

A Kramer Family Update

Here's the Kramer update

Monday-I took off childcare and drove Kramer to his appointment. Chemo and radiation all went well. He was feeling good.

Tuesday-Our friend drove to radiation. He went to working the morning for a few hours. He has an oxygen pack. It had four hours of charge to it. I'm thankful for only 4 hours as it makes it hard for him to work any longer than that. We started oxygen overnight now too as he has been waking up with headaches.

The rest of the week he has some farmer friends driving him so I have a break.

The Gannon report...This comes directly from Kalissa:

"Well this isn't where I expected to be. It is a long story but I'm here now."

I'm going to start with the good news:

Gannon does not have Hirschsprung's disease.



Gannon is doing much better. This morning they came in and clamped his NG tube and stopped his IV fluids to see how he would do. He is tolerating both well.

Another piece of good news is we should be going home in the morning.

Now I'll tell you the okay news:

*They *suspect* Gannon is allergic to milk protein. Gannon has been in a trial of Alementum milk replacement while he is here and it's has been going well. This is a very expensive fancy hypoallergenic formula.*

This means I either have to completely cut dairy and soy from my diet – no exceptions – to breastfeed him or I have to be done breastfeeding. This absolutely and completely breaks my heart. I'm not quite ready to talk about how much that upsets me.

*Gannon does have some abnormal anatomy towards the end of his digestive tract which they *suspect* in combination with the *possible* milk protein allergy caused his problems. This can*

be treated with simple dilation.

*Do you notice how many *maybes* are involved in all of these *possible* diagnoses?*

I'm frustrated. I'm sad. I wanted a definitive answer. I didn't want thousands of dollars workup to be told to switch to formula. I don't want to quit breastfeeding.

I'm thankful Gannon is feeling better. I'm thankful we will be able to go home. I'm thankful it was nothing serious.

Mixed emotions here tonight. We will continue the trial of Allimentum through the night and make sure he tolerates feedings. We will likely head home in the morning. Supposedly he is fixed. Supposedly he will be fine but my mom gut still isn't all the way convinced. Stay tuned."

I am not super confident about the diagnosis. I think Kalissa will be taking one blog reader's advice to have the chiropractor have a look at Gannon. We have a great chiropractor and she's reasonably priced so why not?! I just feel like the doctor's never saw him when he was screaming and obviously in pain. They didn't see those grossly obtuse belly moments. Oh well, we will try this and hopefully it will be the trick...I'm also a believer that prayer is playing a part in him feeling better. Time will tell. I just can't wait for him to be home.

As for me personally....

I had a melt down on Tuesday after childcare. I've not had sleep for the past four nights and it all caught up on me. I've had Carver a few of the nights and he has a terrible cough that only acts up over night. UGH. He coughs and coughs and I can't sleep when he does. I had a short night of sleep Sunday into Monday as we had to leave at 5am to get to his 7am appointment. UGH. I didn't get nearly enough sleep that night. The good thing is I recognized that it's because

of lack of sleep that I melted down so a scrambled happened here to get me some sleep. Kelli took Carver for an overnight at her house. Kramer did a few household jobs.

I'm so thankful that we all chip in to make this work. When one can't the rest do. I cannot imagine all of this without the help of family. Kramer had a bad week last week and for me it was good week. Kelli had a rough couple days last week managing childcare and it was good for me as I could carry the load. It's my turn to be down and although I feel bad about it, I know sleep will make it all better and I feel very loved by my family who worked to get me to bed.

My spirits were also lifted when a blog reader and friend Doreen stopped by with her husband. I'll save that story for another day. Doreen reminded me yet again that we are not alone in this and a whole lot of you are cheering us on!! We appreciate that.

When I was up at the hospital seeing Gannon on Sunday Kalissa shared a message she got from our family friend:

It's okay if we take one day, one hour, or one minute at a time. (A HUGE shout out to our friend Wendy Kuennen for reminding us that it's okay if we only take one minute at a time!) We've been grabbing onto that statement and hanging on.

..and now I'm off to bed. I need to sleep.