

Thursday, June 18, 2026 at 8:20:32 AM Pacific Daylight Time

Subject: [EXT] Dear CIRM Review Committee, Please find attached my letter in support of funding the CLN6 gene therapy clinical trial. Thank you for taking the time to read my family's story and for considering the needs of children living with CLN6 around the w...

Date: Wednesday, June 17, 2026 at 5:09:48 PM Pacific Daylight Time

From: Tainara Silva

To: Lana Moralez

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Dear CIRM Review Committee,

My name is Tainara, and I am the mother of **Manuelli**, a 6-year-old girl from Brazil living with CLN6 Batten disease.

When Manuelli was diagnosed, our world changed forever. Since then, we have watched this devastating disease slowly take away abilities that every child deserves to have. Every day we live with uncertainty, fear, and the pain of knowing that CLN6 is progressive and currently has no approved treatment.

As parents, we do everything we can to give our daughter love, comfort, and the best quality of life possible. But no amount of love can stop this disease. We are running out of time.

This clinical trial represents hope—not only for Manuelli, but for every child and family affected by CLN6 around the world. We understand that research does not guarantee a cure, but without research there is no chance at all. Without treatment, we already know what the future holds for our daughter.

We respectfully ask you to approve the funding for this clinical trial. Your decision has the potential to change the lives of children like Manuelli and to give families like ours something we desperately need: hope.

Thank you for listening to our voice and for considering the children and families who are

waiting for this opportunity.

Tainara
Mother of Manuelli