A young boy with dark hair, wearing a dark shirt and a backpack, is looking up at his mother. The mother, with long brown hair and glasses, is wearing a white lace-trimmed top and looking down at her son. They are outdoors, with a blurred green background. The image has a warm, soft lighting.

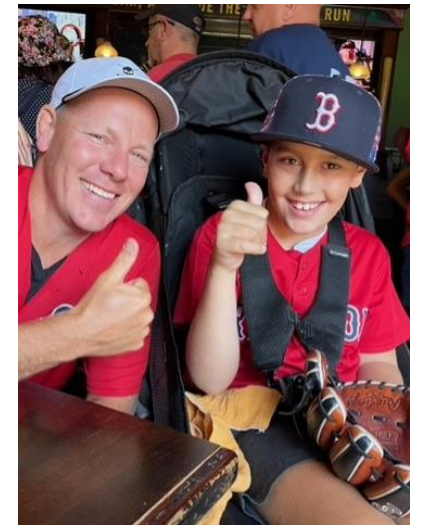
“ I felt like I was fighting for so many years for my son, especially in the beginning, and now I’m watching all of these amazing people show up and work on this personalized treatment for one child that could potentially benefit and change the course of his life and our family’s life. Just that is enough – it’s the best feeling, it’s hope ”

**-Kelley Dalby, *mother of Connor***

# Mostyn

## Clayton Hummel, Mostyn's father

“Mostyn is a very special 12-year-old boy, like no other. Seizures have, at times, stripped Mostyn of his abilities to walk, speak, swallow and eat... but not his happiness. Mostyn loves people and his character touches many lives in a positive way. If someone is in distress, he will walk right up to them or reach his arms out from his wheelchair to give them a heartfelt hug.”







Sep'21  
Twins are  
here!

Christmas  
Eve

Pregnancy

30 seizures  
in 48h

GLUT1 pre-diagnosis  
(**treatable**)  
Good tests results

WES result  
PACS2 diagnosis (**no treatment**)  
Ultra-rare disease (< 50 cases)



2023 Nano-rare Patient Colloquium



***“There will come a time when you believe everything is finished. That will be the beginning.” – Louis L’Amour***



Sep'21  
Twins are here!

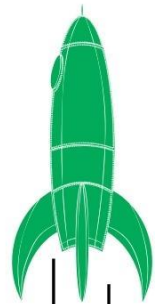
Christmas Eve

Pregnancy

30 seizures in 48h

GLUT1 pre-diagnosis (treatable)  
Good tests results

WES result  
PACS2 diagnosis (no treatment)  
Ultra-rare disease (< 50 cases)



Lena's acceptance to n-Lorem family!  
Sep'22



hope



2023 Nano-rare Patient Colloquium



n-lorem FOUNDATION

1st call with US physician  
Application submitted!



Hosted by

Biogen.

# Ireland

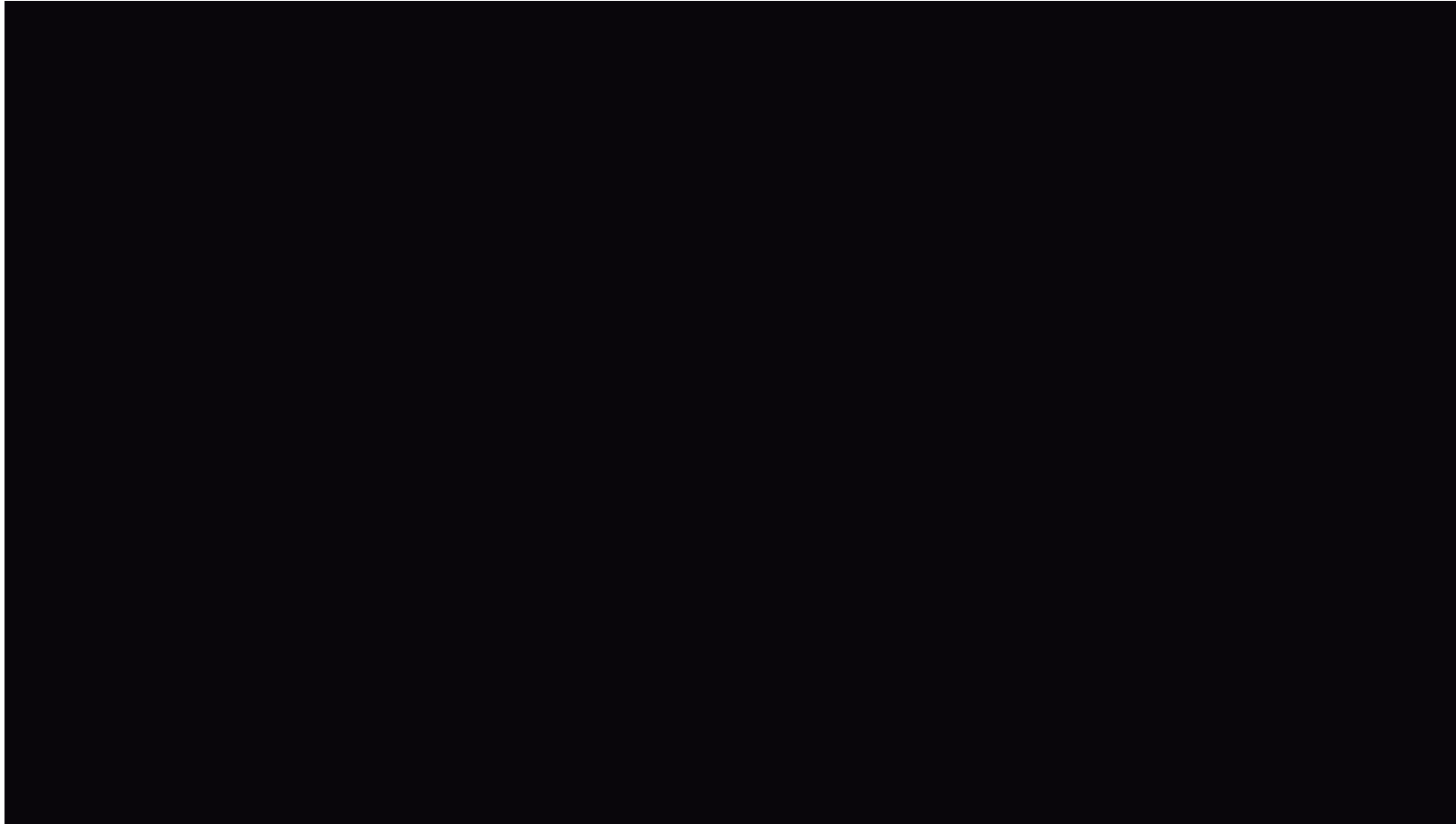
**Shanna Tolbert**, Ireland's mother

- Ireland suffers from a CACNA1A mutation
- Age 8



# Susannah's Story

---





# Susannah

---

**Luke Rosen**, Susannah's father

- Susannah suffers from a KIF1A mutation
- Age 9
- Treated October 2022



Thank you to Corina, Kevin, and Sheila at Biogen for producing 'Susannah's Story'