

01/23/2000

Some of you may know that back in April, we took Violet to the Metroville ED and were admitted into the Pediatric Intensive Care Unit for critically low hemoglobin levels. She received blood transfusions which are usually "a last resort." This marked the beginning of a journey much longer than we could have predicted.

Violet was just ten-weeks-old then. Today, she's a beautiful ten-month-old. She's had more labs drawn over the past eight months than we have had in our lifetimes combined. When we decided to move to Nomanisan, our hematologist/oncologist in Pixar was very intentional about Violet still being monitored closely. We were referred to a hospital closer to our new home. The doctors at that hospital then referred us to Saving Grace.

Violet was diagnosed with something called Shwachman-Diamond Syndrome caused by a rare autosomal genetic mutation. While her diagnosis helps us better understand her previous medical problems, the news is quite difficult to process.

It's estimated that 1:75,000 live births have Shwachman-Diamond Syndrome. That would mean about 55 newborns in the U.S. this year will have SDS. To give you some context, Saving Grace has about 200 new cancer patients each year. They receive a new Shwachman-Diamond patient about once every two years. It is an inherited, multi-system disorder which affects the pancreas, bone marrow, skeleton, and may affect other organs. Children with SDS can be frequently and severely ill with infections that can be life-threatening. She is at a higher risk of developing leukemia, bone marrow failure, and potentially fatal blood diseases.

We have no way of knowing when this will take a turn or how rapidly Violet's health will deteriorate once it does. What we do know is that if she comes down with a fever, we've been advised to pack our bags and head to the ER.

Medical scientists cannot say with certainty what the long term future holds for Violet. The median life expectancy of this condition is more than 35 years. With complications, it could be less.

If you are looking for a way to help, please consider joining the Shwachman-Diamond Syndrome Research Fund. This nonprofit will help you set-up a fundraiser, big or small, to boost the funding going to research on this rare condition. Funds to support these researchers are just as rare as the condition itself so every little bit counts.

We're very optimistic that Violet will live a long life; she's in good hands. The specialists we are working with are so smart and taking this very seriously. They are coordinating her care and will be monitoring her closely. We feel confident that by staying on top of this, she will be able to lead a happy and long life. God Bless them.

Please don't pity us or feel bad for us. We are so blessed to have such an amazing and special little girl who has made our hearts whole. Please pray for us and pray for Violet. She is strong. She has the spirit of a fighter and we couldn't be more proud.

Sincerely,
Helen Parr (and Bob and Violet, too)