

# Letter to the CIRM Review Team

Dear CIRM Review Team,

We appreciate you taking the time to read our letter.

With all respect, we would like to introduce ourselves and our children. My name is Maigualida Zarceno and my husband is Nehemias Martinez. We are originally from Guatemala and currently live in Northern California.

We have two children who were recently diagnosed with Batten Disease (CLN6). Our daughter, Ciara, is a sweet, happy, and kind little girl who loves outdoor activities. This disease is progressing extremely fast. In approximately 18 months, she has lost many of her fine motor skills, much of her speech, and her stability. She has also begun losing her vision. Ciara is only 6 years old, and this disease is taking away so much of her childhood.

Our son, Duaik, is 4 years old and has struggled to develop speech. Both of our children suffer from seizures, and there are many other health challenges that we face every day, with more expected as the disease progresses.

Despite these hardships, we still have hope. We hope that you will help change the path of our children's lives, along with the lives of other children around the world who are suffering from this devastating disease.

This gene therapy could make a life-changing difference for our children and for future families affected by CLN6. We understand that this is not an easy decision, but time is something our children do not have. Every day matters.

Please reconsider, knowing that behind every application there are real children, real families, and real lives waiting for a chance at a better future.

Sincerely,

Maigualida Zarceno  
Mother of Ciara and Duaik







