Beyond Batten Disease Foundation


This report represents Beyond Batten Disease Foundation's responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.

Beyond Batten Disease Foundation
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Mission:
Beyond Batten Disease Foundation was established to eradicate juvenile Batten disease.

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1. What are we aiming to accomplish?
Eradicate Batten disease and hundreds of other rare diseases like it that affect children. BBDF will utilize a two-pronged approach: 1) prevention and diagnosis and 2) raising awareness and funds for research for treatments and a cure for Batten disease.

2. What are our strategies for making this happen?
Continue to lead and elevate Batten research Engage donors actively in our mission Engage all with a passion and interest in Batten and related diseases Ensure continued strong leadership of the foundation

3. What are our organization's capabilities for doing this?
Over 90% of medical research foundations lack full-time scientific leadership. In 2009, BBDF hired neurobiologist, Danielle M. Kerkovich, PhD, to determine the “State of Science,” a comprehensive repository of juvenile Batten research studies throughout history. By identifying gaps in our understanding she has designed a plan for clinical trials that starts with the most promising research available and avoids repeating past efforts. We have developed a comprehensive research strategy elements of success that informs everything we do. Our efforts have increased the average grant for Batten disease research from $40,000 to $100,000, raising awareness of and interest in the disease. We have implemented a thoughtful, deliberate and strategic approach to funding research. We have instituted an objective review process to ensure that all grants have potential for treatments. By hiring experts, consulting and collaborating with like-minded groups such as the American Academy of Neurology, other neurodegenerative disease foundations, and other Batten families, we are pooling the resources and funding necessary to drive treatment-based research. For us, there will only be one clear measure of success: providing treatments and a cure for Batten disease.

4. How will we know if we're making progress?
We have developed milestones for every step in our prioritized research portfolio and we have established fundraising goals to complete clinical trials by 2020.

5. What have and haven't we accomplished so far?
BBDF is extremely proud of our accomplishments and the great strides that have been made over the past five years. We have advanced quickly and more efficiently and cost effectively than most other groups. Today, we can identify mistakes in the DNA that cause juvenile Batten disease, allowing us to understand much of what goes wrong in the cells. Researchers are even able to slow the disease in animal models. However, we know the battle is not over yet. Through BBDF funding, researchers have identified six potential compounds that may be used to treat children with juvenile Batten disease and are looking for more. We are preparing for clinical trial success by engaging world experts in drug discovery, validation, and approval to ensure we stay on track. With their help and the support of our donors, we are building a structure that funnels promising research to clinical trials until children and their families no longer have to confront this terrible disease.