January 30th 2011

The last week has been a very busy week so this will be a long update; bear with it though because everything works out great. Thursday morning Jessika had her fourth dose of Synagis, which protects her from RSV, at the tiny tots clinic, this time it went off without a hitch. Same day we were invited to attend a meeting with the respirology team and the PNAVD to work out some details regarding the Trilogy mainly. In the end we made our point that the Trilogy is the machine that Jessika would benefit the most from and that we would find a way to get it with or without their help. For the time being we have been supplied with a VPAP III (BiPap machine) and the cough assist as well as another suction machine. Whether or not they will ever supply us with the Trilogy remains to be seen, for now Jessika is fine with the VPAP and we don’t have $20,000 to buy a Trilogy anyways. We do need to buy the Pulse Oximeter and have put a prescription in but won’t have the machine for another week as we are waiting for the store to receive it’s shipment of machines.

Directly after the meeting on Thursday we were visited by an RT (respiratory therapist) from PNAVD, Suzanne, who brought us the machines and miscellaneous extras as well as an instructional binder (3” thick). She spent 4 hours going over two of the machines with us and will be back on Tuesday to go over the cough assist. Thursday night we had intended to have Jessika spend her first night on the VPAP at home but there was a crazy useless alarm going off for no reason and we wanted Jessika to get a good night’s sleep so we ended up turning the machine off and letting her sleep without it.

That brings us to Friday morning, day of the surgery. We got to the hospital, they did all the pre-op weighing and checking to make sure she was in good health, we had a chat with the anaesthesiologists to go over the plan for the operation; no muscle relaxants, minimum amount of oxygen, pain meds that would be metabolized quickly and as little time as possible intubated. They had originally intended to extubate immediately following the operation while still in the OR but, after discussing this with us and us telling them we wanted her extubated directly to the VPAP, they decided to wait until Jessika was in the ICU. So, that was the plan going in with an expectation of the whole thing taking no more than 2 hours. I’ll put a mention here to say that we were so happy to have Beatrice’s mom in the room with Jessika, it was a relief to know that there was someone in there who knows Jessika, who we know at least a little better than the doctors, and she came out and said hi to us and we knew she’d be looking out for our little baby girl.

We waited just over an hour before one of the residents came into the waiting room to notify us that the gtube had been put in, no problem, but that the surgeon had noticed something else while he was in the belly; a congenital hernia, and he wanted to fix it while he was in there. We said ok, of course, because even though it isn`t bothering her now and there`s no way of knowing when it would start bothering her, it would eventually and we don`t want to have to operate when Jessika isn`t in any state to be operated on and it would only take an extra 15 minutes anyways. So she has the tube, which is a Mic-Key button, it looks a little like the button on a beach ball but the opening is only a few millimetres. She has one stitch with some tape over her belly button where they went in with the camera and she has tape over two tiny 2 mm puncture wounds where they went in to do the work. I can take the tape off the belly button myself by the end of today and the tape will fall off the two puncture holes by itself once they`re healed and tomorrow we will go back into the hospital so they can snip one stitch off the button and remove the dressing from around it. They`ll also show us how to care for the button, long term, because they didn`t have a chance before we left. But I`m getting ahead of myself; they brought Jessika down to the ICU, intubated and still asleep, they took out the tube, put her on the BiPap and woke her up. Of course she was not very impressed to be in a room full of doctors so was very upset when we were let in finally but she was in excellent shape. She didn`t seem to be in a significant amount of pain, I would say maybe some discomfort but she never seemed to be in pain, all of her scores were perfect the whole time she was in the ICU. She was coughing a bit at the beginning and we had the nurse do some chest physio and some suctioning and that was it, there was nothing to cause us any worry, the operation was a success, the extubation was a success and, two hours after going on the BiPap, she was taken off. She took a well deserved nap, was grumpy most of the afternoon, but went back to her usual happy, smiley self after having her dinner at 5 (first meal of the day, poor thing) and having a little poop.

Of course Friday was Jessika`s birthday and, once the nurses on the ward found out, she started getting extra special treatment; Tim made her “decorations” for her room (computer printouts with a picture of Tweetie that said “Happy Birthday Jessika”), Tim and Amanda went and got her a gift (a snail that plays music, rolls and has a mirror on the front, Jessika loves it!), and everyone, doctors, nurses, RTs, got together and got her a little chocolate cake, they came round in the evening, all together, and sang her happy birthday...she cried of course but only a little. I guess Jessika likes doctors better when they’re singing!

She had a relatively good night on the Vpap, her stats stayed perfect all night but the ward was so loud that her sleep was disturbed a few times. Jeff suggested I go home and get some sleep, so I did, left after Jessika went to sleep around 8:30 and went back for 5am. Jeff stood guard at the side of Jessika’s bed all night and didn’t leave until half an hour after I got there, went and slept on the couch in the parent’s room for a couple of hours. Jessika was doing so well that there was no longer any reason to keep her in the ICU and the doctors had planned to bring Jessika down to the TDU (where we stayed last week) for another night or two so they could do some additional monitoring of her on the VPAP. Basically, Dr Bach doesn’t believe that Jessika can trigger the VPAP but the resps at the children’s noted that she is triggering it just fine so they wanted to study her further to back up their claim that she is triggering so they could rest easy about not giving her the Trilogy. This is my belief anyway. But she is doing fine on the VPAP at the moment and directly after surgery is not the time to start doing additional studies. We want Jessika to heal well, that means bringing her somewhere she can rest and be relaxed, somewhere with no doctors, somewhere like home. We spent our entire stay in the ICU explaining to one doctor/nurse/RT after another that we were not going to the TDU; if Jessika is well enough to leave the ICU, if they don’t see any risks, if there are no respiratory issues and no issues with the surgery then we couldn’t see any reason not to take her home and, finally, they agreed. So we are home, Jessika has been happy and relaxed, taking full naps, she spent last night on the VPAP with no problems, we were able to sleep a full night in our own bed as well.

Apart from the surgery and the machines, we also received a prescription in the mail, from the physiotherapist, for AFOs (Ankle Foot Orthotics) and telling us that she will order a standing frame but she needs to take Jessika’s measurements first.

As always, we thank everyone for your thoughts, your prayers, your birthday wishes and all your love. Our journey with Jessika is just beginning; the road itself may well be peppered with obstacles, we do not know where or when it will end, but the sun is shining, the scenery is beautiful and the company is perfect and I can’t imagine sharing this road with anyone other than my amazing husband Jeff, all of our wonderful kids (Christian, Joshua, Mike, Lex and Jade), our two families and all of our friends and supporters...Thank you!