

Email from Jeanette Hicks, Saturday, June 6, 2020

Friends,

It is time to send accurate info to all our crew How I miss each name on this list. Some of you haven't even been brought in the loop yet- because this is some strange ride and we are exhausted. Here is the story and latest:

Monday, Rebecca was complaining of a backache. She was still herself, mobile and doing school work etc. Tuesday night this went bad fast- chills, vomiting and extremely high fevers. Her pediatrician recommended a urinalysis and after those results, sent us to the emergency room. At the ER, they suspected appendicitis or a raging UTI. She was transferred by ambulance to Yale pediatric hospital. Many tests were run. The diagnosis was pyelonephritis, a kidney infection.

Then things went further south Thursday night. Becca became unstable and all the stops were pulled out. We were moved to an isolation room where anyone who comes in is dressed like a storm trooper. Many more tests were run. So many doctors in one very small room. It was touch and go for a long time.

Now her diagnosis is Multi System Inflammatory Syndrome of children MIS-C. This is the new and very mysterious illness that you hear about in the news. She has teams checking on her and testing various things from critical care, rheumatology, GI, infectious disease, cardiac...

Rebecca has been tested three times for COVID-19 all negative and her antibody test was also negative. She is having a 4th Covid test today, for protocol. They are not fun. In the last 24 hours, some mild smell and taste symptoms have developed typical with MIS-C. She perks up from meds or IV fluids and then crashes. She is in terrible pain with high fevers, very low blood pressure, and racing heart rates.

Rebecca is the ninth child here at Yale to have this diagnosis and she is essentially a guinea pig. While treating her for MIS-C they are simultaneously looking for other causes of infection. Her symptoms and diagnosis seem to change every few hours.

The good news is that she has been off oxygen for 24 hours and her fevers are lower - even normal sometimes. Progress! She was allowed out of the isolation room and we are thrilled with our new "suite" with less scary protective gear. We joke that "Yale Jail" is our big vacation in this quarantine year.

The very hard part is the Covid restrictions over the whole hospital system. I am here with Becca and I cannot leave, or I will not be allowed to come back. That means not even walking in the hallway. Al cannot visit and can only leave personal supplies in the lobby (some sweet cards were passed along through these bags). The nurses tell me he tried hard to subvert the rules and see us. No surprise. This is Al.

So, as a family, we can't be together until Becca is well enough to come home and it is as miserable as it sounds. The standard answer for MIS-C patients is to prepare for 2-4 weeks of

Yale Jail while other docs suggest by mid-week, she might be able to continue treatment at home. Each day is different. Honestly, no one really knows.

This morning was an MRI and we await whatever new information this might bring. Last night, she actually slept a few consecutive hours without setting off alarms or bringing in teams of people. That was huge. Mostly she is lethargic. In her perkier moments, Becca devises elaborate plans of escape or ways to sneak people in. She also feels a second puppy is in order after this ordeal. Becca is still Becca.

I have taken a month medical leave from the church and others are stepping up for me. It is crushing my soul not to preach tomorrow when so many need a good word of hope - but I know when to say when. Al is taking a few days off at a time. Elizabeth, Kate, and David are holding the fort and finishing up the school year. Jack, the wonder dog, is lost without all of us home all the time

Everyone wants to know how to help. For now, we are day by day. We have already had some lovey meal donations and cooking together seems to be something keeping the family sane. It is one of the few things to look forward to.

Jen Stanger is ready to mobilize occasional meals if our stay drags on. Checking in and phone calls are very welcome. We answer when we can but we feel the love. There is no privacy and we cannot leave our room. Becca does enjoy texts of encouragement and funny things, cards, and love - but don't expect responses. If she does, remember that she is heavily medicated;) The other children need just as much TLC right now and your encouragement goes a long way. Quarantine is bad enough and now this. David has been calling this whole season "dumbavirus" and I could not agree with his words more.

If we have major developments, I will keep you in the loop. Thank you for the prayers, kindness, and encouragement. We are truly blessed beyond measure to have so many friends to call family and we do feel your love wrapping around us. Y'all know we are people of faith and hope so there is no fear here... just assurance that all shall be well and we are not ever alone. Lots of real life angels are with us. Her nurses and techs are the absolute all star team-even making creative garbage bag curtains to make the room darker so Becca sleeps. This is true dedication.

Hug your people and show lots of grace in these crazy times we are witnessing.

Love and Hope,

Jeanette (and Al by way too much distance)