The Journey of Diazoxide

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About Alaina
Alaina is a 15-year-old girl who is well known for the love, care, and affection she shows everyone. She is also known for giving the best hugs. Alaina enjoys spending time with friends, playing sports, competing in Special Olympics, collecting stuffed animals, and watching movies/YouTube videos. She loves going to school too! Alaina was diagnosed with Glut1 Deficiency at 9 years of age. Despite everything Alaina has been through, she still finds a way to go through it with a positive attitude and a big smile on her face.

BEFORE DIAZOXIDE

Attempted Treatments
- Over 10 different seizure medications in various combinations
- Ketogenic diet
- Modified Atkins diet
- C7 oil (triheptanoin)
- Cornstarch
- Diamox

Struggles Before Diazoxide
- Seizures: lip smacking, blank stares
- Head not “feeling right”
- Confusion
- Slower processing
- Frustration
- Emotional breakdowns
- Imbalance
- Wobbly legs
- Low energy

STARTING DIAZOXIDE

Alaina began taking diazoxide on April 15, 2020.
- After 13 days on diazoxide, Alaina was admitted to the hospital.
- During this hospitalization, Alaina’s seizure activity decreased dramatically.
- However, diazoxide brought on a new set of side effects:
  - Severe head pain
  - Edema
  - Hair growth
  - Continuous glucose monitoring (CGM) has been a game changer.
  - CGM allows us to monitor Alaina more closely and recognize blood sugar trends.
  - We have had 6 hospital stays for monitoring purposes and/or diazoxide side effects.

NOW ON DIAZOXIDE

In Alaina’s Words
- “I feel less confused.”
- “I can think better.”
- “I can understand people more.”
- “My legs aren’t wobbly.”
- “I have more energy to do things, I feel good!”

Alaina has shown the most improvement on diazoxide of any treatment we have tried. She has had numerous 10/10 days! To see how well Alaina is doing and how she is excelling in the things she loves to do means the world. We love seeing Alaina so happy!

Alaina’s amazing team of doctors: Dr. Darryl De Vivo (left), Dr. Santhi Logel and Dr. Ellen Connor (middle), and Dr. David Hsu (right)

Q&A with Alaina
What are 3 words that tell us how you feel about diazoxide?
“Great, amazing and awesome!”