

**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 2023.
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



This year Our Promise to Nicholas Foundation financially supported the BDSRA Family support fund. Our charity understands families who have children with Batten Disease are often faced with financial challenges that further interfere with their wellbeing. Families can apply to this fund through the BDSRA for things such as: utilities, household equipment (such as a washing machine or a specialized bed for the child), funeral expenses, travel expenses (such as if their child is in the hospital a prolonged amount of time and need is for gas and food). For many of the requests, checks would go directly to the vendor, landlords or company providing the goods or services.



Our Promise To Nicholas
Working Together To Cure Batten Disease

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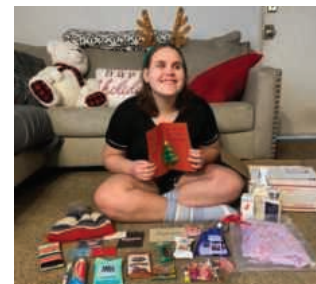


Nicholas Giving Tree Project – Holiday Care Package for Children with Batten Disease

Fifty-five children with Batten Disease received holiday care packages from the 9th Nicholas Giving Tree Project. Seventy-five packages are filled with items the families would purchase to care for their child. These packages give the families a small amount of joy during the holiday season as they care for their ill child. We are grateful for the tremendous amount of donations this year enabling us to send larger boxes. Many families received more than one care package. Thank you to Fore Batten Foundation for their sponsorship. Crocheted



hats by friend B. Knight in memory of her grandson, Southern National Charity League of Mothers' and Daughters organization, Eastern Bank of Bedford NH hosted a Nicholas Giving Tree. Pillowcases by local southern NH sewing group and quilts handmade by quilters in South Carolina. Holiday Bells and care items donated by bereaved Batten families. So many donations from my family, friends and community all over the US! Thank you to the many beautiful elves who helped organize the boxes to be mailed.



7th Annual Translational Research Conference for the Management of NCL's – November 3&4, 2022; Lombard, Chicago



Our Promise to Nicholas Foundation, Dr. Jill Weimer of Sanford Health and a committee of family foundations worked together to host this 7th annual science meeting in Chicago. Invited were elite scientists from around



the world to discuss the latest ideas for translational research for Batten disease (also called NCL). The two-day conference had thirty-eight speakers and over 100 attendees. This year a few folks were able to join this conference virtually as an attendee or speaker. The meeting is designed to incorporate new technologies

and concepts into Batten disease research. This leads to discussions between speakers and the recruitment of new labs and new approaches to researching Batten disease. The history of this conference in that scientists who attend are able to collaborate with each other on how to help solve the puzzle of Batten disease and work toward a cure! One hundred percent of the donations raised for this conference have gone to pay for facilities, speakers travel expenses, hotel accommodation and food. Together, we raised \$75k which covered the entire expense of this year's conference.



The next NCL Translational Conference will be hosted November 2024 in Chicago.

BDSRA Family Support Conference – July 7-10, 2022; Cleveland, Ohio

We attended the BDSRA family summer conference July 8-10 in Cleveland Ohio and OPTN sponsored the childcare for children affected with batten disease. It was great to be back with these families after not seeing them since 2019. I was joined by Meghan Kelley, Bridget Kelley and Erin Kelley volunteering in the affected kids care room. This year, due to the shortage of nursing care, an organization was hired that provided 12 local special needs teachers to help us in our childcare room. Although these women were not medical professionals, they were kind, caring and compassionate toward our kids. This care at the conference gives the parents and opportunity to attend the conference sessions, learn more about the disease, meet experts, receive support from other families and learn how to best care for their children. Between the two days of care, we had between 28-30 children in



our room. It was challenging at times caring for the more mobile unstable active children, keeping them safe as well as engaging the non-active children. We were grateful to have the additional Batten parents' volunteers to help us this year. I could see lot of smiles and hear lots of laughter. We made crafts, art keep sakes, played with toys, games, bubbles and gave lots of love and support to these kiddos! Next BDSRA Family Conference will be July 14- 16, 2023 in Denton, Texas.



Indoor Maze to the Egg Hunt & Easter Bunny

On Saturday April 16, 2022, Our Promise to Nicholas Foundation hosted our 13th annual Egg Hunt event at the NH Sportsplex in Bedford, NH. We were blessed with a crowd of 800 participants (event goers, exhibitors, and volunteers!). The different set up this year made the event even more exciting! Families hopped along the bunny footprints path in a one-way direction through the NH Sportsplex to the Egg Hunt entrance and photos with the Easter Bunny. This special year we had over 15,000 donated eggs filled with candy and prizes for the children. Twenty -four Sponsorship tables were along the bunny path across two indoor soccer fields. Families stopped at each sponsorship table to talk with the exhibitor, play games and get more eggs! Along the maze journey, families listened to music, played kids' games, ran through an obstacle course, took photos with our many cute mascots, and enjoy bunny hat craft. Thank you to our community and many volunteers that made this event happened. Thank you to our title sponsors this year Granite State Gastroenterology and Eastern Bank of Bedford NH. Thank you to the NH Sportsplex for hosting the event. Proudly \$25K was raised.



SAVE THE DATE: Our Promise to Nicholas Foundation's **Indoor Maze to the Egg Hunt & Easter Bunny, April 7, 2023 @ NH Sportsplex, Bedford NH.** Please check our website for details for this upcoming event. We are looking forward to it!



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.