January 20th 2011,

We had an amazing night’s sleep in our own beds after spending two nights in the TDU (technology dependant unit) with Jessika on the BiPap. The doctors didn’t think they would get Jessika to spend more than two hours on the BiPap the first night so they didn’t set up all the necessary equipment to do proper monitoring. Jessika ended up spending the entire night on the BiPap, 9pm to 6am, but since they weren’t monitoring properly we still had to spend a second night in hospital. They increased the levels on the machine a little and set up all the good monitoring equipment and Jessika spent a second night , 9pm to 7am, on the BiPap and did very well. We received a prescription for a Masimo RAD 8 pulse oximeter, a monitoring device that we can get in the next two weeks form Medigas in Montreal. Jessika is scheduled to have her Gtube surgery on the 28th of January, her birthday. The surgery will be done laparoscopically under general anaesthesia and intubation. We expect to be in the ICU over the weekend following surgery. The only machine we do not yet have is the cough assist and we are unsure of what the plan is for this machine at the moment.

While in the hospital Jessika delighted the nursing staff and doctors that were around her and visiting her. She played with a child life therapist who even brought in a “dream machine”, a closet sized contraption with lights and sounds that stimulates and relaxes and that Jessika really loved.

January 23rd 2011

After a lot of back and forth between our respirologist, the Programme Nationale d’Aide Ventilatiore a Domicile (PNAVD) and Jeff’s private insurance company, we think we are on the right track and that we have all the players on the same page. The respirologist is responsible for writing the prescriptions for 1. The cough assist 2. The respirator (trilogy is preferable to BiPap) and 3. the pulse oximeter. We have the third prescription and he has agreed to write the other two, finally, and send them to the PNAVD. They, at PNAVD, now have the responsibility of forwarding the prescription as well as the cost estimates on to Jeff’s insurance company. Jeff’s insurance will either accept or deny the requests for equipment, whatever they accept will be covered up to 80% and we or, possibly, the PNAVD will cover the remainder. The PNAVD will support us with the repair and maintenance of these machines, training us in their use, providing any supplies that will be used with them, such as masks to go with the ventilator, catheters for the suction machine, etc.

We have been doing the back and forth between our Physiotherapist, Occupational therapist and Rehab center (MacKay) to get Jessika a standing frame, some Ankle Foot Orthotics, a Hensinger neck brace, some positioning aids (for postural drainage and side lying) as well as a few other things like arm slings for side lying and more. We have not made exceptional progress but the ball is rolling, slowly, like uphill. I guess this is the main reason why we are constantly asking for things way before they are necessary because by the time we get them they will be necessary.

A fellow SMA parent that we have made contact with, become friends with I dare say, has offered to send us a five point harness vest for car travel. The safest way for Jessika to travel is lying down because she puts a lot less pressure on her stomach, which is where she breathes from. So we have asked the physiotherapist and the people at the MacKay center to help us mould a foam bed to fit onto the back bench in our minivan that Jessika can lay on wearing the five point vest that goes through the seat belts.

We have invested some money in a “nanny cam” so that we can supervise Jessika while she is sleeping without disturbing her. It will be important to be able to see if Jessika ever starts going into distress or even just having difficulty breathing while she’s sleeping. There are some other technological devices that we are looking into; a voice amplification device will help her, as her voice gets lower and weaker, to continue to be heard and grow into her personality and her own social aptitudes. Also the IPad has made a big impact in the SMA world as well for many other disabilities because of its wide range of apps that can be used for teaching and learning as well as it’s sensitive touch screen interface that makes it an irreplaceable tool in helping Jessika function and grow in ways that she wouldn’t be able to otherwise. Already she isn’t strong enough to press on a real piano key and make a sound but she can use an application on Jeff’s iPhone to play the piano or the guitar or just to make animal noises; she’s able to interact with her environment in an amazing way, in a way that will help her learn...learning through play.

Apart from all that Jessika is still in good health, she is still happy and smiley, funny and friendly. She loves having visitors, watching her favourite shows (Elmo and Bear in the Big Blue House and The Doodlebops) likes reading books like Dr. Seuss’ The Foot Book and Goodnight Moon, she loves music of all kinds and sings along to her favourite songs. With her birthday just around the corner I realize that she has grown so much this year and so have we.