Dear Members of the CIRM Board,

I am writing to you as a friend and extended family member of Cade Jobsis, a child diagnosed with SPG50, a rare and life-altering neurodegenerative disorder. This family and many others face an uncertain future, but with gene therapy there is hope. I am reaching out to ask for your partnership in advancing gene therapy research that could change the lives of Cade and other children like him. These beautiful children deserve this chance.

Rare diseases often struggle to attract the funding necessary for treatment development, despite their devastating impact. It's pretty unlucky to be diagnosed with an ultra rare disease, and it's made so much more difficult when the impediment to treatment is lack of funding. Breakthroughs in gene therapy are offering new possibilities. With your help, we can accelerate progress not just for SPG50 but also other similar rare diseases. By investing in SPG50 research, you are not just supporting one disease—you are contributing to a growing field that has the potential to transform lives across many rare conditions. This is an important moment in the lives of so many children.

We believe that by working together, we can create a future where no family has to endure the heartbreak of watching their child's abilities fade away. We urge you to help this movement that changes lives by supporting the SPG50 program.

Thank you for your time, your work, and your commitment to improving lives.

Thanking you in advance for what I hope will be favorable consideration.

Keith B. Levy
Juneau, Alaska