



Children's Hospital



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Dear Mr. Pinto:

I am writing this letter on behalf of Ms. and Mr. Wolff, to inform you on the circumstances of their son Filipe, who is being treated under my care at Dana-Farber/Children's Hospital Cancer Center in Boston.

Filipe is a 3 yo Brazilian boy who was diagnosed with disseminated Langerhans Cell Histiocytosis during the first few months of life. His disease involved multiple organs, including skin, bones, bone marrow, liver, lungs, and spleen. Langerhans Cell Histiocytosis is a form of blood cancer that affects predominantly young children. Filipe responded well to treatment, although responses were not complete; his disease has reactivated in multiple occasions and he has required multiple treatments. Over the last year, Filipe deteriorated and developed progressive liver enlargement. Filipe's parents and his primary doctor in Brazil contacted me for assessment, and we felt it would be better if we could see Filipe in Boston since we have been investigating new treatments for his disease and he could benefit from them.

Filipe, his brother, and his parents, moved to Boston in November 2011 and I have had the pleasure of being Filipe's doctor since then. Upon initial evaluation, we felt that Filipe's Langerhans Cell Histiocytosis was under control, with no obvious signs of activity, and what was affecting his liver was probably a disease called sclerosing cholangitis, a form of progressive liver cirrhosis that is known to develop in children who survive Langerhans Cell Histiocytosis. Filipe was seen by our liver specialists, and the diagnosis of sclerosing cholangitis was confirmed by biopsy. We estimate that his liver damage is very advanced and not reversible, and he will continue to deteriorate to end-stage liver cirrhosis.

The only chance of cure for Filipe is a liver transplant. However, the time course of the disease is somewhat unpredictable. We will need to perform serial studies over then next 6 months to determine the speed of the progression of his cirrhosis and to estimate the time when he will need the transplant.

If you have any questions or comments, please do not hesitate to contact me.

Sincerely,

Carlos Rodriguez-Galindo, MD
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Medical Director, Clinical and Translational Investigation Program
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