



**Our Promise To Nicholas**  
Working Together To Cure Batten Disease

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

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We hope you & your family remain well all throughout 2026.  
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*



As we enter 2026, I reflect on the journey of Our Promise to Nicholas Foundation with deep gratitude. Thanks to your continued generosity, OPTN has raised more than \$1.4 million since 2009, supporting families and advancing research for Batten disease.

In addition to my work with the foundation, I am grateful to be in my second year as Director of Family Support at BDSRA and as a Wish Journey Coordinator with Make-A-Wish New Hampshire—roles that allow me to walk alongside families and support children facing critical illness.

Looking ahead, we are excited for the 2026 BDSRA Family Support Conference in Chicago and the 9th Translational Research Conference for the Management of NCLs, taking place November 11–13, 2026, in the Boston area.

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 healthy, hopeful 2026.



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**OUR PROMISE  
TO NICHOLAS**

2025 NEWSLETTER



## 2025 Nicholas Giving Tree Project – Holiday Care Packages for Children with Batten Disease

In 2025, Our Promise to Nicholas Foundation completed the 11th year of the Nicholas Giving Tree Project. This holiday season, we sent 66 holiday care packages to children across the United States living with Batten disease. Packages were mailed in early December to ensure they arrived in time to offer comfort and support during the holidays.

Each care package included pajamas or bed sheets, toiletries, and over-the-counter items such as children's Tylenol, along with special touches meant to bring warmth and joy. These gifts offered families a moment of relief and a reminder that they are not alone.

We extend our sincere thanks to everyone who contributed, with special recognition to the Southern New Hampshire Chamber of Commerce, our largest donor this year, whose generosity helped cover the cost of pajamas and bed sheets that were not fully sponsored. We also thank the Southern New Hampshire Quilting & Sewing Group for handmade pillowcases, the Southern New Hampshire National Charity League for cards, ornaments, and donations, and Russell's Garden Center for donating bells, socks, and toys. A heartfelt thank you to the many individuals and little elves who helped shop, organize, and pack each box with care.



Once again, Our Promise to Nicholas Foundation included a Visa gift card for each child to help families purchase essential items. As community support for this project has evolved, our foundation ensured that every child received a meaningful and thoughtfully prepared package.

This year also marks the final chapter of the Nicholas Giving Tree Project. After eleven beautiful years, we are lovingly closing this tradition and thoughtfully stewarding our resources to support Batten families in new ways. This project has been a deeply meaningful way to honor Nicholas's life and legacy, and we are profoundly grateful to everyone who made it possible.

Thank you to all who have supported this project over the years. Your generosity has brought comfort, connection, and joy to families across the country, and Nicholas's spirit will continue to shine through the community you helped build. ■



## 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.



## 2025 BDSRA Family Support Conference

July 10–14, 2025 | Lincoln, Nebraska

In 2025, Our Promise to Nicholas Foundation proudly supported the affected childcare room at the BDSRA Family Support Conference for the 11th consecutive year. The conference was held July 10–14 in Lincoln, Nebraska, bringing together families affected by Batten disease for education, connection, and support.

Thanks to the generosity of OPTN donors and Friends of Nicholas, our foundation helped cover travel, lodging, meals, and caregiver support, and once again sponsored KiddieCorp, the professional childcare agency that provided skilled special-education and preschool teachers. We were also deeply grateful for the extraordinary kindness shown by the Lincoln community, whose volunteers and local families donated toys, supplies, desserts, and thoughtful gifts that brought comfort and joy to our children and caregivers.

The childcare room was led by Meghan Kelly, Bridget Kelly, Erin Kelly, Hannah Euler, and Isabella Leguía, whose experience, compassion, and steady presence created a safe and nurturing environment for some of the most medically fragile children in attendance. Approximately 30 children were cared for during the conference; many receiving 1:1 support. Activities included arts and crafts, imaginative play, toys, movies, and a cherished music therapy session, which continues to be a highlight for families year after year.

This year marked a personal shift for me as well. While Our Promise to Nicholas Foundation continued to sponsor and support the childcare room, my role as Director of Family Support at BDSRA allowed me to spend more time supporting parents directly through peer-to-peer groups, one-on-one conversations, bereavement sessions, and sharing our family's story. Though different from years past, it was a meaningful reminder that supporting Batten families extends beyond one room and takes many forms.



We are honored that families continue to trust Our Promise to Nicholas Foundation to help care for their children, and we remain deeply committed to supporting Batten families through every stage of their journey. We look forward to continuing this work and gathering again at the 2026 Family Support Conference in Chicago. ■

## 9<sup>th</sup> Translational Research Conference for the Management of NCLs

November 11–13, 2026 | Marriott Quincy Boston Hotel, Boston, MA

In 2026, Our Promise to Nicholas Foundation will host the 9th Translational Research Conference for the Management of NCLs, taking place November 11–13 at the Marriott Quincy Boston Hotel. This biennial conference brings together leading researchers and clinicians from around the world, alongside family foundations, united by a shared commitment to advancing science and improving care for individuals and families affected by Batten disease.



The 2026 conference will follow the same successful format as previous years, building on the strong foundation established over many years under the leadership of Dr. Jill Weimer, in close collaboration with invited experts in the field, including both long-standing contributors and new researchers exploring related diseases and scientific approaches that may inform Batten disease research. Once the speaker list and agenda are finalized, Our Promise to Nicholas Foundation will coordinate all conference logistics, including hotel accommodations, travel arrangements, and on-site needs. As in past years, OPTN will sponsor speaker travel, lodging, and meals to ensure broad participation and meaningful collaboration.

This conference is made possible largely through the continued generosity of family foundations, whose support remains the backbone of this meeting. As we prepare for Boston, we will also be thoughtfully seeking local sponsorship support to help sustain this important gathering and strengthen connections within the region.

We are deeply grateful to the families, foundations, researchers, and clinicians who believe in the power of collaboration and translational science. Each step forward brings us closer to better treatments and, ultimately, a cure for Batten disease. ■

