



**BDF A FAMILY CONFERENCE AND AGM**

**At the VILLAGE HOTEL, COVENTRY**

**DRAFT PROGRAMME (subject to change)**

**Friday 16<sup>th</sup> October 2015** - Welcome reception 7.30pm

**Saturday 17<sup>th</sup> October 2015**

<b>Times</b>	<b>Main Programme</b>		
<b>9.30am</b>	<b>Registration and coffee</b>		
<b>10.00am-11.00am</b>	<b>Introduction to BDF A Family Conference Weekend and AGM</b> <b>BDF A Annual General Meeting</b> With Keynote speaker Dr Sara Mole and Heather Band (BDF A Scientific Officer) announcing the BATCure European Research Project		
<b>11.00-11.30am</b>	<b>Coffee break</b>		
<b>11.30am – 1pm</b>	<b>Education for children and young people with a CLN3 diagnosis</b>  <b>Barbara Cole</b> , the BDF A education advisor, and her colleagues from Sense ( <b>Ginny Matthew</b> and <b>Barbara Moore</b> ) will offer advice and strategies for families and for education professionals.	<b>“Rising to the Challenge of a Personal Health Budget for a BD Child”</b>  <b>James Jeynes</b> is the proud father of Lewis Jeynes who is a very brave 11 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.	<b>Open session</b> where you can bring your questions on benefits, grants etc to the BDF A Support and Advocacy Team.  New Family Folder collection  <b>Harriet Lunneman</b> <b>Barbara Cole</b>

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)

1pm-2pm	<b>Lunch with poster viewing</b>		
2pm-3.00pm	<b>Fundraising workshop</b>  The BDFA fundraising team are here to support you with all of your fundraising efforts and to offer advice and share ideas.  <b>Kate Shefford Gaynor Heeson</b>	<b>Education for children and young people with an NCL diagnosis (not CLN3)</b>  <b>Barbara Cole</b> , 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.	<b>Pharmaceutical Companies</b> <b>Heather Band</b> , BDFA scientific Officer will introduce the process of clinical trials and two pharmaceutical companies working in the critical area of treatments for the NCLs
			<b>Abeona Therapeutics (CLN3)</b>  <b>Michelle Berg</b>
3.00pm – 3.30pm	<b>Coffee Break</b>		
3.30pm – 4.30pm	<b>Symptom Management and care of children and young people with an NCL diagnosis Q&amp;A</b>  <b>Professor Paul Gissen (Consultant in Paediatric Metabolic Medicine)</b> <b>Dr Manju Kurian (Paediatric neurologist)</b> <b>Great Ormond Street Children's Hospital</b>	<b>Ketogenic diet and Matthew's friends</b>  <b>Emma Williams</b> <b>Matthew's Friends</b>	<b>Registries and the UK contribution to the Dem-Child Project</b>  <b>Heather Band and Dr Ruth Williams</b> talk about the importance of disease registries and how the information from children and young people in the UK can contribute to a worldwide understanding of the NCLs.  <b>European Education Project</b>  <b>Barbara Cole</b> (BDFA Education Advisor) is on hand for those families who would like to know more and/or participate the European Education project.
4.30pm	<b>Finish</b>		

### 7.00pm Dinner at Village Hotel, and BDFA Quiz

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Sunday 18<sup>th</sup> October 2015

Times	Main Programme		
10am	Registration and Coffee		
10.30am - 12.45pm	<p><b>NCL Science and current research updates</b></p> <ol style="list-style-type: none"> <li><b>Dr Brenda Williams</b> (BDFa Scientific Advisor) - overview of current status of NCL research.</li> <li><b>Heather Band</b> - BDFa research</li> <li><b>Sophia Kleine Holthaus</b> will present the BDFa funded keynote research on gene therapy to the eye.</li> <li><b>Professor Jon Cooper</b> - Enzyme replacement in a CLN1 mouse model</li> <li><b>Gina Brickell</b> will present the work from Dr Claire Russell's lab which has been funded by the BDFa and Freeman family on the CLN2 Zebrafish model and drug screening</li> <li><b>Emyr Lloyd-Evans</b> will introduce his work and specifically the CN5 project funded by the BDFa on behalf of Battle batten.</li> <li><b>Dan Little</b> on behalf of Professor Paul Gissen's lab will present the CLN5</li> </ol>	<p><b>10.30am-11.30am</b></p> <p><b>Session for bereaved families by Sally Flatteau Taylor from the Maypole Project</b></p> <p>Sally is the Founder &amp; Chief Executive of The Maypole Project, previous chair of Association of Bereavement Service Co-ordinators.</p> <p>She has many years' experience of counselling provision, including holistic support both for bereaved people and for families facing the diagnosis of a child with a life shortening or life threatening illness. Her work also includes training and supervision for counsellors and</p>	<p><b>10.30am-11.30am Basic Life Support Training</b></p> <p><b>Katie Hanson</b> Batten Disease Clinical Nurse Specialist</p> <p><b>11.30-12.45 Symptom and care management for children and young adults with CLN3 disease</b></p> <p><b>Sarah Kenrick</b> (Seeability, Heather House)</p>

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	project funded by the BDFFA on behalf of Batten Batten.	healthcare professionals.	
<b>12.45pm – 2pm</b>	<b>Lunch and poster viewing (with authors)</b>		
<b>2.00pm-4.30pm</b>	<b>Marketplace</b> A range of related professionals, charities and other organisations will be available to answers questions from and talk to families and those working with children and young people.		
<b>4.30</b>	<b>Finish</b>		

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