

# I want *you* to know...



MEREDITH



NICOLE



RUBÉN



MICHAEL



CLAIRE



CLEO



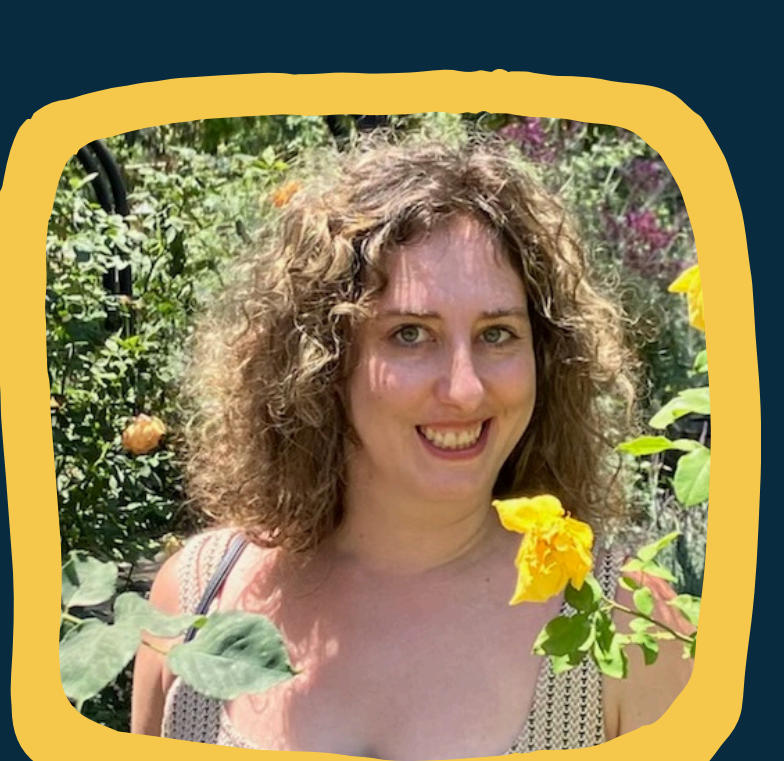
CHRIS



TERESA



BEN



DEVIN

## INSIGHTS FROM THE GLUT1 DEFICIENCY FOUNDATION PATIENT ADVISORY BOARD

“There are much more of us out there to find than you know.”

“My biggest need is to live a life without feeling ill.”

“Each of us are different, with different symptoms.”

“I hope an alternative to the diet is found soon, or something not so strict.”

“I wish it was easier to reach out for help.”

“Anxiety is a big challenge. It can cause other issues, such as not driving, more movements, and can take away time from family and friends.”

“I need better monitoring - like when switching, starting meds, stopping meds, tweaking diet etc.”

“I worry I will have to be on the keto diet for the rest of my life.”

“Glut1 makes life more challenging due to needing to stay on the ketogenic diet.”

“I dream of being able to work with children and help special needs children who are typically overlooked or struggle in an academic setting.”

“Don't forget the person behind the symptoms.”

“Things that have been the hardest for me are making friends, finding and retaining jobs, and being treated differently due to my disability.”

“It has been very challenging to deal with the intermittent loss of leg coordination with extended exercise. Also intermittent cognitive function 'fuzzy brain' and cold feeling in my chest. It would be great to find reasons and/or treatments for these issues.”

“My biggest challenges are my tiredness and my sickness.”

“I do not suffer from the symptoms as much as my children do.”  
  
Leila Nikolas  
*Keto kids can play just as hard as anyone else!*

“I need a cure.”

“I want you all to work together on a cure for Glut1.”

“My life could be easier if I had more energy and could focus more.”

“We need something to stop the movement episodes. They are so frustrating, and we have to worry about one happening at any time.”

“My greatest hopes are to live independently in my own home.”

“I hope for a cure.”

“I need better support.”

“Planning for the future is hard, knowing my children may have a chance at having Glut1 and the unknowns if they will be OK.”

“I need more clarity.”

“My symptoms sometimes hold me back from achieving everything I would like to.”

“My expressive language delay causes me the most challenges in my daily life.”

“My hope is to feel better and to find a different treatment that works.”

“I need a medication that works.”

“I need better communication between doctors of different disciplines.”

“I worry that my symptoms will negatively impact future important milestones in my life.”

“Research needs to be more accessible so I don't have to keep teaching my doctors about Glut1.”