

2019-2020
IMPACT REPORT



TURNING BACK THE CLOCK

The world as we know it today is vastly different from two years ago. It's as though time stopped at the end of 2019, and many of us would rather skip 2020 altogether. What we learned, though, was resiliency. We learned how to work around, how to connect with our phones and our computers, how to move forward without moving anywhere.

While time stopped for many of us, BDSRA plowed forward. The miles covered in 2020 didn't come close to the miles traveled for advocacy in 2019, but so much progress was made. The first virtual conference connected Batten families from around the world with more than 700 registrants. The new website was launched, and the first of many virtual gatherings were held. The years of 2019 and 2020 have stories to tell our community.

Since then, the pendulum has swung forward, bringing new staff to stand on the shoulders of those who served BDSRA before us. We have the benefit of using all the new tools developed and acquired to move through 2021 and beyond, and we look forward to the time when we can share those accomplishments. For now, as we turn back the clock to 2019 and 2020, let us celebrate that BDSRA never stopped supporting, advocating, and providing for research for our community.

With Hope,



AMY FENTON PARKER
BDSRA PRESIDENT & CEO



MEET THE STAFF AND BOARD



BDSRA STAFF 2021

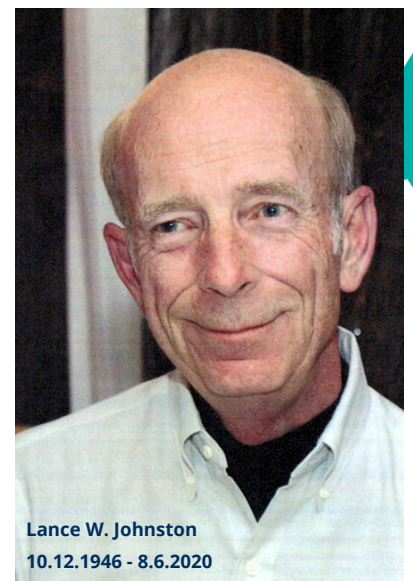
Amy Fenton Parker, President & CEO
Morgan DeBoth, Vice President of Support & Advocacy
Colin Monteith, Development Coordinator
Audrey Albright, Marketing & PR Coordinator
Grace Hunter, Paraclete Planning LLC

BOARD MEMBERS 2021

Darlene Royalty, Chair	Tony Ferrandino	Rene Martinez
Barbara Wuebbels, RN, MS, Vice Chair	Kate Haller	Barbra McDonough
Bob Jensen, Treasurer	John Ireland	David Pearce, PhD
Donna Fogle, Secretary	Trent Lewis	Fred Surrey
Brock Benroth		

REMEMBERING LANCE

The community lost a dear friend in Lance Johnston in 2020. Lance was the first Executive Director of BDSRA, and he helped to grow the organization into what we know today. In addition to the many accomplishments he had in life, Lance remembered BDSRA in his will with annuities.



CONNECTED BY A MISSION



SUPPORT

FORE THE JOURNEY FUND

7 FAMILIES SERVED

Fore The Journey Fund is a joint collaboration with BDSRA and ForeBatten Foundation which launched in Fall 2020. This unique grant offers Batten families experiences, memberships, and gifts in the hope of providing happy moments. Requests are as unique as the families applying and are aimed at bringing families joy.



Fore the Journey fund supplied Harry and his sister a Kindle with an audiobook subscription.

“
Thank you for putting extra smiles on my son’s face. Every smile means so much. This is amazing what BDSRA and the ForeBatten Foundation is doing for all Batten families.

Thank you!
- Jennifer N.

”

BRINEURA

2020 brought with it a close to our collaboration with BioMarin and the Brineura Trials here in Columbus, Ohio. Six children were involved throughout the process and were housed here in Columbus, with two being added during expanded access. Our partnership with BioMarin allowed us to advocate for adequate housing, care, and treatment throughout the clinical trial process.



EDUCATIONAL BOOKS

As the completion of a project started in 2014, we ordered and received 500 books on JNCL and education. It is our belief that the book will be helpful to families and teachers of every form of Batten disease. We brought 6 of the authors to the 2019 BDSRA conference in order to present the book to families, and we gave out all 50 books that we brought with us. If you'd like a copy of this book, email info@bdsra.org.

BDSRA'S LAUNCH OF VIRTUAL EVENTS

2020 changed a lot for not only our families, but our organization. We rely on connection with our families to fuel our support and advocacy efforts and just like the rest of the world, we moved to virtual to stay connected. The 2020 Annual Family Conference was the largest attended conference with 700+ attendees spanning 15 countries!

We also launched head first into new virtual programming.

- Ask-An-Expert
- Quarterly Grief Chats
- Seasonal parties for SIBS and Affected Children



For more information on current events, check out our events page on Facebook.

“
FAMILY FEEDBACK: 2020 BDSRA VIRTUAL FAMILY CONFERENCE

“Thank you BDSRA for getting this going virtually and including those of us who have not been able to attend the conference before. I’m glad to have attended as much as I could and make the connections I did.”

- Katelyn St. Gelais, Batten SIB

“Thank you so much for such an amazing conference, we have learned so much over the past two days and have loved connecting with people across the globe.”

- Lucy Carrol

”

RESEARCH

BATTEN RESEARCH UPDATE

Dr. David Pearce

The COVID-19 pandemic has obviously had far reaching consequences across all aspects of life. Research is no exception. Early on during the pandemic, research laboratories as well as hospital programs involved in clinical trials, were no different than anywhere else in regard to the application of social distancing and masking policies. It seems so long ago now, but even early on at the height of the pandemic these facilities were also closed down for periods of time.

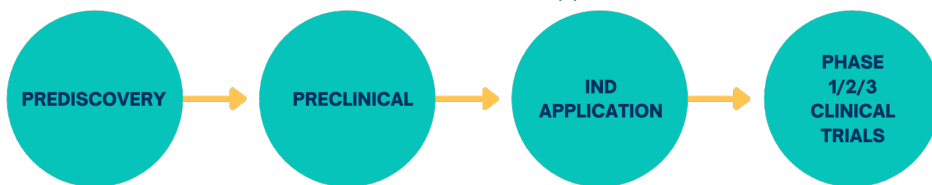
Thus, from the more academic science-based discovery side of things, bench and research with animals was slowed and, in some cases, halted. Perhaps more consequential was the fact that clinical trials which must occur in a clinical or hospital setting were either postponed or put on hold for a variety of conditions. Batten disease was no exception to this.

Early on, the world publicized lack of PPE and medical staff was redirected to managing COVID-19. While the severity of COVID-19 was waning, how the prioritization and execution of clinical trials is evaluated is ongoing.

BUILDING THE FUTURE OF RESEARCH



BDSRA's families have been contributing to the creation of these building blocks for over 30 years. Families have given blood samples, skin punches, and other bio samples at Annual BDSRA Conferences for years. Batten families have flown to the University of Rochester to be interviewed for the Natural History Database or sent blood spot cards through the mail. Many families have even held fundraisers to allow BDSRA to fund animal models- a needed practice for testing new treatment studies in order to be approved for clinical trials.



As the only patient advocacy organization in North America serving all forms of Batten, we know that funding these projects is vitally important for the entire community. These universal research tools are important for researchers studying any form of NCL. It is important to BDSRA that we continue to fund and facilitate projects that evolve, improve and expand upon these components that are crucial to Batten research. As a community, we are united by these research objectives, and BDSRA is dedicated to building and maintaining the integrity of these operations that would not be possible without the generosity of our donors.

2019 RESEARCH GRANTS*

Elena V. Batrakova, University of North Carolina at Chapel Hill (CLN2)
Milen Velinov, New York State Institute for Basic Research in Developmental Disabilities (CLN4)
Thomas M Wishart, Roslin Institute, University of Edinburgh (CLN1, CLN5)
Heather Adams, University of Rochester Medical Center (CLN2, CLN3)

** The constraints of COVID-19 on research laboratories, as well as hospital programs involved in clinical trials, necessitated a grant hiatus for 2020.*

100,614+ MILES TRAVELED
**FOR SUPPORT,
RESEARCH AND
ADVOCACY
IN 2019**

ADVOCACY

RARE DISEASE WEEK ON CAPITOL HILL



Rare Disease Legislative Advocates (RDLA), a program of the EveryLife Foundation for Rare Diseases, brought together over 900 patients, caregivers and friends in Washington, DC for a week of events dedicated to empowering legislative advocates. During the week of February 25th-28th 2020, rare disease advocates had an opportunity to meet with Members of Congress and to learn about policy updates and best practices for successful advocacy. We were very excited to have had so many Batten families join us in Washington DC for rare disease week! For some of them, it was their first time advocating on the hill. Jarrod and Jessica Dickson share their experience with us: *"This was our first time attending the event. We were able to learn key information not only for advocating on the hill but how to advocate in our home state. We look forward to continuing the conversation with our local representatives. It was extremely heartwarming to see so many people there, all with the goal of raising awareness of rare diseases."*

FACEBOOK FUNDRAISERS

\$83,935 RAISED

Social media platforms give us the unique ability to help share families' stories and inspire others to take action. In 2019 and 2020, BDSRA had a collective total of \$83,935 raised by individuals on Facebook. This includes money raised by birthday pledge goals, family posts and BDSRA Facebook campaigns.



Jarrod and Jessica Dickson

**FOR INTERNATIONAL
BATTEN AWARENESS DAY
BDSRA SUPPORTERS RAISED:**

➔ **OVER \$7,500**



183 5k WALK/RUN
PARTICIPANTS
IN 2019

OVER \$13,000 ←

319 5k WALK/RUN
PARTICIPANTS
IN 2020



INTERNATIONAL BATTEN AWARENESS DAY

June 9th is International Batten Awareness Day and was celebrated by our Batten Community in both 2019 and 2020. 50 teams in 30 states in three countries participated in our 2019 IBAD 5k Walk/Run. 2020 saw 29 teams join together across 39 states and six countries to raise awareness and funds for the fight against Batten Disease.



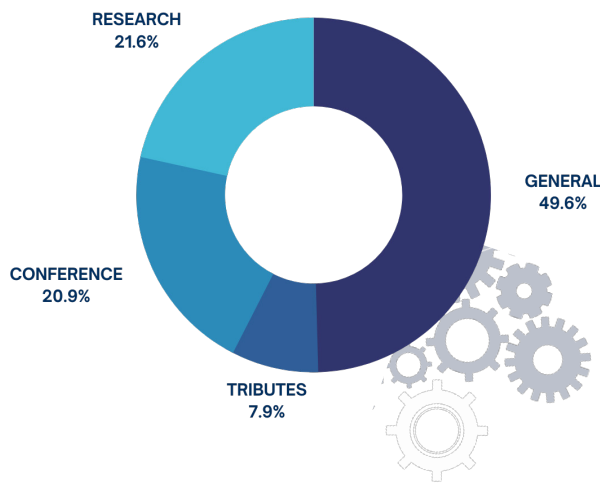
Amelia's Army and Ollie's Army wearing IBAD T-Shirts

FINANCIALS

2019

2019 INCOME HIGHLIGHTS

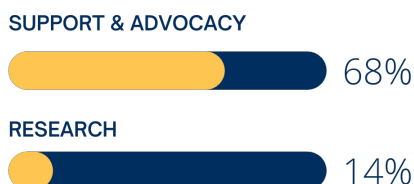
Income in 2019 remained steady, and many in the BDSRA community supported our work through family fundraisers, tributes, and sponsorships. Even the store saw its biggest year!



\$117,641
ANNUAL APPEAL

2019 IMPACT HIGHLIGHTS

Programming brought an in-person conference to Denver, and sponsorships brought in big support for the work. Research awards were used to facilitate research in CLN1, CLN2, CLN3, CLN4 and CLN5.



2020

2020 IMPACT HIGHLIGHTS

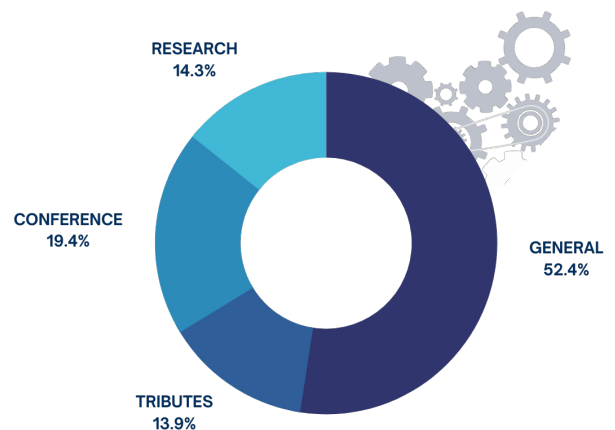
In person programming and advocacy came to a sudden stop after the first quarter, and it is reflected in the spending for the year. Although BDSRA didn't travel and staff tables at conferences educating industry professionals, the programming didn't stop; the spending turned into big savings.



2020 INCOME HIGHLIGHTS

Income to BDSRA was flat in the beginning of the year then slowed down as COVID ramped up, but the Batten community pulled out all the stops at year end, with very generous giving.

\$171,600
ANNUAL APPEAL



THANK YOU TO OUR DONORS FOR HELPING US CREATE IMPACT IN 2019 AND 2020.



5 THINGS YOU CAN DO

TO SUPPORT BDSRA RIGHT NOW



DONATE. www.bdsra.org/donate



ADVOCATE. www.bdsra.org/bdsra-advocacy



FACEBOOK FUNDRAISE. www.facebook.com/bdsra



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GET CONNECTED. www.bdsra.org/news/illuminator-newsletter

BATTEN DISEASE
Support and Research Association