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California Institute for Regenerative Medicine
601 Gateway Blvd, Suite 400
South San Francisco, CA 94080

Letter of support for CLIN2 17091

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 and my brother's face an uncertain future, but 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.

Rare diseases like SPG50 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.

My nephew's case is, I am told, especially promising, but I am no doctor. Although he has experienced slower development, the most debilitating neurodegenerative effects have not yet set in. However, any day now, he will begin experiencing seizures, that damage his nervous system. His life, though filled with love from his family and friends, will become more and more painful. It is only with the assistance of this gene therapy that Cade has any hope for something like a normal life.

By working together, and with your assistance, 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.

Warm regards,

Leo Jobsis-Rossignol, esq.
Uncle to Cade Jobsis