

Dear CIRM Review Committee,

Thank you for this opportunity and for considering The Charlotte & Gwenyth Gray Foundation's application for CLIN2 funding. My name is Stevi, and my daughter, Charli, was diagnosed with Batten CLN6 at 3 years and 9 months old. She is now 5. This funding gives our family real hope, an opportunity to slow the progression of this devastating disease, and perhaps even provide the cure we have been praying for.

If this trial is not funded, there will be no trial in the near future, and time is not on Charli's side. This is her last hope for a different future. Batten disease is cruel, and any developmental loss she suffers cannot be regained.

The foundation has kept us informed of every step, and they recently shared the devastating news that CIRM may not fund this trial. **The foundation has successfully produced the vector and secured FDA clearance; the trial is already live on clinicaltrials.gov.** The only thing standing between Charli, children like her, and a life-saving treatment is the funding for the trial itself.

Please reconsider your decision. There are real children, like Charli, waiting for a chance at life. She is currently still minimally affected and has the potential for a beautiful, full life if this disease can be stopped. She deserves that chance.

Sincerely,
Stevi and Charli

