CureSPG50
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Jan 28, 2025

CIRM Review Committee

We write to you today with deep frustration and disappointment regarding the review of CLIN2_17091—Gene Therapy for SPG50, a program that originated from our organization with the singular goal of saving lives.

On April 2, 2019, our world was forever changed when our youngest son, Michael, was diagnosed with Spastic Paraplegia Type 50 (SPG50). We were told to go home and make the most of our time with him—there was nothing that could be done to halt the devastating neurodevelopmental decline that would ultimately leave him completely paralyzed. But accepting that fate was never an option.

That day, we made a promise: we would not only fight for Michael but for every child affected by this cruel disease. Against all odds, we have raised the necessary funds, navigated complex regulatory landscapes, and taken unprecedented steps to develop a treatment that offers real hope. Today, that treatment exists. It is ready. Yet, without your support, the therapy we worked tirelessly to bring to life—the drug that could change the future for these children—may never reach another patient.

We acted when no one else would. We took responsibility for our circumstances and turned despair into action. Now, we ask CIRM to do the same. The stakes are too high, and the consequences of inaction are irreversible.

We urge you to stand with us and do what is right for these children. The opportunity to save lives is within reach—let's not allow it to slip away.

Sincerely,

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of CureSPG50
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