



## Board Member

### Summary

The Batten Disease Support and Research Association is the foremost Batten disease support organization. We serve families in the United States and 38 additional countries. With nearly 35 years in operation, BDSRA supports patients and families throughout their Batten life cycle. Board Members are asked to advocate and help to resource the organization, which is crucial to BDSRA work. Each Board Member is a key collaborator of the BDSRA team and is an invaluable resource to the Executive Director.

More information about Board responsibilities can be found in the Bylaws.

**Job Description:** The **Board Member** is directly accountable to the Board President and is responsible for the following:

- Serve for a minimum of 3 years, renewable and can be served consecutively.
- Help to set policy and goals for the implementation of BDSRA programs in accordance with its stated goals.
- Provide oversight in the affairs of BDSRA, by regulating its economy, approve expenditures and commitments according to Board policy.
- Participate in searches, hiring, terminating, and evaluating the Executive Director.
- Attend quarterly meetings of the board, which may include in-person and remote meetings annually. The Annual Board Meeting held at the Annual Family Conference is required in person, unless excused. Other meetings may be scheduled as needed.
- Elect board officers.
- Participate in subcommittees of the Board.
- Advocate for BDSRA and its mission.
- Provide support for the organization, families and research needs of Batten disease.
- Resource the organization with knowledge, relationships, and fundraising.
- Work with the Executive Director as needed for the good of the organization.

### Minimum Qualifications:

- Must be a family member or advocate for Batten disease.
- Must be willing to travel at each member's own expense.
- Experience in non-profit, mission-driven organizations (healthcare focus) is a plus.
- Must be able to attend 4 meetings per year.