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
PACS2 diagnosis (no treatment)
Ultra-rare disease (< 50 cases)
WES result
GLUT1 pre-diagnosis (treatable)
Good tests results
30 seizures in 48h
Pregnancy
Christmas Eve
2023 Nano-rare Patient Colloquium

1st call with US physician
Application submitted!

Lena’s acceptance to n-Lorem family!

Sep’22

PACS2 Research Foundation

n-lorem FOUNDATION

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’