BDSRA foundation

2024 Impact Report

Batten Disease

Support + Research + Advocacy

Dear Friends and Supporters,

Each year, we are reminded that progress happens because of people — families who inspire us, researchers who persevere, and advocates who raise their voices for change. In 2024, the Batten Disease Support, Research, and Advocacy Foundation strengthened its mission across all fronts: supporting families, advancing research, and amplifying advocacy for the Batten community.

Family Support

Because of your generosity, $116,932 was invested directly into programs that meet families where they are — offering guidance, connection, and relief. Our new Director of Family Support expanded reach across the U.S. and Canada, while 38 family grants totaling $42,784 provided tangible help to those in need. Together, we gathered 337 attendees at our Annual Family Conference and 201 at our Family Parties — moments that remind us of the power of being seen, heard, and supported. We also strengthened our clinical network, funding 9 Centers of Excellence and Affiliates with $238,314 to ensure families receive expert care close to home.

Research

In 2024, we continued to drive scientific discovery and collaboration. With 133 new family registries and $94,340 in research funding, we expanded data critical to understanding Batten disease. Our research community — 130 strong — contributed 26 abstracts and presentations at our Annual Plenary, produced 1 peer-reviewed publication, and has 5 additional manuscripts in progress. Through 22 grant requests totaling $1.2 million USD, BDSRA continued to represent the top 12 research priorities identified by our families and experts alike.

Advocacy

Our advocacy efforts reached farther than ever before. In 2024, 832 advocates sent 2,332 messages to Congress, championing newborn screening and access to care. The community's energy shone during International Batten Disease Awareness Day, with 954 donations, 34 teams mobilized, 30 T-shirt designs submitted, and supporters from 46 states generating over 110,000 page views — proof that our collective voice is being heard.

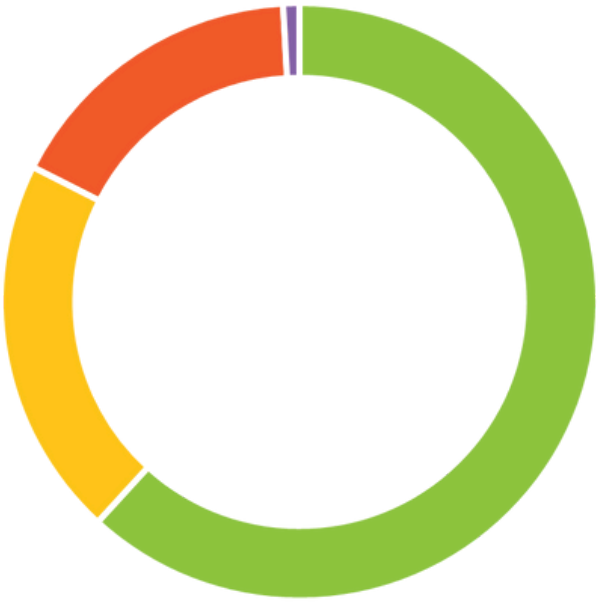
Every number in this report represents a story of hope, connection, and determination. Thanks to your unwavering belief in our mission, BDSRA continues to stand as a trusted source of information, a partner in research, and a steadfast advocate for every family affected by Batten disease.
Together, we are building a stronger path forward — one filled with progress, partnership, and promise.

With heartfelt gratitude,

Amy Fenton Parker
President & CEO

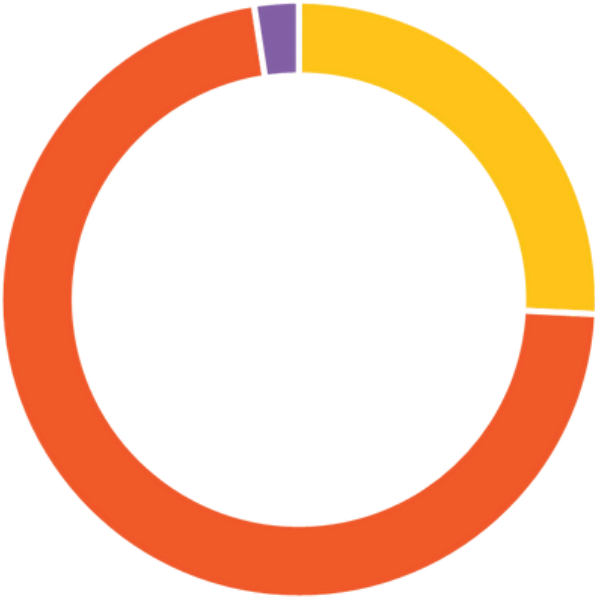
Financial Impact

Donation Summary



- Greatest Need: $349,978.01
- Support: $116,931.53
- Research: $94,340.00
- Advocacy: $5,000.00

Grant Summary*



- Research: $119,157
- Support: $42,784
- Advocacy: $4,000

*This includes grant funding from the ForeBatten Foundation for the Fore the Journey grants.

BDSRA foundation

Batten Disease Support + Research + Advocacy

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