

Hello Grover Family Supporter - Can you believe it has been almost 3 years since we hosted the Boston or Bust for the Grovers Event? Our fundraiser was extremely successful & our efforts sent the Grovers to Boston! For the family, not having to stress about the financial burden of traveling to Boston was a HUGE relief. While nothing concrete was discovered that first trip, so much has happened since then.



In the summers of 2013 & 2014, the Grover family made additional trips to Boston Children's Hospital. The doctors and family knew that more testing would be required for answers and answers are exactly what they got! Brady and Alaina were finally diagnosed. They were the first children in the USA diagnosed with the SLC13a5 mutation or citrate transporter disorder. The diagnosis was a huge stepping stone in the right direction and the journey began for treatment options.



Life has continued while treatment options are explored. Big Brother Landon has become quite the soccer star! He plays on the Players Development Academy (PDA) Competitive U9 team, practicing three times a week with games on the weekends. Brady continues to push past the benchmarks that doctors originally said he would never reach. While still non-verbal and unable to walk on his own, he is more mobile than before in his wheelchair. He attends public school & loves riding the bus to and from the Grover house.

In the summer of 2014, Alaina's seizures took a turn for the worst. She was raced to Miami Children's Hospital by the family. After being admitted and receiving heavy doses of medicine, she endured a 40 minute seizure and stopped breathing. She was intubated and placed on ventilator. As she has done in the past, Alaina fought hard and began breathing on her own unassisted. It was decided that brain surgery was necessary to help alleviate the chronic seizures by removing a damaged portion of her brain. Sadly, the surgery did not help as much as it was hoped to do so & she continues to have seizures daily.



Recently, a treatment for this newly diagnosed SLC13a5 has been identified. It's called Triheptanoin and is not currently FDA approved. Only one company offers the treatment and Brady and Alaina were approved from the company for a "compassionate" trial study. They will be the first to use this medicine for their disease. It is predicted that this treatment option will help reduce the seizures (or possibly stop them completely), as well as decrease the developmental gaps they both experience. The Grovers are extremely hopeful that this treatment will provide much needed relief for their family.

The Grover family will have to travel to Boston twice in the next two months for this treatment because the medicine must be administered at Boston's Children's Hospital so tests can be run during the treatment. They will be required to stay in Boston a week each trip for the trial and then Boston will send the Triheptanoin to Miami Children's Hospital for follow-up treatments.

We are asking all friends of the Grover Family to once again rally in support! Please send healing and safe travel thoughts & prayers their way! If you want to show your support by assisting with travel expenses and out-of-pocket medical expenses, please reach out to Crystal Hill at the e-mail below to find out how. We are all excited about this treatment & are hopeful this provides the results we've been hoping for the last 8 years!

Always with Love & Hope,
Crystal

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Landon on the Soccer Field



Brady playing on a trampoline



Miss Alaina all dressed up!