In Memoriam: For Jacob

An Honors Thesis (ID 499)

by

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Thesis Director

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Dedicated to Jacob James Waggoner, whom I miss very much.

Many thanks to all who have helped me through this, both in the living and the writing of it. Thank you Dr. Adrian, Dr. Johnson, my parents, and my husband to be.
December 15, 1987

BIRTH

One more push, one more! Harder!
OK. . . one more push after this one.
Here he is!
I feel him hit my leg.
He is on my stomach now. Oh, my Beebee.
My smile won’t relax.
The doctor is still serious.
She is taking him to the warmer.
The other doctor is there and they are pumping on him, pushing on him, beating his feet.
Nurses run everywhere, and I watch. Is he OK?
They take him to another room, and I wait.
I don’t know what to do or think.
I am exhausted.
I tell everyone there is no use in worrying right now.
I say a prayer, but I fall asleep before Amen.
December 28, 1987 12:37 am

I am really tired, but I want to start this. My baby is sick. He may die or have severe brain damage. I am really sad. I love him very much.

10:10 am

I named him Jacob James Waggoner. I had him on December 15, 1987 at 11:09 pm. I never knew there would be so much pride involved in being a mother. I get chills just going to see him. I get to say that I am the mom, I love to say that he is my son. But all of this is also very painful because he is very sick.

I don't know where to start. When Jacob was born, he had the umbilical cord around his neck. This doesn't explain all of his problems, but it is the only way I know how to start.

Jacob has been on a ventilator since birth. A few days ago, they did try to let him breathe on his own, but within an hour he was having difficulty keeping his throat clear. I was so disappointed. He was doing so well. The doctor told me if he doesn't start improving soon and fast, we will have to discuss what we will do if his heart starts to slow down. I think I cried on and off for 24 hours straight. If tears weren't
streaming out, I was at least crying inside.

The worst problem Jacob must face is the injury to his brain. That is so ambiguous, I can’t begin to explain. Tests show that his brain does not look normal. Also his electricity patterns are abnormal and involve seizures, and show he needs seizure medication. Dr. E. can’t say if the damage is temporary or permanent, or how severe it is. Also, right now, they can’t tell me how the damage will effect Jacob.

Jacob has a huge bump on his head from the long delivery. We were in labor for 27 hours. I am worried about the bump. Yesterday they did an ultrasound on it. The results will be back today, I bet. Test results are often hard to take. It is kind of like getting back an algebra test you know you failed. You don’t really want it back, but you do want it to get it over with.

I am living at the Ronald McDonald House now. People don’t realize what the function of the house is. It gives a place for parents of sick kids in the hospital a place to stay. I’m really nervous and scared. I’m not sure why, but I feel like my staying here is not going to do any good. I feel like I will be a burden to the doctors and nurses caring for Jacob.
I feel like I will be in the way. I hope I am wrong.

11:58 pm

I saw Jacob twice today. I got to change his diaper which makes me feel more like his mother. Today his poop looked like real baby poop because they have started feeding him. Before, his poop looked like axle grease. Also, a nurse let me give him a bath. I was really nervous about moving him. All of those tubes are so fragile looking. I hope tomorrow will be a good day for Jacob. I feel a lot better when it is. I may ask to hold him again. I haven't since the last time, when I cried. So much emotion is packed into that little guy that when I can hold in my arms, I fear the day that I won't be able to.
December 29, 1987 10:14 am

I'm going to the hospital early today for some good news. I have no reason to expect it, but as far as I can tell, no reason not to expect it either.

Last night they drew some liquid out of Jacob's bump. Maybe today they will know more about it, like maybe there is some secret in that bump on his head, the answer to all Jacob's problems. I hope there will be at least a little good news today.

I keep waiting for Jacob's eyes to open. The first day I saw him, I couldn't believe that he could always be asleep. He isn't asleep like most babies though. He doesn't wake up and cry in the night, and he doesn't move in his sleep. He lies still and breathes. As my dad drove me home that night (Was it less than a week ago?) I cried all the way saying, "When will he wake up? Why doesn't he wake up?"

Now I can't wait till he does. Won't that be nice. We'll show those pessimistic doctors a miracle yet.

Tomorrow will be a big day. My Aunt Linda is coming to visit. My parents are coming, too. In a way I like visitors, but they make me very nervous. I feel
responsible for their grief, their sadness. But right now, I can’t wait to have some company. I feel like I haven’t talked in months.
December 30, 1987

Jacob and I want to stop this world and get off. We are tired of the way things work. It is so unfair that we have to be the ones going through this. We had plans, too, just like everyone else. And we were looking forward to them. Now I have to be the one who decides if Jacob will be restored to breathing when we take him off the ventilator. I have to end the life I am so proud of, so in love with, and so attached to. I also hate the idea of what life is like for him now. He wouldn’t be able to function past his functions now. I hate things this way, but I hate things the other way, too! Will I ever be a happy person again? Will I always have this on my mind? I hate it! Everyone agrees, even me, that not turning the respirator back on is the fair thing. I wish someone would speak up and say there is still one more chance, one more reason to hope. I don’t want to give up this easily.

When Jacob was born and taken to Riley, I stayed in the hospital for five days. I kept remembering wanting to hold him, and the doctor lifting him abruptly off of my belly. I remembered looking into his portable ventilation chamber as all of the emergency team from Riley and my family and friends looked on. I stuck my hand in the gloved hole and
tried to hold his little foot. It had an IV in it. I tried to touch his belly. There were tubes coming out of his chest. I tried to touch his forehead. It hurt to sit up and reach it. His face looked strained and tired. I wanted to cry.

Lying in my hospital bed, I kept thinking of the song, "My little playmate, why don’t you play with me?" Every time I did I would cry. Now "Abide With Me" keeps running through my head. I even sang it to Jacob. Then I gave him a bath and held him tight. I have to enjoy him while I can.

My aunt did visit today, but so did Tom, Jake’s father. We aren’t married. Tom and I aren’t even in love. I used to think that was a big problem. I haven’t really thought about it much lately, though. He was so charming, I thought I was in love, and then he met another girl and got engaged. I think he would have impressed my aunt if she didn’t know what happened to Jacob and me. He got his batch of bad news. I don’t know what he is thinking. I am sorry. I wish I could change it all, too. I love my son very much. Chills.
January 1, 1988 1:30am

Tonight my mom and dad came and played Trivial Pursuit with me in my room. I was so glad they were here. Then my friend Laura and her parents called me. They came to visit me at the Ronald McDonald house. Then I took them to see Jacob, and my parents left. Laura and her mom saw Jacob, her dad waited in the lobby. Then they left, and I rang in the new year with my favorite man.

He fell asleep in my arms.

January 1, 1988 in the morning

Dr. E said we would probably turn off the ventilator today or tomorrow. I said tomorrow. I keep trying to think of what I will do. I can’t imagine what losing him will be like, or what life without him will be like. Will I feel guilty for continuing to live? That’s what I feel now. I know he won’t live, and I feel guilty. I don’t want to live without him though. No other baby will be the same.

What will happen when they turn the machine off? How long will Jake live? What will I do in the meantime? Will he die when I am there? Do I want him to? Will I just show up one day, and they will tell me
he passed away? I don't want to go through this.

Cathy is coming to visit today. I don't know how to act. My parents are coming, too. I want company, but I don't want company, too. I don't feel like visiting and making small talk. I don't want to act happy, or feel guilty for feeling happy. I hate that feeling I get when I have been feeling happy, and then I realize that I have something bigger to be sad about. It is like enjoying yourself at a funeral. When I do show how I feel, I feel responsible for everyone else's grief. I don't want to put anyone through this pain. I would like to shield everyone else from it, too. I have to take it. They don't.

Maybe I should call Tom. I hate to. I don't even want to talk to him. I feel like he is only pretending to care about this situation. I think he is relieved.

If Jacob dies, I am afraid I will feel relief, too. I hate to see Jacob suffer. The other day he had so much trouble when he threw up in his respirator tube. He got formula in his lungs, and they had to change his tube. I felt like I did when he was born. I knew something was wrong, and no one would tell me what. But when I asked if he would be OK, no one would say yes. They went about their duties as though I was
not there. I was sitting there wide-eyed and split wide open after the birth, and they found a way to ignore me. I understand Jacob was the important one. But that is how it is in this situation, too. They just said we would have to wait and see. And we have been waiting since then. I have been just sitting back and watching him suffer.

I wish he would wake up and be fine. A miracle. I hate to see my boy poked and prodded, stuck and tubed. It has to hurt. I feel like he has to work so hard, just to breathe, to stay alive. I don't want to lose him, but I want to see him happy, too. I want to be happy.

I am going to the hospital now. I hope he is still OK when I get there.
January 3, 1988 11:30 am

Today is the day we are supposed to turn off the ventilator. Jacob could die today. He could go on breathing indefinitely. I don't know how to behave. Am I supposed to be crying? I feel so terrible because I am not. In fact, I feel the way I do every day. I can't understand why this is happening to me. What purpose is all of this pain going to serve?

My brother and his girlfriend are coming today. Tom might come, too. It makes me nervous. Andy and Tina haven't been here yet, so I have to prepare them in a way. Tom makes me nervous anyway.

I feel like I should be the only person there when they do it, too. Everyone else has a right, but I feel like I am the closest person to Jacob. That's no reason to be selfish, but selfish is what I am. I want my boy all to myself.

I do need support though. I am just afraid to be myself with too many people around. I feel like I am responsible for their pain, too. I feel like I have to comfort them before I am comforted. It is like when we were waiting for the Riley team to come and pick up Jacob at the Greensburg hospital. I told everyone there was no sense in worrying until we knew what was
going on. I had to take charge to keep my own emotions intact. Just saying it made me feel like it was true. Why do I feel like I have to calm everyone down?

I think the feeling I want to get rid of the most is that I am somehow doing Jacob a favor by not restoring his life if he should die. If I am honest, I am doing it for me just as much as I am doing it for him. I feel selfish in that, too. I don’t want to do Jacob a favor by ending his life. What kind of logic is that? It is like the logic people use when they abort their babies. They say it is the best thing for the child. He wouldn’t have a happy life. He would be poor. He wouldn’t have a father. But it is not the best thing for the child, but for the parents. They don’t have to deal with the baby anymore. They don’t have to deal with the uncomfortable situations. I don’t want to end Jacob’s life for me. But also, every time I think about Jacob spitting up into his respirator tube and stopping his breathing, I feel sick. He was so stressed out after that. He was working so hard just to stay alive. I felt like we were forcing him to stay alive when all he wanted to do was rest. Everyone says he will be going to a better, happier place. Why shouldn’t he go?
Hospitals are so cold, even Riley. I can’t be there all the time, and even though I want to be, I feel like I need to get out of there sometimes. There is so little I can do. I am helpless. I can hold him, I can change his diaper, I can play with his hands, feet, belly, ears, and hair. I can peel off his strips of dry skin has has from the warmer. I can give him a bath. He is like my doll. He doesn’t complain or cry. He doesn’t go anywhere when I set him down. But I can’t stay away. No other baby could make me feel the way my son does.

What makes me sad is when I think of what Jacob could have been. I think of all the things little boys do, all the things they do with their moms, and the way everyone feels about a healthy baby. No one is afraid to hold a healthy baby. People are naturally happy around them. Only an elite few have been able to find happiness with Jacob. Being one of those few makes me feel important.

I am more accepting now. I have tried to give up on trying to reach for what could have been. I try to focus on the way things are. Jacob will always be a baby, I am told. He won’t wake up and do all those little boy things. I am always going to be Jacob’s mom. I love him very much. I hope he fools the world
and defies all logic and wakes up a normal baby. That is probably impossible though. We can only pray for the best for him. We can only hope that somehow he will be happy. I dread today. I hate to lose him.
January 6, 1988

We turned off the ventilator Sunday. When I got to his module, I was so afraid. I knew that Jake could die, and we expected him too. I wasn’t really afraid of losing him. That was just sad. I was afraid of what he would have to go through to die.

We left for a while to eat. Before we left, we noticed that his oxygen hook up was cut in the line. We told a nurse. When we returned, he was almost yellow and his alarm for low oxygen saturation was going off. I was really afraid. They turned up his oxygen, but he continued to have poor color. Later we noticed that the line was still cut. They fixed that, and then he was fine. Just that little incident was horrible for me. I hated seeing him suffer, but I was so afraid of the end coming. I felt relieved for Jacob and me, even though I didn’t want it to end. We are going through so much.

Jake is still breathing three days later. I haven’t seen him yet today, but they haven’t called me yet. Yesterday, his new doctor, Dr. Y, said that I needed to start thinking about if I want to take him home or put him in a nursing home facility. I am so afraid to even think about either option. I think, and
I can't get past the idea that either would be so unfair to Jacob and I. We are one unit, even though he probably doesn't know I exist. It is like he is one of those people who linger on after their breathing supports are turned off and the family goes through more grieving. I should be happy he is alive, right? But knowing he may die, that is what is scary.

I feel so terrible. I almost feel like I want Jake to die. His hanging on is so hard on him and me. . . . I don't want to lose him, but he looks so sad. He doesn't seem to rest anymore. He always has this stressed look on his face, and he is always rasping because of all the mucous in his lungs and throat. Only when I hold him does his rigidity relax. Maybe even than relaxation is my imagination and pride. And he isn't even awake. He doesn't see his toys, and I don't know if he can hear his music box.

It is almost noon, and I haven't been to the hospital yet. I have been doing laundry. I am about to go crazy. I won't be satisfied until I see for myself that he is still OK, even though I can't do anything for him. When I get there I will see he is OK, and then I will watch him. I could watch him for hours. He just sleeps. I don't think he moves as much as he used to. I tickle his feet and he squirms, but
he wrinkles his face now when he squirms. He rasps a little more when he moves. It makes me feel like he doesn’t want to be touched. Maybe that is painful for him.

He is three weeks old today. I love him very much. I am going to get ready to go so I can see him.
January 8, 1988

I am going to be busy for a couple of days. My friend Donna is coming tonight, and then my parents Saturday morning, then Deb, and then Cathy and maybe Regina. All of these people make me nervous. They know it is a bad situation, but they could never understand how bad. My parents may understand, but not from my perspective.

Yesterday, I was watching a mom and her son watching TV. She had her arm around him, and he was holding her hand. I kept thinking of Jake and how I wish I could do that with him. I guess I will always feel like Jake and I missed out, that we were gypped out of being a happy mom and son.

I thought the other day that I couldn't bear to see Jacob for very long. I felt so guilty for wishing that he would pass away and end his misery (and more selfishly mine). But when I got to the hospital, I thought, how could I not be happy that he is still alive? He is so beautiful, so quiet, so peaceful, I couldn't help but be glad to see him. I had to stay and hold him for hours. I could just watch him breathe for an entire afternoon.
I hate the idea of putting him in a home. I feel selfish for wanting to go on with my own life. I almost feel like I am cheating on him or being disloyal if I try to go on without him. A nurse told me yesterday that it would be best for Jacob, too, if I put him in a home. She said that there he would be getting the best care. I couldn't possibly provide as much care as those nurses do. They don't sleep on the job. They have relief come in at the end of their shift. That's the first time anyone has said that it would be better for Jacob. She even said that parents fool themselves when they think they can provide better care than a nursing home. She admitted that Jacob might not even know I am there. I may not be a comfort to him. I may be, but my constantly being there would probably be meaningless to him. I think the decision in my mind is made. I don't have a choice in the matter. Maybe I should put Jake in a home. I just have to convince myself it is the best thing. I have to learn to like the idea, or at least tolerate it.

I still think Jake knows when I am there. I don't care what that nurse says. That is one of my few joys right now.
January 11, 1988

I finally got rid of all my guests. I enjoy all of their company, but I get too stressed out when people come to visit. I feel like I have to entertain. Everyone wants to see Jacob, and they all have questions. All of the questions I try to answer truthfully, but they always disregard my truthful answers. They ask if Jacob has improved any in the last week. I say he hasn’t. Then they say, well, at least he is holding his own. I don’t know what to say then. I know he is still breathing, but that is all. I can see that he isn’t going to change much. They always say that kids are strange, they can change from sick to well in a minute. I give up.

My visitors don’t really say these things, mostly acquaintances do. But my visitors have their own little tricks. They say they saw his eyes move or heard him cry. They want to believe that a miracle may happen. My pastor even prayed for a miracle. I welcome that miracle, but I can’t expect it to happen. If I expected it, it wouldn’t be a miracle anyway.

I made myself feel terrible this weekend. I am so sarcastic with my parents. My mom called to tell me they couldn’t come on Saturday. I really wanted them
to come. I need them sometimes. She says they can come on Sunday and maybe go to church. I didn't know what to do. I really didn't know. I got mad and said they could come whenever they wanted to, and I would see them whenever they got here. I cried when I hung up. Then, I had to go back to my room at the Ronald McDonald House. I had to face the people in the hallway saying, "Are you all right?" and then go to my room where my visiting friend Donna was waiting. Uncontrollably crying.

Donna didn't understand why, but she said she did. I cried some more. My parents came on Sunday when my friend Deb was here. I tried to treat them kindly, but I still came off as a bitch. They are the people who support me the most, and I treat them this way. I wanted them to stay longer, but I knew they couldn't. Why can't they come and stay a long time, play a game and maybe watch TV? I am lonely.

Maybe I have stayed up here at the Ronald McDonald House too long. I don't know how I am supposed to act. Maybe after you find out that your baby isn't effected by your presence, you are just supposed to go home. I hate not being there, though. And when I am there, I feel helpless. I feel like people are watching me and wondering why I continue to hang around when there is
nothing I can do. Those people watching me can't understand why I have to put Jacob in a home.

I wish there were someone who could help me. My parents don't address the whole problem. In our conversations, we avoid the sad subjects and focus on the pleasant whenever possible. Can't they see I need help? I am tired of being strong. I am tired of being the one who has to explain everything and make sure everyone understands. No one understands when I tell them, and they don't believe me. They adjust the story to their own little world. Optimism hurts me too much. When will something start to go my way? Or Jacob's way?

Yesterday Jacob and I had some fun. (I know I thought it was fun.) I patted his stomach until he was relaxed. His left eye would slowly partially open. Then I would tickle his feet. He would squirm and squeeze his eyes shut tight. Then I would pat his stomach for a while again. His eye would start opening. I did this for about an hour and a half.

The nurse showed me how to do range and motion exercises, and how to suction all of that mucous out of his nose and throat. It isn't hard. Actually, it kind of feels good to do something. I enjoyed being alone
with him again last night.
January 13, 1988

Yesterday they told me they were going to put in the G-tube on Thursday. The G-tube is an easier method to feed a baby who does not suck, like Jacob. Instead of feeding him through a tube which goes down his nose and into his stomach (which is very irritating), a tube is surgically placed into his stomach to feed him through. I am not worried about it really. They say it is a pretty routine procedure. They asked me if I had any questions. I think they ask that question so you won’t be able to think of any questions. Every time they ask that, I draw a blank. All of these doctors are standing around, and I am on the spot trying to think of a question to ask them. I still can’t think of any questions. I guess I am pretty trusting. Jake has been through so much, this doesn’t seem too bad.

Last night I started to learn how to percuss Jacob. That is a method of beating on his chest with this little plastic hammer which breaks up the junk in his lungs. In jealousy, I have watched the nurses do this to Jacob, and wished I could do it. Now I am scared to do it. It is much more technical than I thought.
The nurses have been teaching me things this week. I guess it is because I may take Jacob home. It makes me want to take him home. I know I can't, but I want to. One nurse said I should try to keep teaching him to suck. She said, "One never knows, he may pick it up someday." I was amazed. I thought they told me the damage was irreparable. No one before her had told me otherwise. I want Jacob to be everything he can be, and I thought what he is now is what he always will be. I feel like everyone (the important people) is giving up on Jacob and waiting for him to die. I think they almost convinced me, too. I feel like they think I should go home and visit my boy less. Maybe I'm not doing any good, now. Maybe I am in the way. I can't leave though. I would be even more sad.
January ?, 1988

Whatever date, today is Saturday. Jacob’s G-tube surgery is over. I don’t think he looks well, but everyone else keeps saying he tolerated the surgery well. I can’t believe that. All day Thursday he had seizures, and he is still having them. His blood count is low. He looks yellow. I hated watching him look so sick, so sad.

I told a nurse I was glad no one was visiting me that day. She couldn’t understand that. I don’t understand it either. I don’t want to make anyone sad. I don’t want to be responsible for their sorrow. I don’t want them to try to comfort me, when they are sad. When I cry I feel like I have to be sure everyone else is OK. I don’t know if I can comfort them. If they knew what I know about Jacob, they probably would need comforting. I keep thinking that they aren’t as close to Jacob as I am, so why don’t they lay off? But that is ridiculous. They care about Jacob and me, too.
January 23, 1988

This week has gone fast. I must be getting better. I have been able to go for a week without writing. I did write a few letters, so I have written something. That is a sign of wellness, too. I usually can only write letters when I am happy.

Jacob makes me happy though. I used to wonder what I would do if he would stop breathing in my arms. Last night I was holding him and he kept gagging and breathing slowly. I did everything to keep him breathing short of mouth to mouth. I would stop percussing (beating on his chest to break up the junk in his lungs) to make sure he was breathing. I would shake him a little. I don’t want him to die. I don’t want to send him to a home. I don’t want him to suffer. I want him to be happy.

We found out with an EEG that he is not having seizures. The anesthesia lessened his control over his muscles even more than what it is. He was just making immature movements that he couldn’t stop. He has stopped making strange motions now.
His eyes were open so wide last night. He moves his eyeballs. I have tried to make his eyes move, and just when I think he reacted to me, he does it on his own. Last night I tried to see if he reacted to things coming at him. I would move his "Ernie" toy quickly to his face, as though it were dropping. I swear I saw him flinch. Three times. Am I going to keep on seeing him do things other people can't see? Will he do something for me and no one else? Does he know who I am?

I had such a great time with him last night. I gave him a bath, percussed him, put his clothes on, helped move him to a crib and put moisturizer on him. I felt really needed and important.

He is so beautiful. He doesn’t need oxygen any more and there is no more tape on his face. I am so proud of him. He has gone from not breathing at all to no oxygen!

I wish he would get better. And I pray for that, even though they say he won’t. It is so frustrating. Everything I get in the mail, everything people say, tells me that nothing is impossible to God. Why doesn’t he do something about Jacob then? Is my lack of faith stopping him? Someone else? Why does he let
my boy suffer? Why can't Jacob get better? Why does any baby have to suffer? They don't do anything wrong.
Jan. ?, 1988 Tuesday

Tomorrow I am going to Heritage House, a children’s home, to visit. I am afraid. I want to like it, and I want it to be a good place for Jacob. But I have weird thoughts about it. I am afraid Jacob will forget me. I don’t want him to love them (the nurses and the staff) before he loves me. I feel that I can be easily substituted.

At Heritage House, I want them to tell me they can help him in some way. I want them to say that they can make Jacob better instead of just waiting for him to die. I can’t stand the thought of it.

I have been really weepy lately. I feel I have nowhere to turn. No one to talk to. I went to see Jacob late Saturday night. I was crying and I couldn’t sleep.

I keep imagining him getting better. Maybe it isn’t as bad as they say. Doctors should keep reminding you somehow--little updates of doom. Instead I get a mass report once in a while detailing how there is no hope for Jacob, he will remain this way. Asleep. Nurses should know who they are taking of. They build false hopes when they talk to my baby and act like he can see. I am so afraid.
People wouldn’t leave me alone when I wanted to be alone. Now no one is around. I need someone to hold me and help me. I can’t ask for help. It wouldn’t be right to burden anyone else. I want someone to care, who understands, and who won’t cry or get upset when I cry and talk. I feel like I have to help them, or that I am responsible for their sorrow. Basically I need superman with emotions of steel.

I can’t understand the hospital. Sometimes I get vibes that I am there too much, others I feel guilt because I’m not there enough. Sometimes I feel silly and weak because I don’t want to go home until Jacob leaves. If you talk too much to a nurse, the staff worries that you are getting too attached. But they encourage you to talk. Who in the hell are you supposed to talk too? How do you not make friends with the nurses you are around daily? I feel so alone.

I am so proud of Jacob. He has been wrinkling his eyebrows.

Why? I don’t know. He sometimes acts like he can see or hear, but I couldn’t say why I think that. He isn’t consistent. He seems to have waking hours and sleeping hours. He falls asleep when I hold him. That makes me feel important. He is beautiful. I sure do
love him. I know what real love is now. All these other feelings come out of it. Fear, guilt, hate, happiness, pride, all of them. Also I know what insecurity is. I feel it in myself. I see it in Jacob sometimes.

My favorite nurse, Jacob’s primary nurse, is on days now. I feel better more often. She keeps mentioning that she wants to take me out for pizza sometime. I wish we really could go out some night. I know it’s not going to happen though. Dangerous. She could even lose her job.

I feel almost stable here sometimes. Maybe I am afraid to leave.
January ?, 1988

My grandma and my great grandma came to visit. They are so optimistic. I hope I didn’t hurt their feelings. I tried to tell them, Jacob probably will never wake up. But they tried and tried to convince me otherwise.

We took a lot of pictures. It is neat. We took pictures of all of us together. Great Grandma, Grandma, Dad, Jacob and I are five generations walking (or sleeping, in Jake’s case) on this earth all at once. We decided to take the pictures when we kind of thought about how long Jake might live. We need to do what we can with him before he dies.

Jacob has been moving his eyes a lot. I think grandmas really liked that. I do too. I get a chill, every time I think, well, maybe he does know I am there.
February 9, 1988

Beth, Jacob's primary nurse, and I finally went out for pizza tonight. We have talked about doing it for a long time, but I never really believed it would happen. We had to kind of sneak to do it. She went to her car, and then I left the module and Jacob. I met her at the emergency room entrance, and then we were off.

I expected it to be different though. We talked, but I wanted to talk more about Jacob. Find out things she couldn't say at the hospital. She did talk about Jacob, but it was different for her. She loves Jacob, I can tell that, but he is also work. She tries to protect him as much as I do from rotten nurses, heartless doctors, and pessimistic attitudes. But she knows these things so well, it is overwhelming to me.

After we ate, she dropped me off at the hospital. I went up to be with Jacob again. I felt kind of weird because it was like I had never left. I had taken the hospital with me, and now I was back. A nurse asked me, "Did you have fun?" I was a little shocked and embarrassed. I didn't think anyone knew about Beth and I going out for pizza. "Yes," I told her. I did have fun. It just felt strange seeing Beth out of the
hospital.

Will it be strange seeing Jacob out of the hospital, too. They keep saying any day now, he will be ready to go. The other day he was all ready, and then he had a fever. Can’t go with a fever. Then his stitches around his G-tube were all swollen and pussy. Can’t go with all that either. We will be waiting a while. I can wait. Being here is comfortable now. The home will be a change, and it is one I am afraid to make.

Jacob and I have been practicing developing strength in his neck. Beth showed me this. It isn’t really anything which will prove anything. It is just something neat to do with him. I hold him on my lap and then pull him up by his arms. Sometimes he holds his head up with the rest of his body. Other times he doesn’t, and then his head dangles back, looking limp. It looks and sounds terrible, but it really is OK. I love it when he can do it though.

I have been helping with Jacob’s care a lot lately. I bathe him every night, change his clothes (I bring in clothes people gave to me at his shower.), and percuss him. Then I play games with him. Sometimes I get to help weigh him. Some of the nurses will even
let me apply medicine to his stitches which are swollen and angry looking.
February 11, 1989

I went home today, but it was not fun. I usually am not very comfortable at home now. I worry about Jacob, and I am afraid the hospital won't call me if something is wrong. They never have needed to call, but I still worry. I feel guilty that I am not there. I shouldn't be having fun when Jacob is lying still in a hospital crib.

I actually had a good time at home. I ate dinner with my parents and watched some TV with them. I decided to go back about 9 o'clock, so I would be there about 10:30. I drove back, feeling a little nervous. I usually do, but I kind of think this time was different. I felt an urgency which I had never felt before. I wanted to drive faster, but I knew I shouldn't. I was tired when I got there, but I had to go see Jacob immediately.

The module looked normal as I entered, so I thought at first everything was OK. But then I saw Jacob. He was on oxygen. He seemed to be breathing OK, but still, he was on oxygen. We had worked so hard to get past that, and we were back to it.
A doctor came up to me and said, "We have been trying to call you. I think we have the wrong telephone number." What? They never call. Why did they need to call? "Jacob stopped breathing a few hours ago. We were concerned about whether he would continue to live. He started breathing again on his own."

Fear rushed over me. How could he not be breathing, and then start again. The doctor called it apnea. It is like what happens to babies who suffer from Sudden Infant Death Syndrome. I asked if it would happen again soon. He said he couldn't say for sure, but it was likely.

I cried a lot leaning on his crib today. The nurse didn't really bother me. I kind of wanted someone to, just so I could talk to someone.
February 14, 1988 Sunday

I am still spending all my time at the hospital. Jacob doesn't change. We just wait to go to the children's home. Everyday, they say maybe tomorrow. Probably next week. But then Jacob has a fever, or maybe he has a little infection around his G-tube. He needs to have a clean bill of health to leave. So we wait.

Today all of the babies had little Valentines on their cribs.

The nurses made them for the mothers, and the babies signed them with little ink foot prints. Jacob's little footprints were adorable. They reminded me of when he was born, and his feet were so tiny. They still are, but he is getting a little pudgy now. Inside it said, "Mom, you're special." Funny, that's what he is.
February 23, 1988

Jacob and I had been rocking for two hours before the sun began to lighten the dim private isolation room of the children's home. All I could think about was, "Breathe!" It seemed like that was all I had thought about since we arrived at the home only a week before. Had it only been one week? Unbelievable. Jacob's chest rose and fell inconsistently.

* * * * *

One week before, a Tuesday, Jacob and I were riding home from Riley in the backseat of our family car. My mother drove, but her eyes were mostly in the backseat, and not on the road. Jacob was perched in the carseat. I thought he looked as though he were sleeping. His chest rattled from the mucous in his lungs, as he seemed to labor over every breath. Maybe we should have let him ride in the ambulance.

But this was Jacob's first time in two and a half months (his life) outside the hospital. He was not within sight (if he could see) of a single nurse. No doctors in this Ford Taurus Wagon. Only me, my mom, and my son (and a portable suction device a lot like those used to clean babies' ears) were in the car. Mom's friend, Bev, followed close behind in her own
car.

And we were rejoicing. We had collected his gifts (secretly given to Jacob as going away presents by the nurses), put him in his car seat, and we were out of there. I almost skipped through the hospital lobby. No more rules, no more gowns, no more Riley hospital! Maybe at the home we could take Jacob home sometime. Maybe there would be hope.

Jacob’s primary nurse, Beth, carried him out to the car. It was a rule there. She had to ensure that we had a car seat and that he got out of the hospital safely. She seemed upset about Jacob leaving, but happy for me. It was time for me to go home, too.

Jacob breathed fine until we got out of Indianapolis, but then he began to slouch, cutting off his airway. I propped him up a little. Sitting up like this was difficult for a baby who had trouble breathing. He slouched again, and I propped him up. He began to rattle, and Mom turned around.

"He’s a little blue, Beck," she cried.

In fear and frustration I picked my Jacob up out of the car seat. What if he died before we got there? What if I lose him right here and now? I suctioned him
as best I could with the little thing they had given me. I couldn’t tell if it was really working or not.

I told my mom to drive faster, and she did. Our friend following us seemed to disappear in the traffic behind us.

I held Jacob almost the whole way to the home. I kept suctioning and suctioning, but he just rattled more and more. By the time we arrived, Jacob had a blue tinge that made me feel like swallowing. Could he be dying without Riley? Were we killing him?

And the worst part was that he couldn’t be revived if he were dying. It was my decision, but I questioned it daily. How could I let my baby die? How could I take him to a home to wait to die? How did we know he wouldn’t wake up? How could we believe the tests were true? It made me feel sick to watch him labor to get oxygen, knowing it may be the last time I would be with him.

Somehow we got into the home. I tried to tell the nurses who I didn’t know, "He needs suctioning, BAD!" without crying. It seemed like forever, but they finally brought a machine and a tube that was the size we used when he was a newborn. A nurse did a little suctioning in his mouth, and then went on. After she
left the room, I tried to get the goop out of his throat myself, with little luck. There was just too much for that tiny tube.

The nurses at the home were surprised at my desire to help with Jacob. Actually, I didn’t want to help. I wanted to do it all myself. Why didn’t I take him home? I could suction. I could feed him through the G-tube. I loved to bathe him. I did such a better job, too. I would have to have him all I could at the home. No one could take my Jacob away from me.

Jacob’s color returned. Everyone wanted to see the new baby. They had only one other baby, and he was a toddler. Jacob was the youngest client there. And I took some pride in that, until I thought about why. He was there by my choice. I couldn’t take care of him and live my life as I knew it.

I think every staff member and even some of the clients got to hold Jacob when he was supposed to be in twenty-four hour isolation. At first I enjoyed the attention, but soon it became a fight to get my baby back. How can all of these people hold him? Never had he been passed around this way, except once when we had a five generation picture taken with him. They were close relatives, though. These were strangers. The
rest of the time at Riley, he had never had more than two visitors at a time.

A nurse came to give Jacob an inspection. She asked a lot of questions, but really didn’t listen to my answers. I don’t even think she had read the nurses’ notes from Riley yet. She asked questions which were obvious, yet she didn’t seem to care what I said. Then she took an anal temp., something I was taught to avoid. They hurt the poor baby’s butt and eventually could damage his muscles. "That’s all we use here," she said. "More accurate." Yuck. I felt like throwing up.

After she left, and the commotion died down, I sat and rocked Jacob who I thought felt tired and worn. I felt the first peace I had felt all day, but still feared the rattling in his chest. Could he die from lack of efficient suctioning?

I cried and pretty soon a nurse walked in. I think she knew I was crying, but did not mention it. She did start talking to me though.

"I am so glad you chose to come here. There is hope for him you know. It is all in the attitude. The hospital sometimes makes people pessimistic. Does he suck?"
"No," I replied.

"We can teach him that-- I have seen babies really progress."

Suck-- I couldn't believe it. Jacob had never had this ability, hence his G-tube.

"Has he cried?"

"No. I got him to make a few sounds once though."

"Vocal cords are intact. Maybe he'll cry someday."

I tried to imagine that. Wouldn't it be wonderful to hear him cry? Music to my ears. God!

"Keep praying, Becky. Don't give up on God. He'll pull Jacob through."

Suddenly I didn't mind Heritage House so much. I hoped she was right.

* * * * *

But watching him breathe that morning, you would have never thought about sucking or crying. Just breathe. Keep breathing.
By seven o’clock, my mother was there. She coached him verbally as I held him, trembling inside.

* * * * *

To the surprise of his nurses, I was back early the next morning. I found Jake in the children’s wing, already out of isolation.

He was already dressed and bathed. He reeked of baby shampoo. I know he had been, but I asked anyway. "Did he already have his bath?"

"Oh, I think the night nurse bathed him. You can bathe him again though."

Like I would want him to sit through two baths just for my pleasure. Why couldn’t they just tell me? Why couldn’t I have something to do? I hid my jealousy and said, "Can you save his bath sometime for me?" She said, "Oh, sure." But I never got to see where to draw the water.

He seemed to be doing well that day. Pretty normal behavior, although he still rattled quite a bit. A little movement. We rocked all day. By the end of the day, they were even starting to leave the rocker by Jacob’s bedside for me. I liked that.

* * * * *
Jacob stopped breathing. I looked into my arms, and he didn’t move. For minutes, he lie lifeless in my arms. I tried to speak, but all that escaped my lips was a whimper.

The nurse came over to me, and checked his heart rate. Slow but present. Suddenly, he gasped. I gasped. The nurse gasped.

I laughed in delight. He was alive again. I could breathe more easily now, as though his lungs were mine. We had fooled the world. He would live!

I talked to Jacob, but I don’t remember what I said. Some sort of encouragement, I think. I kept him rocking, believing it was keeping him alive.

* * * *

On Jacob’s third day there, I was a little shocked when I saw him. He looked yellow to me. When I held him, his arms and legs fell lifeless over my cradling arm. Usually he felt rigid. We did exercises with him to loosen his muscles. But that day he was limp and lifeless, like a rag doll.

We walked around the home, something we couldn’t do at Riley. We could go anywhere we wanted. Our favorite place was the front lobby because it was so
quiet. Bibles were there. I read to him sometimes.

That day we visited the school room, too. The teacher showed us the stimuli toys Jacob and I could use. She said my manipulation of his stimuli could benefit him. I looked forward to returning anytime, as she suggested. We never got to go back though.

* * * * *

Jacob had apnea attacks more and more frequently then. I began to ignore them, believing they were temporary. It began to become difficult to tell where one ended, and the next began, his breathing was so shallow.

* * * * *

On Friday I made it there early, I think before nine o'clock. I was supposed to go to school to register. My life was to continue, not stop, when Jacob began his stay at Heritage House. It was time to move on, as much as I hated to leave him.

Everything was planned to be quick today. I really needed to get to school by noon. But reality kicked in. When a nurse saw me come in the front door with my mother, she immediately approached me and began to escort me to Jacob. "Jacob is having some trouble breathing," she said as though she were trying to
lessen the blow.

Jacob wasn’t in his room. He was directly in front of the nurses’ station, and his face had an oxygen mask on it. They didn’t have a nose piece small enough for Jacob’s face. Again he appeared blue. Had he been suctioned? His chest rose and fell abruptly and visibly. He seemed to be making deep sighs over and over again. He rattled from deep in his chest. My face must have shown fear and worry. The nurses seemed to spring into action.

"I’ve called the RN. She’s on her way. He has just become this way, this morning."

We waited for the RN, who I learned was the thermometer maniac. When she saw Jake, she called the doctor. The doctor ordered a chest X-ray. They called the ambulance, and we waited.

* * * * * *

My mom held Jacob for a while. The nurse came in to take his vitals. Heartbeat present. I dreaded when it would disappear. She was supposed to take his temp., but she was nice and gave Jacob’s poor butt a break.

* * * * *
The ambulance drivers came. They loaded Jacob on the stretcher, all neat and bundled like a papoose. Mom and I rode in the back with Jacob and a paramedic. He held Jake still.

When he heard the rattling, he suggested Jacob be suctioned. I about screamed, "All right!" He suctioned Jacob with a portable machine. Jacob seemed to improve, and I felt a lot better. Both of the men talked to us a lot. The really seemed sympathetic to the situation and concerned.

The test results came back. Jacob had pneumonia. He would need oxygen, to keep him comfortable.

I hated leaving him that day. I felt so helpless and alone. He lie on the crib, sighing repeatedly. I worried the whole time and I couldn't return until Saturday morning.

* * * * * *

People began to pass by the open door to our private room.

The home was beginning to come alive. Sometimes the passer-bys would glance in at Jacob, Mom, and me. It seemed that everyone knew. A few nurses popped in to say hello (but they said mostly good-byes).
The days that followed are fuzzy. I don’t remember what happened from one day to the next.

One day I got a phone call fairly early that said they were afraid Jacob wouldn’t make it. Would I come?

I was there. I went as fast as I could possibly go to get there. Dad came, too. The nurse suggested "Riley." The doctor said he needed that kind of care.

I was kind of excited. We were going back to Riley. Our old nurses who knew us. Our special intense care. The place I had already won some independence with Jacob.

The same two ambulance drivers loaded Jacob into the ambulance. Dad followed in his car. We were watching Jacob breathe, up and down, but suddenly he stopped.

The ambulance drivers reacted quickly, as they changed their destination to the county hospital. We were brought in, and for a few moments, I was afraid they would revive him. I knew if he was going to die, he couldn’t be revived. We had decided that. I had decided that. But what if they didn’t know that? What if they just started to save his life without asking
me? Would I try to stop him? Could I go against my decision, so I could keep my baby for a while longer?

He started breathing on his own, in only a few minutes. The ER doctors called Riley, our previous destination. Riley said to talk to me about it, I think. The doctor in ER told me exactly what they always told me at Riley.

"Taking Jacob to Riley would probably prolong his life. They would isolate the virus, they could provide excellent care, and he could improve. If he didn't die before he arrived. Heritage House could do the same thing. But the point is, if Jacob goes to Riley, when he returns, this could all happen again. He could be in and out of the hospital forever, only getting worse each time. They suggest we do our best, and remember what is best for Jacob."

How could this get worse? He was dying. We returned to Heritage House. Dad drove, while I cried, all the way home.

The next day, Mom, Dad, and I came to visit Jacob. I think it was Sunday or Monday. Jacob was still so limp and tired looking. Mom and Dad noticed it too. They held him. He didn't feel the same, but he looked a little better, didn't he?
We went out for dinner and overate to make ourselves feel better.

* * * * *

I got the call about five-thirty in the morning. I told Mom and Dad, and I left. I'm not sure what transpired on the way there. It is a twenty minute drive, but I don't remember much of it. I know I felt skeptical. He seemed better, only the night before, Monday. I hoped it was a false alarm.

I rocked Jacob and talked to him. His breathing was so shallow, I didn't even notice he quit breathing the last time.
Fade

His heart
it beats
slowly
but sure.
The nurse
listens,
but then
it's gone.
She says
I can't
find his
heartbeat.
And then
my heart
screaming, crying, exploding,
skips
every
beat
in pain.
It wasn't long before Dad was there. I was still holding Jake's cold body when he arrived. Dad held him, too. We all talked to him, and rocked him, even though we knew he was dead.

A nurse asked if I would like to change his clothes. When he died, all of his body's secretions escaped his body, so he had a dirty diaper. I said I would like to, so we picked out his best new outfit (one his primary nurse had given him with a duck on it) and I put it on him. His body was cold. I was surprised how fast it got cold. I could feel the coldness go through his body, it wasn't a slow process.

After we changed Jacob, we left him on this changing table in the room. He lay there while we waited for the pastor and the funeral director to come.

When the pastor came, he had some Bible verses picked out to read. The twenty-third Psalm was one of them. It kind of washed a calm over me. While he was reading them, the funeral director came. He sat down in our circle, and we all held hands for a prayer. Then we talked about funeral arrangements. Jacob quietly rested on the changing table.
It was time to leave. Everyone was getting up, and the funeral director was going towards Jacob. He picked him up, covering his head with a blanket. He was dead, and I didn't cover his face when I changed him.

We all walked out together. It was very windy outside, so few words were exchanged. Or maybe we all felt we weren't supposed to talk. What would we say? As the wind whipped my hair around my face, I watched him carry my Jacob to his car. Jacob was swaddled in a lacy white blanket. I felt confused when he was carrying him. Why wasn't I carrying him? This man didn't even know Jake. He had no idea what he was all about, and now he was carrying him. Away from me. I guess all of those thoughts were irrational, but I felt them. I wanted him to be in my arms again. I wanted him back.
April 1988

"All the Cool Poets Are Dead."

Keats, Shelley, Wordsworth, Donne,
But the coolest was my son
Because he could sum up the universe
With the wrinkle of an eyebrow.
He never said a word.
He didn’t have to.
He expressed love, beauty, and sorrow
Eloquently.
I could read all of the world’s poetry
and I’d find no better soliloquy
than a quiet sigh
of that little guy.
Why?

On December 15, 1987, my son, Jacob, was born. He
was a beautiful boy of seven pounds and ten ounces. I
loved him more than I ever imagined love could be.
Unfortunately, when he was delivered, the umbilical
cord was wrapped tightly around his neck causing severe
brain damage. At two months and ten days on February
23, 1988, Jacob died of pneumonia. I used to think I
should be thankful that he lived at all, for he lived
two months and ten days longer than the doctors thought
he would. But now I find all of this very unfair, and I miss his breath on my face and his heartbeat against my chest. To hold him again would be my wish, but that would only leave me wanting more.
April 1990

Epilogue

It has been over two years since Jacob died. I am further removed from the emotions, but I still think about him. I wonder about what could have been, and I miss him. Now I know it all was for the best. I have only respect for his caregivers at Riley and Heritage House.

Some of the experiences I had with Jacob my mind has tried to forget. But I would like to remember more. I’d like to remember holding him, and feeling his breath on my chest. He used to drool and blow bubbles a lot. His body was always warm, and comfortable against mine. He could speak to me by just wrinkling his forehead and hiccupping, or grabbing my pinkie. He had a tiny dimple on his chin, like Cary Grant. He was beautiful. I felt important to be with him and be his mother. Everyone said he knew me, and I believed them.