

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

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Heather Dainiak – CEO/Co-Founder

Dotty Noyes – Chief Correspondence Officer



We hope you & your family remain well all throughout 2024.
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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Looking back at our journey to Our Promise to Nicholas Foundation fills me with pride and honor. I see our charity as a gift from you, our family, friends, and community. Giving us a purpose, passion, and perseverance to not give up. Rolling into 2024, our foundation will be turning 15 years old in April! Together we have raised 1.4 million since 2009. This is from over 40 different fundraisers. November 2024 we proudly will be hosting our 8th annual Translational Scientific Conference for the Management of all Batten disease. Here the elite Batten scientists come together from all over the world joining forces toward this cure. We have had some setbacks in treatments due to the 2020 pandemic and changing economy, but we will not give up and will continue in the fight against Batten Disease!

The future of OPTN is not slowing down. It will look different as we will have a different approach in raising funds. We still need your support. Please continue to follow our web site and social media. We hope you and your families have a wonderful holiday season and good health in the new coming year 2024.



**OUR PROMISE
TO NICHOLAS**

2023 NEWSLETTER



Nicholas Giving Tree Project – Holiday Care Packages for Children with Batten Disease 2023

This is the 9th year of sending out holiday care packages to children in the US with Batten Disease. We sent 60 children, which is the most we have ever! They were mailed November 29th to arrive before the December holiday. These packages are filled with donated new items from family, friends, and our community that families would purchase anyway to care for their child. It gives these families joy during the holiday season as they care for their critically ill child or children. Thank you for the many donated gifts from this year's Amazon Wish List and sponsorships of entire care packages.



Thank you to Barbara K. for the crochet hats, Lynne V. and her southern NH quilting group for the pillowcases, jingle bells from Maria S, Southern National Mothers/Daughter League for the cards, ornaments, and extra donations. Thank you to Fore Batten Foundation for their sponsorship of the mailing and visa gift cards. This year Our Promise to Nicholas Foundation was able to sponsor each child a \$500 Visa Gift card. Thank you!

We appreciate your generosity and kindness toward these families.



Egg Hunt Maze to the Easter Bunny

On Saturday April 8, 2023, Our Promise to Nicholas Foundation hosted our 14th annual spring Egg Hunt. It was in Bedford, New Hampshire, attended by 1200 people and proudly raised \$20,000 for the fight against Batten disease.

Families hopped along the bunny footprints path through the NH Sportsplex to the egg hunt and photos with the Easter Bunny. This year the hunt included 15,000 eggs filled with candy and prizes. Sponsors had tables along the bunny path, across two indoor soccer fields. Families stopped at each sponsorship table to collect an egg and special treats. Along the maze journey, families listened to music, played kids' games, and took photos with many cute mascots. There were over 100 Easter raffle baskets, a scrumptious bake sale just in time for the holiday weekend, and bunny crafts for kids. Entertainment was from The Party Palace princess and pirates, DJ Hoopster, Granite State Clowns, Fungo the NH Fisher Cat as well as Troy Wunderlee from Big Top Adventures walking on stilts.

OPTN thanks its many sponsors, especially this year's title sponsor Eastern Bank. The venue sponsor was NH Sportsplex and Executive Health and Sports Center. This egg hunt was supported by corporate sponsorships, local businesses, and many community volunteers. This event was featured on channel 9 New Hampshire WMUR on the day of our event.



BDSRA Family Conference July 13-16, 2023, Denton Texas

We attended the BDSRA Family Support conference this year July 13-16 in Denton, Texas. It was our 9th year volunteering/working in the affected kids care room and again I was joined by sisters: Meghan, Bridget, Erin Kelly and Hannah Euler. In addition to Our Promise to Nicholas Sponsorship toward this conference a big thank you to Mary Payton Miracle Foundation, Fore Batten Foundation, and many other family foundations like ours that sponsored the affected care room this year. We are grateful.

A teacher agency was hired who supplied our room with various types of teacher staff who came to our help including special need teachers, childcare workers, preschool teachers and grade schoolteachers. Due to the nationwide nursing shortage, hiring a nursing agency was not an option. This group of ladies (and one gentleman) were fantastic being



hands on with our special kids. This year we had approximately 25- 30 kids and were lucky to have most of the children with a 1:1 staff. We played games, enjoyed arts and crafts, played with toys, watched movies, had a music therapy session and a visit from therapy dogs. Lots of laughter and smiles all around the room for two days!



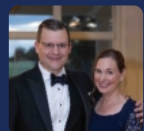
OPTN Supports the BDSRA Family Support Fund



Our Promise to Nicholas Foundation continues to financially support 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). The stipend check does go directly to the vendor, landlords or company providing the goods or services.

2024 Egg Hunt

The OPTN Egg Hunt Fundraiser has been a beautiful journey for our family, and we will cherish these memories for the rest of our lives. This event has blossomed over the years, becoming bigger and better each year. Unfortunately, all good things do come to an end. The 2023 egg hunt will be our last year hosting. Your generosity and kindness toward this our family and this fundraiser have touched me deeply. I want to express my heartfelt gratitude for the support you all have given us. Our family, friends and Bedford community have graciously gone above and beyond for my family and foundation. Thank you to you, I am truly grateful.



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.