

Hello everyone, my name is Ceeariah and i have a 4-year-old daughter named Azylah who was diagnosed with CLN6 Batten Disease 4 days before her 4th birthday.

I Would like you to imagine having a healthy child, that was never sick, no hospital visits, no illnesses, walking, running, jumpin,eating and being your typical toddler. Everything was great. Life was good.

Now Imagine one November day you wake up to your child having a seizure and rush them to the hospital and there's doctors saying there is nothing that can be done and follow up with a specialist.

Imagine going to the specialist and getting test run and 2 months later, on one late January day reading the worst diagnosis possible. Your child has CLN6.

You look the diagnosis up, and your child has every symptom there is, and all you see is FATAL, NO CURE, NO TREATMENT.

Imagine since January in 5 short months, your child is unable to walk unassisted, they can no longer eat by mouth, they have myoclonic seizures numerous times a day & the child you once knew is a child that is no longer.

Imagine every day you wake up; it is one day closer to your child dying.

Imagine sitting across from doctors who want to help but have no treatment to offer. Imagine hearing that the only option is to let the disease run its course.

Imagine having to fight insurance companies for basic services, equipment, and support while your child continues to decline.

Now you are imagining it, guess what? I do not have to imagine this, this is my everyday life, this is my reality, this is my CHILD and what we have gone through for the last 6 months and what will continue to happen, if no treatment becomes available.

People often say to trust in a higher power and we aren't giving more than we can handle but as a parent to a child who was once so full of life you have to question why something so precious has to suffer in the most worst way.

These children are innocent, they don't understand what's going on with them or why is this happening to them. They dont understand why they arent walking anymore, they dont understand why they arent able to talk anymore and its truly not fair. No parent should have to watch their child deteriorate before their eyes.

No child should lose their future because treatment is out of reach or because funding came too late. Our children are dying while we wait. We cannot wait years for treatment. Our children do not have years. Our hearts break every single day not only for Azylah, but for every child living with this cruel disease today and every family that will receive this devastating diagnosis tomorrow.

There should be no question about whether this funding is needed. There should be no debate about whether these children deserve a chance. Without funding, research stops. Without research, treatment remains out of reach. And without treatment, our children will die. We are not asking for miracles. We are asking for a chance. A chance to save our children before it is too late.

Thank you for giving me the opportunity to speak and thank you for taking this into consideration.