

## Maddy updates

7/5/07

Hello everyone,

Mike and I had another ultrasound this morning and we got the unfortunate news that one of the twins has not survived. We were devastated but thrilled to learn that the other baby seems to be thriving. This is something that they warned us about early on. We were able to meet with one of the doctors and she assured us that it posed no risk to the other baby because it happened so early in the pregnancy. While we mourn the loss of yet another baby we are encourage by the progress of the second baby. We think back to last winter when we lost the first one and how lonely and empty we both felt. The Lord has chosen to bless us with a child still and we will do everything we can to make sure that he or she remains healthy.

7/20/07

Paula,

I wanted to let you know that I ended up going home today. We got some bad news at the Perinatal Clinic this morning. There is something very wrong with the baby apparently. They suspect Trisomy 18 which is a genetic abnormality that causes the baby to only live a few days once it is born. As you can imagine I am a wreck and just didn't think I could make it through the day at work. The next step is an amnio but they can't do that until week 15 so now we wait.

I just need the day to get myself together and do some research on the internet. The most frustrating part of this whole thing is that yesterday when we were at the OB she said that we should start considering this a "normal" pregnancy. We even got to hear the heartbeat. I have to say, this up and down rollercoaster is enough to put me over the edge.

I will send something out to the team but if you could keep the details to yourself for now I would appreciate it. I have to figure out how to tell everyone.

7/23/07

Hi everyone,

I just wanted to send an update with some news on the baby. Today marks the end of my 12th week! What a milestone. We had our 12 week checkup last Thursday and met our doctor for the first time. Typical of doctors offices we waited around for 20 minutes to talk to the nurse for general Q&A and then another 25 before the doctor came in. When she walked in she said, "Typically we sit and talk to the patient for a while before we get started with the exam and listen for the baby's heartbeat. I am going to do things differently considering everything that you two have been through." She left the room for me to change and Mike said, "I like her already." High praise coming from him.

She gave me an exam and everything checked out. The best part was when we actually got to hear the heartbeat for the first time. It is one thing to see it on an ultrasound but completely different when you hear it. We were on cloud 9! She then went on to say that I should now consider this a "normal" pregnancy. I didn't realize how stressed I was about being a "high risk" pregnancy until she said that. We really like her easy going way and look forward to seeing her throughout the pregnancy.

On Friday we visited the Perinatal center for something called a Nuchal Translucency test which consisted of a detailed ultrasound and a blood test to help determine if there are any genetic defects with the baby. This is a fairly new (voluntary) test here in the US but they have been doing it in England for about 10 years. It is non invasive and does not pose a risk to the baby like Amniocentesis does.

We met with a genetic counselor for about an hour and she took a detailed family history (at least as detailed as I knew). I then went in for the ultrasound. That is when the bomb dropped. The doctor came in and said (with very little emotion I might add), "Mrs. Carlson, I see some abnormalities here that are quite severe." It was like I was in a dream. One day we are flying on a cloud of a normal pregnancy and the next day we are shot down. Here is the story.

The ultrasound apparently found something called a cystic hygroma which basically means that there is a pocket of fluid behind the baby's head running all the way down it's back. There is also apparently one on the baby's chest. He said that this is typically a result of the lymph nodes not draining properly. In addition, he said that he saw a defect in the

baby's abdomen (basically some of the intestines are protruding). These two alone are not necessarily tragic (both can be repaired after birth but together they generally indicate something called Trisomy 18 (also called Edwards syndrome). This is the worse possible news. Baby's with this defect rarely make it to term and if they do they rarely live past infancy.

I felt like someone had ripped my heart out and poured acid on it. The next step it to have an amniocentesis to confirm or rule out these anomalies. Unfortunately we cannot do that until week 15 which would be August 9th. As you can imagine we have been on the internet all weekend doing research. The majority of it isn't good but there are a handful of reports that say the hygroma will sometimes go away on it own. As for the abdominal defect, I find that curious because in our Ultrasound at week 10 the tech pointed out the umbilical cord and said that it all looked just right. I can't imagine that the baby's intestines suddenly decided to pop back out of the body.

There is also a slight chance that the Ultrasound results may be mistaken due to the twin that didn't survive. Even our regular doctor had warned us of this. We are choosing to hold on to that hope. I refuse to believe that there is something wrong until after the amnio. We are also going to ask for a more detailed ultrasound (3D). This is not typically covered by insurance but we will pay for it out of pocket if we have to. Depending on the results we may even head down to Mayo for a second opinion.

Needless to say we ask you for your prayers and positive thinking. We need all we can get right now.

8/8/07

We had our second opinion appointment this morning and I wanted to let you all know how it went. Let's just say not well. Not only were they able to confirm what the Perinatal clinic saw but now they have diagnosed the baby with something called Hydrops. This is basically fluid around the heart. It will most likely eventually suffocate the baby and it will die. Needless to say we are just crushed. We talked to our doctor and she did not give us much hope. There is a very minor chance that the baby could be normal genetically and that the Hydrops will go away but it is very slim. If we were granted that miracle, then we would be dealing with a small baby that just needs to have some cosmetic procedures after birth.

We are now faced with some big decisions. Do we have the amnio, do we terminate or do we just let the pregnancy continue hoping for a miracle? As I write this email I think that we will have the amnio tomorrow morning.

They tell me that the results will take about 10-14 days. We both feel that we just can't make any decision if there is even the slimmest chance that this baby could survive.

Needless to say we are both emotionally drained. We don't really know what to say to each other so for now we are just spending time together giving each other support. We are trying to hold on to that little glimmer of hope but it is getting harder and harder with each piece of bad news.

I want to say thank you so much for all your prayers and support though this whole thing. Without that this would be so much harder. I am sorry to do this via email but it is actually easier than talking about it. I am happy to answer any questions you have this way but I just don't feel like I can talk on the phone right now.

I am sorry we didn't have better news.

Jean and Mike

8/9/07

We went in for the Amnio this morning and it went as well as expected.

There was very little pain, just some cramping during the test. I really liked the Ultrasound tech (who's name was Trish by the way) and the doctor that did the test was much nicer than the last guy we dealt with. I had the procedure at one of our hospitals and they asked me what I did for the organization right before he stuck the giant needle in my stomach. I said, "I am not sure I want to tell you before the test. I manage one of the teams on the electronic medical record project that you use but don't hold it against me." (the clinic was an unhappy early adopter :) ) At least we all got a laugh out of that.

They are going to do something called a "FISCH (sp?)" test which will give us preliminary rapid results within about 24 hours. At least that is a blessing. The full results will not be done for about 10 days but at least we will know something in the next day or two. The waiting is the worse.

It was so hard to watch the ultrasound this morning. To us the baby looks so normal. There was a lot of movement and activity and I could see the fingers grasping and at one point the baby almost started sucking its thumb. Mike and I had to just look away after a while.

This should be such a joyous time and instead I just feel cheated every time we see an ultrasound picture. We didn't even ask for any copies to bring home.

The doctor told me to take it easy for the next 24 hours so that is what I am doing. I am blessed with a boss that is incredibly supportive and has told me to take all the time I need despite this being a critical point in our project.

We will let you know what we get from the preliminary results. Please continue to pray for a miracle.

8/10/07

We heard from the Perinatal clinic late this afternoon with the preliminary results. It is as they suspected, the baby has an extra 18th chromosome. Trisomy 18. As you can imagine this was the worse case scenario. She said that the only thing the final results will show is whether this was spontaneous or if there is evidence that it might occur again in a future pregnancy. There is a lot of information on the web about this disease. Just google Trisomy 18 if you want to learn more. The odds of this occurring are 1 in 3,000. Leave it to me to be that 1.

I can't begin to tell you how we feel. Right now we are just numb. The genetic counselor couldn't really tell me what to expect. The baby could stop breathing in the next few days, it could take weeks or it could go all the way to term. From everything I have read, if the baby happens to make it to term they rarely live more than about 5 days. A few live as long as 6 months and there are only about 10 reported cases of children living into their teens (although with many physical and mental challenges). The one thing we did learn is that at this stage whether we chose to terminate or if the baby dies naturally the only option is to induce and I would have to go through labor to deliver the baby. The thought of that tears me apart.

Mike and I are going to spend the weekend alone on the boat. Obviously we have a lot to think about. I am sorry to sound bitter but this whole thing seems so unfair. I hear stories every day of terrible parents beating and neglecting their children and we are faced with this. Frankly it makes me as mad as hell. I am trying not to question God but how can you not when you face this type of challenge. My faith has always given me such comfort so I am trying to find a way to hold onto that.

Thank you again for all your love and support. Without that, this whole thing would be so much harder.

Jean and Mike

8/13/07

Michael and I spent all weekend thinking about what our next steps would be and it comes down to this.. This is not just a baby, this is our daughter. That's right. Along with the horrible news we got on Friday we found out that it is a girl. Neither one of us could think of terminating this life regardless of the apparent challenges she has and when she is born she will be christened Madelyn Grace.

We both feel that God has gotten us this far and so we put our faith in him that he will know the right thing to do. We are hoping he will bless us with more time with her but we are willing to take it week to week. At this point we will have weekly visits with our Dr. so that she can confirm the heartbeat. I begin my 16th week tomorrow. If we are lucky enough to get close to term we will discuss next steps but for now we are just concentrating on getting to next week and then the week after that etc.

We know that some of you may not understand this decision and believe me when we first got this news I was convinced that there was no way I could carry a baby to term that I knew was not going to survive. That has changed however by thinking of her now as Maddy and not "the baby". In addition all the testimonials that I have read of parents that have gone through this have said that they never regretted their decision to continue regardless of the short time they had with their child.

Please continue to keep us in your prayers.

8/17/07

We had another appointment this morning to check for Maddy's heartbeat and not only was it there but was "strong and normal" according to Dr. Levitan. I can't tell you how relieved we were. It is so hard at this stage to know if she is OK day to day because I can't really feel her move yet. We are going to go in weekly until that happens just to check.

Our doctor was great. She said that she fully supported our decision and gave us several things to think about for the future of the pregnancy. She said that we could come in as often or as little as we want, she would order an ultrasound whenever we wanted one and that she would ensure that we were able to be seen as the first appt. of the day so we didn't have to wait around in a room full of pregnant women.

Her only concern was that if the pregnancy gets to a point that it starts putting my life in danger (like with preeclampsia) she would strongly encourage us to deliver early. We told her that we agreed with that decision. As much as I want to give Maddy every opportunity it would be hard to justify taking that risk given the situation.

We are so thrilled to have some more time with Maddy. Mike said that she was strong and a fighter. I said all the women in my family are so of course she is. We know that we may have months with her or as little as days or weeks but we are just grateful that for today she is still with us. We will take whatever we can get. I have to say that it was nice leaving an appointment with nothing but good news for a change.

Hope you all have a good weekend.

8/24/07

This little girl appears to be as stubborn as her mother. We just got back from the doctor and are happy to report that Maddy's heartbeat is once again strong and normal. The doctor was also encouraged when I told her that I am starting to feel Maddy move. She said that this was evidence that the hygroma had not affected her vascular system and that our chances of getting closer to term just went way up. We were thrilled. That may sound a little silly but to us it means more time with her. The other good news is that my blood pressure was down to normal this week. It had been a little elevated the last few times. Normally it tends to run low so she had been a little concerned.

Just wanted to share the good news. Hope everyone has a good weekend.

8/31/07

We had another appointment this morning with Dr. Levitan and true to her spirit, Madelyn showed a heart rate of 130! Normal ranges from 120 – 160 so she falls just right. Once again it was a good day. There has been a lot of activity this past week. I am really starting to feel her move now. It is the strangest sensation and makes me smile each time it happens. It is like she is announcing, "I'm still here, don't give up on me yet." I can't wait for the day that Mike can put his hand on my stomach and feel it too.

We have decided that we will not go see Dr. Levitan now for 4 weeks unless something happens. She feels confident that this should be fine. At that time, we will be having another ultrasound to gauge the progress of the hygroma and hydrops. We will of course send an update once we get the results.

All in all I am feeling good. The tiredness comes and goes and I am now in the phase that I am eating everything in sight. The good news is that my weight gain is not out of control considering how often I am eating. The hospital where we plan to deliver has a Patient Care Coordinator service that we have been in touch with. They will be able to help us develop our birth plan. There is so much to consider such as whether I would want a c-section, what level of medical intervention do we want them to take with Maddy, arrangements for services such as a baptism, what their infant hospice program is all about, etc. It is nice that there is a group to help guide us through these decisions. The truth of the matter is that we need to make these decisions fairly quickly just in case something happens. Although it is difficult to think about I know that we would rather have that all taken care of so that when she is born all we have to focus on is spending what little time we will have with her and not planning the next steps.

I hope you all have fun plans for the holiday weekend. We will be spending it on the boat enjoying the beautiful weather.

9/17/07

Hi all,

It has been several weeks since I wrote and I guess you could say that no news is good news right? Our next appointment is next Friday. We are going in for an ultrasound to see if the hygroma has gotten any bigger. Dr. Levitan said that that will give us a better sense of whether Maddy will make it to term or if she will be still born. While we would love to go in there and find out that it had dissipated, we are really hoping that it has just not gotten worse.

I met with the patient care coordinator (Sue) at the hospital last week and although it was a much more emotional discussion than I expected, it was very helpful. She helped me think of several things that had not occurred to me. I told her that we were just trying to enjoy the pregnancy with Maddy since we were likely not going to have a lifetime with her. Her response was to say that this is Maddy's lifetime; it is just not the traditional one that everyone tends to think starts at birth. We had never thought of it like that but we will now. She was so understanding and compassionate and we are grateful to have her help through this process. Michael and I are discussing our exact plan but here is what I can share with you for now.

The plan is to deliver at Abbott Northwestern Hospital in Minneapolis. They are one of the best in the city and happen to be right across the street from a renowned Children's hospital which gives us easy access to top neonatal care if needed. The other bonus is that it is connected via skyway to my office so if I should go into labor at work I am only a short distance away not to mention all the nurses I work with that would be here to help.

We will be having a consult with the head of Neonatology in a few weeks just to go over what to expect. When Maddy is delivered (assuming that it is a live birth) we will have them do an assessment right away to confirm the diagnosis. The delivery room has a fully equipped NICU assessment room right next door.

We have decided that we do not want to take any extraordinary measures like a feeding tube or a breathing tube. They will give her a few puffs of oxygen if she needs help getting started but we feel strongly that we should let nature take its course.

We will have her baptized as soon as possible and would like anyone interested to attend and witness this event.

In addition to the hospice program at the hospital, there is also a home program if we are able to bring her home with us. This thought had never occurred to us I have to say. We were not preparing to bring her home. When I asked at what point they would send her home with us (If she survives 5 days 10 etc.) I was shocked to hear her say 2! We love the idea of possibly bringing her home but it is certainly scary. I have to say if she shocks us all and survives beyond all expectations we will be so unprepared as far as baby supplies go but we will be happy to deal with that type of stress.

The counselor also told us about an amazing program that is done through local photographers. They volunteer their time to come to the hospital and take remembrance photos of the baby and our family. It is a totally free service and is supported through donations. Apparently this service is offered nation wide and in several other countries. If you would like to learn more, their website is <http://www.nowilaymedowntosleep.com> I warn you, have tissues near by if you look at it. The pictures are beautiful and I can't believe that they do it for free. We would pay anything for this. They also do maternity pictures which we are going to look into.

We still have not decided if we want to have a formal memorial service for her as well as will she be buried or will she be cremated. We welcome any input into this decision that you want to give us. We realize that we are not the only ones going through this and want to be respectful of other peoples wishes.

That is what we know for now. Maddy has been very active the last few weeks which just makes us smile. She either loves or hates when we Mike drive us around on the boat because that is when she tends to move a lot. The same thing holds true for when I eat spicy food but since I love both I am choosing to believe that she does too. She also appears to be growing because I have had to go out and purchase maternity clothes in order to have something to wear to work.

We will let you know what happens next Friday. Please keep Maddy in your prayers.

9/26/07

The following is an email that was sent to me by a co-worker following a baby shower that was thrown for us.

Hi Jean,

I hope you had fun today! We knew there were tears, but hoped that laughter would dominate.

I wanted to share with you the email that we sent out with the invitations to the shower so you know what information we shared with everyone.

I hope you know that you are SO special to so many people!

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From: Johnson, Amber J - Excellian  
Sent: Thursday, September 13, 2007 2:54 PM  
Subject: Shhh... Surprise Baby Shower Potluck!

As many of you know, Jean Carlson, our fellow Excellian Support Team member, is expecting her first child, this winter, to be named Madelyn Grace. Unfortunately, this happy event has been shadowed by the heart breaking discovery that Maddy has a fetal genetic condition called Trisomy 18. Jean and her husband, Mike, have decided to continue the pregnancy with hopes that Maddy will at least make it to full term. To learn more about this rare and serious condition please refer to the following link: <http://www.nlm.nih.gov/medlineplus/ency/article/001661.htm#Definition>

Jean has been the mastermind behind countless Excellian baby showers over the last two years. So, as you can imagine, we want to do something for her to support her throughout this challenging time and help Jean and Mike celebrate their daughter, Maddy. You will be receiving a non-descriptive invitation to a surprise baby shower potluck for Thursday, September 27th from 11-12:30 in conference room 441. If you will be contributing to the potluck please let Mariann know what you will be bringing. Food can then be set up in Conference Room 441 between 10:30-11:00 on the 27th.

Sadly, Jean and Mike are not preparing their home for the arrival of a new baby so they will not need traditional baby shower gifts. However, if you would like to give Jean a shower gift, but are not sure what to do, here are some options...

Madelyn Grace Fund – Starting next week, donations to the “Madelyn Grace fund” will be accepted at the US Bank office located on the ground level of the Commons for medical, memorial or other expenses that Jean and Mike will incur. Please stop by Mariann’s cube to sign the card if you choose to contribute to the fund. Mariann will also be sending out information regarding the ability to contribute to the fund via the web.

Special Gift Contribution - Mariann will be collecting donations to purchase a few select gifts for Jean including a personalized baby blanket for Maddy and a mother’s pendant. If interested, please stop by Mariann’s cube to contribute and sign the card by Friday, September 21st. Any extra funds collected will be allocated to the Madelyn Grace Fund.

PTO - Jean will be taking a leave after the delivery of Maddy to recover. Short term disability only covers approximately 60%, but can be subsidized with PTO. Since she does not have an over abundance of PTO, you can donate some of yours, using the PTO Donation Agreement form and then stop by Mariann’s cube to sign the card. <http://idoc3/content3/groups/public/documents/forms/ptoagree.pdf>

Pampering Gifts - Personal gift items for the expectant mother; could include pampering items like scented bath and body products, candles, etc...

Please forward this invitation to anyone we may have missed and if you have any questions please contact me, Mariann Opsahl or Paula Halbach.

Thank you!

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9/27/07

I wanted to let you know that we are going in for another ultrasound tomorrow morning. The purpose is basically to see if there is any change in the abnormalities. A good visit would be that the hygroma has not gotten any bigger. A great visit would be if it has shrunk.

Dr. Levitan said that this will give us a better idea of what to expect as far as the duration of my pregnancy as well as if Maddy will be stillborn or not.

Please keep Maddy in your thoughts tomorrow. I will send an update when we know more.

I also wanted to share something that happened at work today. My co-workers threw me a surprise baby shower. I was floored! I didn't think it was possible to have one without it being a sad event but they managed to make it a wonderful experience. I have attached the email that was sent out inviting people to the event. It is very well written. We received some wonderful gifts which included:

A wonderful gold necklace with a pendant of a mother and child.

A gift certificate for maternity pictures with a great local photographer.

A frame with a place for a picture and a clay handprint.

A keepsake ornament with a place for a picture inside.

A baby blanket that has Maddy's name on it.

Several people donated PTO (paid time off) so that we don't have to worry about taking the time we need after she is born. I only had a small amount accrued (about 3 weeks) and short term disability only covers about 60% of my salary for 4 weeks. This is a huge gift.

They also set up a fund at a local bank (US Bank) in which people could donate money to the Madelyn Grace Fund. We plan to use this money for the many unexpected expenses that I am sure we will face.

The shower was a blend of tears and laughter which was perfect. To quote Truvy from Steel Magnolias, "Laughter through tears is my favorite emotion." They even arranged for Mike to attend as well as some of my friends from my former job. It was a wonderful experience and a memory that we will always cherish. I work with some amazing people.

Well that is all for now. I will let you know what happens tomorrow.

9/28/07

I wanted to give you an update from my appointment today.

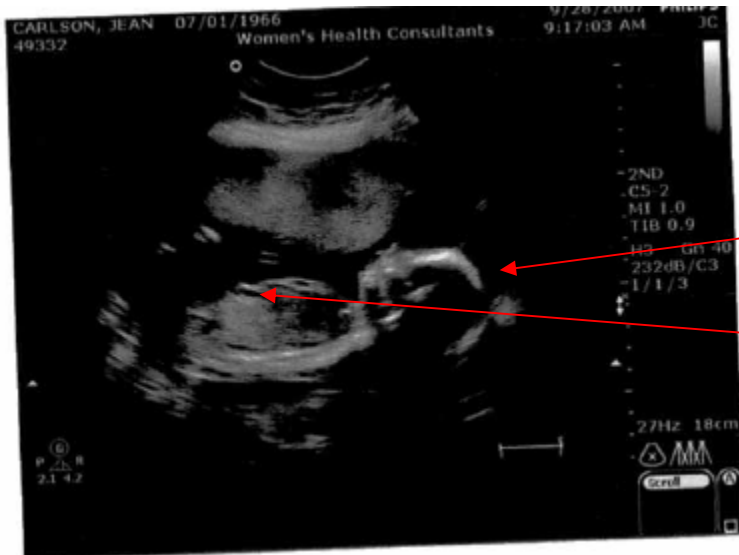
We had a wonderful, if not confusing appt. this morning. The ultrasound went really well. We went in hoping that the hygroma and hydrops (pockets of fluid around her body and heart) had not gotten any worse. Our best case scenario was that it had shrunk a little. What we were not prepared for was when the technologist said (and our Dr. later confirmed) was that there was NO evidence of either. We were floored. It was like it was never there. In addition, the tech had difficulty finding the abdominal defect. She brought our doctor in and they both went back and forth. The tech says she could not see it and Dr. Levitan said that she could see it but it would be considered minor by her standards.

What does all this mean? Well the biggest thing is that Maddy's chances of going all the way to term just got even better. Without the hygroma and hydrops putting pressure on her heart it is free to beat on. Her heart rate today was 146! That is up from 130 when we went in 4 weeks ago. To quote Dr. Levitan, this is good news but you can't argue with chromosomes and they still showed that she has Trisomy 18.

We are thrilled with this latest good news but we know that there are still battles for Maddy ahead. Unless there was some kind of lab error (very unlikely) we are still facing a short time with her. The other piece of news was that it did appear that she may have club feet. While to many this would be devastating news, we were like, "is that all??...that's nothing that can't be fixed if we had to."

We can't explain what is going on other than to say that someone is watching out for her and that she is tough. If she is not giving up, then neither will we!

Please feel free to pass this on to anyone that may be interested. I am also including her latest portrait. Isn't she cute!



She is lying on her back with a profile view.

Head

Stomach



This view is very similar.

10/18/07

Mike and I met with the head of Neonatology at Children's this morning to discuss Maddy's birth plan. He was very compassionate to our circumstances. He reviewed our chart and was also a little surprised that we couldn't find any evidence of Hydrops any longer. He said that he had never known that to just go away. We just nodded and I thought, "Well you have never met a baby like Maddy before either, she is full of surprises."

In addition to my doctor we will have someone from Neonatology on call for the delivery. We confirmed that when she is born she will not receive any "extra ordinary" measures like a feeding tube or breathing tube. They will confirm the diagnosis (visually) after she arrives. If there is no clear evidence of Trisomy 18 they will do additional genetic tests on her to confirm it. They will wash her and give her oxygen if needed, wrap her up and then she is all ours to hold. We will give her fluids if she can swallow but nothing beyond that. At that point we will just wait for her to pass naturally. There is no way to tell how long she will have and there is even a chance that she might not make it through the delivery. We are praying for even a little bit of time with her but are grateful for what we have had so far.

Our next event will not be until November 13th. We are having a 3D ultrasound done. If you are not familiar with these, they give extraordinary images of the baby. In some cases, you can even see the baby's eyelashes. We are hoping that we will see the same improvement that we saw last time. It is hard to believe that I will be 28 weeks along at that point.

These last months are flying by. Physically I am doing well. Just tired at times but overall I am really enjoying the pregnancy despite the circumstances.

11/13/07

I wanted to share the latest update on Maddy. I wasn't sure who to include so I am just sending it to you all and feel free to pass it on to anyone that is interested.

It is another GREAT DAY! Actually we have had a couple of busy days. Last night we went to our 1:1 birth class at the hospital. Our Instructor (Jessica) was great and full of energy. She shared her story of the birth of her first son who had Trisomy 18. He was conceived through IVF after many years of infertility. He went all the way to term and then lived 29 minutes. Hearing all the challenges he had (basically everything on the indicator list) we felt fortunate that Maddy only has a few challenges. We feel much more prepared for what is to come. She is also the photographer that will be on call for us to do the photos once Maddy is born. It was nice to feel that connection with her.

This morning we went in for the much anticipated 3D ultrasound. What an amazing experience! We were thrilled to see that there was still no evidence of a hygroma or hydrops and in addition, the ultrasound tech was convinced that there was no evidence of the abdominal defect either! That makes two techs that said it wasn't there. We were also thrilled to note that there is also no evidence of a cleft pallet and her hands and fingers appear to be normal (although she was clenching them the whole time). We did see clear evidence that her feet are clubbed but as you can see in one of the pictures; her feet are the right shape just not in the right position. If by some miracle the lab test is wrong, that is easily fixable.

I have attached a couple of the best pictures for you to enjoy. She appears to like to lay on her back most of the time which made getting the face shots much easier even though she was continuously on the move. We love her chubby cheeks and cute little nose. Unlike many of the Trisomy 18 babies that the tech had seen, Maddy appears to have a good amount of body fat. These babies tend to lack a lot of body fat.

In picture 45 it appears that her head is misshaped but this is just because the camera could not keep up with her movements. In other shots it looks normal. I think that shot 48 looks like she is signaling "Girl Power" with her fist. Shot 25 shows her foot which you can see does not look normal but does have 5 cute little toes!. Number 13 looks like she is contemplating deep thoughts. I hope you enjoy looking at them.

Her heart rate was a little lower today (125) than it normally is but the tech said that could be because she was sleeping. We have an appt. with our Dr. on Friday and will have it rechecked at that time.

Once again we want to point out that although these improvements are great news we still can't argue with the genetic test. We still face a reality where she will not survive but we see each of these positive outcomes as another chance that she will have just one more minute of life. We are so grateful for every second with her and I really feel like I am getting to know her personality. She appears to like spicy food, rocking in a chair, the cat on my lap purring, and lots and lots of bread! (or is that just me?)

That's it for now. We will give you another update after our Friday appt. Keep the prayers coming..



11/16/07

We met with Dr. Levitan this morning and got more good news. Maddy's heart rate is back up to 140. In addition, she is measuring as a 30 week baby (I am nearing the end of my 29th week). This was amazing because she had been measuring anywhere from 1-2 weeks small since about 12 weeks. When she was measuring me she got this puzzled look on her face and repeated the measurement 3 times. I said, "What now? How small is she measuring?" Her reply was, "30 weeks. I don't understand this. You have me puzzled." She went on to say that all along she really didn't expect me to be pregnant at Christmas time but now it looks like that is definitely going to happen.

We told her about the 3D results and she said that she took another look at the last US and agreed that the Omphalocele was not there. The only explanation she gave was that it must have been a misread to begin with. I find it funny how they were all so convinced for weeks that it was there and now they are saying it was just a mistake. Misread, miracle.. We will take either.

I have to say, it is very hard for Mike and I not to get excited that it might all be a big mistake. Frankly we just can't go there. It would lead to heartbreak all over again.

The other piece of good news we got is that I passed my diabetes test with flying colors this morning which means I don't have to go in for the dreaded 3 hour test! I know, surprising considering how many diabetics we have in the family... Apparently my hemoglobin levels are right in line as well (although I don't really know what that means )

At this point we will be going in every two weeks for about the next month and then once a week until delivery. Stay tuned for further updates.

Have a great Thanksgiving holiday everyone.

11/30/07

Good morning everyone. Mike and I had another successful visit with Dr. Levitan this morning. Maddy is growing normally and her hear rate was up to 160 today. That is the highest yet. Normal is 120-160. She is very active which is also a good sign.

We also talked to the Dr. about traveling if we need to come down there for mom. She said that it really came down to our comfort level both physically and with the possibility of delivering in a strange hospital. Physically she said that I would likely be fine if it happened in the next month or so. Obviously the risk gets higher as I near my due date (Jan 28th).

I am really struggling with this because I want so much to be with mom. If this was a "normal" pregnancy or I wasn't so close to my delivery date, I wouldn't hesitate but that is not the situation. Given our diagnosis, the thought of delivering in a strange hospital where I haven't met the staff and won't have access to the support group (care coordinator, photographer, our Dr., etc) we have put together is a little uncomfortable for both Mike and me. If we are lucky enough to bring her home, we would be traveling a long distance with a sick infant without the support of our hospice group.

I would love to hear what you all think about this. I know mom would say, "Don't come, I understand" but I am looking for some other insight or options here. Dr. Levitan did say that she was going to have the hospital and clinic put together a copy of my records so that I can bring them along just in case. She also said that there was no real difference between driving and flying. Either way, if we were going to make a trip we would need some notice just because of the distance so please keep that in mind.

My instincts tell me that it will all work out and the Maddy will actually be late. I had a dream she was actually born on Patrick's Birthday. However, I would like to have a plan B in place just in case. Please let me know what you think and Mike and I will talk over all of our options.

Have a great weekend,

12/14/07

Hi everyone,

We had another successful visit with Dr. Levitan this morning. Maddy is measuring at a little over 32 weeks which is about right. Her heart rate was 145 so she is strong as ever. We continue to be amazed by her progress and thankful for every kick and movement. I am feeling good but getting to the stage where I can't put on socks or tie my shoes.

We will see Dr. Levitan again in 2 weeks and then we go to weekly. Strange to think that on Tuesday we will only have 6 weeks to go!

Another thing I wanted to share was that our care coordinator at Abbott (Sue) has been laid off. She has been so instrumental in helping us put together our birth plan. She was the one that said, "This is Maddy's lifetime." We were devastated. However, amazingly she has asked for special permission to still be present at the birth to help coordinate things for us. She has given us her home and cell numbers as well as email address. This is really above and beyond if you ask me. This info is also on our chart and the other nurses know to contact her. This is just another example of the amazing care we are receiving from Abbott and the Allina Corporation as a whole. I am proud to say that I work for this organization.

Hope this finds you all well. Have a good weekend.

12/28/07

Mike and I went to see Dr. Levitan again today. Maddy's heart rate was still up around 140. She refuses to give up. She doesn't appear to have grown much since my last appt. 2 weeks ago but the Dr. estimated that she is probably about 5 ½ to 6 lbs which is actually on the large size for a Trisomy baby. They are generally 3-5 lbs. Her movements have changed as well. No longer is she doing summersaults as she is running out of room. I still feel her move but not as strongly and not as often which can have a tendency to freak me out at times I have to say. The doctor said that this is actually normal and that activity does tend to decrease with Trisomy babies in the last trimester.

We talked about induction and she said that unless I develop preeclampsia we won't look to induce until 41 weeks. We start to see her every week at this point and will just take it day to day. I am feeling great and other than the occasional bout of insomnia, all is well. Thank goodness for our DVR. Lots of recorded shows to watch at 2 am.

Hope you all have a great weekend.

1/4/08

Another good appt. today. Heart rate is 140 again and no signs of early labor. She still has not grown much but that is to be expected. They still think she is around 5-1/2 to 6 lbs which is fine with me. I have no desire to give birth to an 8 lb. baby.

I am wrapping things up at work "just in case" I end up going early. The official due date is 1/28.

On another front, my mom is doing well considering. She continues to have good days and bad but the hospice nurses have done a wonderful job of regulating her pain meds enough that she can still get out and about occasionally. My siblings have been down there with them full time since November. Mom swears that she is still planning to be up here when Maddy is born even if they have to hire a nurse to travel with her. And you wonder where I get my stubbornness from?

We are meeting with our pastor on Tuesday to discuss Baptism/Memorial services so I will let you know what we decide about that.

Hope everyone has a great weekend. More later.

1/14/08

Hi everyone,

Sorry I didn't get this out on Friday but it was a busy day. Another good appt. with the Dr. on Friday. We actually had to see a different doctor because ours was out of town. We were fortunate to see Dr. Kilburg who helped us with our procedure following our miscarriage last year. She is very nice.

Maddy's hear rate is still at 140 and beating like a champ. The doctor was a little concerned that I haven't gained any weight in the last few weeks and told me to "eat more". Never had that happen before. No real signs of labor but she said that I am progressing. Likely nothing will happen in the next week.

We have an appt. with our Pastor this afternoon to discuss Baptism and Memorial plans. We have had to reschedule a couple of times because she had an emergency with her mom. Give what is going on with my mother I fully understood this. This is something that we have needed to do for a while but I just couldn't bring myself to call her about that particular subject.

Hope this finds you all doing well. More next week.

1/18/08

Email from Paula re: Jean Carlson:

This is not the update you were all praying to receive from me. Jean called me a short time ago with the sad news that Madelyn Grace (Maddy) was not granted the opportunity to enter this world as we all hoped and prayed for.

I'm sorry I do not have any further details at this time. When I learn more by talking and seeing Jean later today I will update you again.

Please keep Jean and Michael in your thoughts and prayers today and as they grieve the loss of their daughter. As my aunt told me and Jean, they now have their own "little Saint" to pray to for all their needs.

1/21/08

I know that you are thinking what are you doing? You just gave birth a few hours ago and you are already checking email. Are you crazy? Perhaps, but this night has been full of adrenalin for us and I just had to share the story before I fell asleep.

Maddy was born Sunday evening at 8:45 pm. She weighed 3 lbs 9.8n oz. She was 16 inches long and her head was 11 1/2 inches big. She doesn't look like your typical newborn but of course we think she is beautiful.

The 2 days of labor were actually very manageable until this afternoon when I started getting really bad back labor. I said YES to IV drugs that just made you feel yummy and then soon after an epidural which was not easy to put in but wonderful once it is there. Things moved slowly most of yesterday and today but picked up quickly this evening. At 6pm I was only at 6cm. About 45 minutes later I was at 9 and they were calling the Dr. the Care Coordinator, the photographer and our Pastor. She hung around for 2 days but then when she was ready she came quick.

As you can imagine the hardest part was being wheeled into the delivery room. I sort of lost it and my BP spiked up to about 165 over 90. Thank goodness 2 of my sisters and Michael were there to talk me off the ledge. The actual delivery was easy because I only pushed 5 times and she was here. She has spoiled me for my future deliveries. When they laid her on my stomach she was so heavy and so warm. It was the most incredible moment of my life. Michael was able to cut the cord and helped to celebrate her birth. My sisters know me like no one else and when I got back to my room, my niece handed me a super sized Diet Coke. It was liquid heaven. I think I have had about 3 gallons of liquid since returning to my room. Ice chips just don't do it.

We started right away with the pictures and the photographer was so good. She and the care coordinator Sue (who was actually laid off last month) worked like a well oiled team. They quickly had footprints and hand prints on her birth cards and she was dressed in the first of several outfits. She is a girl after all. After we applied her "bling" that her aunts gave her (necklaces and a bracelet) we went downstairs to the chapel for her Baptism and more pictures.

Pastor Wayne was there to perform the service because Pastor Carol was out of town. This weekend was the first time Mike and I had actually met him and he was wonderful. He offered so much support and prayer and it was truly a blessing. The baptism was so wonderful and Maddy looked beautiful in the Baptism dress that has been worn by every generation of my family for the last 50 years. She was wrapped in her pink Madelyn Grace blanket that we got at the the shower and she just lay in my arms through the whole thing.

Then it was upstairs for a few more pictures, clay molds of her little feet and hands and alone time with Mom and Dad. As you can imagine this has been the most wonderful and hardest day of our lives. We will spend the night with Maddy tonight and then send her on to Heaven tomorrow. I don't know how long I will be admitted but it is likely that I will be here one more night.

We will be having her memorial next Saturday at Pilgrim Lutheran Church in St. Paul. We don't have the specific details until we work it out with the church ladies tomorrow. I will send it out when I know more. All are welcome.

Thank you so much for the beautiful flowers. If you would like to further honor Maddy we ask that you forgo the flowers and make a donation in her name to the Now I lay Me Down to Sleep group. Here is their website:

<http://www.nowilaymedowntosleep.org/start.php>

Well that is it for now. Thank you to everyone that has helped us through this process. We could not have done it without you all. Please feel free to pass this on to anyone that you would like to.

Jean and Mike