



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

### **DR RAHUL DUBEY**

I would like to introduce myself for election to the the post of Trustee member of the BDFFA. I am a medical graduate from India and migrated to UK in 2004 for Higher Education in medicine. My wife Swati joined me in 2006. We were blessed with our son Kavyansh in 2013. Unfortunately, Kavyansh was delayed with his milestones and in March this year he was diagnosed with CLN2, Late Infantile Batten disease. We are very fortunate that he got a place on the BioMarin-funded early access programme of the Enzyme Infusion therapy.

I have recently taken a Consultant position within NHS in London. In my spare time I hope to play an instrumental role in educating parents with the clinical aspects of Batten disease, to improve their understanding of the disease process. I hope to work towards getting the CLN2 enzyme replacement treatment commissioned in the NHS. I will be collaborating with the BDFFA to reinforce our case before the NICE panel.

### **AMANDA MORTENSEN**

Amanda has 12 years' experience in the voluntary sector, 20 years' experience as a journalist and 10-years' experience as a school governor. She has four children the eldest of whom has Lennox Gastaut, a complex and life threatening epilepsy syndrome, alongside severe learning disabilities and autism.

Her voluntary sector experience includes running Face 2 Face, a befriending project that provides emotional support for parents of disabled children through 1:1 and group work. The service was part of the national disability charity Scope and has recently been taken over by Amaze, a local charity in Brighton. It has a team of twenty volunteers and reaches around two hundred families a year. Amanda has also been Chair of the Parent Carer Council in Brighton and has represented parents on key local strategic groups, directly influencing decision making, particularly in the health sector. She set up a local outreach project supporting families in the most deprived areas of the city and this now runs as monthly coffee mornings as part of Amaze. Ten years ago, Amanda set up a parent-led preschool group for families with disabled children called Sweet Peas which is still thriving.

Amanda Chair of Governors of a local primary school and a parent governor at a local special school. She also holds a city-wide position as parent governor representative for the Children, Young People and Skills Committee, a key strategic group. Amanda is also a freelance journalist, having spent over a decade in trade and women's magazines, most recently as Commissioning Editor of She magazine.