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Ref: Special thanks to CIRM

Four years ago, we sent a very special letter to Mr. Kevin McCormack who in that time was Director of Public Communications & Patient Advocate Outreach for CIRM, seeking not just for a chance of life for my son Jakob but to highlight the importance of getting back the license for Dr. Donald Kohn to continue his clinical trial and advances for ADA SCID. Four years ago, we came to CIRM with a very clear and very personal picture of what it means to have a bubble boy at home, the challenging situation we were submerged due to the lack of access to treatment in Canada and the uncertainty of life expectations while fighting for my own life due to cancer.

Today we come back to all of you happy, humble, excited and proud to recognize the bold efforts you have done supporting the incredible Dr. Kohn, the kindness in your procedures to accept families into this clinical trial and the very sharp moves you have executed to fight hard for advanced therapies that would revolutionize the world and change the lives of patients and their families.

Five years ago, our son Jakob was diagnosed with ADA SCID 10 days after he was born, heartbreaking news that came with the possibility of two-years life span maximum without proper intervention. On July 19th 2024 at UCLA and thanks to your support and financial assistance, this Little Fighter, "the Edmonton bubble boy", became the first Canadian child on this second phase of the clinical trial for ADA SCID, to receive this gene therapy that today is allowing him to have a second chance at life, an opportunity to be unstoppable, a revolutionary therapy that has broken the limitations of his condition and has modified our entire dynamic at home, our future and his life itself.

Today we find imperative to show the world and the Government the importance on taking a chance in the life of patients through innovative therapies like this gene therapy created by Dr. Kohn, to recognize the efforts and significant financial investments CIRM has taken on to bet on research projects, treatments, patients and their conditions. You have given us **MORE THAN HOPE**; thanks to all of you today we are not just touching the dream but living in a place where we feel confident enough, we would be able to see Jakob grow, learn and finally enjoy a normal life around friends, family members and zero medication to support his body, his life.

During these five years we have fought hard to keep our son safe, healthy, and happy and today more than ever we need to continue standing strong by the commitment made

of treating ADA SCID patients, a future of a commercialized therapy that brings access for treatment to all, collaborative work between scientist and physicians around the globe and the urgency of showing our governments that the life of our ADA SCID children matter.

This is Jakob´s first Christmas without SCID, our first holiday where we spared our wishes into new hopes and desires, the end of a 2024 year with a stem cell transplant that has given our son back and a bright welcome to a 2025 year and many more, where we ease our worries little by little and we are concentrating our thoughts on the first real vacation as a family in this new life.

Thank you for giving us the possibility of being heard, for making the life of our son and other pediatric patients personal, for being loyal to your promises, for caring and stand by your commitment to support Dr. Kohn and his team.

With sincere gratitude for all you do,

Paola Andrea Fernandez de Soto AbdulRahin

Board member for ImmUnity Canada, Published Author for In My Magical Bubble, Parent Partner for RareKids-CAN, Creator of Jakob Little Fighter, ADA SCID advocate.