Dear Members of the CIRM Board,

RE: Letter of support for CLIN2 17091

I write to you today not just as an aunt, but as someone watching their niece slowly lose the abilities we all take for granted. My niece, Naomi Lockard, has been diagnosed with SPG50, a rare and devastating neurodegenerative disorder caused by mutations in the AP4M1 gene. SPG50 is relentless. It strips children of their ability to walk, to communicate, and eventually, to care for themselves. It brings seizures, cognitive decline, and a future filled with uncertainty. As an aunt, it is devastating to not only watch Naomi struggle and suffer, but also watch my sister be powerless to get an existing treatment to her daughter when it is within reach but remains unfunded.

Time is not on our side. Every day without action means another day closer to irreversible damage. That is why I am pleading with you—please recognize the urgent need for funding gene therapy programs that offer real hope. Your support could mean the difference between despair and a future where children like my niece have a chance at life.
Please, do not let these children be forgotten. Stand with us in this fight.

Sincerely,
Megan McElhaney
Aunt of Naomi Lockard

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