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**JOB DESCRIPTION OF THE BDFA FAMILY SUPPORT OFFICER**  
**Maternity Cover 1 year**

<b>JOB TITLE</b>	<b>Family Support Officer (Maternity Cover)</b>
<b>RESPONSIBLE FOR</b>	<ol style="list-style-type: none"><li>1. Developing, maintaining and promoting the Support services offered to families, carers and professionals involved with children and young people who have Batten Disease.</li><li>2. Implementing with the Charity Manager agreed strategic support objectives.</li><li>3. Providing a high quality, responsive service by the Charity to affected families and related professionals.</li></ol>
<b>RESPONSIBLE TO</b>	BDFA Charity Manager
<b>LOCATION</b>	Work generally from home with some travel mainly in the UK
<b>SALARY</b>	£13.40 per hour for 15 hours/week =£10,452/annum (£26,130 per annum pro-rata)
<b>HOURS OF WORK</b>	15 core hours/week plus some overtime for training and occasional weekend/evening work to support events. Some fixed hours/week, the rest can be flexible.
<b>ANNUAL LEAVE ENTITLEMENT</b>	75 hours/year (equivalent to 5 weeks part-time leave)
<b>DURATION</b>	The post is for 1 year
<b>CLOSING DATE FOR APPLYING</b>	The closing date for applying is 2 <sup>nd</sup> February 2012.

<b>JOB PURPOSE</b>	To play a key role with the Charity Manager in delivering the Charity's Support Services Strategy.
<b>BACKGROUND</b>	<p>The BDFA's objective is to be the central point of excellence in the UK for children and families living with Batten Disease. The BDFA also seeks to raise awareness and facilitate research into Batten Disease.</p> <p>Currently, the BDFA has a team of 4 members of staff: a Charity Manager, Fundraising Officer, Family Support Officer and Finance Officer.</p> <p>It now requires someone to provide maternity cover for the Family Support Officer Role. .</p>

## MAIN DUTIES OF THE BDFA FAMILY SUPPORT OFFICER

<b>SUPPORT SERVICE ADMINISTRATION AND DEVELOPMENT</b>	<ol style="list-style-type: none"><li><b>1. Managing the UK's Batten Disease Helpline</b><ul style="list-style-type: none"><li>• acting as a first contact point for support and information enquiries via telephone, post, message board and email;</li><li>• providing immediate emotional and practical support;</li><li>• recording and coordinating responses with referral to the relevant support link where necessary;</li><li>• monitoring follow-up outcomes and being proactive in offering further support;</li><li>• maintaining confidential database records of contacts made and support provided for reference</li><li>• reporting on service activity and areas for development;</li><li>• making the initial contact with families after diagnosis as part of the recommended positive action plan.</li></ul></li><li><b>2. Resource signposting and family-focused research</b><ul style="list-style-type: none"><li>• signposting families to the BDFA's professional advisors as part of the referral process or other relevant helpful organisations as indicated in the BDFA Referral Protocol;</li><li>• making effective links and developing partnerships with appropriate clinicians and care professionals, professional groups and other relevant organisations eg the National Educational Advocacy Partnership, to expand on the resources – Advisors and information - available;</li><li>• coordinating the action plan for the implementation of the BDFA Family Support Project recommendations;</li><li>• supporting the outcomes of the BDFA Clinical Assessment Project.</li></ul></li><li><b>3. Management and development of support information</b><ul style="list-style-type: none"><li>• proactively researching, collating, and drafting new written resources and revisions in liaison with various professionals and families e.g. on-diagnosis guides, disclosure guidance,</li><li>• coordinating updates of the Support section of the BDFA Referral Protocol, newsletter, website and member e-bulletins;</li><li>• maintaining stocks of information sheets and developing BDFA Library resources;</li><li>• archiving past newsletter articles and message board responses;</li><li>• checking/updating information on Batten Disease and the support activities of the BDFA held by other organisations on websites and databases worldwide.</li></ul></li><li><b>4. Linking families and professionals</b><ul style="list-style-type: none"><li>• coordinating and developing the BDFA Family Networking Scheme;</li><li>• supporting the BDFA Batten Professional Development Group – including maintaining e-contact groups and coordinating professional development and parent training days, organising accreditation, good practice dissemination;</li><li>• organising the annual BDFA family conference.</li><li>• Supporting the organisation and delivery of NCL 2012</li></ul></li><li><b>5. Coordinating and contributing to the BDFA Strategy</b><ul style="list-style-type: none"><li>• project-managing the Support-related strategy objectives;</li><li>• making presentations at Board meetings, AGM and other events;</li><li>• being proactive in communicating and increasing the</li></ul></li></ol>
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	<p>awareness of what the BDFA has to offer in support services to the members, professionals, media and the public.</p>
<p><b>GENERAL WORKING PRACTICES</b></p>	<ol style="list-style-type: none"> <li>1. Adhere to the requirements of the BDFA's Vision, Mission statement, Constitution and adopted Policies and Procedures.</li> <li>2. Develop an understanding of the children and young people who have Batten Disease and their needs in liaison with their families, carers and professionals.</li> <li>3. Act in a responsible and sensitive manner at all times, respecting the privacy of information stored and received and safeguarding the interests of affected families.</li> <li>4. Assist in maintaining a safe working environment and to follow the requirements of the BDFA's Health and Safety Policy, Home Working Policy and any other set of working practices established.</li> <li>5. Ensure compliance with statutory requirements laid down under: Data Protection Act, Equal Opportunities and Diversity, Charities Act, Protection of Children and Vulnerable Adults, Health and Safety at Work, The Children Act, any other relevant legislation including EU directives.</li> </ol>

**PERSON SPECIFICATION FOR THE ROLE OF  
THE BDFA FAMILY SUPPORT OFFICER  
(MATERNITY COVER FIXED TERM TO JANUARY 2013)**

The person appointed will be expected to have the key essential skills, knowledge and experience listed below (E for essential). The items under 'desirable attributes' (D) will also be useful for the BDFA and the post holder. However, candidates who do not have these desirable attributes should not be deterred from submitting an application for consideration.

<b>QUALIFICATIONS/ EXPERIENCE</b>	<ol style="list-style-type: none"> <li>1. Professional qualification in social work, nursing, counselling or community work or equivalent otherwise minimum of education to 'A' level standard</li> <li>2. Experience of direct work in delivering services or involvement in services to disabled children and their families</li> <li>3. Experience of managing multiple projects and events</li> <li>4. Experience in providing support/advice and information in an effective and manner responsive to individual needs and situations</li> <li>5. Experience of working within a voluntary organisation</li> </ol>	<p>(D)</p> <p>(E)</p> <p>(E)</p> <p>(E)</p> <p>(D)</p>
<b>KNOWLEDGE</b>	<ol style="list-style-type: none"> <li>1. Knowledge of local authority and health service structures</li> <li>2. Project and time management techniques</li> <li>3. Familiarity with statutory legislation and issues affecting children and young people with disabilities and their access to services and therapy opportunities</li> <li>4. Knowledge of Batten Disease</li> </ol>	<p>(E)</p> <p>(D)</p> <p>(D)</p> <p>(D)</p>
<b>ABILITIES TO:</b>	<ol style="list-style-type: none"> <li>1. demonstrate an understanding of the needs of people with progressive multiple disabilities and the impact on the family</li> <li>2. interact with families in a sensitive, empathic and empowering manner</li> <li>3. communicate and present effectively (written and orally) to a wide variety of audiences using a variety of media</li> <li>4. contribute ideas, develop new projects and services to meet specific needs</li> <li>5. research, produce and publicise publications and good practice</li> <li>6. collaborate with and develop good relationships with a variety of care professionals including clinicians, social workers, educational advocates and voluntary sector organisations.</li> <li>7. analyse and interpret a range of statistical and financial data</li> <li>8. organise information effectively and use ICT systems including office software, email, databases and the internet</li> <li>9. establish good relationships both internally within the BDFA and with other organisations as part of a team effort to achieve the BDFA's Vision</li> <li>10. work on own initiative under pressure and to seek advice and support as appropriate</li> <li>11. Willingness to travel</li> <li>12. be flexible to accommodate a varying workload with the ability to work outside prescribed hours as required to meet specific deadlines</li> </ol>	<p>(E)</p> <p>(E)</p> <p>(E)</p> <p>(D)</p> <p>(E)</p> <p>(E)</p> <p>(D)</p> <p>(D)</p> <p>(E)</p> <p>(E)</p> <p>(E)</p> <p>(E)</p>