



∞♥∞

Chapter 14

Thirteen Months Old

PICU Abdominal Issues & PCU Thanksgiving

♥ November 17, 2005 at 11:15 AM CST

Aunt Becky here with some news from the "Blake" front. As you know Blake is still in his own room at TCH which requires 24 hour parent supervision.

Unfortunately, Kimberly started feeling ill on Tuesday and had to leave Blake's side for a while. Grandma Mary was at the hospital with Blake that day. When it became clear that Kimberly was not getting better, Chad was called in from Austin to be with Blake so Kim could go to Santa Fe and recuperate. She seems to be feeling better with the much needed rest and TLC from Mom and Dad. She'll be heading back to the hospital today as Chad needs to go back to Austin for a big work day tomorrow. Please keep them all in your prayers.

On a good note, there seems to be more positive talk of a discharge within the week. Keep your prayers focused on Blake's ability to stay germ free so he can leave the hospital and hopefully be home before the holiday rush.

One last quick reminder-- The Blake's Buddies Benefit Dinner, Silent Auction and Golf Tournament are this weekend. We're hopeful that the weather will be cooperative and give us a great golfing day. Then later that evening, we're looking forward to meeting and greeting all of you faithful Blake followers at the dinner and silent auction.

In case I don't get to speak with you personally this weekend, I just want to offer you my most sincere Thanks and praise for all of the devotion you have shown to Blake and his family. It warms my heart like you can not imagine knowing that Blake has so many caring people in his life.

Take care and I hope to see you this weekend.

Aunt Becky

♥ November 20, 2005 at 01:29 PM CST

Greetings to you all. Blake has had a change in his status since you heard from us last. He was moved to the Pediatric Intensive Care Unit (PICU) on Friday AM. Last week his abdomen began swelling more and more, which makes it difficult for him to breathe. He began struggling even more on Thursday night and his abdomen began to look worse-swollen and discolored. Friday AM, Blake was transferred to PICU. Friday he had 300cc of fluid drained from his abdomen, but it made no change in his respiratory status. He continued to have trouble breathing, because the pressure of the fluid was constricting him.

Saturday he had to be intubated and he was taken again to have his belly drained and a drainage tube inserted. As soon as the drainage tube was placed 575cc was released. An additional 300cc was drained in the room and the tube was clamped, because his blood pressure dropped. Blake's electrolytes and blood pressure have been watched very closely, because of all the fluid that has been drained. They weren't able to drain more fluid until Sun. (500cc) It has been clamped again because his blood pressure dropped significantly, but is now stable. Blake is stable on the ventilator. The doctors are working to find the reason for this fluid build up???? Today the thought is it could be a CLOT?? Another abdominal ultrasound is scheduled for today. IF it is inconclusive a CT will be done.

I am crying out for your help in PRAYER. I don't know what to think anymore. I am scared and continue to need your help. I love you all and hope to have better news in the next few days.

Thank you all for a successful benefit yesterday. Chad and I wish that one of us could have been there to thank you in person, but Blake needed us both here. We have the most incredible and AWESOME family and friends. We can not **THANK YOU** enough.

LOVE,
Kimberly

♥ November 21, 2005 at 05:33 PM CST

Monday Report... I wanted to send out an update this afternoon, though we don't know much more than yesterday. The cardiologists have scheduled for Blake to have a heart cath. tomorrow at 10:30 am. to see how Blake's heart is functioning. The echocardiogram from this weekend showed similar heart function to the last echo., but this heart cath. will give them the most accurate information. We are not sure whether Blake's abdominal swelling is primarily heart related or something else. Tonight Blake will have a CT scan to look at all the primary blood vessels to look for clots or other problems.

We are hopeful that answers will come soon, and that we can get Blake back to that happy place again... Thank you all for the continued prayers!

♥ November 22, 2005 at 07:41 PM CST

We do not understand it...but we'll take it! Blake was taken up to the 18th floor this afternoon for a heart cath. to look inside his heart and take pressures in each area of the heart. This cath. would tell us if there was any part of the heart that was not functioning well and may be causing the swelling due to fluid around his abdomen. The cath. took four hours and the results showed conclusively that Blake's heart is functioning well. Not great...but good. Blake will not need any kind of heart surgery again, if ever. But we did not get any answers as far as what is contributing to the swelling. Included in his cath. session, the cardiologist drained some of the fluid around his lungs with two small chest tubes. We were relieved to hear that the heart was doing well, but also somewhat concerned for Blake as a whole.

Then when Blake was back in his PICU room and we could see him again...we could see a dramatic difference in him. His belly was relieved of much of the swelling, his pressure was much better, and his color was better. He looked much better! We are hoping this is not

short lived and we return tomorrow to find the swelling back. It was hard to believe or understand that anything the doctors did during the heart cath. could have caused such a change. Like I said above...we'll take it. The cardiologist thinks that the swelling may be from Blake's slow recovery state caused from all the health issues Blake has faced in his ICU from birth. We pray that Blake is turning another corner and that things will start looking up. Please God.

Though we are somewhat discouraged from the past week and Blake's set backs...we know that we have lots to be Thankful for. We are blessed with a wonderful, loving family...and extraordinary friends. We hope everyone has a great Thanksgiving! Please take time to appreciate all the blessing in your own life...and if possible, help someone who really needs it.

We love you all!

Chad & Kimberly

♥ December 01, 2005 at 09:04 AM CST

Good Morning All. Hopefully this sunny winter day will be the last time Blake has the breathing tube in. The plan is to extubate Blake later this morning and see how he reacts. Over the past several days Blake has been breathing over the ventilator quite a bit. Blake will have gotten two steroid shots to boost his system before they try to take away the tube. He will still need the nasal canula, but he will be so much more comfortable if we can get the tube out. Hands in the mouth...Larry the Lizard (pacifier) ...rubbing his new teeth...life will be good. Please keep Blake in your thoughts and prayers this morning as he faces this big change.

Blake is back on full feeds, with slightly less volume than before. His belly is having small amounts of fluid being drained off, but has stayed down with the increases in formula the past days. We hope that this pattern continues. No clear reason surfaced for why the fluid came on so aggressively after the heart surgery. This is good in

Rainbows For Blake

some respects as no particular organ was in distress...but concerning still as that it could potentially return.

We also wish to pass on a sincere thank you to all who supported the Austin Benefit. Blake is so fortunate to be loved and prayed over by so many... We really wished Kimberly or I could have attended so that we could thank you all in person. We appreciate all the generous support and hope everyone enjoyed the day as much as we heard from some of you. Thanks! And for all of you that planned the event for months...we love you! "It's all about love..." as Pastor Fetter so eloquently spoke. Special thanks to our families who spent countless hours planning and executing the events. You continue to astound us! We are so lucky to have such caring support around us. We love you all!

Well, we will face today like every other day...not sure of the events ahead...but ever hopeful in small improvements and good days ahead. Here's to a good sunny day...

Chad

P.S.- Happy 40th Birthday to our good friend James Hoffmann.

P.P.S.- Congrats to the Stapletons for their healthy baby Cameron McKinney.

P.P.P.S.- Belated Birthday wishes to Becky and Gregory Kramr.

P.P.P.P.S.- Much Belated Birthday wishes to my 'lil sis' Sasha Thompson & Grandpa Kramr & Lee Ann Hoffmann!

P.P.P.P.S.- everyone get back to work!

♥ December 02, 2005 at 03:24 PM CST

Good Afternoon to you all, TGIF!!!!!!! Blake has done very well off the ventilator. Praise the Lord!! He slept well through the night. I was able to hold him yesterday and today. I sure enjoy holding my son and I hope he enjoys being held.

He has been a little fussy today. The docs are weaning him off the 'Happy Medicine' plus he has had secretions that he just can't cough up by himself. Blake looks great overall, his belly looks normal in size and he is back to smaller diapers! He still has the drainage tube from his belly, but is draining minimal. We hope it will come out soon. The docs started his feeds back today, not yesterday. He is eating continuously 40cc/hr. Hopefully he will not have trouble with the feeds. The talk is to transfer him back to the regular floor PCU (progressive care unit) tomorrow if a bed is available. We would like to get him out ASAP so Blake doesn't catch any bugs.

Thank you again for being so involved in our life. We truly are blessed to have so much support for our son. I hope everyone enjoys their weekend. Watch the crazy Christmas shoppers.

Love,
Kimberly :)

♥ December 09, 2005 at 05:25 PM CST

Hello to you all. We are so sorry we haven't been able to update you, but we have been busy. Blake was moved to the PCU (progressive care unit) last Saturday. I have been able to do more things with him.

The doctors are anticipating discharge next week, but I am staying neutral. He has been doing well with weaning the oxygen to 1L nasal canula. The problem we are having today is gagging and reflux. He hasn't tolerated his feeds very well, so the new strategy for this evening is feed him every 4 hrs, but feed 115 cc over 2 hrs. I am crossing my fingers this works, because I can't stand to see him gag and vomit.

Yesterday we did have a milestone of eating applesauce and milk with rice cereal. It's like the light bulb came on and he went to town with the spoon, rooting for it too. I wanted to try today, but didn't want to push it. The drainage tube was removed from his abdomen yesterday. The great news is the ascites or fluid in the abdomen is not returning!!!!!! We hope he continues to move forward

Rainbows For Blake

not backwards. Thank you for your continued thoughts and prayers. Please pray for a safe return for Chad, he is in Santa FE, New Mexico for work. He will return to Austin on Sat.

Thank you. Stay warm

Mommy Kim:)

♥ December 14, 2005 at 09:31 AM CST

Happy Holiday Season to All! Daddy is back in the saddle after a work trip to New Mexico. Kimberly laughs as I call it 'work', since I'm so fortunate to be doing what I love to do and that hardly makes it seem like work some times. After returning home to Austin Saturday night, I got up early Sunday to join Kimberly and Blake in Houston. I'm afraid I'm wearing ruts in the road between Austin and Houston with all the trips back and forth. As with most trips...getting there goes much faster than returning home.

We are hoping and praying that we will all be coming home before Christmas or the New Year. But what is most important is that Blake is stable and feeling good again. The current focus for Blake is getting the regular feedings he's receiving through the feeding tube to a proper amount for his nutrition. Yesterday the doctors adjusted to a new formula as Blake was still on the infant formula which requires more volume for the same nutrition. We're crossing our fingers and toes. Its not pleasant watching our little boy retch and reflux so much. It's keeping him from relaxing and resting as much as he needs. And if Blake is not resting well...then Mommy can't rest much either. Prayers for improvements in these areas would be greatly appreciated.

We have made more special friends at Texas children's Hospital. Dr. Stein has made a big impression on us. He has taken special time to listen to Mommy especially and include her thoughts and diagnosis on the current care of Blake. He also shared a wonderful book with us that he co-authored of Art from TCH patients. We will share the pages with you all when you come visit us at home next year.

Dr. Stein also has a special interest in Blake's blindness and inspires us that children without sight CAN and WILL amaze us with their spirit and abilities. Thank God for special doctors like Dr. Stein. You should have 'seen the scene' Sunday evening. After working a 12 hour shift ...Blake's angels (Wayna, Sandra, & Tonya) came up to see Blake from the NICU. They rushed in, straight past Kimberly and I and straight to their Blake-y. Blake was on the floor in his circular pad now with his angels all kissing and comforting him. What a scene...we are so fortunate to have met such wonderful nurses. Another of Blake's Angels, Lori, continues to visit Blake and Mommy when taking a break or after a shift also. There are many others who take time out of their busy days to stop by and check on Blake. We feel blessed to have met such wonderful people in our days...year now...in the hospital. We hope future visits will be in the HCU as we are telling Blake, the **H**ome Care Unit.

I will try to send updates a little more frequently in the coming days to keep everyone informed on Blake's progress. We will not include the H-word until we are actually there. Happy Holidays to everyone...and good luck with the shopping...though the greatest gift is Love. "Its All about Love"

More to Come,
Chad-the-Dad