



A Note from Karen and David,

This Thanksgiving we are thankful for two girls that are the healthiest they have been in some time. This is not some miracle. It is the result of proper nutrition and hydration. We discussed a Gastrostomy Tube (G-Tube) for almost 2 years but it seemed like resigning, not ghting, the next stage of the disease. It took a crisis a couple of months ago to make that scary leap. But instead of resignation, the G-Tubes have brought back energy and skills to both girls.

Over the past 6 months, Amelia's mobility declined to the point of being wheelchair-bound. Since the G-Tube, she has been regaining strength and was able to walk 75 feet, with guided assistance, at school the other day! Makenzie was recently removed from choir class for doing cartwheels and loudly singing her favorite song. We will take this rebellious behavior of a typical pre-teen over the hospitalized, non-verbal, and lethargic Makenzie of just a month ago! We are thankful that this Thanksgiving the girls can eat as much pie and whipped cream as they want while we supplement their nutrition to keep their energy up.

We are also grateful for the many caring and devoted supporters such as you. This journey is lled with every emotion imaginable, including hope, provided by the support we have received from so many we now call friends.

Wishing you a very happy Thanksgiving that includes all the pie and whipped cream you want. With Hope,

Two handwritten signatures in black ink. The first signature is on the left and has the word 'MOM' written below it. The second signature is on the right and has the word 'DAD' written below it.



Research Update

The 7th Translational Research Conference for Management of NCLS was held earlier this month. This conference brings together families and

scientists of varied backgrounds to discuss strategies for advancing rare disease therapeutics and gaps in NCL Research. Karen attended and proudly watched as many of the ForeBatten funded projects were presented to the larger group.

Dr. Michelle Hastings, Rosalind Franklin University

Antisense Oligonucleotides for the Treatment of CLN3

May Khanna Ph.D, New York University

CLN3 Protein-Protein Interactions

Dr. Jon Brudvig & Melissa Pratt, Weimer Lab

Translatable Biomarkers for CLN3

Dr Jonathan Cooper, Washington U. School of Medicine

Peripheral and Enteric Nervous Systems in Juvenile Batten Disease

Dr. Heather Adams, University of Rochester Medical Center

Sleep Dysfunction in NCL Disorders



We've achieved so much in five years, imagine how much more we can accomplish



\$5.5 MILLION
funds raised



90% OF FUNDS
support research



16 PROJECTS
funded for research



9 LABS
across N. America