Allie (a student in our Pre-K4 class) was diagnosed with Charcot-Marie-Tooth (CMT) disease when she was just two years old. CMT disease is an inherited neuromuscular disease characterized by a slowly progressive degeneration of the muscles in the foot, lower leg, hand and forearm, accompanied by a mild loss of sensation in the limbs, fingers and toes. It affects 1 in 2,500 people worldwide. There are various form of CMT disease and its severity can vary greatly. But, in all cases is can be extremely painful and limits the individual's ability to do everyday things the rest of us take for granted. As Allie’s mom, I want her to live the fullest life possible. Clinical research in rare disease is so important to us because we are confident about the impact it will have shaping her future, as well as futures of others who struggle with rare disease.

-Mrs. Virginia