



**THANK YOU
TO THE
OUR PROMISE TO NICHOLAS
FOUNDATION BOARD
FOR KEEPING US GOING EVERY YEAR**

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Amy Noyes

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Heather Dainiak – CEO/Co-Founder

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We hope you & your family remain well all throughout 2025.
We look forward to an exciting new year for
Our Promise to Nicholas Foundation.
Wishing you peace, light, love and good health
to your family from ours,

Chris & Heather Dainiak



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As we enter 2025, I reflect on the journey of the Our Promise to Nicholas Foundation with deep gratitude. Thanks to your generosity, we've raised over \$1.4 million since 2009, supporting families and advancing the fight against Batten disease.

In addition to my work with the foundation, I'm honored to serve as the Director of Family Support at BDSRA and as a Wish Coordinator at Make-A-Wish New Hampshire, roles that allow me to further support families affected by Batten disease and bring joy to children with critical illnesses.

Looking ahead, we are excited for the 2025 BDSRA Family Support Conference in Lincoln, Nebraska, and the 9th Translational Research Conference for the Management of NCLs in 2026, potentially in Boston.

As we move forward, OPTN's mission remains strong, and we continue to rely on your support. Please stay connected through our website and social media for updates.

Wishing you and your families a joyful holiday season and a happy, healthy 2025!



**OUR PROMISE
TO NICHOLAS**

2024 NEWSLETTER



Nicholas Giving Tree Project – Holiday Care Packages for Children with Batten Disease 2024

This year marks the 10th anniversary of the Nicholas Giving Tree Project, and we are proud to share that we sent out 67 holiday care packages to children across the United States affected by Batten disease. These packages were mailed on December 9, 2024, ensuring they arrived in time to bring joy during the holiday season.

Each care package was filled with thoughtfully donated new items from family, friends, and our community—items that families would typically purchase to care for their children. These gifts offer a moment of happiness and relief to families navigating the challenges of caring for a critically ill child.

We extend heartfelt thanks to everyone who contributed this year: The Southern NH Quilting & Sewing Group for their handmade pillowcases, the Southern NH National Charity League for creating cards, ornaments, and providing extra donations, and Minha K. for handcrafting bracelets for all

the children. We also appreciate the generous contributions from Hope for Sam Organization, Ethan's Reason Foundation, Global Good Foundation, and Russell's Garden Center. A big thank you to all the little elves who helped organize our packages!

Additionally, Our Promise to Nicholas Foundation sponsored each child with a \$300 Visa gift card, making an even greater impact for these families during the holidays.

To everyone who shopped from our Amazon and Target Wish Lists, made donations, or sponsored entire care packages—thank you! Your generosity and kindness continue to make a meaningful difference in the lives of families battling Batten disease. ■



BDSRA Family Support Conference

July 11-14, 2024, St. Louis, Missouri

This year marked our 10th year volunteering at the BDSRA Family Support Conference in the affected childcare room. I was joined by sisters: Meghan, Bridget, and Erin Kelly, who are medical leaders in the room, as well as my high school niece Isabella Leguía, whose first year volunteering was a tremendous help as she lovingly played with all the children. We are honored that the families at the BDSRA Family Support Conference trust us to care for their children with Batten disease. The conference took place from July 11-14 in St. Louis, Missouri.

We are deeply grateful for the generous support of the OPTN Foundation donors, whose contributions helped fund this childcare, as well as the travel and hotel accommodations for the Kelley family and other essential costs. We also want to thank the

Fore Batten Foundation for their additional sponsorship of the childcare room.

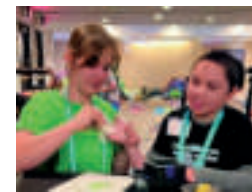
The childcare agency provided a wonderful team of professionals, including special needs teachers, childcare workers, and preschool and grade schoolteachers, who were instrumental

in helping us care for the children with Batten disease. Due to the ongoing nationwide nursing shortage, hiring a nursing agency wasn't an option, but this team did an incredible job providing hands-on care for our special kids.

This year, we cared for approximately 30 children, with most receiving 1:1 staffing. Activities included games, arts and crafts, toys, make-believe camping, and movies. One of the highlights of the two days was this year's music therapy session. The therapist was so exceptional that we've

already requested her to join us again at the 2025 conference in Nebraska. We were also blessed with a visit from adorable therapy dogs, who stayed with us for three hours, filling the room with love, laughter, and joy.

Thank you to everyone who made this experience so memorable for the families and children we serve. ■

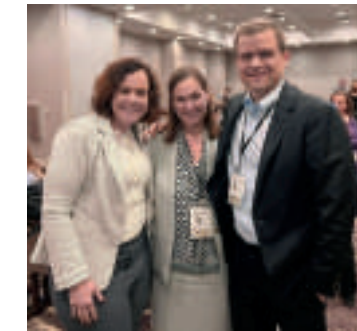


8th Translational Research Conference for the Management of NCLs

November 20-22, 2024, at The Westin Lombard Hotel, Chicago

The 8th Translational Research Conference for the Management of NCLs took place in Chicago from November 20-22, 2024, bringing together 93 attendees, including leading researchers, medical doctors, and family foundations—all united by a shared commitment to advancing science and medical care for those affected by Batten disease.

A special thank you to Dr. Jill Weimer, Melissa Pratt, and Joelle Anderson of Sanford Health for their tireless efforts in ensuring the event ran seamlessly.

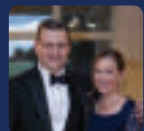


Their work in organizing the impressive lineup of speakers, managing presentations, and coordinating logistics was invaluable to the success of the conference. I also had the privilege of coordinating the hotel and event logistics, ensuring that rooms were booked, meals were set up, and AV equipment was arranged—all crucial elements for a smooth and successful event.

We also extend our heartfelt gratitude to the family foundations whose sponsorships made this event possible. Their generosity not only drives critical conversations but also inspires everyone involved. Together, family foundations are a powerful force for change. A special thanks to the BDSRA, BioMarin, and Tern Therapeutics for their continued support.

Reflecting on the progress made over the past 15 years, we are inspired by the incredible collaboration between scientists and medical doctors, who are pushing the boundaries of research and medical care. Their dedication is making meaningful strides in the fight against Batten disease.

We look forward to continuing this important work and are filled with hope for the future. Our promise is to keep building on this momentum because every breakthrough brings us one step closer to a cure. ■



Thank You

to our family, friends, volunteers and sponsors for believing in our mission. You have given us the gift of Our Promise to Nicholas. It is because of your support and donations, time and love that we can make a difference in the lives of children suffering from Batten Disease.