

Subject: [EXT] CIRM Review - Batten CLN6 family
Date: Tuesday, June 23, 2026 at 2:37:43 PM Pacific Daylight Time
From: hodeilargi batten CLN6
To: Lana Morales
Attachments: 1000173552.jpg

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Dear CIRM Review,

Thank you for this opportunity and thank you for considering The Charlotte & Gwenyth Gray Foundation's application for CLIN2 funding.

My name is Joana, my children Hodei and Ilargi were diagnosed with Batten CLN6 at the age of 5 and 3, and are now 10 and 8.

This funding gives us real hope at an opportunity to slow down the progression of the disease and maybe become the cure we have been waiting for. If not funded, there will be no trial in the near future and time is not on Hodei's and Ilargi's side. This disease is cruel and moves at a rapid rate of progression.

The foundation has been keeping us up to date on progress and now has shared that CIRM will likely not fund this trial. Please reconsider as there are real patients, children waiting for a real chance at life.

Sincerely,

Joana, mother of Hodei and Ilargi





