected children and young people.
4.30pm	Finish		

7.00pm Dinner at Holiday Inn Stratford upon Avon, and BDFA Quiz. Sunday 20th November 2016

Times	Main Programme	
10am	Registration and Coffee	
10.30am - 11.30pm	Clinical Trials TBC	Batten disease diagnosis and Carrier screening Dr Claire Beesley (Great Ormond Street Children’s hospital) and Heather Band will explain the procedures and genetics involved in screening. NCL International Registry and patient participation in pre-clinical studies Dr Ruth Williams (Evelina Children’s Hospital, London) will explain the DEM-Child registry and the importance of collecting data. Dr Kevin Mills and Professor Sara Mole
11.30pm-12.30pm	Your BDFA needs you TBC	Advanced care planning and palliative care Julia Hodgson from Together for Short Lives and Francis Edwards, a palliative nurse consultant at Bristol Children’s Hospital will lead a workshop for families on advanced care planning for their children and young people.
12.45pm–2pm	Lunch and poster viewing with authors	
2.00pm-4pm	Care and symptom management for children and adults with a CLN3 diagnosis TBC	Educating children and young people A drop-in session on how to access the best educational support for your child, EHCPs explained and what they mean in the classroom. What to consider in your school choice? Barbara Cole (BDFA Education Advisor) Harriet Lunnemann (BDFA Support and Advocacy Team)
4.00	Finish and thank yous	