Dear Members of the CIRM Board,

RE: Letter of support for CLIN2 17091

I am writing to you as a grandfather parent 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.

There is a gene therapy treatment waiting in a freezer until the funds can be found to treat children in a Phase III study. It has already been shown to be safe and now we need to take the next step. If this study shows the treatment to be effective, children in California and around the world will be saved from this devastating neurodegenerative disease. Imagine watching your child decline for the next 20 years until they are unable to move and unable to speak. That is what these patients and their families are facing.

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. We invite you to be part of this movement for change by supporting the SPG50 program.

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

Best regards,

Paul Jobsis