

## Maxwell Soke Brenner's 3 Plus Month Journey via e-mail Messages

May 13, 2007

Dear friends and colleagues,

I am so sorry for the mass e-mail. I just am not allowed to sit upright for too long and wanted to get this out to friends and colleagues. I wanted to make you aware that if you do not hear from me for awhile you will know why. As you know I am 28 weeks pregnant. I went in for an ultrasound b/c my belly was measuring 40 weeks and not 28. I had to go to SF for a higher resolution ultrasound. I was diagnosed with polyhydraminos (too much amniotic fluid. This is due to me producing too much or my baby not removing enough through swallowing. The causes are idiopathic, gestational diabetes (I am negative), RH negative second pregnancy (this is my first), genetic problem with the fetus: GI abnormalities (atriska - requiring surgery), neurologic, other. As far as the ultrasound we could not see any abnormalities with the baby - however they will run more tests. To make things worse my cervix is 1.5 cm thin instead of 3-4 cm making my risk of going into pre-term labor high. Since I am already having too many contractions due the fluid irritating the uterus and given the above findings they sent me directly to the hospital (CPMC - highest level NICU plus perineonatologists). I am on strict bed rest, drugs to stop my contractions, steroids to speed-up fetal lung development all to try and prevent me from delivering this baby before 34 weeks. I will not be allowed back home to Novato until I give birth or reach 36 weeks. They will consider letting me go to my parent's house in SF 15 min from the hospital for the remaining two months for strict bed rest. There is nothing like leaving your house for what you think will be a few hours only to find out you will not be back home for 2 months and you are not prepared to be gone for so long. Luckily most of our 21 pets can come stay with me at my parents house or at least visit. The chins are on their own with Matt who will quickly learn to medicate them. Poor Matt will be doing a lot of commuting between SF and Marin and have to do in the house what is a two person's job alone. I am staying positive about being type A and being bed ridden. I am going to catch-up with friends, journal reading, books, movies, etc.

So, if I have scheduled something with you or there are loose ends please accept my apologies. If they can be dealt with over e-mail or the phone we can attempt that. Please feel free to e-mail me (I will check it several times a week as possible), call my cell 415-595-4792, or my hospital room 415-600-9038 good until Mon - then subject to change.

If you live in SF and want to visit I would love the company as it keeps me from going stir crazy.

Thank you all for your support and understanding.

June 19, 2007

Hello All:

I am sorry for the mass e-mail, but this is the easiest way for me to update those who have asked for an update. If you are on this list and do not want to be - please let me know. If you are duplicated on this list let me know. If you think I have forgotten someone please let me know (I may not have an e-mail address). If you are on this list you will receive an e-mail when the little guy is born.

My high-risk pregnancy OB released me today to go back home on bed rest and to follow-up with my regular OB. I will be moving back to Novato this Friday or Sat. I finally get to see our feathered and furred kids. I am currently 34 weeks and 3 days and can now deliver at Marin General. The little guy passed all his fetal tests with A's today except for the fact that he is still in a breeched position. So, Matt and I need to decide if we want to try inversion (manual manipulation of the fetus to encourage him to turn head down) in 1-2 weeks or just see if he moves on his own. If he is still breech when I go into labor, I will have a C-section.

My amniotic fluid level is now in the normal range and decreasing weekly - yeah! If I am still pregnant by June 25th (36 weeks) I will be allowed to get out of bed. I will not physically be able to do much due to 2 months of bed rest and the size and weight of my belly, but I can start regaining my strength and endurance.

Thank you to all who have sent their well wishes or visited - it has helped me pass the time and make it this far. Matt and I cannot wait to introduce you all to the little guy. We have finally decided on 5 potential names (thank you to those who have offered suggestions) and will decide when we meet him.

Thank you for your support,

Serena

June 22, 2007

Hello All:

Well my water broke this morning at 8 AM and we came to Marin General Hospital. I am in bed getting my bolus of LRS. No bad contractions yet - hence my ability to send an e-mail. He is still breech so we are waiting for the on call OB and then they will prep me for a C-section. He is one month early 25 weeks and 5 days. So, we will keep you posted. Now Matt and I have to decide on a name.

We cannot wait to introduce you to XWZ Brenner  
Serena

June 24, 2007

Well we finally named our son: Maxwell (Max) Soke Brenner. Thank you to all of you that gave us name suggestions.

Max is getting stronger by the hour. He has the best NICU nurses. We are concerned he may have Beckwith-Wiedemann syndrome (plenty of good info on www if interested). Monday one of the neonatal geneticist from UCSF will consult with the neonatologist here and decide what testing needs to be done to decide if he has BWS. If babies are treated for the medical issues that arise and are closely monitored the first 7 years of life - they often go on to lead normal healthy adult lives.

As many of you know Matt has always been uncomfortable around newborns and infants, but he is so at ease with his Son. He is a great Dad. See enclosed picture

I will stay at Marin General until Tues and Max may be able to come home with us, stay in the NICU for a few more days (I would then stay longer so that I

can feed him every 2-4 hours), or he may get transferred to UCSF next week for further tests/care.

I am recovering well from the C-section - I am definitely sore and walking is challenging. I have a new found respect for my patients that have abdominal surgery - proper pain management and getting out of bed and moving is the key to a faster recovery - better living through chemistry.

Thank you all for your e-mails.

Serena and Matt

June 26, 2007

Hello All:

Thank you to everyone for your supportive e-mails over the past few days. Several people have asked about the name Maxwell Soke Brenner and here's the short version. Matt's grandfather's name was Max. We liked Maxwell better than Maximillion and Maxwell has many great predecessors like James Clerk Maxwell (Maxwell's Magnetic Equations) and the legendary Maxell Smart. Soke was the nickname of Serena's grandfather Maurice Sokolow. Serena liked Soke, I liked Sokolow. Serena won. You already know the Brenner part. And now the update:

The geneticist from UCSF came to Marin General early Monday morning and felt it would be in Max's best interest to be admitted to a level 3 intensive care nursery. There was nothing urgent but they thought he might need a special IV which is administered by a stronger support crew at UCSF. Long story short, Max got a fancy ambulance ride to SF and crossed the Golden Gate for the first time. Matt followed and Max was admitted around 1:30pm. Serena was discharged later in the day and arrived at SF around 6:00pm.

Max had an ultrasound this morning and we are still waiting for the official word from the radiologist. The fancy IV (can you tell that this is Matt writing yet?) was placed this afternoon and went well. They need the special IV as it allows larger doses of dextrose without all the water of a conventional IV. The endocrinologist team is planning on slowly decreasing Max's dextrose levels to see if he can maintain his blood sugar levels on Serena's milk. They will have a protocol pending those results.

That's about it for now. Other than the barrage of doctors and nurses that see him (this is a teaching hospital), things are relatively good. He is feeding well for a preemie but falls asleep mid-meal - he's a Brenner. He has a good spirit and kicks and punches just as much outside of the womb as in. We are staying at UCSF at least for one more night and will have a better game plan as the week unfolds. Max will likely be here for at least one week but possibly longer. We hope to have good news soon.

June 29, 2007

Hello,

Getting every ones e-mails really helps - THANK YOU!!!! This is Serena writing: Well he did it; Max was pulled off his IV dextrose. Unfortunately, I came into the ICN about 5 min after Matt had started bottle feeding and being type A - I checked his medical record to see what his pre-prandial (before meal) blood sugar was. The nurse had either not recorded it yet or forgotten to take it. So, I asked her and she had that deer caught in headlights look and said she had forgotten. I went into doctor mode and treated the situation as I would when my nurses forget a

treatment and suggested she take it now and then note how much milk he had gotten. She took my suggestion well and his blood glucose was in the 80s so we know it was stable before his feeding - we just do not know the actual value. Now you know why I have not left the hospital b/c I feel like I need to stay on top of his care. Staying here allows me to go into the ICN every 3 hrs for feeding and stay for an hour. However, we are going to go home and sleep in our bed tonight after Max's 9 PM feeding. The social worker, Matt, the nurses all feel I need to get a little sleep (I agree) and sleeping at the hospital is challenging given the code red drills they like to run at ungodly hours. It is just hard to leave your child. After tonight we will sleep at my parent's House so we are close.

Max has remained Jaundice, but the docs were waiting to see if his bilirubin would continue to climb or he would self-regulate since he has been feeding and having frequent BMs. Today his bilirubin was too high so they started photo-therapy again. He hates wearing his little goggles, but it is good practice for skiing.

Max is feeding well and demanding more food.

We met with the team of specialists today and if Max progresses as he has been he should be able to go home mid week. Max's jaundice needs to resolve and he needs to be fasted for 6 hours to make sure his blood glucose does not drop too low and then he will be able to go home. The social worker recommended we room in with the baby for 1-2 nights after he is released from the ICN to make sure we can handle his special needs. We also discussed with the geneticists which of the several tests to run to see if this is Beckwith Wiedemann syndrome. His karyotyping (chromosome mapping) should be back in 1.5 weeks. If it is normal then we would do further genetic testing. After discharge next week he will be monitored as an out-patient for awhile with various specialists along with his pediatrician in Marin.

We were going to have the Brit Milah (Jewish circumcision/celebration/baby naming) at our house, but given the situation the doctors feel he should be circumcised in the hospital and so we will do it just before he is discharged. So, for those of you that I know expressed an interest in coming to his Bris - I am sorry that we cannot share this with you. However, once we are all settled back at home you are more than welcome to come visit and meet Max - he has gotten used to being doted on by nurse and doctors. He may have withdrawals once home.

So keep your fingers crossed everything goes as planned and that we are all home by the end of next week.

Serena, Matt, and Max

July 2, 2007

Hello,

Well Max had a little set-back this morning. His blood sugar dropped into the high 40's low 50's so the contingencies were to let it drop into the mid 40's and pull blood samples for testing. They then gave him Glucagon (this tells your reserve sugars to go into the blood stream). He responded to his Glucagon and his blood sugars came back-up. Therefore, the endocrinologists feel that we are dealing with a hyperinsulinism issue. The pancreas is producing too much insulin which drives the blood glucose (sugar) out of the blood stream to be stored. However, it is not leaving enough in his blood stream to feed all his organs. The feedback mechanism between glucose and insulin is not working properly. Tomorrow we should have some of his blood work back. If it looks like hyperinsulinism then he would be started on Diazoxide (Proglycem) - this inhibits insulin secretion. The most important value is his insulin level - this will help rule in/out hyperinsulinemia. If it is this, it could be part of the Beckwith Wiedemann syndrome, part of just being a preterm baby, or other - there is an extensive list (I actually read there is an autosomal recessive mutation found in Jewish populations). I am not sure if I was tested for this in my pregnancy genetic screening - I will be investigating. So, back in went an IV to give him dextrose again - b/c we cannot let his blood sugars drop too low again as this can result in brain damage. Just as we were getting him unplugged from his multitude of wires, he

has to get more. Matt cannot wait for him to go wireless. This also means he will not be going home this Tuesday as hoped. B/C of July 4th lab tests will be delayed and so some may not be back until later in the week and he cannot go home until we know why he is not maintaining his glucose levels (blood sugar). So, maybe by this Friday - Matt's birthday.

He has also dropped weight - greater than 100g and has been having some difficulty maintaining his body temperature without being bundled. This is probably related to his difficulty maintaining his glucose levels.

On the positive side:

His jaundice has resolved. And he still has the most pinchable/kissable cheeks.

It is time for another feeding - luckily I am producing enough milk.

Serena, Matt, and Max

P.S. Thank you for all the birthday wishes yesterday. And for those of you concerned I am not taking care of myself, I admit I could be better, I did get out of the hospital and go out for dinner. I got some sleep at my parents last night. I am just trying to get my dependant edema under control. It has improved overnight b/c I slept in a good bed, but as soon as I am vertical and at UCSF even if I am in a chair with my feet-up it returns with a vengeance. UCSF has been so busy that they have not had a room for me to go into during the day in between feedings to get my legs up. I have been wearing my anti-embolism stockings and Matt thinks they are very sexy. Hopefully, things will be quieter this week and they will have a room for me. They have a lounge/waiting room with sofas, but there has been a very large extended family 20+ occupying the room so other Mom's have no access. So, I sit by Max's bed side (I love to watch him sleep) and put my feet-up on the little ottoman that comes with the rocking chair.

July 3, 2007

Hello,

The endocrinologists decided even though the test results were not back that they felt fairly confident that Max's glucose issues are due to hyperinsulinism (producing too much insulin driving his blood sugars too low) that they started him on Diazoxide late last night. While this drug can take up to 72 hours to reach effect - it appears to have already made a difference. His blood glucose levels have been in the high 80's (this is great!). He is taking 80 ml or cc (2 3/4 oz) milk every 3 hours up from his 60ml or cc (2 oz). Tonight the nurses will wean him off his IV dextrose drip. So, if his blood glucose remains high tomorrow - then we know the Diazoxide is working. Hopefully, we will have some of his blood work back as well. Then he will be fasted for 6 hours this Thur or Fri. If his blood sugar does not drop too low then he is safe to come home. We will circumcise him the next day. Matt, Max, and I will then spend the night at UCSF in a room together with no nurses (except if we need them) to see how we do over night all alone and then he can go home. He was also switched out of the incubator back into a bassinet today b/c he is maintaining his body temperature.

He seems to have recovered well from his temporary set-back yesterday. After all, he is stubborn like his Mom and Dad.

The ICN at UCSF on a clear SF day has an amazing view (15th floor) of the Bay, the Golden Gate, and part of the city. So, if it is clear July 4th we will watch the fireworks from the ICN with Max. I am sorry that we will not be able to have the Annual Brenner 4th of July BBQ - next year!

Thank you all again for your continued support,

Matt, Serena, and Max

P.S. Matt promises to upload new pictures of Max and send them.

July 4, 2007

Hello,

Max is doing well on his Diazoxide. His blood sugar has remained in the 80's, 90's and even 100. At some feeds he has taken 3+ oz of milk. 2 oz is norm for his age. He will have his 6 hour fast tomorrow and if he passes that he will be coming home Friday. We have decided to have him circumcised tomorrow afternoon after his fast. The pediatrician performing the procedure checked him today and he is good-to-go. Our Rabbi is coming to the hospital and while it will not be the bris (brit Milah) we had hoped for, (doing it at our home with both sets of grandparents, family, and friends) it will be what is safest for him.

Yesterday, Matt and I received training on testing Max's blood sugar using a glucometer and administering an emergency dose of Glucagon (drives glucose from the cells into the blood stream during hypoglycemia - too low blood sugar.) Glucagon is given as an IM (intramuscular injection in the thigh) injection. The glucometer is the standard one used in diabetic patients. We use the lancet to poke a little hole in the meaty heel of his foot. It is beneficial that I have used them so frequently in testing cats with diabetes. Who ever thought my veterinary training would come in handy in treating my child, a human! Matt has handled all the medicine like a pro. He is ready for his MD.

Once Max comes home our focus will be on working with his tongue to get him to be able to breast feed, to not tire-out so fast while using a bottle, and to not have his tongue turn purple from putting too much pressure on it sucking. Plus, getting all the genetic tests back along with all the endocrine tests to determine what his true diagnosis is so that we can be treated appropriately medically.

So, Matt is thrilled to have his son come home for his birthday. The three of us will probably have a quiet night Friday at home with all the pets (Max's siblings). We will probably room in at the hospital tomorrow night to make sure we can handle everything pseudo alone.

For right now I am working on getting over the cold I got. I went to the hospital for one feeding today just so I could see Max - I could not give him a kiss which was so difficult. I scrubbed my hands as if going into surgery just so I could practice getting his blood sugar, change his diaper, and stroke his head. Matt then brought me home and I have been in bed sleeping or pumping.

Keep your fingers crossed that he passes his fast tomorrow.

Happy 4th of July!

Matt, Serena, and Max

July 5, 2007

Hello,

Max passed his fast with A's - he maintained his blood sugar above 80. He then was circumcised and did not cry - I am sure the nice local anesthetic and sugar water helped. The kosher wine helped Matt and me. Matt and I decided not to room in tonight b/c the accommodations were two sofas in a closet with a sink. We decided to take advantage of the expensive babysitting (\$13,000 a night just for a bassinet in the ICN - Intensive Care Nursery) to try and get some sleep tonight. The doctors feel that because we have spent so much time by Max's

bedside and have performed all of his treatments multiple times - we are good-to-go. So, tomorrow we have to watch 2 videos: 1) car seat safety and 2) baby CPR and then demonstrate we know how to draw-up Max's oral meds and administer them. If you could only meet some of the wild animals I have had to orally medicate - Max is a piece of cake. Even Matt is well versed after having to medicate the chins while I was on bed rest at my parents.

We got Max's Insulin blood results back and they were low. With hyperinsulinism his insulin levels in the face of hypoglycemia should be high. So, he is clinically responding to hyperinsulinism medication, yet his blood work does not correlate. So, a few of the endocrine specialists are scratching their heads and will have an answer for us shortly. Until then he will stay on the Diazoxide and Matt and I will have to test his blood sugar before every feeding - his poor heels are soooooo bruised. The endocrinologists want us to keep testing his blood sugars before every feeding until his recheck in 1 mo.

Matt gets his birthday wish of having Max go wireless. We promise to send pictures once we are home.

Serena, Matt, and Max

July 12, 2007

Hello,

I am sorry we have not sent-out an update in several days - things got a little crazy. We brought Max home Friday afternoon and Matt and I fumbled through the night figuring out an alternating feeding schedule so that each of us might get 2-3 hours of sleep. Saturday, Max's abdomen (belly) appeared more distended (bloated) to me so I measured it and his girth was up from UCSF's measurements. I called the pediatrician and we decided to watch him and start him on simethicone (gas-X) since his "output" was normal (i.e. things were moving through his system). Sunday he was much fussier and after a feeding he would not settle down to sleep and his BMs stopped. I called his pediatrician and they scheduled us an afterhours appointment at the pediatric urgent care clinic. The MD there decided he needed to be admitted through Marin General's ER. So, we took Max to the ER where he was seen by the on-call pediatrician who knew Max from when he was born. They ran tests and took a whole baby x-ray (chest and belly). His entire gastrointestinal tract - stomach, small intestines, and large intestines were full of gas. For all my colleagues a babies x-ray looks a lot like a small dog. So, he received a glycerin suppository, IV fluids, jaundice light therapy and was placed NPO (Nothing per OS - i.e. no nothing allowed in the mouth - food or water) overnight. He was a bit better the next day and so we started him on bottle feedings again and he got worse. He was also not oxygenating well and was extremely fussy. The doctors felt his tongue was starting to cause problems and we agreed. I think he is swallowing air with his feedings and the doctors feel that when he is sleeping he may be partially blocking his airway with his tongue. He was therefore, given supplemental oxygen and kept NPO again overnight. They also placed a tube down his mouth into his stomach to decompress it (remove the gas). By this morning his belly had decreased in size significantly and he was much more comfortable. We had decided with the MDs yesterday that he needed to be transferred to UCSF today for further work-up. So, once again he received an ambulance ride over the Golden Gate Bridge.

Max is now at UCSF and the plan is for him to remain NPO to get rid of all the gas and then to perform the following: a sleep study to see if his tongue is blocking his airway when he is sleeping, feed him tomorrow via NG (nasogastric tube or a tube that goes down his nose into his stomach) to see how he responds, and perform a barium fluoroscopy study of him swallowing. The NG tube allows us to remove the excess air he seems to get when nursing on the breast or with a bottle to see if the problem is excess air with feedings due to his large tongue or if he is having a reaction to my breast milk. The fluoroscopy allows us to visually see him taking barium (contrast medium) from a bottle and see how he swallows. This will tell us if his tongue is causing a problem. The doctors, nurses, Matt and I all feel his tongue has gotten bigger which is consistent with Beckwith Wiedemann syndrome. His chromosome test came back today and was normal. Therefore, we need to run further more sensitive genetic studies.

It appears Max will be at UCSF for at least another week. In the meantime, we will be staying at my parent's house and commuting back and forth to the hospital. A very good friend has been taking care of Emma for the past two+ weeks. Not only is she having the time of her life with her chocolate lab pal, but she has lost all her winter weight and has her young puppy figure back. It is our hope that we will maintain that figure with frequent strolls with Max very soon.

Lastly, we have a temporary website where we will post pictures (e-mailing them really takes a long time). Please use the following link with password "sam" for access - <http://www.babyjellybeans.com/web/do/site/home?ID=231225>. We hope to have more pictures up soon.

July 13, 2007

Hello,

I am not superstitious, but Friday the 13th has never been a good day for me and Max seems to agree. When we arrived at the ICN Max was hooked-up to oxygen via a nasal tube. He had not been oxygenating well (desaturating into the 70s). The barium swallow study that was supposed to have been done got pushed to Monday b/c the department was busy (got to love UC - you need to be dying to actually get a test run when it is scheduled). Plus the sleep study scheduled for Monday got pushed back to Wed. Max's bilirubin is climbing back-up - not to a level yet where he needs phototherapy - but the MDs are not sure why this is happening.

Max received an EKG/ECG and an echocardiogram to evaluate his heart murmur. He has had it since birth and it is believed to be a PPS (the pulmonary arteries coming off the heart in newborns makes a very tight turn and the high velocity of blood flowing through causing a whooshing sound - i.e. murmur - this is usually outgrown with time). The concern was that the murmur was more audible and because his HCT/PCV has been low (anemic) the heart murmur could be due to his anemia or something more serious than a PPS. My evaluation of the echo was that things looked pretty good - no PDA - the ultrasonographer agreed, but we need to wait for the official cardiology report. Max is named after my grandfather (Soke) who was Chief of Cardiology at UCSF and lived and breathed UCSF - so it only makes sense for Max to be at UC for his medical work-up and Max felt slighted when he did not receive a cardiac work-up on his first stint at UCSF.

The plastic surgeon from the pediatric craniofacial dept. performed his exam on Max and agreed that we need to get more studies on Max to decide if Max needs to have the tongue reduction surgery now, wait until he is older if his breathing issues can be stabilized, or if he will require a trach tube (a tube that is placed in your trachea and left there for months to years). Head and neck X-rays were ordered and should be done tonight or tomorrow along with another chest and belly film. He had slightly wet sounding lungs this morning and the x-ray was normal - but they want to make sure he does not develop an aspiration pneumonia since he is at relatively high risk for this. He will continue to be fed via NG tube (Nose to stomach tube) until all the studies are completed next week. By the time Max comes home he will have had a life time supply of radiation and will glow in the dark ;)

His nurse today had to fashion a special pacifier for Max so that while he was sucking on his pacifier he could breathe through his mouth. Most pacifiers have a flat plastic part up against the lips which does not allow for mouth breathing. So the hole was made so that there is airflow from outside to inside. Max gets very frustrated and cranky if he is not sucking on a pacifier and then the bells go off on his monitors because he is not oxygenating well and his tongue turns purple. We believe this is because the pacifier puts his tongue in a better position to allow breathing.

I think that is everything that is going on. There are many things to sort out - some related and some that are not. Max will remain at UC for at least another week. We will keep you all updated as we hopefully get some answers soon.

Matt, Serena, and Max  
July 16, 2007

Hello all:

Max is doing better. He is fairly wired though. He still has his nasal cannula delivering fresh oxygen (25%) and he still has his nasogastric tube (NG). He finally had his barium swallow study done today and luckily it showed he does not aspirate oral feedings. He did get some reflux back up the esophagus to the nose. Based on the study the docs decided he can start breastfeeding and bottle feeding. Max was very happy and took to the bottle better than he ever has.

His blood sugars today reached into the 220s and so endocrine finally agreed to decrease his Proglycem dose. I have been requesting this for over a week along with the neonatologists. Endocrine is very academic and sometimes they forget there is a patient attached to the lab values. As veterinarians we are taught to treat the patient not just the lab values.

Matt donated blood for Max (they are the same blood type) the other day since Max has continued to be anemic. Matt was actually quite pale and I thought I might have to admit him after he donated.

We were concerned over the weekend Max may require a blood transfusion b/c his HCT had dropped into the low 20's. Of course it turns out there was a lab error and an attending that reported another patient's HCT to me instead of Max's. Max's HCT was a good 8 points higher (28-33%) - the difference between transfusing and not transfusing. All of you who know me well enough know that I did not let that one go - I made sure to alert the appropriate parties in the dept. that a physician (an Attending to boot) making an error like that is not acceptable - in fact had we not stressed the importance of Max getting Matt's blood, which will not be ready for transfusion until tomorrow (it takes 3-4 days to process), that doctor could have come close to a little thing called malpractice. Of course when the doctor was paged to come talk to us at the bedside - he never showed and one of his residents showed-up in his place and explained the discrepancy. So, once again I peruse his chart every day to try and stay on top of his care. I would really like to just be a parent and take off my doctor hat for awhile. Maybe once we get Max home.

So, now we await the sleep study on Wed. I have asked for a family meeting where the representatives from each of the specialty depts. are present and we discuss Max's care and the plan. I am hoping that by Thursday we should have some answers and a plan to get Max home.

On the positive side with the expensive babysitting - I am getting 6 hours straight of sleep (the longest my body will let me go without pumping). Matt gets more b/c he does not need to pump. While we would like more sleep it is more than we would be getting at home with a newborn. Now I just need to figure out how to sleep at the hospital during the day when Max is sleeping. Matt has the Brenner sleep anywhere gene and so he falls asleep in the ICN. Actually both Paul (Matt's dad) and Matt sleep in the ICN.

Matt, Serena, and Max

July 19, 2007

Hello,

Max will be 1 month old tomorrow on Matt's and my 4 year anniversary. He is getting stronger and more coordinated in pulling out tubes and other monitoring devices. He has his sleep study last night and kept pulling at the monitoring devices attached to him and only slept for 20 min out of the almost 6 hours they monitored him. The official report is not back, but he does have some central sleep apnea.

Because Max has so many issues I will list them below and give you the update for each:

- 1) Anemia - holding steady at HCT 25-30%. He never has a chance to replenish because he has his blood drawn daily to measure various parameters.
- 2) Bilirubin/Jaundice - down a bit today (14), but a lingering problem with no answer. So, GI has gotten involved. Another Liver ultrasound was performed today, (I was not present so I cannot give you my DVM interpretation) - results pending
- 3) Feeding - the bottle Max needs to feed from, the Haberman, requires a little training on how to use it. All of Max's nurses have not been trained and so his nurse overnight and the one on today - incorrectly used it causing Max to swallow more air and again became very bloated (abdominal gas distention) and uncomfortable. Therefore, Matt and I requested that unless Matt or I are there to bottle feed he needs to be fed through his NG tube. Max is still receiving breast milk, but is not breastfeeding due to the mechanics of his swallowing. He cannot get the milk from the front of his mouth to the back to swallow it. The lactation nurse will still argue that he is getting milk even though, the swallowing study and the specialists disagree. The nipple on the bottle he feeds from is very long and is actually designed for a cleft palate. Nature cannot mimic that. It is amazing how far many of the lactation nurses will go to push their breastfeeding agenda. I figure he is getting breast milk, which is according to the most current studies, the healthiest thing for him - that should be good enough given Max's feeding issues. At least I now have a better appreciation for what dairy cows go through.
- 4) Oxygen - Max still requires oxygen via nasal cannula. He will most likely go home on oxygen. This is because of the belly distention pushing up on his diaphragm which does not give his lungs much room to expand. Therefore, he is not oxygenating well and his CO2 builds-up - confirmed on blood gases drawn daily.
- 5) Diazoxide-- Max is no longer getting this insulin suppression medication b/c his blood glucoses have been in the 200's and even 300's. So, he actually may have outgrown his hyperinsulinism - time will tell.
- 6) Genetics - will be sending in more of Max's blood next week to perform the second genetic test - methylation. The insurance has finally approved it. (In case you have not seen Sicko - go see it. Matt and I are moving to Canada or maybe Cuba.) Max is being treated as a Beckwith Wiedeman baby b/c all the specialists are convinced that is what he has and are treating him as such - the genetic confirmation is almost superfluous.

There are several more tests that need to be run and Max will have to pass another 5-6 hr fast off the Diazoxide before he will be allowed to go home. The hope is he may be able to go home midweek next week. He will go home on oxygen and possibly a NG tube. Matt and I will be trained in placing them in case he pulls it out (he has accomplished this several times). Unfortunately, by the time Max comes home Matt's parents will have gone back to NJ and we will not have any help in the house.

Thanks,

Matt, Serena, and Max  
July 22, 2007

Hello,

Well tomorrow was to be my due date and the tentative date to bring him home is Tues or Wed. So, the reality is if I had delivered him closer to tomorrow he would be coming home at the same time he is now having been born 1 month early.

Matt and I are rooming in at UCSF tonight. Max will be in our room. The MDs want to see how he does with 12 + hours of only bottle feeding. Even if we are tempted we cannot feed him via his NG tube. We need to make sure he can take what he needs calorically by mouth without his abdomen becoming to gas distended. We will both be trained on how to place an NG tube because he will go home with one and given his propensity to pull them out, we need to know how to put it back in. If this were an animal we would staple (surgical not desk) or suture the tube to the animal's face. While they still manage to pull them out, the frequency is less. I am not sure what would be more uncomfortable tape (humans) on the face or staples.

Max's nose down to his vocal cords was scoped with a fiber optic camera Friday and revealed that he has laryngomalacia- basically his epiglottis is swollen and folds in on itself accounting for some of his airway issues and reflux issues. This can be surgically

corrected along with the tongue, but the consensus with Max is to keep him on O2 and feed him as we have been and allow him to mature. Ideally he will grow out of his issues with refluxing and airway obstruction. If not we can always turn to surgical correction. He is now on Reglan which increases GI motility and seems to help in moving air through his GI tract so he is less bloated. Down side - more diapers to change.

Anemia - Max was transfused yesterday with Matt's RBCs (Red Blood Cells) and his HCT is now 39!!! He is much pinker and oxygenating better. Go figure more RBCs to carry those precious O2 molecules.

Bilirubin/Jaundice - The liver ultrasound was normal. His jaundice appears to have improved from the transfusion.

Feeding - Max is feeding well from the Haberman. He has decided though that he wants to eat every 2 hours - it will be a fun night! We have to suction his nose frequently because of the reflux. The hope is the insurance will pay for one at home b/c using a bulb syringe is not as effective and more irritating to his nose.

Oxygen - Max will be going home with oxygen - he could need it for weeks to months.

Max has now gone 4 days off the Diazoxide and his sugars are holding strong. He will be fasted tomorrow for 5 hours to see if he can maintain his sugars in the absence of food. Then the hope is he will be discharged Tues or Wed.

That is all for now,

Serena, Matt and Max

July 29, 2007

Hello,

We brought Max home on Wed. He loves riding in the car and in his stroller. The evening before Max came home or should I say the late hours of the night (11:30PM) the oxygen guy came to our house to deliver the 175# O2 tank and Max's suction machine. Matt and I had an hour long tutorial on maintaining the O2 tank, filling the portable tank, and on using the suction machine. We had to place signs on the house stating O2 being used in the house so no smoking or open flames.

Matt and I have figured out our shifts - I take the 9pm to 2-3 AM and he takes the 2-3 AM to 7-8AM. Of course Max dictates when he feeds, sleeps, and when we sleep. During the day we try to sleep when we can and take care of all the other household things. It has definitely been challenging with all of Max's special needs on top of being a newborn. It has been a full time job for both of us leaving little for anything else.

Max has kept us busy taking him to the pediatrician each day. We get a weekend break b/c the office is not open. Thursday for a check-up post discharge from the hospital and then Friday for severe diaper rash. As if he has not been through enough his poor hinney was so red and raw that he needs topical steroids, an antifungal, and a barrier cream. He was in so much pain that he would cry during his feeds and kept both of us up all night. I used Tylenol, but that barely helped. We decided to discontinue his Reglan (the medicine to increase GI motility and move gas through and decrease some reflux) b/c it causes him pain with the increase GI movement ... We will be back at the pediatrician tomorrow (Mon).

Just when we think we have Max's routine down he changes things on us. His bottle feedings have increasingly become prolonged so Matt tried a regular nipple today and he did better. But, then he had too much reflux so back to the Haberman. We will have regular check-ups with OT/maxo-facial to keep up with Max's ever changing oral changes due to his tongue and poorly functioning epiglottis. We have been tempted to put his NG tube in, but we keep saying - we will give him one more feed - that was 8 feeds ago.

His blood sugars have been in the 60's and 70's. We really have to push him to eat more b/c he often only wants 60ml (2 oz) and he needs to be taking more to grow. We have had to fortify my breast milk to increase the calories. He definitely has Matt's metabolism not mine. Has anyone noticed that formula is

predominately corn syrup - the one form of sugar that is so processed and the worst for us. It has been associated with diabetes, obesity, and other poor eating habits in children and then later in adulthood. Unfortunately, all the formulas I have seen have corn syrup solids in them and are the first or second ingredient. Anyone know of one that has unprocessed sugars?

Max had his first tub bath yesterday and was not so thrilled, but liked being wrapped in his hooded towel. Max's hair is getting a little lighter - it just may have a little red in it.

Matt put up new pictures chronicling some of the above comments.

Matt and I are going to be interviewing nurses/nannies starting today to help us 2-3 days a week so we can get some good sleep and to allow us time to do something together or just to get normal everyday things accomplished (thanks to my parents for providing this much needed reprieve). If you know of anyone, please let us know.

Matt and I are hanging in there, but it has been really tough. Matt seems to be coping better than I am. I think the last 5+ weeks have finally taken their toll. I have had 2 migraines for the first time in years and now I am a bit under the weather. Matt has been getting out to play basketball 2 x week. When I even think of taking a walk or getting fresh air I would rather sleep. We are going to try and take a walk with Max and Emma today.  
Max, Serena, Matt

Aug 1, 2007  
Hello,

Thank you for all the referrals for baby nurses/nannies, formula info (unfortunately - he needs one that is designed for preemies and has extra calories b/c he has to catch up on his weight gain). We were actually supposed to meet with a potential baby nurse/nanny today - but we had to take Max to the doctors.

I called one of Max's MDs at UCSF yesterday b/c Max was taking too long feeding. We had been told he should only get 30 min to feed. His feeding time had extended to 1hr to 1hr 15 min and he was barely taking enough formula/breast milk to gain weight. He then wanted to feed every 2 hours instead of his usual 3 hrs and his sugars have not been great (high 60's to low 70s). The MD said we should put in the NG tube. So, we did and thought we may actually get some sleep between feeds - NO. The plan was to let Max take whatever he could in 20-30 min via bottle and then the rest would be given by NG. We placed the NG tube (a little stressful for me!). Max was not taking much from the bottle and was not settling down after his NG feeds. His cries were that of pain. Plus he had been over the past 36 hours a bit clammy/sweaty, but his temperatures were normal. He also had not had a BM in 24 hours (not so unusual given we had to switch him to 75% formula). We called the pediatrician today to see if we should give him an enemy. While waiting for a call back from the nurse - Matt was bottle feeding Max and felt he was warmer and very clammy so he took his temperature and he was running a fever. I had given Max Tylenol 2 hours prior to help with his pain of unknown origin. I called the pediatrician office back and told them he now has a fever - so again off to the pediatrician office (he has been there every day except for the weekend since being discharged from UCSF last Wed.)

The pediatrician admitted him to Marin General and consulted with UCSF. He had his urine cultured, his blood drawn and a spinal tap to look for a possible infection. So, Matt and I are going to try and get a full night sleep given out expensive babysitting again and try not to worry too much. Hopefully, tomorrow we will have some answers. Max's MD from UCSF will be doing rounds by chance at Marin General tomorrow and Max's regular pediatrician that has been out-of-town will be back tomorrow.

On the positive side b/c he has not had any BM his diaper rash has started to heal.

It has definitely gotten more difficult for Matt and I b/c Max's more current issues seem to be more painful and uncomfortable for him and it breaks our hearts. He looked at me today with his blue/grey eyes and said Mommy I am in Pain FIX IT! There was nothing I could do except give him Tylenol. I have never felt so helpless. It is true nothing breaks your heart more than not being able to remove your child's pain. At least with our other kids" (feathered and furred) I can tell what is bothering them and fix it.

What a roller coaster - I am glad Max will not remember any of this, years from now.

Serena, Matt, and Max

Aug 4, 2007

Hello,

Max was not improving at Marin General Hospital (MGH) in fact his breathing worsened, his blood sugars were dropping into the 40's, he continued to be intermittently febrile, and he continued to feed poorly. So, in consult with some of his doctors the decision was made to transfer him to UCSF yesterday (that's right his 3rd ambulance ride over the Golden Gate Bridge). There were also issues with the competency of a couple of his nurses and the level of care he was receiving at MGH - long story - maybe I will expand in a future e-mail.

Max's main issues are his breathing, his ability to eat, his blood sugar, and a possible milk protein allergy.

Max is now on 2 L/min oxygen (he was on 0.5 L/min) and if the nasal cannula is not in his nose (it tends to slip out or he moves it) he cannot maintain his oxygen saturation. He becomes more cyanotic (turns bluish/purple) in his face and scalp now - it is not just his tongue anymore. He moves his chest more (increase abdominal excursion) and the area between his chin and collar bone in order to breath. Therefore, the pulmonologist from UCSF that saw him at Marin General felt that his ability to breath has worsened and warrants a further work-up and to be at UCSF. So those studies will probably take place this next week and will determine if he needs to have a tongue reduction surgery (Leslie I got your message thank you) and/or epiglottis surgery. The last resort would be a trach tube.

Max's feeding issues are compounded by his breathing issues. He has had difficulty consuming enough volume to allow him to grow appropriately. This is why an NG tube was placed, but it may be affecting his airway and causes more reflux. So, he may have a G-tube (a tube/port that goes from the outside of the body into the stomach) placed which requires surgery. He will still be able to bottle feed to satisfy his suckling reflex.

Max's blood sugar has dropped into the 30's twice today. So, blood was taken today when his sugar was low and Monday the endocrinologists will decide whether to put him back on the Diazoxide or determine based on blood test results how to deal with his low blood sugars.

Max is on a special formula - hypoallergenic where the proteins are hydrolyzed to rule out milk protein allergy.

After 3 days of running a fever; he has not had a fever today. All of his cultures came back negative. So we do not know why he had a fever - viral, milk protein allergy, low blood sugars??? (FUO)

Today, Max slept well between his feeds for the first time in a week. He always looks so peaceful when he is sleeping and I feel that is the only time he is not experiencing some type of discomfort/pain. Max is in better hands at UCSF and that gives Matt and I some comfort. At least, Matt and I will at get more than 3 hours of sleep in a 24 hour period with Max at UCSF.

Max's team of doctors at UCSF is now even more determined to get to the bottom of this now that this is his second readmission. Even though, it is believed Max has a mild case of BWS he has been one of the more complicated cases for the MDs. And now they realize that his required daily care was too much for any parent to handle at home regardless of their medical knowledge. One of his doctors admitted that he would not have been sent home this last time with the majority of parents they deal with. The gaggle of doctors felt Matt and I were so capable and I was a doctor so they felt it would be fine with frequent out-patient visits.

On another sad note, I had (a colleague did it for me - Thank you Melissa!!!!) to put TOV (one of my chins) to sleep today for untreatable dental disease. He was 8 years old and I raised him from birth.

Thank you for your continued support - we would not be making it through this without all of you.  
Matt, Serena, and Max.

Aug 6, 2007

Hello,

It is with much regret that we find ourselves writing this update. Max took a turn for the worse in the past 48 hours and is now in respiratory failure among his myriad of other problems. All specialty departments provided their input and surgery is eminent. There are several procedures and the discussion is which to perform first and what the benefits/detriments are to each (tracheotomy, epiglottis surgery, PEG tube, tongue reduction).

Many people have called and e-mailed requesting updates and unfortunately, this one must be brief. We will provide a more detailed update tomorrow when they have determined the best course of action. In the meantime, they are carefully watching his breathing and we hope they do not have to take any emergency actions overnight.

We are heading back to Novato to get our affairs in order to prepare for the upcoming events so we can stay in the city for the next week.

Aug 7, 2007

Max is scheduled for a 5:00pm tracheotomy today. His IV is back and he is NPO (without food) through surgery. Max will not receive his PEG tube at this time as UC does not have a surgeon available. All agree that the trach needs to be performed as soon as possible. They will reevaluate his condition post surgery to determine whether the tongue reduction and/or epiglottal trim will eventually become necessary.

Serena and I will be in San Francisco for the next few days. Our neighbor now has Emma and will be watching over the Zoo while we are gone - she has truly eased our burden and we cannot thank her enough. Thank you to everyone who has offered their assistance - we may take some of you up on those offers in the near future. We hope to have positive news for everyone this evening or tomorrow.

Aug 8, 2007

Hello Everyone:

At the risk of freaking out the non-medically trained folks on this list, Serena has opted to delay her report. Accordingly, you will be reading my (Matt) observations from the past 20 hours which are less medically involved and probably a little less scary.

Max's surgery went well but post-op has kept the doctors and nurses on their toes - he has not been comfortable with the trach tube and gave a little fight against the ventilator. Accordingly, Max had three major sessions with the doctors this morning resulting in an upped dosage of Ativan and morphine as well as the administration of a drug called Pancuronium. Pancuronium is a paralytic that basically puts Max in a state of paralysis. While this sounds distressing, it was important to do as Max decided to pull the ventilator tube out of his trach last night and aside from bed restraints, this was the only option to keep his hands off the area (Max has removed every NG tube on his own, has kicked out several IV lines, broke four nasal cannulas and routinely rips off his monitoring leads). They will continue to keep Max sedated for the next few days.

The good news is Max's belly actually looks normal. The doctor was able to palpate and, for the first time in a while, actually feel his organs. His breathing (or should I say the ventilator's) is rhythmic and his stats are quite good right now.

Serena and I have been photographing just about every aspect of Max's life, which I mention for two reasons. First, we joined the BWS registry ([www.beckwith-weidemannsyndrome.org](http://www.beckwith-weidemannsyndrome.org)) and genetics is hopeful that with all the documentation, we may be able to have Max enrolled in a BWS study (i.e. we wouldn't have to worry about whether our insurance would pay). Second, we will post some pictures of Max post-op and want to warn you ahead of time that you may find some of them a bit disturbing. He has three tubes that intersect at his trach and they cannot clean the area for several days until the trach tubes become secure. But please remember that all of this stuff is actually making his life better (I keep reminding myself that on a regular basis).

Aug 9, 2007

I thought this puts our current experience into perspective and reminded me that while we have not been able to experience many of the joys of being new parents like many of our friends, we have been blessed with a son that we have fallen in love with. There will be plenty of time for us to experience the "normal" ups and downs of parenthood.

Serena

Welcome to Holland  
Emily Perl Kingley

I am often asked to describe the experience of raising a child with a disability to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby it's like planning a fabulous vacation trip-to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum...Michelangelo's David...the gondolas of Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

"But there's been a change of plans," says the stewardess. "They've landed in Holland and there you must stay."

The important thing is that you haven't landed in a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you have been there awhile and you catch your breath, you look around and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's where I had planned."

And the pain of that will never, ever go away because the loss of that dream was a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special and lovely things about Holland.

Aug 10, 2007

Hello all:

The last 48 hours have been tough to say the least. Max had several episodes of dropping his heart rate into the 20's BPM, not breathing despite being on the ventilator, and turning blue (3 in 3 hours). He had mucus plugs in his trach that prevented him from breathing and had to be bagged with some chest compressions. I hate performing CPR on patients, but watching your child with a team of MDs and nurses is beyond stressful (Please note: he did not go into cardiac arrest - he stopped breathing and his heart came close to stopping - not good but not CA).

He is still extremely swollen (edematous) around his neck and face and his distal extremities. This for us is his most pressing issue and after our discussion with the neonatologist tonight - they are considering putting him back on Lasix. Unfortunately, no one truly knows what is causing his edema, but there are several very plausible explanations and most likely it is a combination of a few of them. Do not worry I will not bore you with my list.

The most difficult part of all of this, is that we cannot hold him b/c the trach is so fragile for the next few days and when we hold his hand or talk to him he gets agitated and closes his airway. So, we limit contact and just sit by his bed side. They are keeping him well sedated and on a CRI (continuous rate of infusion) of morphine to manage his pain to get him through this difficult post-op period. Then we get back to my parent's house and we do not have any of our animals to snuggle with either. Snuggling with Matt definitely help though.

I have been on the Yahoo BWS chat room and posted a synopsis of Max's life the past 7 weeks and received a lot of supportive e-mails from other parents who have been through what we have been through and now have healthy kids age 2 and up. They have offered good advice. I also spoke to the nurse at WSU at SL who works with Dr. DeBaun (BWS expert) and Dr. Marsh (plastic surgeon/leading expert on tongue reduction surgery in BWS patients) and she told me a lot of what Max is going through is all within the norm for BWS kids. She will also have Dr. Marsh get in

touch with me. I have requested that the UCSF team consult with the WSU team to figure out the best course for Max in terms of surgeries and the timing of them.

We hope that we can start Max on some formula tomorrow to get his GI tract moving. He has been on TPN (Total Parental Nutrition - what he needs to sustain life in a liquid form delivered via IV) since his Trach was placed. Other than that Max's blood sugars are remaining stable and his abdomen (belly) and umbilical hernia are the smallest they have been because he is no longer gas distended from swallowing too much air.

So, for now we wait while he recovers from his trach surgery and then they will wean him off the ventilator. Then we can consider placing the G-tube, then the tongue reduction, and epiglottis reduction.

Thank you again for all your support. I do not think there is another kid out there that has so many people pulling for him.

Serena, Matt, and Max

Aug 12, 2007

Hello all:

I have had several people ask about WU SL = Washington University in St. Louis - sorry!

We are sitting by Max's bedside and he is actually responding better to Matt and I holding his hand and talking to him. For the first time we actually calm him down a bit. He has been increasingly agitated today and so they put him back on Ativan and increased his morphine. Max likes his Ativan (relaxant). I think they may need to put Matt and I on some as well. He opened his eyes a bit today and so I read him a little from a book called "Good Night San Francisco". He also likes looking at a little stuffed cow/pacifier. They say the black and white colors are what are easiest for them to see at this age.

Max had another bradycardic/desaturation (low heart rate/poor oxygenation) episode this morning requiring chest compressions and hand ventilation. I learned today that any infant with a heart rate less than 60 BPM receives chest compressions. His poor chest must be sore. The MDs are a bit stumped as to why, now that Max has a secure airway and his airway obstruction (tongue/epiglottis) has been bypassed, he is requiring such high ventilator settings and still requires a ventilator. Pulmonary and ENT are going to have to figure out the answer. Since it is the weekend he will not be evaluated until tomorrow. They are going to have to assess his lower airway. His lungs on x-ray are still not expanding fully.

They have started Max back on his formula. He only gets 2-5 ml (he was getting 75-100 ml) every 3 hrs because they need to get his GI tract started and because he has poor perfusion (blood flow) to his GI tract given all that has been going on and the narcotics.

Max's edema (swelling) is improved, but his face is still quite swollen.

Hopefully tomorrow the MDs can come up with some answers and a plan b/c the tracheostomy was supposed to have solved Max's breathing issues and it has not. Plus Max needs to start growing and the TPN (IV nutrition) is not cutting it. He really could use the G-tube, but he is in no condition to undergo another surgical procedure since he is not recovering well from his last one.

As if Matt and I are not going through enough . . . Emma (our dog) escaped from our neighbors house 2 blocks away (they are doing construction and the gate was open) and another neighbor only called our house and not my cell listed on her tag and when we did not answer at home she called the humane society. So, Matt and I instead of going to the hospital had to head to Marin and bail Emma out. Emma knows our neighborhood and was probably heading back home to find us. Since we were in Marin we stopped off at our house to check on the animals and give them some attention. One of my chins (pastel) who has dental disease was not looking well and one of my most senior chins was being harassed by his cage mate and had not been allowed to get water or food. So, I packed both of them up and brought them to my parent's house along with Emma. I think it may be time to adopt out the rest of the chins. The cats and the birds are doing fine they just miss us and need some TLC.

Anybody want some chinchillas? Not the two, I have in SF - my other special needs kids. We are trying to decide whether to move the birds to my parents - where they can have time out of their cages. The cats will do better staying in Marin and having someone check on them periodically. Max will probably be in the hospital for another 3-6 weeks - it all depends on if and when he has his surgeries.

If any of you are in SF let us know - we can always use a brief distraction. I do not think Max is up for visitors yet, but if you would like to visit him let us know and we will let you know when he is ready. Thank you to Irv, my aunt Debbie, and Uncle Joey for taking us out to dinner to give our minds a break and to fill our tummies. Irv thank you for keeping my parent's fridge stocked with food. Matt and I have taken over my parent's house in their absence - they may have to live in our house in Marin :)

Thank you for all your support and e-mails - it really is helping us get through this difficult time.  
Serena, Matt, and Max

P.S. Matt says he will put more pictures up - they are not for the faint of heart.

Aug 13, 2007

Hello,

I am still digesting the information I am about to share - so bare with me. Writing this helps me do that. Every day we are hit with more and more "bad" news and it almost seems like a bad dream that we cannot wake-up from. Max had a bronchoscopy today b/c he was not improving despite the tracheostomy. The bronchoscopy revealed lower airway disease. An area in his right and left lung at the level of the bronchi are completely collapsing along with part of the trachea = trachea-bronchomalacia (sp? - too exhausted to look it up). This means he needs the ventilator to force positive pressure into the trachea/bronchi to keep them open. This is why he was not able to be weaned from the ventilator and why he keeps having "crashing" episodes on a regular basis. He will require a ventilator until his lungs mature/outgrow this, if they are able to (some kids are unable to outgrow it). If he can outgrow this it could take months to years! He is also developing right sided pulmonary hypertension. The right side of his heart has had to work much harder to compensate for his lower airway disease. He is scheduled for another echocardiogram tomorrow since his EKG is showing right sided hypertrophy (right side of the heart is getting larger).

At this point we have to cross our fingers and hope that now that they know what is causing his airway issues the correct ventilator settings can be made to lessen the load on the heart and to help his lungs "heal". In the meantime, they will be increasing his NG feeds so that he can grow and become stable enough to undergo surgery to put in a G-tube. He will not be able to take formula from a bottle for a while, if at all, since he will be on a ventilator. His little body needs to grow and hopefully outgrow these issues. We have been prepped for the fact that he may require a long-term care facility and we may need to look at what type of care is in Max's best interest. We hope to know more this week and hope that he will be able to come home with round the clock care in a month or so instead of the alternative. . .

We will keep you all updated via e-mail as possible. We just cannot be updating people via telephone - it has become too difficult time. If you need an update and we have not sent one please contact Matt's parents or my parents.

Thank you all!!!

Serena, Matt, and Max

Aug 14, 2007

Hello Everyone:

We met with the ICN attending physician Dr. Bob Piecuch (pronounced pee\*yah\*tsu - don't ask) and social worker Stephanie Berman late this afternoon in order to clarify some of the issues presented late yesterday. Dr. Piecuch did apologize for the information conveyed by pulmonary and noted that the specialists often don't explain things within the context of the specific patient. More on that in a second but the meeting was extremely beneficial.

As Serena noted yesterday, Max's breathing issues are primarily caused by bronchial collapse. The pulmonology team explained the full spectrum of problems associated with lower airway complications and left us believing that Max's condition was on the more extreme end of the scale. Dr. Piecuch painted a much different picture. Max was not born with the respiratory issues but they did get worse over time, particularly in the past few weeks. Dr. Piecuch (remember, that's pee\*yah\*tsu) explained that Max's other issues coupled with recovery from surgery likely placed a tremendous strain on his respiratory system leading to the collapse (he likened the condition to sucking through a weakened straw - eventually the straw collapses and stops working).

The good news - Dr. Piecuch believes the problem will resolve itself with time. How much is difficult to say but this does not seem to be a lifelong condition. They were able to work with the respiratory nurse to dial in the settings on Max's ventilator. The most important setting is the positive end expiratory pressure or PEEP. This keeps Max's airway open and helps prevent the collapse and is set at 8. They were able to reduce the number of breaths the machine performs to 30 per minute as Max is able to pick up another 30 on his own. This is good because Max needs to do some of the work in order to strengthen his respiratory system. Since the setting changes, Max has only had one bronchospasm which occurred early this morning. It was mild and only required minor intervention.

In addition to the ventilator settings, they were also able to reduce his morphine IV and they eliminated the Ativan. They also are increasing his feeding and hope to get his full nutritional intake via NG tube by the morning which will eliminate the IV nutrition.

Max's outlook is much brighter after today's events. Serena and I are feeling much better about his current health and his ability to get better. The plan for now is to let Max recuperate for the next few days. It is likely Max will undergo surgery sometime next week for the PEG tube assuming he can keep his breathing patterns regular and grow a little for strength. Maxo-facial is scheduled for Monday and we will know more about the timing for a tongue reduction.

That is it for now. Hopefully you won't hear any new updates for a few days as Max gains his strength and prepares for the next round. Thanks again for all your encouraging e-mails and we hope to have more positive news soon.

Matt

August 19, 2007

Hello,

Max is sleeping right now in Matt's arms. I just gave him a sponge bath, a massage with Aveno cream (dermatologist recommended), learned how to change his trach ties and gauze, suctioned his trach (I hated doing it when I did my ICU rotation at UCD - who knew that experience would help me with my own child), changed his diaper and then off into Dad's arms. Max and Dad could not be happier sleeping and rocking despite the Red Sox's loss today (he was not wearing any Red Sox's gear today - the Brenner's and his Uncle Avi made sure he has enough gear to last the rest of the season). At least the 49ers beat the Raiders last night! Max has his 49er mobile above his crib in the hospital

(thanks Megan and Steve!) - maybe that means they will win a few this season. We still need to get Max a 49er outfit to wear on game days. We were hoping to take him to his first game this season, but that will have to wait. He did get to go to Red Sox Spring training in Florida when he was still in the womb.

Max has been improving each day. He is initiating all of his own breaths and the ventilator just helps him reach the appropriate pressure to keep his bronchi open. He requires less Ativan and Morphine (he gets it on an as needed basis). He has not had any "crashing" episodes for a few days (except for one last night - but he recovered quickly). He will be getting his PEG/G-tube this week. We are just waiting to hear when they can fit him into the overbooked peds surgery schedule. We have decided to wait on his tongue reduction (TR) surgery until he has grown a little. He has been putting weight on and he is now off the hypoallergenic formula. He is getting the breast milk I had frozen. That supply will last 2 weeks and then he will get regular formula. So far, he does not appear to have any allergies.

Blood glucose is holding steady on the Diazoxide. So, now he just needs to let those lungs heal and he needs to grow. Then we will deal with all his "little" issues that require medical intervention.

GO MAX GO!

Serena, Matt, and Max  
August 21, 2007

Hello all:

Max remains stable - yeah! He does require a little bit of Ativan and/or Morphine and/or Tylenol periodically. I do not blame him given what he has been through. Better living through chemistry!

There really is not much new (thankfully!) to update you all on except his g-tube surgery is scheduled for this Friday afternoon.

Old stuff that is stabilizing or improving : his blood sugar's are stable on the Diazoxide (a bit lower than Endocrine would like, but the rest of us are fine with it - 70's-90's), he is about 11# or 5kg now give or take a few hundred grams and depending on the amount of edema he has, he gets 100 ml or 3 1/3 oz every 3 hours - he is a growing boy! He has been weaned a bit on a few of his ventilator settings except the one that keeps his pressure up (PEEP) enough to keep open his bronchi. When the ventilator is detached from his trach in order to move him or to clean/switch out his trach he is able to maintain his O2 saturation and heart rate, but he does get pissed! As long as he can have his pacifier (the nipple to his special feeding bottle) - he is usually happy. If that does not work he is given drugs. Matt and I have learned this week how to suction his trach (remove the build-up of secretions that can clog the trach and prevent him from breathing - very scary b/c if you do not keep-up with it or do not realize it needs to be suctioned he can die). He needs it about every hour or so. Matt and I have also learned how to change the different parts of the trach and the trach itself. It takes two people - one to hold his arms and pacifier in his mouth and the other to change or clean the parts. While, I am getting a little more comfortable with "dealing" with Max's trach - I do not think I will ever be completely comfortable with it. As a doctor, I know all the little things that can go wrong and it scares me. Matt is able to take it in stride and is dealing with it better than I am. Max needs to be watched 24/7 since he is not old enough to ring an alarm bell if he gets into trouble with his trach. This means he will require nursing care at home at least part-time. The real issue is finding qualified nurses (if anyone knows an RN with infant/trach care experience - let us know) and getting your insurance

to pay for all or even a part-of-it. We have learned a lot during Max's stay from the nurses because what we thought nurses made is only a 1/3 to a 1/4 of what they make. They have a great union. They make more per hour than either of us - which would defeat the purpose of working if you have to pay for home nursing care out-of-pocket. If anyone wants to have a political discussion about how screwed-up insurance companies are or our government is in terms of providing services for children with major medical needs give me a call. I am now an expert on all the state and federal agencies that provide support to families with children that require extensive medical care or should I say lack or support - another plug to go see Sicko. I digress . . .

Max is holding steady and that is all the matters. The rest we will figure out as we need to. The next update will probably be post g-tube.

Serena, Matt, and Max

Aug 28, 2007

Hello All:

Max had a pretty good day in general. We changed Max's entire trach system and got our first good look at the surgical sight. The nurses agreed that the site looked very good (a little red) but it is still a difficult image to digest on your son. The whole process took about half an hour but felt a lot longer. They said it will get easier as we do more of them in the future.

Sometime later in the evening, Max somehow grabbed his PEG tube extension with his foot and kicked the tube right off his belly. Fortunately, Max's favorite nurse, Linda Gribbon, was right there when it happened (as were we) and got the system back inside without too much of a problem. Max also pushed his trach tube off at least a dozen times today so that seems like old hat to us. Perhaps we'll get used to this PEG problem too.

Overall, Max's recovery has been slow but he is progressing. The doctors are thinking he will likely spend the next few weeks in the ICN and then may be discharged. There is still discussion regarding when the tongue reduction will occur. Originally we were thinking he would come home and then go back for the TR. Now, we are thinking sooner may be better as Max does seem eager to bottle feed. We are meeting with OT/PT to discuss options this week.

Max has been opening his eyes more in the past few days. He has been tracking nicely and seems to like his 49er mobile and his fish aquarium on the side of his crib. He is now 12 pounds 5 ounces so growth doesn't seem to be an issue. His lungs are the big focus for the next few weeks and hopefully he will respond well to being weaned off his ventilator and on to CPAP.

August 31, 2007

Hello all:

Max is holding steady. He has good days and bad days. More bad days which make the good day's ones you do not want to let go of. Today was a bad one. The doctors are doing what are called sprints where they switch Max from the ventilator to CPAP. What this means is that Max has to do more work breathing. The CPAP just makes sure that there is a certain amount of pressure maintained in his lungs when he exhales so his bronchi do not collapse. The idea behind this is to slowly strengthen the muscles that support his lungs. Well someone had the bright idea of placing an IV catheter (they were unable to place it earlier in the day b/c Max has had so many IVs in all his IVable veins over the

past 10 weeks and gets poked every 3 hours for blood samples that most of his veins are scarred) in Max for his blood transfusion (I will address this in a second), doing his blood transfusion, and sprinting him all in the same hour. Last I checked there are 24 hours in the day - maybe splitting-up some of these not so pleasant treatments would have been better medicine????? Anyone, who has dealt with Max knows you do several unpleasant things to him at once and he will have a meltdown. You have to take it slow and spread things out. So, the nurse on last night (first time with Max - Max's primary requested him and she was trumped by the other baby's primary that shares a nurse with Max) gave him Ativan and Morphine to sedate him. I am all for sedating Max when he is really uncomfortable, but he should not be snowed because of some one's stupidity. So, of course when Max has a bad night he follows that up with a bad day - requiring more sedation so he can get some sleep and to get through the day. Now you know what is coming next - YES I made sure to let my feeling be known in as polite a way as possible that Max's primary needs to trump the other baby's primary b/c Max is a higher needs and more critical baby and has been on 1:1 care (rare in the UCSF ICN) until yesterday (this is purely from a medical stand point not my baby is more important b/c it is mine) and that performing 3 procedures to Max's all within the same hour at the same time is not acceptable. Max's nurse today is one of his primary nurses and she raised a little hell before I got there and the attending on knows us well and agreed that the "people" in charge last night should have paced his treatments and he should have had his primary.

Max required a transfusion b/c his red blood cell count has been low (24-28% HCT) and so Matt donated blood earlier in the week for him again. Maybe they should stop drawing his blood every 3 hours and then maybe his body can keep up with the loss of blood.

I am working on some physical therapy with Max, but on days like today I do not do it because it could push him over the edge (where he crashed requiring CPR). Matt got to bottle feed Max 20 ml/cc of milk today. Occupational therapy at our request and the Attending's is allowing Max to bottle feed a bit since this is Max's favorite passion in life (sucking and eating). We put green food coloring in the milk so we will know if he aspirates any of it. When we suction his trach we will get green out if he aspirates. He gets green food out of his nose since he refluxes so much. When Max is allowed to feed via bottle it is better than any drug at relaxing him. So far after 2 days no aspiration. We have taken pictures so when Matt has a chance he will put them up on the [www.babyjellybeans.com](http://www.babyjellybeans.com) website (Max Brenner and then sam for the password).

Max is now over 12.2 lb or 5.55 kg or 5550g. He no longer fits into his 0-3 month clothing - which he never got to wear. Thankfully most of the clothes he received were for 3-6 months or older. He now fits into several of his Red Socks outfits. We put one on him yesterday and took pictures. He slept beautifully in his outfit despite the Red Socks' defeat.

Max pulled out his G-tube this morning - luckily we were not there to see this. They were able to get it back in easily. His skin has been really irritated around the site and so he will be getting a pediatric dermatology consult from his grandfather. I have been applying a Vaseline based product (no product endorsements in this e-mail) and that is helping. Max has been blessed with Matt's fair skin and so it is easily irritated.

I continue my battle with the insurance company every day - 4 hours today on the phone after 3 hours of sorting through 100 EOB (estimation of benefit) letters last night and finding so many errors. I called and got all the errors corrected today - the women joked that I should work for the insurance company. They

would fire me b/c the errors I find are in the patient's favor not the insurance's. I found out today that the insurance maximum coverage for private duty nurses for home care is \$10,000. That equals ONLY 3-4 weeks of 8 hours per day/overnight care so Matt and I can sleep. Then you have to fight and see if you can get more coverage, but they only have to approve it out of the kindness of their hearts b/c the policy only allows for \$10,000. Max will have his trach for at least 6 months if not longer according to the doctors. My advice, read your insurance coverage thoroughly and know your options before you will ever need them. I think I am going to start a patient advocacy business where we help people go through their EOB's and bills and make sure they are accurate. The insurance companies and providers would be out of business in no time. You also have to watch the providers because I have been double billed for the same service. I get a bill from the provider after they have been paid in full by the insurance company. UCSF billed for Max's ambulance transfer and then I got a bill from the ambulance company. When I called UCSF billing they told me that should have never happened i.e. double billing-illegal) and I was asked to fax the bill to UCSF for verification. Enough of my diatribe on insurance companies and medical care.

Max's doctor estimates that he will be in the hospital for at least another month more like 2 months to get his lungs to a point where he can come home. At that point they will do the tongue reduction and when he is recovered from that he can come home.

I have rambled long enough - if you have not realized it by now my e-mails are my therapy. I find them very cathartic. The social worker is always checking in with us to make sure we are still sane - I assure her we are, but the jury is still out :) I think I am ready for some Ativan (Valium relative).

Take Care and thank you for tuning in,

Serena, Matt and Max

September 5, 2007

Hello Everyone:

Max's respiratory status over this past weekend and since he received his trach almost 1 month ago has worsened requiring more support from the ventilator. The pulmonology team performed a second bronchoscopy on Max yesterday, and the results were not good. Max continues to suffer from complete collapse in his trachea and the upper and lower portions of his lungs. Last month, the doctors were hopeful that many of Max's respiratory issues would improve with growth and development. Max is now thirteen pounds, almost double his birth weight, and the tracheobronchial malacia has not improved and requires increasing pressure support from the ventilator.

We had a family meeting today with the attending neonatologist who delivered some potentially devastating news. According to our doctor, Max's respiratory condition falls into the severe category and while many children can make full recoveries and develop healthy lungs over time, many do not. The mortality rate is about twenty-five percent and does not include those children that require ventilators for life. Unfortunately, the doctors have done all they can medically at this point and Max is dependent on a ventilator to live. Now it is up to Max.

The one thing that was certain was Max will require care at UCSF for at least the next four to six months and possibly longer depending on how his condition progresses. Max has been quite the little fighter through all of the problems he has faced and we are cautiously optimistic that he will continue to fight. We

hope to have better news in the upcoming weeks. In the meantime, thank you in advance for all your warm thoughts and prayers.

GO MAX GO!!!!

Matt, Serena, and Max

September 13, 2007

Hello all:

We had our family meeting on Friday. The doctor told us he felt that Max's respiratory status has not improved and if anything has worsened. It is felt among all the specialist that nothing more can be done because there are no viable treatments. They believe the chances of Max's tracheobronchal malacia improving is unlikely. None of the doctors with their collective experiences have experienced tracheobronchal malacia so severe in a patient along with all of Max's other issues. His tracheobronchal malacia is completely separate from his BWS. Some of Max's care team feel he is uncomfortable the majority of the time and being poked and prodded all the time does not help. So, the doctor felt it was time to discuss quality of life and what we as his parents want for Max. Do we want to stay the course or switch to palliative care.

Matt and I have decided to wait and access him over the next week or two and make a decision. In the mean time we have signed a detailed DNR (do not resuscitate) because we do not want him to get any more tubes or receive heroic measures. We are hoping he will give us a sign as to whether to let him go or to fight. He still seems like he wants to fight. Plus, whenever we get bad news he tries to prove everyone wrong and he did that today - he had a good day today. He did not require as much in the way of drugs and respiratory wise was fairly stable today.

At this point we just want to spend as much time as possible with him and to decide the best course for Max. We thank you all for your continued support and there is nothing anyone can do for us other than pray/think positive thoughts for Max and keep the supportive e-mails coming. If we need something we promise to ask.

Serena, Matt, and Max

September 21, 2007

Max passed away this afternoon at 11:40am. Max gave us several signs in the last twenty-four hours that he was ready to go. He passed peacefully in our arms, and we miss him dearly. He gave us the greatest gift that we didn't know existed until we became parents.

Our parents are currently arranging funeral plans, which we anticipate will occur on Tuesday. We will let you know more detailed plans sometime on Sunday. Thank you all for your continued support throughout his fight.  
Matt and Serena