

A Letter From The Parents

Ask any parent, being a parent is hard. Period. Being the parents to a critically ill child is the hardest thing we have ever done and continue to do. Since our first ultrasound in 2012, we have been on an emotional whirlwind. Finn was and constantly is sick. We're not talking the common cold, but fevers of 106 degrees, chicken pox/shingles, stomach bugs every month, etc. Also, he didn't reach any of his milestones when he should have. Yet, family and friends labeled us as overprotective, paranoid parents. Each specialist we saw either referred us to a different specialist or was unwilling to investigate our concerns. It wasn't until August of 2015, that we finally had an answer that made sense. However, it was an answer that we could never be prepared for. Our little Finn was diagnosed with PNP Deficiency and without immediate treatment he would die. PNP Deficiency is a metabolic disorder that damages the immune system and causes severe combined immunodeficiency (SCID). Children like Finn with SCID lack almost all immune protection from bacteria, viruses, and fungi. As a result, they are prone to repeated life-threatening infections. The only cure for SCID is a successful bone marrow transplant. In addition to SCID, PNP Deficiency has also caused Finn to have neurological problems, developmental delays and intellectual problems. To date, there is no cure of definitive prognosis for these symptoms. Luckily, we found a bone marrow match for Finn very quickly. In November of 2015, Finn had his transplant after receiving intensive myleoblative chemotherapy treatments. It usually takes six months to a year after a transplant for the immune system to work, as it should. In the meantime, Finn stays in isolation and we do our best to keep his environment as clean as possible. This journey has taught us many things, but one lesson we remind ourselves daily and want to reassure other parents is that you are your child's best advocate and it is so important to do your best job at it. Always trust in your instincts; you know your child better than anyone.

*With our best regards,
Katherine and Robert Stever*