Subject: [EXT] PUBLIC COMMENT – June 25, 2026 – Support for CLN6 Gene Therapy Clinical Trial Funding
Date: Tuesday, June 23, 2026 at 11:12:43 AM Pacific Daylight Time
From: Weronika Czmoch
To: Lana Moralez

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Dear Members of the CIRM Application Review Subcommittee,

I am writing to you as a mother from Poland, but above all, as a parent standing face to face with something no parent should ever have to accept.
My 5-year-old son, Igor, has CLN6 Batten Disease — a fatal, ultra-rare neurodegenerative disease that is slowly taking away his future.
For the committee, the vote on June 25th is a decision about funding. For our families, it is a decision about time — and time is the one thing our children do not have.
The international CLN6 community is ready. Families are prepared to travel immediately and participate in this trial. We are not asking for guarantees. We understand that research carries uncertainty.
But we also understand the certainty of this disease.
CLN6 does not wait. Every month means irreversible loss — vision, speech, movement, independence. Children who laugh, play, and dream today may lose abilities they will never regain.
As a mother, I ask myself impossible questions every day: How do I explain to my son that his world may become darker? How do I prepare him for losing things no child should lose? How do I keep hope alive while watching time disappear?
This grant cannot promise a cure.
But it can preserve something that our children are running out of: a chance.
CIRM was created to bring hope where few options exist. For families like ours, this trial is not an abstract scientific project. It is the possibility that our children may still have time.
Please do not let time become the reason they never had that opportunity.
Thank you for your consideration.

Sincerely,
Weronika
Mother of Igor (age 5)
CLN6 Patient Family, Poland