

ELPIDA THERAPEUTICS SPC

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Date: February 4th, 2025

Dear Domingues Family,

As you know my name is Terry Pirovolakis and on April 2nd of 2019 my son Michael was diagnosed with a terrible disease called SPG50, I was told go home love him as there is nothing that could be done. Fast forward to March 24th of 2022 and my beautiful boy was treated with a Gene Therapy we created for him. Our Story: <https://www.sickkids.ca/en/news/archive/2024/gene-therapy-halts-progression-of-rare-genetic-condition-in-young-boy/>

After saving my son I made a promise that I would save as many kids as I can, so I started Elpida Therapeutics a company setup as a non-profit to make genetic therapies to save children with rare diseases. We have since treated 7x children with SPG50 disease and will be treating 22x this summer across Europe (Spain, Germany, UK & Denmark) and North America through strategic partnerships. We have also advancing 5x more pediatric neurogenetic diseases to the clinic and will be treating over 50+ next year through a partnership with the NIH & CIRM (California's Institute of Regenerative Medicine).

Over the past few years, my team and I have been working to advance the CLN7 program to help save children affected by this devastating disease. However, due to the ultra-rare nature of the condition, there has been no interest from pharmaceutical companies or foundations to fund a second clinical trial.

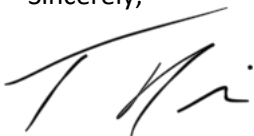
We continue to explore ways to help these children. Given the current challenges in the U.S. with little interest in investment for drug development for rare disease, it is unlikely the program will move forward without the support of a patient organization.

Inspired by the determination of the Domingues family, I am committed to supporting their efforts to treat children suffering from this disease. If the family can raise \$2,800,000 USD, I will assist in sourcing and manufacturing a treatment for 6-8 patients. We will then work with our consortium of partners at Elpida will help move the program into the clinic at an estimated cost of \$500,000 USD. We will also work to find a hospital willing to support and treat the children on a humanitarian basis. If no such hospital is found, an additional \$350,000 USD per child will be needed to cover treatment costs, excluding travel and accommodations.

These costs are substantial, and we wish there were alternative options. However, due to the rarity of the disease and the lack of pharmaceutical or grant funding, it unfortunately falls on families to raise the necessary funds and manage such programs. Additionally, given the severity and rapid progression of the disease, time is critical. Delays could result in the Domingues' child reaching a stage where their child will not qualify for the trial.

This is an immense burden for any family to bear, but we are here to support them in any way we can.

Sincerely,



Terry Pirovolakis
Founder