February 7th 2011

Not much to report this time, Jessika is doing great! She’s been sleeping with her BiPap on every night, except for one, since her surgery. Only difficulty with that is getting the mask on just right; if it’s too tight she gets blisters on her face around her nose, if it’s too loose she’s up half the night because of air leaks, I still haven’t found a perfect middle ground. We’ve also been using the cough assist for the last 4 days; I’ve worked it into her bedtime routine. She absolutely hates it but, eventually, she should get used to it, hopefully. We’ve moved Jessika’s room around to suit all the equipment better, and to have all the supplies on hand when we need them.

Jessika celebrated her birthday through the whole week following it; she was smothered in gifts like a 2 foot Bear (you can put your arms in his to give Jessika a giant Bear hug), a little Elmo, a big Elmo, cookie monster and Ernie, a singing Elmo microphone, etc. (Can you tell that she likes Elmo?)And she had lots of chocolate; cake, bars, cookies, etc. That little girl was (is) spoiled!!

We found a good way to transport Jessika in the van, using her stroller; Jeff bought some ratchet tie downs and a ramp and we’re ready to go.

We went to an orthopaedist last week to have Jessika fitted for her AFOs. She formed a cast around each of Jessika’s legs (foot and calf only), then immediately cut it off, so they have a mould for the AFOs that will be perfectly fitted to Jessika. We even got to pick the colour...we’ll post a photo once we have them, next week sometime.

We’ll be going to the MacKay center again at the end of the week to add some additional neck support to Jessika’s chair since she’s starting to flop over more. We’ll be going to the hospital twice next week for appointments; one with a new neurologist at the Children’s who has a lot more experience with SMA than our current neurologist, and the other is a follow up with the surgeon to check the gtube.

I was able to take Jessika out for a beautiful stroll Saturday afternoon, the temperature was in the plusses, the sun was out, it was the nicest day this year and Jessika really enjoyed the walk. She looked like a star with her sunglasses on!

Well, that’s all I can think of writing at the moment; as always, thanks to everyone who has supported us, not just those who have donated money or time or even groceries, but also all those who have offered their kind words and prayers and their shoulders and ears. Thank you!