



Batten Disease Family Association Safeguarding Policy

The Batten Disease Family Association (BDFA) exists in order that no family should walk the path of Batten Disease alone.

Our primary commitment is to ensure that every child, young person and adult is enabled to live their life fully and to their maximum potential.

- We are a centre of excellence and the national patient organisation for the UK.
- We work holistically with the whole family, understanding the complex impact of Batten Disease on every family member.
- We advocate and dynamically challenge individual practitioners and multi-disciplinary teams across health, education and social care.

Our work is underpinned by four strategic pillars:

- Advocacy
- Care and support
- Research
- Community

Fundamental to our person-centred ways of working are:

- Being professionally caring and kind
- Being trustworthy and reliable
- Being empathic and receptive
- Being an active listener and deeply respectful

The life-lived dimension of our work is a driving force in our work with families; they work closely with us, thus reflecting our 'family association' in a meaningful way.

Governance and Management

Our Board of Trustees owns its accountability for safeguarding with regards to:

- The staff team
- The children, young people, adults and families we serve

Their commitment is demonstrated by the allocation of time, finances and resources. This ensures that safeguarding is both current and meaningful.

The named Trustee for safeguarding is **Dr Zlatko Sisic, Chair of Trustees**

The **Head of Fundraising, Liz Brownutt** is the DESIGNATED SAFEGUARDING LEAD (DSL) for safeguarding for the BDFA at a strategic level. She works closely with the Board of Trustees to ensure that the strategic vision is translated into effective day-to-day practice.

Safeguarding at an Operational Level

The operational DSL is **Family Support Partner, Sarah Kenrick**. In Sarah Kenrick's absence, **Jo Nightingale** or **Liz Brownutt** deputise.

All members of our Designated Safeguarding Team attend professional training at Level 3, (Groups 4/5), to equip them to fulfil this role. Professional learning and development is updated at regular two-yearly intervals, in step with standards across the wider Children's Service workforce.

In addition the DSL, the Family Support Partner, Sarah Kenrick, calls upon support, advice and expertise outside of BDFA, as and when required.

How Safeguarding is embedded in our work

Our duty of care includes recognising the interface between family support and advocacy on behalf of the child, young person or adult. This includes using our professional expertise in noting a marked change in the health and well-being of the individual.

We own our responsibility to guard against families becoming over-dependent on us.

Often the first indicator of a safeguarding concern arises through parental ill health or a direct disclosure made by that parent and/or family member.

We recognise our safeguarding responsibilities across a number of areas of work at an organisational level.

Safer Recruitment and Selection

The Safer Recruitment and Selection Consortium guidance is embedded in our practice in regards to manager, practitioner and volunteers. Equally, all family-facing managers, practitioners and peer befrienders are subject to DBS enhanced checks.

Induction and CPD

The induction of team members is a stepped process within the first months of employment including level two training in safeguarding and thorough introduction to all BDFA policies. We allocate a training day per year for all staff members with the aim of building on prior knowledge and developing professional practice.

How we communicate our safeguarding role to families

We routinely talk to families about our safeguarding role from the beginning of our professional relationship and at regular intervals. We also take time to explain how professionals might misuse their professional position of trust within families including an abuse of professional power.

Information sharing and confidentiality

We encourage a professional and rigorous approach to the sharing of information. We understand the difference between information sharing and confidentiality and bring discipline to implementing this in day-to-day practice.

Recording

We have a comprehensive recording system to note our interactions with all families and professional services. In addition, we record our interactions on family work on a secure database, with restricted access to key managers. We have a secure area for safeguarding concerns and record individual incidents, which may or may not go on to meet the threshold for a safeguarding referral.

Lone Working

The BDFa Lone Working Policy specifies practitioners' responsibility to conduct a risk assessment at the first visit and periodically thereafter, in consultation with their manager. When contacts are on zoom, attention should be given to what can be seen, heard and 'sensed' and not, as opposed to assuming that the interaction is a reflection of what may be occurring in the household. When conducting home visits staff must inform their line manager upon arrival and departure from the home. In a similar vein, staff members attending events alone should check in with a colleague upon arrival and departure.

Supervision

The BDFa has a structured supervision policy that provides the opportunity for reflection on practice, a focus on professional development, including key elements of the professional role. In addition key senior staff receive clinical supervision.

Keeping our safeguarding approach current

We pride ourselves on keeping abreast with modern safeguarding practice, regularly scanning for developmental trends, strengths oriented models and evidence-based approaches. We do this through:

- Ensuring that safeguarding is a standard agenda item on the quarterly Board of Trustee meetings and the monthly staff team meeting.
- Initiating interprofessional discussions with our national and regional partners including Great Ormond Street Hospital (GOSH) and key consultants in Batten disease.
- Innovating in the area of interprofessional understanding of a complex and unpredictable disease, to instil a meaningful understanding of change for families.

Volunteering

We recruit volunteers to a high standard and provide regular supervision and support. We acknowledge the lived experience of many of our volunteers, by drawing on their strengths and individual family journeys and assisting in establishing effective professional boundaries. We do this through ongoing contact within our Batten staff team, attendance on our training programme and regular support by our Peer Befriending Coordinator where appropriate.

BDFa Chair of the Board of Trustees

Zlatko Susic

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Date: 5th July 2023