



## Educating children and young people with a NCL diagnosis

**10<sup>th</sup> June 2016**

Barbara Cole (BDFA Education Advisor)

Harriet Lunnemann (BDFA Support & Advocacy Social Worker)

10.00	Welcome and Introduction Barbara Cole and Harriet Lunnemann		
10.10	The BDFA and the services it delivers to families and professionals who support them Harriet Lunnemann		
10.30	The Amber Trust – Music In Neurodegenerative Disease Project – Adam Ockelford. A new project looking at music and music therapy with children and young people with Batten disease.		
11.30	Coffee		
11.45	Key educational issues for children and young people with NCL diagnosis including the impact on memory and learning. Split session Barbara Cole and Harriet Lunnemann		
12.00	Speech and Language Therapy – Barbara Coward		
12.30	Using Moon for children with CLN3 – David Nelson Advance Skills Teacher	‘What it’s like working day to day with young people with Batten disease’ Aly Whelan	Anticipatory Grief for Professionals – Harriet Lunnemann
1.15	Lunch		

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)

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1.45	Epilepsy and Movement Disorders within Batten Disease – Barbara Csanyi, Research Fellow, Great Ormond Street Children’s Hospital
2.45	SENSE – An Introduction to SENSE and how to use Sensory stories and massage.
3.30	Sharing good Practice – Q & A Session
4.00	Close

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