

For the first time in almost 16 months, we visited my daughter Sarah, her spouse Kate, and their daughter Aila Olivia. We've had steady contact on FaceTime, of course, and I've been able to connect with Aila (as has her grandfather) pretty well. We play and sing and do nursery rhymes and she has seemed to recognize who we are via phone. She kisses the phone, blows kisses, signs "I love you."

Aila will be 3 on May 26.

Tremendous progress: she is now completely off her vent, all day, even napping, and uses it only at night; she still has her trach, of course, and she is still fed by G-Tube. She walks and climbs, goes up and down stairs (she's pretty fearless, physically). She knows colors and articles of clothing and body parts and signs and pictographs. She is at the very very first stage of acquiring speech (babbling). So developmentally she is still probably somewhere under 2 years old, but she is bright and engaged and curious and hitting all her developmental milestones. It will take a while, but she will catch up. She is physically quite small, and looks much younger than she is; likely she'll always be small. Although she is eating pureed foods and trying as many foods and textures as her moms can offer, full nourishment sans G-tube will take a while, as will her speech development. She still has some complex medical issues, being monitored, but she continues to astonish with her progress, both medical and cognitive.

Seeing her in person was just indescribable. We played and played, and finally I could see the full range of her activities and her wonderful disposition--she's a calm, good-humored little girl, especially considering all the procedures and exams she's had to undergo. Her moms are wonderful with her.

For the entire month of June, she'll attend a special preschool program five mornings a week for three hours. Her nurse will go with her. Because of the pandemic, she hasn't seen any other children at all for months; ordinarily she would've had visits from her moms' friend's children, girls ages six and three. We know that once she sees other kids, her development will take off.

I'm reporting at length because so many people at St. Mark's have kindly taken an interest, heard my worries, heard all about Aila's rocky start, and because she's been on the prayer list her entire life. I am very very grateful, believe me, as are her moms, who understand that their family has a GR community rooting for them.

Someday I hope the three of them will visit, and come to St. Mark's and thank you all in person.

With love and gratitude,
Carmela McIntire

