January 30, 2025

Dear Members of the CIRM Board,

I am writing to you as the uncle of a child diagnosed with SPG50, a rare and life-altering neurodegenerative disorder. Families like mine face an uncertain future, but we know that with the right support, there is hope. That's why I am reaching out—to ask for your partnership in advancing gene therapy research that could change the lives of children like Cade Jobsis.
Rare diseases often struggle to attract the funding necessary for treatment development, despite their devastating impact. But breakthroughs in gene therapy are offering new possibilities, and with your help, we can accelerate progress. 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.

I 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. I urge you to be part of this movement for change by supporting the SPG50 program.

Thank you for your work and your commitment to improving lives of children and adults.

With my best regards,

Gerrit J. Jobsis, III