

## **Selected Entries from the Harper Diary**

*By Jenn, Harper's Mom*

### **June 2004**

I wanted to write a quick email to all of you to update on where we are with Harper. Obviously we are home from the hospital.... I'm guessing you figured that out by the fact that you were no longer getting those great emails from Tammy... now that it's on me, they stop, right? :) We were finally discharged on Saturday late afternoon. It was, in sum, a really long, hard week. Really hard. I've been telling everyone that it was probably the biggest negative and biggest positive experience of my entire life. Without a doubt the most gut-wrenching and emotional, in both regards, too. Positives? After the entire time there, all we have is a big fat case of severe reflux. Harper, because of intense reflux pain, has been refusing to eat solids of any form and has been refusing to nurse except to take in the bare minimum of calories needed to exist, basically. As a result of the severe reflux, he has been diagnosed with failure to thrive (falling off of the growth chart, below the 3rd percentile, missing milestones developmentally) and hypotonia (low muscle tone because he's so little) and dysfunction in sensory integration (basically this means that he is hyperaware and hypersensitive to things like stimuli or reflux pain, etc.). We have no deficiencies, no metabolic or genetic diseases, no brain problems, no immune compromise, and no allergies. How glorious!

So what's the deal from here? Harper now wears an NG tube that goes into his nose and down his throat all the way to his tummy. It is taped off to the side of his face with a big patch of Tegaderm and gets quite a few horrified looks from little kids. Twenty-four hours a day he can nurse as much as he wants, and he takes in about 24 ounces this way, so 480 calories. Unfortunately, this is all he will tolerate and take in voluntarily, so we have to hook him up to a pump at night, every night for 8 hours, and it pumps in 16 ounces of high calorie stuff at the rate of two ounces an hour. This gets him to his needed total of about 900 calories a day for catch-up growth. The stuff that gets pumped in is base plus carbohydrate plus fat for a total of 27 calories an ounce. I have managed to get my supply ramped up to 32 ounces a day so that every other night is breast milk, the alternating nights are a formula base (grrrr). The pump looks really great in our master bedroom, and it makes a really nice whoosh, whoosh sound all night long. :) Harper's Prilosec, or reflux med, has been doubled to hopefully give him some symptom relief. Nights are rather challenging at this point from merely a logistical sense in that we are trying to get two kids to sleep, then Harper to sleep, then syringe Harper's meds down his tube, flush with water, then hook him up to the pump. And by then he's really mad and no longer asleep, and he grabs for the pump tube that goes into his belly, so he can't be left alone. Not to mention the fact that every time we open up the NG tube, stomach contents come rushing out (totally gross, I know) and we are yelling for towels and

syringes and it is just general chaos. So then the other boys are awake from the commotion. Hmmm....

We have 2 weeks to 30 days on the NG tube... as long as it takes to put on some weight but no longer. They really don't like to do these things long term for a number of reasons. Harper has already gained almost a pound, so he is in the high sixteens. Almost the 2nd percentile! :) Amazing what forced feedings can do, right? When the NG tube comes out, Harper must be able to take in the necessary calories on his own, or he will immediately get a G Tube... this goes directly into his belly, and looks a bit like a gas tank on a car. Quite charming, really. It is for long term caloric supplementation, and is common in severe reflux kids. Although we are doing food therapy twice a week, I feel this tube is lurking in our near future. It will, however, hopefully be a bit easier and less messy than the NG tube.

So we have weekly physical therapy, weekly sensory therapy, twice weekly food therapy, and weekly weight checks with our GI doc at the children's hospital. We're kind of busy, I guess you could say. At least for now.

I think that the thing that stands out in my head most after all of this week is the people we met on the pediatric floor. Like the doctors. But especially the nurses and other kids and their families. They were the most amazing people I have ever met. They had things like heart transplants and liver transplants. They were waiting for liver transplants. They had spinal fusions and colostomy bags. They had cystic fibrosis. And then we were right next to the bone marrow transplant unit. And next to the leukemia kids. And all of them... ALL OF THEM... were happy and upbeat and fighting. It was incredible. I promise I will never, ever, ever complain about something trivial like reflux or a G Tube ever again. The realization of how lucky we actually are was the most special part of the week.

The week was a huge one for Harper. He started reaching milestones even as he began putting on weight... it was crazy. He got his two front teeth. He rocked back onto all fours. He can sit confidently. He laughs more heartily. He sleeps more solidly. (Andy says I would too if I had milkshakes piped into my gut for eight-hour stretches!) The nurses were so wonderful... every time they left the room, a bazillion times a day, they said bye-bye to Harper. His first word of his life was bye-bye... he said it to Charlotte, this delightful nurse who fell in love with him and carted him around at all hours of the night and day. And then he said fish.... or really fssshhhhh..... from the countless hours we stood and rocked in front of this beautiful aquarium they have for the patients on the pediatric floor. It was very special. We will be getting a little aquarium in our house as a constant reminder of our time at the hospital, and as a reminder of how blessed we really are. If I can figure out how to do it, I will send with this note a picture of Harper and Charlotte.... she was so special to us.

I will keep you all updated as time goes on. Please hug your kids....

\*\*\*\*\*

## July 2004

It seems like every time that I get my head on straight, and I am prepared for what I am sure is coming next, someone yanks the rug out from under my feet and I lose my balance... not a bad type of losing my balance, just a surprise, catch-my-breath and recollect type of losing my balance.

I was fully prepared to end up with a G Tube surgery scheduled after today. This past week has been less than stellar "on the tube." We have lost one entire night's feed due to vomit and then one night's feed, stomach contents included, emptied all over the bed (on the featherbed, actually) when the line disconnected. Harper did not seem to gain by appearance, either. In addition, Harper has really not ramped up on daytime feeds at all to compensate for his decreased volume at nights. I've even had both Andy and myself convinced that a G Tube is our most appealing option, as it guarantees food going in and takes some of the pressure and hysteria off of me with regards to trying to make progress with solids. It's a very nice security blanket.

So we weighed in at GI clinic today, and Harper had lost 40 grams. Our goal, you might remember, was to gain or at the very least, maintain weight. Hmmph. But then our GI doctor came in and actually spent a really long time with us (I think that we have graduated... is this a good or a bad thing?... to being priority patients). He took a different approach. He starts off saying that he's really not ready to schedule surgery for Harper. He feels that we haven't exhausted all of our options, and that it would be unfair to Harp to stick a PEG (G Tube) in him without trying everything else first. At this point, he announces that he has been ignoring our only abnormal lab work to this point, the endoscopy tissue results that showed sucrose and lactose intolerance. He now feels, though, that as a last ditch effort, we've got to try Harper on a week of being lactose and sucrose free via special fortified hi-cal formula. He wants to do this until our next appointment. He feels that if the lactose in breast milk has been the problem, we will start seeing improvements in Harper's tummy problems (like the reflux, pain, gurgling, etc.) within a few days. If not, we haven't really lost anything, and we've have gained the confidence of knowing that we've tried everything. Potential G Tube dates with failure of this program would be two weeks from now.

So here's the regimen.... gears shifting.... daytime feeds have become five bolus feeds of four ounces each of high calorie Prosobee. A bolus feed is when I hook his ng tube to a big syringe and line extension and hang it over his head... gravity drips it into his belly within about thirty or so minutes. Tammy swears I'll get better at this and my time will come down with practice. Right!... Nighttime feed remains eight ounces pumped over four hours via pump through the ng tube. He is actually allowed to nurse if he wants any time during the day or night, since the volume he will take in with such a full belly will be minimal. The good thing about lactose intolerance is that it is not an all-or-none type of problem like

an allergy, but it is dose-related. therefore that minimal amount of breast milk ( one? two? ounces...) won't bother him. Meanwhile, I have to keep pumping with every bolus so that if this week changes nothing, he will have some breast milk to come back to next week.

We are expecting some really awesome weight gains over the next nine days...one of the benefits of force-feeding your child huge quantities of lactose-free Crisco... we don't go in until next Thursday afternoon to the children's center. Hopefully you guys will see some really fat cheeks in the near future... and not on me, on Harper!

Meanwhile, no labs back yet from Metabolics.

Since things have been progressing so slowly, Andy and I have been talking with Genetics and we will be doing a full blood workup of all three of us Thursday morning at the hospital. The Genetics team will consult with us and draw blood, and send the three samples off for chromosomal analysis. These results would show us if there is any genetic cause, like a disorder or syndrome or disease, for the number of things we have going on here with Harper. Results do take several weeks to get in, though, so it's a waiting game. At this point we just want answers and help in whatever form it comes.

My allergy labs came in, and there are significant antibodies to chocolate... go figure!... so the GI doctor advised me to continue to avoid chocolate and dairy since Harper might get minimal amounts from the small amount of breast milk he will be taking in.

Since Harper's reflux pain persists, we have also increased Prilosec from 10 to 15 mg/day.

Food therapy and physical therapy are fine. Physical therapy is actually good... Harper continues to meet goals that his physical therapist sets for him. He still cannot crawl, but can push backwards when lying down and has even transitioned from lying down to a sit twice this week. At food therapy, Harper still refuses everything but water, and doesn't like it thickened or flavored. Last Friday night, though, he downed 25 spoonfuls of the broth from miso soup at a local Japanese restaurant... it was so amazing!!! Andy and I joked that the problem all along is that Harp just has too much culture for us...

Harper loves his weekly massage.... he is madly in love with his therapist and gives her his hands and feet the second she places him on the table... Andy was just telling me that he thinks his own growth might be off... can he get a weekly massage?

Huge thanks to every single one of you for all of your support and help recently. The phone calls, the emails, everything. Elaine for the meals (!), both grandmas for the babysitting, Aunt Lisa for schlepping to food therapy, Tammy

for those retubes at eleven-thirty at night, Wesie for the BTDT talks, Kathryn for going way above and beyond on helping with my big boys at all hours... you have all been so wonderful and we appreciate it all. And to those of you who have been calling and talking to and emailing Andy.... it means so much to him. He is totally stressed right now and is bending over backwards to work so hard at taking care of all of us... he's not so great at telling everyone how much the support means to him, but it does, believe me.

As always, I will keep you updated. Next week I might not post until Thursday after our GI appointment... I try to keep these things down to one a week as I know they must get monotonous....

\*\*\*\*\*

## **August 2004**

Today has been a beautiful day!

First of all, Harper started crawling today! He can inch like an inchworm... this is really a big deal for us, as this means we are that much closer to reaching normal developmental milestones for an 11-month-old.

Secondly, we scheduled our G-Tube surgery.... it will be August 16th at the children's hospital. Although it might not seem like it, this is actually a really "good thing" at this point. Harper is no closer to taking in a significant number of calories voluntarily than he was two months ago, and the time has come to support him calorically on a more permanent and comfort-friendly basis.

The lactose-free formula was a wash, and we are back to 27 cal/oz breast milk or formula... whatever is on hand. We are still bolusing five times a day, and Harper is on the continuous pump each night. He is also nursing on demand. In one week he has gained over 12 ounces. We still have four and a half pounds to go for his height until he reaches the 50th percentile... can you believe it? That's the goal that the GI doctor has set for us. The funny thing is that as these ounces have gone on, he still looks really thin and practically the same... and just think... since his admission, he has already gained over two pounds!

G-tube surgery will be a short one... we will not be doing a Nissen wrap, just the tube insertion, and it is actually partially done by scope, so is minimally invasive. Relatively speaking. We will check into the pediatric floor again Monday morning, do some pre-op stuff, have the procedure at noon, and then recover and get feeds and pain managed. We hope to be home in two days, so late Tuesday. If pain or feeding management is not as expected and hoped for, it could take a day or so longer.

For the first four days at least after the surgery, we will have to keep Harper on continuous pump 24 hours a day. We want his belly to stay fairly constant in size

to promote healing of the insertion site. We want it moderately full at all times. Then it will be business as usual.... the GI doctor has granted us carte blanche to play with bolus and continuous pump volumes....whatever we feel is most conducive to Harper's comfort and our ease and his food skills acquisition... we need to get in 100 kcal/kg/day, so we have to fortify what goes in for volume's sake. The substance we pick to use as base is up to us. We will build to 30 cal/oz as his caloric demand gets closer to 1000 kcal/day... right now it's only about 800.

For the first eight weeks, Harp will have a temporary tube that looks like a hose and is about five inches long coming out of his belly near his belly button. Actually it looks a lot like his NG tube, just in a different place. Then when he is fully healed, we will insert a Mickey button... (just an office procedure for the switch) ...it is less than a half-inch or so in profile, not very large at all and relatively unobtrusive. When Harper is fully clothed you won't see a thing. And he will be much more comfortable than he is right now with this annoying NG tube taped to the side of his face and down his nose and throat.

Best of all, we can now progress in "Harper time" and he can acquire food skills when he is ready without our worrying about missing milestones or worse yet, having the long-term effects of malnutrition. The G-Tube will remain in indefinitely, until he is able to eat solids proficiently. Harper's doctor says kids usually go 6 months to three years "on the tube" if they are otherwise within normal ranges.

We are feeling really great about this here... we finally have a plan and it's on paper. No more questions, no more worrying, no more craziness with regards to feeding management. This is much more clear-cut, we feel much more in control, and more importantly, Harper can take things at his own pace, and we can just help him out a little bit in the interim. Beautiful.

On top of all that, when I got home from our appointment, our babysitter Kathryn as a surprise had folded and put away the piles of clothes that were overtaking the playroom. As I said earlier... today has been a beautiful day!

As always, will keep you all posted....

\*\*\*\*\*

## **Mid August 2004**

Well, it's done. We are so relieved to be home again!

Harper's surgery went well on Monday. We got to hold him as they put him under for anesthesia, so he never really knew a thing going into the procedure. The G tube was placed without any problems, and they also did another look but there was still no esophagitis. They also took more tissue

samples of small intestine to see if we still have abnormal levels of lactase and sucrase or if that was a temporary thing from before.

We got our labs back on the lysosomal storage diseases like Tay Sachs and GM1 gangliosidosis... we are within normal limits on all tests. Awesome news. But Wesie, I've been thinking of you and Elizabeth and William a lot. :(

Recovery from surgery was really yuck. Harper had gone in with a bad cold, but they decided to continue as planned since he had no fever. As a result of the upper respiratory infection and getting intubated, when they removed the tube in recovery his airway swelled and constricted. He couldn't breathe and he became tachycardic.... his heart rate was about 210. He was making these awful noises and people were moving very quickly... I was holding him in my arms... but they got racemic epi in a nebulizing treatment with oxygen and gave him steroids IV. It was shocking how quickly he turned around after that. He still had to stay on oxygen for about an hour because his levels kept dropping and his heart would go to about 200, but they realized that he was responding this way from the pain. We started Phentanyl IV (10 times stronger than morphine, they said!) and he would respond really well for the 20 minutes that it lasted, then his levels would go off again. Finally they got him stable on morphine... they wouldn't transfer to pediatric care until he was off the Phentanyl and off oxygen... and we were admitted to our room for the night. Ironically, as Elaine and Andy and Harper and I were leaving recovery and getting wheeled to our room, our rabbi miraculously (!) showed up and spent some time in the room with us. After Elaine and Andy left, she stayed with Harper and me for another hour, talking, and that really made me feel very special and safe. I mean, what can go wrong when the rabbi that converted and married you is right there praying for your baby? :)))

It was a really long night. Maybe because the rabbi bailed at dinner time, I don't know. I feel awful complaining, because I know that lots of the chemo kids have twelve lines running in and out of central lines to the heart, and we only had four (IV and morphine, feeding tube, oxygen and heart rate monitor... and of course the phone line. Damn thing kept getting all caught up, too.) So the deal for the night was that we had to try to get off the morphine... if we needed it through the night they would give it, but not release us in the morning to go home. Harper was also only allowed to throw up one time, or we would have to cut off the stomach pump and stay another day, too. So it was kind of stressful, as Harper was crying, wanting to nurse, I couldn't nurse him for fear he would eat too much and throw up and we couldn't go home, and I knew he wanted pain meds, but I really wanted to stay with just Tylenol and avoid the morphine, but it was so hard to settle him without nursing. Andy and Nurse Tammy left around 10, and it kind of went downhill from there. I couldn't get him to stop crying, was scared he would throw up from crying, so finally nursed him, and then of course he threw up from that and the pumped feed combined. So it's 1 am, I'm stuck in all the lines, both of us are covered in vomit, he's already used up his wild card for vomit for

the entire night, and he's still upset. His pulse oximetry is alarming and I can't reach the silence button on it. And my nurse is nowhere in sight. So of course, Elaine sleeps in the playroom, poor Andy gets dragged back to the hospital, gets there at 2:30, and proceeded to be the glue that held us all together for the rest of the wee hours. Harper settled, I changed and settled, and the nurse even showed up. We actually (all three of us but not the nurse) slept for about 45 minutes in the hospital bed... it was kind of cozy. Except for that phone line.

So morning finally came, Harper awoke very pale but much more himself and even smiled at Aunt Lisa, and we were able to come home today. Thank goodness.

So amazing, too, the resilience of a baby.... by tonight Harper is laughing, waving to the neighbors, laughing at his brothers, and feels and looks good... even without the Tylenol. I can bet that I would not be quite so strong!

Our stylish Zevex backpack pump is awesome... I've worn it on my back and Harper in the sling all night... it's completely mobile. Braxton wanted to know if I was going to my first day of school tomorrow morning, too!

So here we are.... long awaited G Tube in the belly... feeling better and strong... and as always, we will keep you updated as things progress...

\*\*\*\*\*

## **September 2004**

So here we are. Today is Harper's first birthday. :))) Last night we celebrated as a family by going out for sushi and shrimp tempura and miso soup.... miso soup happens to be the only thing he eats. So that was a lot of fun. Today the boys and I made cupcakes with sprinkles and marshmallows on top, and we all sang "Happy Birthday to Harper" and Brax and Tate blew out his candle for him. I think they are probably glad that he's not eating any cupcakes, as that means there are more for them!

Weekly physical therapy is going okay.... sometimes I wonder if it's worth anything at all, but then again I'd be scared where we'd be if we didn't have it. Harper can crawl really well and he can pull to his knees in front of steps and tables. Our latest goal is trying to get him to bear some weight while held up on his feet, and to get him to go from being held up on his feet to leaning back into a fall/plop/sit. He strangely enough has no "step" reflex with his legs.... he just doesn't pick his feet up and move them at all when being held up in a forward-leaning stand.

Food therapy is also basically the same. He'll do miso soup, a few spoonfuls of other thin-broth soups, and water. Although he really likes the taste of cookies or French toast or yummy warm, sweet things on the tip of his tongue, he gags

when any pieces get to the middle of his tongue. He hates anything cold. It's a hard balancing act because although we want to get him used to the idea of food, we don't want him to throw up at all, because that's such a yucky experience for him. Plus he can't spare any calories. The clincher is that in the next few months, the window of receptiveness for learning eating behaviors is slightly shutting down on us because of his age, and at that point things will become even harder to learn. You know, the "old dog new tricks" adage.

We finally got into our long-awaited appointment with a really great occupational therapist, and she did Harper's evaluation last week. Occupational therapy, for those of you who don't know (and I didn't previous to Harper) is really an all-encompassing sort of field. She is the umbrella over all of our other therapies. She does a little physical therapy, some food or oral therapy, fine motor skills, everything.... but she ties it all in with an emphasis on sensory integration, which is where Harper has a lot of problems. Here's an example... when we first got there, she started by placing Harper in a sit on a really shaggy furry rug. He drew his feet up, curled his toes, and lifted his legs completely off of the rug so that his didn't have to feel it on his skin. That's a typical response of a hypersensitive kid... the input from the sensations really is just too much for him. At another time, she laid him on his back on kind of a huge billowy beanbag, to see how long until he braved the squishy fluffy feel to roll over and start exploring. Length of time until response indicates degree of stress, really. He didn't move for twelve minutes. At that point, she said, "Does he really know how to roll over?" He was too freaked out to move... he just laid there and looked at us with these huge round eyes. So we have a bunch of take home exercises.... brushing him all over three times a day with this soft brush on his skin. Joint compressions to simulate weight-bearing movement. Etc. She ranked him as severe in sensory dysfunction, but stressed that although she is here to help him "work through his issues" she is not here to speculate on causes of issues. She did say that he fits both the profile of a child with a severe emotional response to the physical discomfort of reflux disease or a child with a genetic disease. We talked about the goals of OT, and she really just wants to see him maintain his deviancy from normal or improve on it.... but she is worried that if we don't stress his issues now, they will be exacerbated. Kind of like me with public speaking, I guess. Anyway, OT is once every week.

Harper's massage therapist will like this next one. The occupational therapist stressed how important deep tissue stimulation was for Harper. She actually recommended that we start infant massage, at which point I told her we had already been doing it. She said it needs to be at least once a week in a best-case scenario. Again, more of that desensitization. At least he likes massage. It is his favorite appointment of the week. Last time he ahhed all the way through his scalp massage.... it was really cute.

We just found out that we got approved for Early Intervention which is a support system the state has for identified high-risk kids that have the potential to

become classified special needs. This is good in that it helps out with co-pays and bills and bad in that it makes things sound more serious.

The GI aspect of things is at a constant right now, which is good. We've gotten as used to the G Tube as one can be, I suppose. It's still pretty disconcerting to have a twelve-inch tube hanging out of your kid's gut at all times. The long tube doesn't get exchanged for a Mickey button until the first week in October, because the stomach has to heal really well first around the stoma (hole). We have graduated to real food during the day, which is so cool. After talking with Harper's nutritionist, we've agreed upon a regime where I mix up certain foods (one recipe might be avocado, banana, garbanzo bean flour, and apple juice) and puree them in our blender and then tube them in through a syringe. So Harper gets real food for his three meals a day. He still only tolerates three ounces at a time, so it has to be about 60-70 calories per ounce to get the needed calories in. Then at night we do the fortified formula by pump. (I just said the "F" word, didn't I?) And he's still nursing, which is so much more special this time around than before. I appreciate it much more. So I'm feeling a little bit better about this all. Plus the real food refluxes less since it is thicker than milk. Harper seems to be weighing in at a gain, but we haven't weighed in since the surgery, and don't go in again until next week for a GI recheck.

Our genetics results don't come in until the 30th of September. It should be illegal to make parents wait that long. It's awful. Then again, a friend of mine has a baby recently diagnosed with Down's syndrome, and she said to me, "Look on the bright side of things. If it's genetic, there's no rush in getting the diagnosis, because it's not going anywhere, right?" Amazing how those of us in this "club" can joke about things like that now.

I think what's really hard right now is just the emotional aspect of things. Here we are at a year, and things are really kind of parked. But parked on the uphill, so it's not an easy rest, you know? Each week there's the schlepping to the four appointments, plus any random doctor's appointments that we might have. And as hard as it is to just keep up, there's not really any encouraging progress, nor is there expected to be. I mean, if we're lucky, he might eat on his own in a few years. He'll hopefully figure out walking in a while. He's not setting any bridges on fire with his verbal abilities, but he's still the best laughter I've ever met. He's just so damn happy. I think that I am just afraid to breathe right now, so I'm holding my breath, because we're really at the point where he can either start showing us he's just fine and going to catch up to normal in a few years, or he's going to show us that we have a bit more to think about long-term. It's pretty stressful.

Then there are the other boys. They are being so great about getting sloughed off, but I feel pretty bad about the whole thing. I'm constantly bolusing Harper, or cleaning him up from vomit, or doing meds, or bathing, or whatnot. Braxton is in school five days a week in the mornings, which is great. Tate is in a three day a week program, which I didn't want to do in the first place, but now I am this close to bumping him up to five days a week with the same teacher, as it is either that

or he'll have to be with a babysitter while we are at PT each Thursday. It's funny.... I have always been so judgmental about those who put kids in school for too much while they are too young, and I still feel that it is absurd to have a two-year old in this much, but I am so stuck in such a hard place now. I feel like I've got to focus on Harper while we still have a fighting chance of mainstreaming him. I'm finally understanding why we have been offered full-time home health support by the hospital (i.e. in-home nursing care).... this is all very time-consuming.

As I'm rereading this letter, I'm feeling like it has a negative tone to it, and that's not my intent at all. A few weeks ago, Harper was on the prayer list for sick at the temple, and I was absolutely mortified. Seriously. I mean, he's not sick. Just slow working through these issues. Sick is leukemia and cystic fibrosis and liver disease and heart transplants. I've had lots of people coming up and saying how sorry they are and how hard it must be and what can they do to help.... which is so thoughtful and considerate, but not necessary. I'm not sure what awful things they're hearing, but it's really not that severe. This is sooooo not a big deal. There are so many millions of others who really are ill or in rough situations. I mean, Harper is going to be just fine in the long run, it's just hard right now figuring out what we're working with and how best to deal. That's all. Perhaps Andy and I are doing it to ourselves by being so up front about what we're working through, but we really do want everyone to know what's going on with us. Anyway, I guess my point is that it's busy and hard, but that's enough. No "woe is me" needed.

Hope you are all well. Please continue to stay in touch.... we love to hear from you all... and forgive us for forgetting birthdays, return phone calls, thank you notes, and the like. I'm lucky enough that I have not forgotten a child or two on my errands these days! We'll update more at the end of the month....

\*\*\*\*\*

### **Late September 2004**

I'll try to be quick, as this is two messages in only a few many days. This one's worth it, though...

Met with the GI doctor today for Harper's one month post-op check up. He has gained three quarters of a pound in weight, grown three cm longer, and his head circumference has grown very significantly, too. These are all wonderful signs that Harper is getting what he needs to grow and thrive, thanks to the G Tube. He has actually officially hit the 5th percentile in weight..... wow!

And.... drum roll, please.... they gave to us the Genetics tests results. No Fragile X. No Prader-Willi. No VCFS. No Angelman's. No lysosomal storage diseases. Absolutely normal chromosomes. Final official diagnosis? Some

wicked, wicked reflux. Prognosis? Keep up the therapies to stay on track, and with a little time when Harper outgrows the reflux, he'll be absolutely normal!

Does life get any better than this? In celebration.....

\*\*\*\*\*

## May 2005

So it's been right under a year since I first sent you all an email on how Harper, our youngest was doing. We had just been admitted to the children's hospital and as I reread those words from that first email, I can honestly say it's not a flood of particularly fond memories that comes rushing back. It's been a really long time since I've updated you all; I've tried to lay off of the letters as they seemed to get kind of redundant towards the end of 2004. As we come up on our one year anniversary of beginning Harper's tube-feeding saga, though, I wanted to take this chance to give you all an update on where we stand today. Some of you are new to this list and have simply expressed an interest in hearing what's going on. Some of you ask in passing how Harper is and I never know exactly how much of an earful you want, so you simply get a "fine." Some of you hear the details every single day, ad nauseum, and could probably better relate this update than I. A lot of you have called or emailed, and more often than not, I have just not returned messages. Please know that I'm sorry, I do really intend to get back to each and every one of you, but you know how that goes, and then I don't. I'm really having a hard time keeping up with the day to day details of it all. Anyway...

Harper is doing really, really well today. He is now twenty months old. He's small and very thin, but fine. He has caught up to, and in some cases passed every single developmental milestone for his age. Climbing, running, throwing, drawing, you name it. He is actually incredibly proficient with words, and has turned into a very verbal little boy, which is shocking and wonderful given the fact that early on we were convinced that there would be significant mental impairment to live with. Not the case at all. He has stopped going to weekly physical therapy, weigh-ins, massage, and for the most part occupational and food therapy... and we are dropping those down now. We do check-ups at GI and Nutrition every three months. Harper has just been accepted as a patient of Marsha Dunn Klein, an OT in Tucson, Arizona who specializes in non-oral feeding reflux kiddos. Her website is [www.mealtimenotions.com](http://www.mealtimenotions.com) <<http://www.mealtimenotions.com/>> . We just returned from our first visit with her and will be seeing her every six months in person and consulting every month over the phone. She's totally incredible.

Harper continues to eat nothing by mouth other than juice, watery soup, and breast milk. He is still completely tube-fed for his three meals a day and/or any snacks. There is nothing physically wrong with him other than severe gastroesophageal disease, which he will one day hopefully outgrow. Most tube-fed reflux kids who have no other issues eventually start eating orally and

voluntarily around five years of age, which is our optimistic goal. By then they have less reflux pain and throw up less regularly, so the negative food associations start to go away. Until then, we will continue to do therapy with food at every mealtime, and hope that he finds an interest and comfort level in wanting to try to begin eating at some point when he is ready. He gets normal food pureed, whatever the family is eating, at every single meal. I burn out our Vita Mix blender regularly, and can regurgitate (sorry) the fat, carbs, calories, and protein of almost any food out there. Try me.

Andy, Braxton, Tate, and I are all doing well. We're hanging in there. Just keeping heads above water, but doing it. The good news is that it's all good news; the bad news is that it's just a really long time, and it's really hard time-wise and effort-wise. It's not worth mincing words over, really. We remain thankful, optimistic, and exhausted, and continue to feel very, very blessed. Thank you to all of you for everything.

\*\*\*\*\*

## **October 2005**

Congratulations! You are one of the survivors of the old email update list on Harper. This means that you are one of the chosen few that I've kept around to again badger with the latest and greatest. This also probably means that you are one of the ones whose phone calls and emails I haven't returned... We just got back from a trip out to Tucson to visit with Marsha Dunn Klein. She's the one who specializes in tube-fed kids. She's at [www.mealtimenotions.com](http://www.mealtimenotions.com) <<http://www.mealtimenotions.com/>> . We spent two days with her and also got feedback from an integrative pediatrician out there and a nutritionist who specializes in tube-fed kiddos' diets.

It's hard to regurgitate (sorry) the information over and over and do you all the justice that you warrant as you ask how our trip went. A few times today and yesterday as I was trying to rehash to someone (my mom most recently, actually) I even gave up because it was just too hard to put into words concisely and effectively. "I'll email you," I said. Sorry, Mom. It's just easier to spell it all out as it doesn't seem to make sense orally... I catch myself rambling and then confuse everyone involved, myself included.

Up until this point Harper has jumped from the 5th to 20th percentile in weight. He just turned two last week. He's doing great in every aspect of life except for eating orally. We are done with all therapies except for occupational therapy every two weeks for Sensory Integration issues. He's developmentally and cognitively on track in every way possible. Negatives... he throws up one to two times every day and eats nothing by mouth except for juice and nursing. Period.

I anticipated this trip would be informative, but not enormously so... I thought we would work on eating skills, ways to help Harper want to eat, whatever. I don't

know what I thought we'd do, really.

We did do about four hours of work with Marsha and Harper and food play and all of that stuff. Different utensils, textures, foods, tastes, sizes of crumbs, etc. He did a great job and was really fun to work with and was rather agreeable and cooperative. He ate a few Pringles. Okay... a few parts of Pringles. That was about it. But we worked at where his comfort level was, what he could tolerate touching without gagging (yes, he gags when he touches some foods, even), tolerate without shuddering, what he liked, what was fun, the whole thing. I have a lot to work on with regards to tips, approaches, you know.

Then came the hard part. Marsha and the pediatrician and the nutritionist overhauled his feeding program. Here's why. Harper, although on high levels of Prilosec, still has an incredibly acidic tummy with lots of awful, painful reflux. If he were controlled on his meds, he would not produce stomach acid like a normal person. We actually checked the acidity of his empty belly and it was very acidic... about 4.0. He also is not digesting food at the rate that he should.... He should clear a meal in about three to four hours, but he still had a belly full of food at four hours. We checked both of these things by pulling stomach contents out of his tube and testing it. Yuck. Our options were to do nothing, change meds, or change diet. Doing nothing means that he is constantly in pain, refluxing, throwing up, and will not eat until he is symptom-free. Not a good choice. Changing! meds would mean throwing in a second reflux drug like Zantac, changing the main drug to something like Nexium, and/or adding on a motility drug like Reglan (scary) or Erythromycin to move his digestion along. Moderate choice. This is what we will do if the third option doesn't work. So option three... we are overhauling diet.

As I've been cranking his gut full of things like lasagna and ice cream sandwiches and orange juice and shepherd's pie, I've gone for high fat, high carb selections that include fruits and vegetables that he needs. The most bang for the buck. Here's the problem... my choices have been very acidic... orange juice, citrus, apples, chocolate, etc. Then add the incredibly high fat, and his tummy just can't digest it all. I've been going by the growth chart, and my very impressed GI guy, but enormous weight gain doesn't parallel health and comfort in this case. Poor Harper has been gaining, but has had a very awful-feeling tummy as a result of the combination of evils. What to do...

We are now at eight small tube-feeds a day ranging in size from two to five and a half ounces. We previously were doing seven ounces three times a day. Now he's much more comfortable. Instead of all heavy meals, we are interspersing two heavy, two light, and four liquid meals. He's getting all whole grains... quinoa, millet, etc. instead of refined starches. All fruits are basic.. mango, papaya, blueberry, guava and were selected for properties such as digestive motility enhancers, GI soothers, etc. No citrus, apples, chocolate. His four liquid feeds give him much more free water than before to help with digestion and

eliminating toxins... he was chronically dry before. The liquids are things like chamomile tea, ginger tea, aloe vera juice, etc. These aid digestion, help with nausea, reflux, etc.! Also we are supplementing with flax seed oil, ginger, cloves, cinnamon, acidophilus, Swedish bitters, and a prescription multi-vitamin powder. There's a lot of thought in here. Things like his last meal of the day has aloe and is light so is easily digested, but if it refluxes up the aloe will have some effect on his esophagus. The chamomile tea is a pre-meal wash that soothes the digestive tract and calms it before the food gets dumped in. Nice things.

We feel good about all of this. It's harder, though. I've had two crock pots going and two blenders going three days running now, and I've got out the calculator and notebook again measuring and recording pH and residual volumes and body weight and ounces in the tube and such.

The good thing is that these are means to help Harper feel better, and until he feels better, he won't eat. That simple. Marsha still hopes for eating by age five. That would be really cool. Regardless, she promises he will eat eventually, even if not by five, and that is the best news of all. I just want him to be comfortable and pain-free as soon as possible, and I feel as if we have made some huge steps in that direction these past few days.

We will be consulting monthly on conference calls with Marsha and her team and every six months in person with them. That will help to keep on track, too. It's nice to go at it as a team approach, because each individual has areas of strength and knowledge to add.

Thanks for your interest and sticking through the details... that's about all I can put together right now.

\*\*\*\*\*

## **May 2006**

This past weekend was a really exciting and busy weekend for us, as some of you might know. I wanted to take the chance to let you all know how well Harper is doing.

Harper's food therapist Marsha Dunn Klein was in town for a workshop she was doing at the hospital over the weekend. She ended up coming in two days early to work with us in our home, which was such a treat. The past visits have been in hotel rooms or her office in Tucson, so this was a fun change. We got to do two full days of "food fun" in our home, and even brought Marsha to an occupational therapy session and a pediatric consult.

Harper has been doing such an amazing job with being really enthusiastic about trying new tastes, textures, and food experiences. Anything that is on a plate he

will try (sushi included!), and he gets a plate at every meal just like the rest of the family. To this point, however, he has still been chewing all food (except chocolate chips) and spitting it out instead of swallowing it. We did a lot of work to try to encourage Harper to put manageable size pieces into his mouth. What's happening is that he has no experience with "bite size discretion" (me too), plus he is loading everything in as he's so excited to finally be able to taste food without fear. Then he's getting this whole big mouthful and having to spit it all out. We started using toothpicks to spear little "mouse bites" as that is an identifiable term for him. So when it's a very small piece of food (pea size or smaller) and if it is mushy (think melon, not carrot) then he can chew it up and swallow it!!! So now we are working on offering speared mouse bites at every meal, plus the normal plate, so he has some options and practice in confidence building with swallowing. Of course, each person less than four feet tall HAS to have mouse bites on his plate, too...

Then we did some cool teaching. Marsha is big on building on the developmental readiness and cognitive level of the child to facilitate foodness. Right now we are trying to get Harp to make the connection that you put food into your mouth when you're hungry. She said it's kind of like teaching us that we have to eat with our ears... it's just a crazy thought to him. So we're using a lot of words like full, hungry, etc. to try to get him to notice "Hey I'm hungry, let's do something about it!" Marsha worked on cutting up a melon, for example, and having him put it into the blender, add the water, and have Harper blend the melon juice. She wants him to understand that he can pick the foods he likes to taste to eat, and then he can help blend them up. That way he understands that what doesn't go in by mouth goes in by tube. That was fun.

It's all interwoven. He's at a great cognitive level now, so we can draw some parallels for him that we couldn't before. For example, at dinner, he gets a plate like everyone else, then what doesn't get eaten (basically all of it) goes into the blender, then into his button. And while we are bolusing him, we say things like, are you really hungry now, is your belly full, would you like some more, etc.

Scheduling-wise we are trying to cut down from nine to eight feeds a day so life will be more manageable. In doing so we are trying to up volume per feed (from seven to nine ounces), so that significantly increases time per bolus session. It works... I'm getting more food and calories in per feed, but yesterday I was forty-five minutes late getting Tate to school. I think I need to find a moderate balance, huh?

We had a great therapy session with Harper's local OT and Marsha. That's a weekly thing long-term, as he's got some sensory issues that are very challenging for him in everyday life, so we're trying to work through body confidence, dealing with situations, etc. Harper just has a hard time with lots of different inputs.... loud noises, unexpected movements, body perception, things touching him near his face or neck, strange feelings on his skin, etc. The sensory

input piece has been increasingly challenging for him, I would say, as he has gotten older and encounters more and more different situations. So that's a work in progress.

It was also cool for our pediatrician to meet Marsha and to see that (perhaps he saw, anyway) there is a method to our madness. She basically gave him a rundown on all things Harper, where we're going, where we're headed, etc. Harper's obviously his only little guy like this.

We'll be following up with Marsha every three months now in Arizona instead of every four to six, as he's really at an important point skills-wise to make sure that we move in the right direction.

Then on Saturday and Sunday, we (the two grandmothers and me) went to the two days of Marsha's workshop. It was a whole course on tube feeding and was mostly OTs and SLPs (food therapists) and dieticians, then some parents of tube-fed kids. It was really awesome. Marsha does such an amazing job of portraying the emotional side of things from the kid's perspective, and also from the parent's perspective. She spent the entire time giving the parents and therapists and nutritionists ideas on causes of feeding problems, ways to treat these problems, and then ways to address the feeding issues themselves. I'm really struggling for the words to express the amount of information and nature of the workshop, as it was really just fantastic and all-encompassing. It was incredibly emotional, too, for the people there. On both days, Marsha had me speak (yes, with a mike in front of an auditorium of 70 people!) on several of the aspects of tube feeding. I talked about blenderized food and how we've traveled that path and gave tips and answered questions on that (lots of people don't know that there are options for G Tube food other than canned formula). Then the second day I addressed a bit the emotional aspects of having a tube-fed child. Throughout both of these times when I could look up at the audience, a number of the participants were crying. I don't think (hopefully) it was that painful to listen to me, it's just that this is such a hard thing to discuss on so many levels... it's hard, and time-consuming, and "progress" as the typical person would define it is slow, and on and on. Anyway, it was a very moving experience.

I would have to say that the most resounding caveat of the four days we spent with Marsha was the one that I have been most eager to share with all of you. I hope I can express it appropriately. When you look at a tube-fed child like Harper, you need to realize a few things. Because of his issues with sensory integration, little things that to us are so simple (shredded cheese in your mouth, a two foot slide, hair on your fingers) are truly terrifying to him. We need to try to be more compassionate and see the world through his eyes. It's not saying "Oh, he THINKS that is an overwhelming thing" but rather "That IS an overwhelming thing to him." It's perception. We still have to help him to learn work through it, but we need to understand that it is very, very real to him. The journey to being oral with food, although he is doing so incredibly well, is not a short one. Marsha

told us this weekend that he will not have a tube at 10, or 9, or 8, or hopefully not at 7, but she feels like 6ish is a reasonable estimate. There's a huge distance between eating a handful of chocolate chips and being able to eat four to five foods from every food group to maintain caloric and nutritional needs for growth and health. To most of you another three or four years sounds like an eternity, but you have to realize to us merely eating is cause for celebration. You know what, though? All of us tend to focus on how much he ate, how many calories, when the tube's coming out. Those things don't matter. What matters is that Harper continues to be as happy and enthusiastic with food as he is to this day. He should never feel stressed, or forced. He will eat when he feels safe and ready. Andy and I feel very strongly about this. He should know every minute of every day how great he is and how proud of him we are. And in that way, when he does eat, he will have a healthy life-long relationship with food, not a continuous struggle with emotional baggage and nervousness. This G Tube is the greatest gift we could have as parents, because Andy and I can nourish Harper with awesome foods like kale and hummus and cantaloupe and grains and yogurt and know that he will always be healthy and supported until he can support himself. I challenge you to find a better nourished two year old! J It is NOT a race to be oral.

Finally, and most importantly, when you guys look at Harper, and think of him, I want you to try to think of him as the precious little guy he is, not as the precious little guy with the tube. Let's talk about how he loves to jump on the trampoline or wallow in the fish pond or how he spits on his brothers and punches his best friend or how he's a great dancer and loves to sing. Remember as the afterthought how he is tube fed, not as the headline. I know that it is out of love and thoughtfulness that everyone asks "What's he eating, how's he doing" etc. but Andy and I would rather talk about all parts of Harper, not just that part of Harper. There's so much more to him! J He's such a special guy in our lives, such a gift, and I want us all to celebrate how far he has come and how wonderful he is in every way.

I will also forward some great pictures of Marsha and Harp playing with food; they give you a real idea of how ingenious she is, how well he's doing, and how much he adores her. He says "Marsha is my SPECIAL friend!"

Thanks for listening and supporting, as always...

Jenn