Dear Members of the CIRM Board,

We write to you today not just as parents but as someone watching their child slowly lose the abilities, we all take for granted. Our daughter, Noemi Mueller, 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 parents, there is no greater pain than witnessing this slow loss, knowing that treatments are within reach but remain unfunded.

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 ours have a chance at life.

Please, do not let those children be forgotten. Stand with us in this fight.

Sincerely,
Maxine Silvestrov and Clemens Mueller (mother and father of Noemi Mueller)