



We are delighted to announce that three people are planning to stand for election as BDFFA Trustees at our AGM in November.

NEIL DUNFORD

Hello, my name's Neil Dunford. My daughter, Yanna, has the CLN2 variant of Batten Disease. Yanna has been enrolled on the BioMarin Clinical Trial since September 2014, which she started in Rome. We returned to England at the end of January 2016. Before diagnosis, I worked in retail banking for several years. Since returning to London I have been developing a Befriending Network for parents with disabled children with Scope. I am interested in promoting this model within the BDFFA, in order for parents to have a coherent structure of support from fellow parents within the Batten Disease community.

JAMES JEYNES

James is father of Lewis Jeynes, who was diagnosed with Batten disease in 2014. For many years Lewis remained undiagnosed and James hopes to make people more aware of Batten disease through his work with the BDFFA. He is Chief Executive of MemNet and its Founder Member. For over 24 years he has been working within the membership and associations sectors as a senior manager. He worked in public sector development roles overseas in South Africa, France, Switzerland, UAE, Barbados, Jamaica and Trinidad. James has a passion for creating and developing businesses and is currently an Associate Director with Advantage Public Services, Director of Executive Office Ltd, Director of the Football Argument Ltd and a proud Fellow of the Royal Society of Arts. In his spare time James is a Trustee of The Lewis Jeynes Fund and an Advisor to the NHS England Personal Health Budgets Team.

ROGER COLE

Roger Cole worked in the British Telecom development department on remote computer management and control of equipment and retired in 2006. He has many years' experience writing technical specifications and seeing through contracts from tender to deployment. Roger is putting his skills to use in supporting the smooth running of the BDFFA office.

Roger has had involvement with BDFFA through his wife Barbara Cole who works as an education advisor volunteer with the BDFFA. Through this he has met a number of families around the UK. His leisure activities include narrow-boating and travelling.