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# The Journey of Rebecca Rose

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Front cover photo



*(Rebecca 5 days old)*

Thank you for buying this book. To show my appreciation and thanks to the two organisations who most gave Rebecca a chance, I am donating 30 cents to the March of Dimes and 20 cents to the Gloucester Royal Hospital SCBU for each copy of this book sold.

*Other books by Stephen Kovach*

*The Journey of Rebecca's Family (due out Sept 15, 2006)*

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# The Journey of Rebecca Rose

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*For my family,  
And especially Rebecca,  
You taught me that all things are really possible.*

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# The Journey of Rebecca Rose

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# Introduction

When we unexpectedly gave birth to an extremely premature infant in March of 2003 we were thousands of miles away from our family in a foreign country. Fortunately our neighbours proved to be the best of friends as they filled in every bit as well as our family would have. To call them dear friends is an understatement – they became the family we needed and shared our everyday joys, frustrations and wonder at this little girl who was beating the odds.

Our own family and American friends felt completely helpless and could do little more than offer moral support and prayers. In an effort to include them in our everyday trials I began to write an email every day immediately after returning from the SCBU when the details were fresh in my mind.

Over a short period of time the email chain stretched across several continents and literally almost a thousand people were reading about Rebecca every day and praying for her.

I wouldn't have believed the figure until after Rebecca came home and strangers would ask (remember our accents gave us away as Americans) if this was the little girl they had been reading about. From America I would receive emails and phone calls from strangers offering prayers and support.

I have been asked several times if I would please compile the daily updates into a book form so people could reread and relive the daily progress of our amazing daughter. You are reading the results of this request.

I have only added a few sentences here and there for clarification; removed references or changed names of people who wanted to remain anonymous and deleted a few passages that didn't make sense (I occasionally had a pint of Boddingtons while typing up my daily journal!)

I wish you peace and love and may you find reading this book to be as uplifting an experience for you and your loved ones as it has been for me rereading and editing our journey of hope.

Sincerely

Steve Kovach

17 March 2006



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## Prologue

**A**t the start of 1999 a new project began for CAO, Ceres Ace Orb (name changed), the software company for whom I worked. The project was the first major one to be tackled from our European office located in Surrey county in the United Kingdom. Because of a shortage of technical staff in the overseas office I was asked if I would be interested in a two year assignment getting the project “off and running”. It sounded like a lot of fun so in July 1999 we moved house from Freeport PA to Walton-on-Thames, Surrey. At the time our family was composed of Margie and I, Jennifer aged 3 years 10 months, and Daniel aged 2 years and 2 months.

After 9 months on the project, the responsibilities drifted more and more to British Energy’s technical centre in Barnwood, part of Gloucester in Gloucestershire, about 100 miles to the west of Walton-on-Thames. Thus for the second time in less than a year we packed up our household things and moved to a little house at the end of a treeless cul de sac ironically named The Copse in Barnwood. Barnwood, once a small village in its own right, was now a suburb of Gloucester, an ancient town founded over 2000 years earlier. Gloucester had an interesting history first as a Roman frontier outpost and later, as the frontier receded (much as the American old west) it became a more civilized post for career centurions to spend their retirement. We enjoyed our new life in Gloucester; unaware that one of the best centres for premature infant care in the west of England was only two miles from our doorstep. Even had we known we would not have paid it much attention as we believed our childbearing years were past.

In fact, we had fertility problems going back almost 10 years. After we were married in 1990, we waited for a year before taking the big step of having children. Only something was wrong. Doctors told us to be patient but after a year they began to also be concerned. We had several miscarriages with each occurring in the first trimester. Despite painful tests and having our hopes dashed several times, by 1993 medical science shrugged its shoulders and said they had done everything they could. It looked as if we might remain childless. There was no treatment except prayer. I believe most of Ford City’s population was engaged in a prayer chain at the time thanks to my grandmother Albina and many others.

Then in late 1994 Margie was laid off from her job as a Pittsburgh deli manager. Only a short time later, just before Christmas, we got a positive result on a pregnancy test. Guardedly, we did not tell our families for a little while because we were afraid of another sad episode, but we passed into the second trimester and everything still looked good. We announced the news to the delight of our families. Tragically, my grandmother Albina suffered a stroke in May 1995 and passed away only days before it was possible to feel the baby

moving. On the other hand she may have stormed the heavens as she admonished St Peter, “This child had better make it or I’m not coming in!”

Through luck, lack of stress, or miraculous means, Jennifer was born to two very happy parents on 5<sup>th</sup> September 1995 and we gave her the middle name of Helina which was made up of both my late grandmother’s first names (Helen and Albina). To this day Jennifer is proud of her name and her heritage.

Since it had taken five years to have one child, we decided to waste no time in trying to have another. Besides we both ascribed to Bill Cosby’s rule of thumb that you need at least two children to be parents. After all, if something in the house got broken and we had only one child, we would know who did it. At least with two children I had the chance of blaming them both when I broke something, and maybe I’d get away with it. We would try again as soon as Marge forgot about labour. That took about a year...

Well you know, God has a sense of humour. For Jennifer we had tried for five years through countless memorably passionate evenings, however, our son Daniel was conceived the second time we had unprotected sex. He was born a mere 16 months after his sister on 6<sup>th</sup> May, 1997. Jennifer had been born Caesarean after 17 hours of “failure to progress” but Margie was ABSOLUTELY determined to have Daniel using “natural child birth”. Medical nomenclature describes this as VBAC (Vaginal birth after Caesarean). Dan, however, did not agree with the “natural child birth” plan and put himself stubbornly in an obtuse presentation (that’s face up). Marge managed to push him out anyway. Which one of them was more determined? (Years later, Rebecca showed the same determination and strength at her own birth.) It took 76 stitches repair the damage when Daniel was born. Now who do you think was more determined? What a tough woman I’ve married.

After Daniel we mused about having a third child and eventually Marge must have forgot about the 6 dozen stitches because after a few years we started trying again, however, but after two more years of nothing happening, we resigned ourselves to being a comfortable four unit family. Margie remained a happy stay-at-home mom and as we began to stabilize, we began to look for outside interests. The opportunity to move to England had come at exactly the right time in our lives.

Now we had uprooted our young family and travelled 4000 miles to a foreign country. Still, as parents of school-age children, we begin to make friends with the parents of the other school-age children. I think perhaps we were a bit of a curiosity to the neighbours at first because we did some things differently. Our children enjoyed playing out of doors and got the whole neighbourhood of children all playing together on the street rather than in their own “back garden” as was more commonly done.

In the autumn of 2001 we were just getting settled into the start of the school year when Marge unexpectedly became pregnant again. We were pretty

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excited, and despite the years that had passed, we were thrilled that our children could share in the joy and excitement of expecting a new brother or sister. We did have a couple of sonograms done and we participated in a new test which could predict with some reasonable accuracy whether the foetus will have Down's Syndrome. It was with great relief that we found that despite Margie being 37 years old all indications were that it was to be a normal pregnancy and the infant would be completely normal.

Everything progressed very normally until March 2002. We had even planned one last trip while we were a four-unit family and had booked a week stay at Tenerife in the Canary Islands. We were looking forward to the trip because Margie had never been to a tropical destination and we were excited to visit a part of Africa. The doctor had given his ok as well.

About three days before we were going to leave on our Spanish holiday, Marge was getting ready for bed and turned to me with a surprised expression and said, "I think my water just broke". More frightening words were never spoken in our home on The Copse. The infant was only 26 weeks gestation and we couldn't even really feel it moving yet. Margie was only barely showing. We went to the hospital where they could not confirm the water had broken. Their rationale was that if the integrity of the womb had been broken, the action of checking could further endanger the baby. Instead, they waited to see if labour would begin. It did not, so they sent us home telling Margie that she was just suffering from the indignity of prenatal incontinence (she was spontaneously wetting herself).

It was during this time that we made the decision for Marge to have an injection of steroids which would help the baby's lungs develop enough to breathe. Unfortunately the painful injections required a day to take effect. Marge was able to stay at the hospital and the critical day passed. The hospital sent Margie home and we tried to figure out whether to cancel our holiday or not. The doctors felt there wasn't anything that a set of Depends couldn't solve.

Only a day later the labour pains started and we went back to the hospital. This time there was no mistaking it, and a monitor confirmed the worst. A doctor came in to talk to us about the prospects if labour continued and the staff tried all they could to stop the labour with drugs. Marge held in and labour seemed to slow down. The staff claimed it had been stopped, but Marge was certain that it had not. Still things were relatively stable so I went home at around 9pm.

I got a call from the hospital at 2:45am that I had better get back immediately. I pulled on my clothes and knocked on our neighbour's door. Debbie Harding answered the door and went over to our house in case the children should wake up and need someone. I remember very clearly her answering her door in her bathrobe and wishing me the best. The drive to the hospital was very quick, and I recall being chilly outside as I pressed the buzzer.

I identified myself and walked into the hallway being told to go in the fourth door on the right.

I found Margie looking pained as her labour had now progressed to the point of being dilated. The baby was going to come out and there was nothing to stop it now. The paediatrician had told us the infant had only about a 40% chance of surviving the birth and the nurse was wheeling in a sonogram machine to check the baby's heartbeat. As we watched (in the UK you can see it all) the machine's display showed a small blackish blob that we all took to be the heart. It was completely still. Softly, the nurse said, "I'm sorry, but your baby has passed away". Silent tears filled my eyes but there was no time for grief as Marge still had to deliver the baby and she needed my support.

The attending midwife began to do an internal exam on Margie to check the progress and then turned to me and said, "Oh my, get the paediatricians in here immediately! The baby is in the birth canal." I did as I was told and ran out the door and told the desk nurse. Three doctors appeared out of nowhere including our favourite whom we had affectionately nicknamed "Big Nose". By all the activity something critical was happening, but I didn't really understand what. Was there a chance for the baby? Was there some way they might be able to restart its heart? Wouldn't there be brain damage? How could there be any hope?

The doctors told Marge to push and I recall seeing an impossibly tiny baby born in only one little push. I was standing there feeling sorry for our child thinking how she never had a chance at life, would never take her first steps, say her first words or get her first kiss but the doctors were all working frantically. As they whisked her across the room to a brightly lit table, I observed the baby was a girl. The doctor said quietly, "it's a girl".

I said, "I know, her name is Rebecca". I began to have the briefest glimmer of hope. The paediatrician had told us that girl babies did much better than boys.

As the doctors rubbed her tiny body and worked to put a long L shaped tube down her throat, I felt a little bit of wonder and pride in how far medical science had progressed. 100 years ago this child would simply have died and nobody would have even thought of trying to resuscitate. Then I heard a little gasp. Then another. I realized this baby was fighting – fighting for her life. She wanted to breathe. She wanted to live. But how had her heart started beating again? It didn't matter, the tiny gasp said more than the entire unabridged Oxford dictionary. Before this moment, I had heard the cliché, "My heart leapt for joy" but never before in my life had I realised what it really meant.

She was not dead. My innermost thoughts turned to rally for her. "Fight! Breathe! I Love you little Rebecca!"

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The doctors whisked Rebecca away nearly at light speed. Suddenly and unexpectedly, we were alone again with the nurse who had done the sonogram. After thinking for a minute, she apologised to us, “I think we must have been looking at her bladder as she was turned upside down and already in the birth canal.” So that was it: her heart had not stopped beating at all.

Now there wasn't much we could do for her. She was in the care of the Special Care Baby Unit at Gloucestershire Royal Hospital. Luck or fate or divine intervention had dropped us exactly in one of the few places in the world where Rebecca would have a chance.

And that's where our story really begins...



## Week Ten

*Subject: Rebecca today 19 May, 2002 - gained 85 grams in four days.*

*Originally published on 05/19/2002 11:21 PM CET*

**R**ebecca did really well over the past few days. She's managed to get off the oxygen (I think we can say at least conservatively), and she's



managed to bulk up more than any other time yet.

On the home front, Sunday morning 3am Dan came into our room and the only words out of his mouth were “ahh-barf-barf-barf?” as he threw up on the doorstep coming

into our room. Now Marge, intelligent woman that she is, realised exactly what was going on and ran for towels while I ushered Dan into the bathroom. He then put the rest of his dinner into a better place. (He's just finally learning to do this and here we are starting all over with another child; we must have totally lost our marbles?) So Mum went into Dan's room and the whole night continued much the same. In the morning Dan was still not feeling terribly well but I got up with him to give Mum a little sleep. Dan drank a little Sprite and I made him some toast. He wasn't interested in the toast and after only a short while he began repeating that his stomach hurt about every five minutes. Poor lad. After about an hour of this, he showed us that he wasn't better yet but again credit to the boy for putting it all in the bucket. What a good boy. He stayed on the sofa in exactly the same position until about 6pm when he seemed to improve a whole lot. In the afternoon Mum rented *Harry Potter and the Philosopher's Stone* from Blockbuster and we all watched. This took Dan's mind off his stomach.

Well, we all had grand plans to go on a family outing and the fine weather just teased us. I convinced Jenny that the time had come to take the butterflies out of doors. The cardboard box had still not recovered from

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yesterday's session with Cadbury (nor is it likely to recover much more), so I took the whole table and box outside into the back garden. We made it a great production and carefully released each butterfly to a location appropriate to its condition. Some of the butterflies were in excellent health and simply flew off. Others had been damaged by Cadbury or had never properly dried their wings so we put them on a large clump of flowers where they enthusiastically begin drinking nectar. Later, however, the inevitable happened and we found one of them on its back now recently deceased and being dismembered by ants. This upset Jenny a bit and she quietly said, "I could have saved him". I tried to console her by telling her that he would have died anyway and that his body now was food for the ants - they would turn him into nice rich soil. She asked if that was what would happen to her body when she died and we talked about it a bit so I guess she learned something. So did I, I was impressed that she was had made the connection and pleased that she was thinking about the cycle of death and rebirth. The subject actually led to organ donation, and I explained to her that her Mum and I would donate our parts to other people in the event of our early and untimely death. At least it took her mind off her sadness. She then rescued one of the remaining butterflies and took him into the house to nurse him. Because of his condition, it is inevitable that it will not be able to fly and will shortly die, but Jenny did take excellent care of him. His last day(s) were as pleasant as they could be for a butterfly who can't fly. Still kind of sad but I tried to focus on the healthy ones and we went on a hunt and found a couple that were healthy and hanging about.

Mum went in and Miss Rebecca nursed enthusiastically at noon and again at 6pm. The nurse told Marge not to be discouraged if she doesn't appear to be getting very much as it depends on the position of the tube and how much the nurse wants to pull out to look at. So Miss R might really be getting more milk than it would appear. This is good news and helps to ease the feeling of discouragement. She is more tired these days; they are trying to avoid another transfusion so she's a little anaemic at the moment while her body attempts to make all her red blood cells. She seems to be doing well at the blood thing because she is staying well-saturated on plain air. She has been on air continually for more than two days now and other than the times natural gasses are emanating from her top end or the bottom, she stays in the 90's on saturation.

Her weigh in was a big success. She is now 1710 grams or 3 pounds and 11 ounces. This is the biggest weight gain yet. She is now on 29ml every three hours of EBM. Good news too is now she can wear sweaters (in fact they are now a requirement since she's in the cot) and so Mum took a couple of photos of her in a nice yellow sweater (jumper) knitted by the wife of my friend Colin at work. Thank you very very much for your beautiful gift Elaine, Colin and Gareth.

When I went in she was asleep but managed a quarter smile for me. I took advantage of her being asleep by taking photographs of Rebecca holding my wedding band and a US dime. I also took photos of her holding a 5p coin (the same size as a US dime) but the reflection from the coin makes it hard to see what it is.



I did get to feed her for her 9pm top up and it took almost 1/2 hour for all that milk to descend into her little tummy. I had to stop twice to burp her and although the initial sit up awakened her, her eyes quickly rolled back into her head even while sitting up. After I was sure she was well settled, I left for home to make an early night of it. Both Daddy and Mummy need some extra sleep tonight. Let's hope Jenny doesn't come down with the sickness.

Good night all. -Steve

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*Subject: Rebecca today 20 May, 2002*

*Originally published on 05/21/2002 12:06 AM CET*

**H**ard to believe we're already at the 20th of May. Miss Rebecca moved house again tonight, in the right direction - toward home. The nurse explained she was first Intensive Care, then High Maintenance Care, and today she was downgraded to Special Care. Go Rebecca!!!

There aren't any more rooms for her to move into – just her bedroom at home! The nurse said that in this new room many new privileges and changes will occur. First, she gets a monitor that only attaches to her foot and

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measures pulse and saturation. Respiration and heart rate (not to be confused with pulse) are no longer monitored. Next, she is allowed to have a bath! Mum will be able to give her the first bath tomorrow during the noon care cycle.

Earlier on, we all had a nice visit at 6pm. The children got back from swimming class and arrived with Mum. I went in having left work a few minutes early and had started her care. She was wide awake and everybody got to cuddle her. The doctor had been in earlier in the afternoon and demanded a sacrifice of blood! She had been poked in both hands and one foot and was sporting sexy cotton balls from each of the appendages. The blood tests all came back normal I am happy to report. One test for blood sugar didn't come back ok, but they had the machine checked and when they redid the test it was normal.



Now that Rebecca was wide awake, we got some fantastic photos. The kids were actually cooperative, even Rebecca. Today Mum dressed her in the beautiful sweater knitted by Anne Bebbington's Mum, Monica who lives in West Yorkshire. Thanks Monica!!! Doesn't she look cute? See attached photo. As an added bonus, Rebecca also found that the sweater knitted by Monica not only looks great but tastes great, too! At least that's the impression I got while watching her lick it repeatedly.

Mum stayed and nursed Rebecca while I took the kids through McDonalds for the usual greasy but strangely, tasty food. Not good for diets, however.

Rebecca nursed a good while and managed to get enough estimated milk that the nurse didn't give her the full feed. When I went in for 9:00, she wasn't acting hungry (in other words she was sleeping soundly instead of trying

## Week Ten – Blustery Days

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to eat her clothing). I held the syringe while she got her full 39mls. Afterwards I burped her by putting her on my chest and patting and she gave out a very ladylike BELCH!! Even Rebecca seemed surprised by the volume and started looking around to see what the noise was.

After she finished making noise, she happily settled onto my chest and didn't move a muscle for about an hour. She barely moved as I put her back in her box and quietly left for home.

Good night! -Steve

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*Subject: Rebecca today 21 May, 2002*

*Originally published on 05/21/2002 10:49 PM CET*

Miss RRK nursed “enthusiastically” for Mum. She seems to be getting the hang of things and she wasn't quite as tired as she had been the last couple of days. She did not get her bath, however, as there just wasn't time. She nursed for a good while on one side and managed to load up her nappy at the same time so Marge changed her nappy. This woke her up and she managed a good drink from the other side as well. Marge was so encouraged she is going to try and nurse her three times tomorrow.

While Mummy was in the hospital for 18:00, I was left to provide an inspiring dinner. I asked the kids what they wanted while making suggestions. Spaghetti? Yuck. Leftover Pizza? Yuck. Hot dogs? Yeah! So we were “inspired” with beanie-weenie followed by “blocks and balls” (fruit cocktail).

When I went in the nurse was excited to tell me about Rebecca's good nursing sessions. Rebecca was equally excited, or perhaps she would have been if she hadn't been snoring. Sister Emma came in for the shift change and saw me burping Rebecca and said, “You might as well get her out - I can see you're going to keep that up until she wakes up or I let you take her out.” So the nurse changed her foot probe and I put her on my chest. Miss R gave a small burp and settled down. Or so I thought. Soon she was looking all around so I put her on her back to play. Just as soon as I did, her eyes rolled back into her head and she started to snore again?! So I put her back on my chest and we stayed that way for about 30 minutes. Then I put her back in the box and came home.

Tonight is weigh in night so we'll have to see how much weight she has gained. Last time she was 1710 grams; with a little luck she will be over 1760 (3 pounds and 14 ounces). She did have an apnoea monitor on her tonight.

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Unlike the device that measures respiration, this one measures the lack of it. If more than 20 seconds pass without a measurable breath, an alarm goes off. I noticed that all the babies in the ward seemed to have these little blue apnoea monitors. The nurse explained how it worked to me and said that they might soon remove the other monitor that measures heart rate and saturation, but that the apnoea monitor would stay on Rebecca until she came home. Hopefully that day is not too far off.

Good night all. -Steve

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*Subject: Rebecca today 22 May, 2002*

*Originally published on 05/22/2002 11:33 PM CET*

**T**oday was a windy day. In Gloucester, windy days are sometimes WINDY days. As a child I remember the story of *Winnie the Pooh and the Blustery Day*. Pooh stories originated in England and the hundred acre wood is a real place here that you can visit. (The real Christopher Robin lives here too, but I've heard he hates *Winnie the Pooh*; he must have gotten teased a lot as a child.) Anyway, I never knew what a real blustery day was until we moved here. Even the children were aware of it as they pointed out that the clouds in the sky were moving in double time.

We had a little "risk of thunder" a few days ago and it was a subject of much conversation at work the next day. We had about six lightning strikes in a swift passing storm. Not much in comparison with the big scary storms we sometimes get in Freeport this time of year, but still unusual. In the Severn Vale we get thunderstorms only a little more often than measurable snow. I wonder how the children will react next year when we're in Freeport in May and one of those big storms rips through at night. With the windows open and the river valley just 1/2 mile away, the thunder is really loud and wakes you up with all the echoes. It's majestic but a little unnerving and humbling.

I went in early so I could be there when they did Rebecca's hearing test. The good thing to report is that she passed with no hearing deficiency. Of course when she gets about four years old I might argue that her hearing has gone away, and I've heard this continues until about age 30. I know that I can stand in front of Jennifer or Daniel and talk to them and the only purpose of the exercise seems to be to make my lips move and give my voice box a workout. But go into the next room and whisper, "Hmm, what should I do with this ice cream?" and they come running.

## Week Ten – Blustery Days

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I found one of the AWOL butterflies upstairs in the room where Cadbury usually sleeps. It was in pieces and quite past its prime with its little remaining legs in the traditional crossed position that indicates that it is not sleeping. I can see it now, this butterfly bravely sacrificing himself on the day of the butterfly cataclysm. He would be saying to the others, “Go, hide yourselves, while I distract the fanged monster!” OK, I'm being silly; he was really the unlucky or impatient one who moved first - probably natural selection at work (which always makes me wonder why \*I'm\* still here). I quietly removed him from sight putting his tattered, brave, wingless body into a bit of tissue before Jennifer could get upset over him. Then I buried him at sea with full military honours (two flushes). Well, Gloucester is a seaport don't you know? The drains have to empty somewhere...

After Rebecca's hearing test, the nurse wanted to talk to us so we had to wait around. The nurses are always cognizant of the fact that this worries parents “we've got to talk”, so they usually follow it up with “NOTHING BAD”. During the wait we got to give Rebecca her first bath! My niece Emily heard Rebecca was going to get a bath and said, “That's a good thing 'cause she's got to really stink by now”. There was a student nurse present who wanted to watch, and the ward nurse was in attendance as well so Marge felt she was on trial. Rebecca had her eyes wide open as she got her bath. She showed that she is a pretty normal baby. She did not like having her face or hair washed. She seemed to enjoy the rest of the bath, with her eyes wide open and looking around the whole time. Mum towelled her off and redressed her while I watched and videotaped. Then Rebecca did the nursing thing, being pretty well awake.

Rebecca did nurse well and Margie estimated she drank about 15ml. She is up to 40ml per three hour feed thanks to her gaining a healthy 20grams a day since the weekend. Now she is 1710 grams or 3 pounds and 15 1/2 ounces. By this afternoon I'm sure she will have passed the four pound mark. Mum and I went to Pippin's, the volunteer run hospital snack bar, where I had the “All day (miniature) breakfast” and Mum had a toasted cheese sandwich. The size of the meal may be diminutive but you can't complain about the prices; the all day breakfast was only £1.75. The woman at the till was confused. She added up our order several times and then called over another woman. Our grand total was £5.60 which I paid in exact change. After some deliberation they decided that the till was wrong and my total really was £5.30, but they didn't refund any of my money. Since they were such nice ladies and since I know that all the proceeds go to the hospital and ALSO since I was hungry and didn't want to confuse them any more (or eat cold food) I didn't point out my missing 30p.

It was nice to talk to Margie for a few minutes for a change instead of the usual conversations we have passing in the hall. I complained about work for a few minutes then caught myself and said, “I thought we were supposed to

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be talking and here I am whinging about work”. Marge replied, “I thought we WERE talking?” Whew, we have so much to catch up on, don't we?

On the way back to the car, a particularly strong gust actually pushed me off balance for a second and I took a few staggering steps to the right. At exactly the same time a big arm-sized branch fell out of the tree I was walking under and landed with a loud thump in exactly the place I had been headed. Strange but true. Someone is still looking out for me upstairs. I said a silent prayer of thanks.

Margie continued to try to nurse Rebecca at 3 and 6pm but she didn't do very well at either time. The nurse told us that it is time for us to schedule a “preliminary discharge meeting”. This will entail her nurse, the health care worker, our GP, the ped consultant, and anyone else needed for the meeting. Oh yeah, Mum and Dad too. The idea is to discuss the details of when Rebecca will be ready to come home and what we can expect. We are also encouraged to ask a lot of questions. No date was set. We also were asked to sign for her first round of vaccinations. We obliged, but they did not have the vaccine on hand which means she will get her first jabs tomorrow.

I went back to work where things were hectic as usual and managed to get home only a few minutes later than my target time of 5pm. I had to collect the children from the neighbour Debbie who had collected them from school (thanks for such great neighbours as we have here!) As I entered the Harding home, the children looked disappointed to see me. I granted them a small reprieve with the neighbour children while I went next door to prepare our tea. On my way out however, Lydia announced, “I'm going back now!” and started to follow me out the door. It was really cute that she thought of our home as going back.

I made chicken soup from scratch! Well I did scratch my finger on the vegetable peeler, so I'm taking credit for it. I chopped up two carrots, put some extra star noodles in three English pints of water (20oz each) and opened two packets of Knorr Superior Chicken Soup. (As opposed to what, the Knorr Lacklustre Chicken Soup?) I also opened a can of pears for dessert and made some bread and butter sandwiches for the kids. I cut the sandwiches up into squares and triangles and thought this would make them more prone to actually be eaten. Not so, Dan left his sit on the plate and Jenny wanted “plain bread”. She was pretending to be a duck and wanted to tear off little bits and put them in the soup - then she would pretend a human had put the bread in the water and slurp it up with her beak (tongue). After watching the duckling for a few minutes, I went into the kitchen to tidy up after my impressive culinary achievement. A few minutes later Dan slipped in quietly to say, “One of the butterflies has a problem with his wing.”

I came back into the living room to see what had gone on. Jennifer has “saved” several butterflies that couldn't fly and has been nursing them. Rather than seeing this as a cruel activity, I figure that in the wild these couple of

malformed creatures wouldn't survive anyway so Jennifer is probably giving them a higher quality of life than they would otherwise have. They may also lay some eggs and she might get to raise another brood. I might have to alter my thinking now. Jennifer looked up at Dan and said, "I knew you would tell". Then she made up a story that would have made the Grinch proud. She said, "I was holding him and his wing just fell off!" Suddenly brother and sister forgot their differences and bonded together. Dan changed his story and said the same thing, "Yeah, she was just holding it and its wing just flew right off!" I was so touched by their cooperating for a change I decided to humour them, "Oh my, that's a terrible shame, I hate it when their wings just fall off." (Sarcasm is still totally lost on them). We talked about it some more, and then a cruel streak hit me. I told Dan (who probably didn't really know what happened) that yes this sort of thing does happen all too often and he better watch out in case one of his arms flies off. In fact I suggested he try and see if they were loose. He seemed afraid to attempt it and immediately folded them. His sister knows me too well and was giving me that funny look that young children give you when they think you are pulling their leg. I managed to get back to the kitchen before starting to laugh. Not really being a cruel Daddy, I made sure to tell Dan I was kidding later when cuddling him in bed.

After night time cuddles, I went in for my usual hospital night visit. The nurse fed Rebecca early as they were preparing to "download" her. This involves clearing out the monitor and letting it record for eight hours. Then they print it out and put it in her file. The doctor analyses it. If it turns out positive, the monitor goes away and all we will have left is the apnoea monitor. She will be on the "download" until 4:30am. The nurse didn't want me to cuddle her because Rebecca was doing very well at 98 - 100% on air and having great signals. Rebecca wasn't in any mood for much of anything besides; she was knackered pretty thoroughly by all the things that happened to her today, and didn't react when I sang to her or held her hand. So I left her be and came home early. I do still have great memories of last night's cuddle to sustain me, where Rebecca sang along with me when I sang, "Hush little baby don't you cry". She was pretty loud for a little while which almost made me think she really was trying to sing along. Almost. She does this really cute thing that Marge calls the sleepy song. She will hum with each breath when she is tired and sort of sing herself to sleep. Another musical child, I can see it now.

Tomorrow Mum is going to start a trial of a few days "rooming in". I think this assumes she will be off monitor tomorrow. She will stay in the family room with Mum overnight and Mum will feed her every three hours followed by top up with the gastric tube depending on how much she eats.

Well that's about it for now. Talk to you again tomorrow. -Steve

*Subject: Rebecca today 24 May, 2002 - Changes today.*

*Originally published on 05/24/2002 12:38 AM CET*

Miss Rebecca's download did not go smoothly last night. The doctors are concerned that she might need oxygen after a feed since she dipped into the low to mid 80's each time she was fed. Worse, during the day she continued to dip low and by 5pm she was back on the nose prongs full time. It's only 20cc, but it means that she won't be able to room in with Mum, and she certainly won't lose the monitor any time soon.

Mum decided to continue to try rooming in anyway and stay at the hospital overnight. They have moved Rebecca's feeds to every four hours now, and this afternoon Rebecca was spitting up a little and having wind. I cuddled her for a little while after work and then brought the children home. Jenny got ill in the car and not having anything else for her to use, I gave her the McDonald's happy meal box. We were almost home anyway. When we pulled into the driveway Jenny got out of the car and actually managed to get most of it in the box. However those boxes weren't meant to be watertight, so I still had a lot of cleaning up to do and Jenny needed some clean clothes.

It was getting quite late and past the normal bedtime hour by the time I was finished cleaning. Jenny seemed a lot happier so I put them both to bed. Jenny woke up again about two hours later and gave me the rest of her stomach contents. At least she put it all in the bucket - what a good girl. Since then, I don't feel all that great either. And we'd all thought we had missed it after Dan was sick almost a week ago. I hope Marge isn't getting sick. We're worrying if we've given Rebecca this illness and that is why she is not doing so well at the moment. There's probably a very good chance of it. Since it's a virus, there isn't much treatment for it but the good thing is that it only lasts about 24 hours. Either way it's a setback for everybody.

Rebecca has been started on another mineral; I think it is Phosphate this time. I hadn't noticed but she's been off the caffeine for some time now. Mum was not optimistic about how much Rebecca would nurse being so utterly tired. She hadn't nursed much throughout the day and she barely woke up when I visited with her - she was not her normal self.

Oh well, off to bed until Jenny gets sick again. If she is sick again tomorrow morning, I'll have to take the day off work. At least we have great neighbours who can take Dan in if I can't go, but he'll be disappointed since I promised to take him to work tomorrow. On the brighter side, just maybe we'll all feel better in the morning.

Cheers. -Steve

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*Subject: Rebecca today 24 May, 2002*

*Originally published on 05/25/2002 12:27 AM CET*

Jennifer woke up with no trace of the tummy troubles she had the night before. Starting at 5 a.m. she begged me to go to school, and I told her she could go as long as she left me go back to sleep in peace. Meanwhile at the hospital, Miss Rebecca slept right through her midnight feed but at four am the nurses called Mummy saying, “Someone is looking for you”. Now that Rebecca had a good sleep with some oxygen, she was wide awake and nursed well for Mummy. She continued in that vein and nursed well again at 8am but was tired at noon.

At home, I got the children out to school. Daniel helpfully pointed out to all the neighbours where Jenny had left her deposit next to our driveway the day before much to the embarrassment of Daddy. In the dark it certainly looked like I’d washed it all away. I went to work where it was the usual hectic day with several “critical emergency red hot can’t go live crises” as is usual for any IT project. I ran to the school to get Jennifer from music at 4pm and made it with four minutes to spare. We picked up Dan from the Hardings, our fantastic neighbours, and ran off to the hospital.

Rebecca was asleep but Mummy had her out for a cuddle when we arrived. We played pass the baby and I was lucky to have her when she got her 4pm feed (about an hour late). She woke up enough to look around a couple of times and smile as we sang a song together. Dan sang and Rebecca sang and I sang. Would have been nicer, but all three of us were singing a different song.

The nurse talked to me for a few minutes and tried to reassure me that it is not that unusual for a baby to go off oxygen and then have to take a little now and again after a few days. In fact Rebecca had not been on oxygen full time according to Mum, only 20cc every few hours and then for only about an hour at a time. It appears that things aren't too bad so Mum decided to room in again tonight.

Mum came home to put the children to bed. I got home first as the rest of the family had gone to the grocery store to stock up. *The Fanged Beast of Gloucester* had struck again, and the two remaining butterflies and their crumpled box were the sad victims. When I arrived home, one of the butterflies was on its back frantically trying to make its mauled legs and wings work. I felt so bad

## **The Journey of Rebecca Rose**

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for the poor thing that I did kill it and then gave it the standard ceremonial burial at sea with full military honours. I did not tell Jenny what happened to it. The smaller (and perhaps smarter) butterfly had stayed perfectly still and was just fine. I considered releasing it, but the weather outside wasn't nice and I thought that since it was the last one, Jenny should get the chance to let it go. I captured it in a glass and showed it to Jenny. I made the right choice as she was really happy.

Well that's about it for today. Good night. -Steve





# Glossary of commonly used British and medical terms

These definitions are generally accurate but also represent my American interpretation of British slang and my medically- uneducated interpretation of medical conditions which my daughter or other SCBU infants experienced. They are certainly no substitute for a doctor's explanation and I encourage you to consult with a doctor before making any determinations or drawing any conclusions based on the information I present here. I welcome any corrections or additions and will include them in a future edition

AGENCY NURSE	A nurse who works for a central agency and is assigned duties as needed to one or more hospitals and/or surgeries in any given week.
APNOEA	(US = spelled Apnea), In this book I am describing a condition which is called "apnea of prematurity" or AOP, a fairly common condition in which premature infants stop breathing for 15 to 20 seconds during sleep. It can be life-threatening, hence a device is typically used to monitor the rate of respiration.
BABY GROW SUIT	In the US, this is often called a one-piece or "onesie". It is a garment or undergarment meant to cover the infant from top to toe and usually contains snaps to make it easy for a caretaker or parent to change.
BILI LIGHT	Bili lights (phototherapy) are commonly used to help infants with jaundice, a yellow coloring of the skin and eyes related to premature liver function.
BRADYCARDIA	Bradycardia (a.k.a. brady or bradys) happens when the heart slows down below acceptable limits. In babies, whose normal heartrate is around 150 beats per minute, bradycardia occurs when the heart rate is lower than 100 bpm. Bradys are not uncommon amongst preterm babies. If the body does not recover spontaneously the medical staff will usually stimulate the infant gently until their immature nervous system "remembers" and takes over again.
CANDY FLOSS	Commonly known as "cotton candy" in the USA.
COTTON WOOL	Cotton Balls

## The Journey of Rebecca Rose

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CPAP	“Continuous Positive Airway Pressure”, a CPAP machine is a breathing device for respiratory therapy. A rigid mask or tubes through a baby's nostrils push a continuous flow of air or oxygen to the airways to help keep lungs expanded and tiny air passages in the lungs open. This kind of respiratory therapy is preferable to a ventilator as it is less damaging to tiny lungs.
CUPPA	British slang term for a cup of tea as in, “Would you like a nice cuppa?”
DADDY LONGLEGS	British slang term for a night flying insect that has rather long legs and a slender body and which has the annoying habit of flying in an open window and right into one’s face whilst trying to read a book. Also sometimes called a crane fly. It does not bite.
DAILY CARE	SCBU term for the general care of an infant. Usually involves a change of nappy (diaper), thorough cleansing of the genital area and any other soiled body parts. Is typically finished by a change of clothes. At Gloucester Royal Hospital, daily care was performed at 12 hour intervals.
DESATURATE	A description of the condition where the level of oxygen in the blood drops. If the level drops below 92% for more than a few seconds, a monitor alerts the nurse. The treatment for this condition was to give our infant a higher percentage of oxygen in her breathing mask/prongs.
DUMMY	British slang term for a baby’s pacifier.
EBM	Expressed Breast Milk
FOLLY	Name given to an architectural garden feature which typically is made to look like something that it is not. An example would be to build an artificial cave or a false ruin.
FOOTIE	A football match, keeping in mind that outside of the US, the word football is used to describe what Americans call the game of soccer.
FOREMILK	Watery milk produced by the human breast which helps to quench a baby’s thirst. This is the first milk expressed when an infant nurses.
FULL OF BEANS	British slang expression meaning someone has “loads of energy”. Perhaps too much.

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GIT	British slang for a silly fool.
GRAND ROUNDS	A term describing when all the doctors visit all the areas of the hospital together to discuss the patients. These were conducted only once per week.
HINDMILK	Creamy, fatty milk produced by the human breast which helps an infant to grow and satisfy their hunger. This milk is expressed later in the nursing cycle.
HOMEBASE	A popular DIY (Do it Yourself) store in England, similar to a Home Depot or Lowe's in America, and having a similar mix of merchandise.
HOOVERING	British slang term describing the act of using a vacuum cleaner.
JAB	British slang term to describe receiving an immunization or other medication via a hypodermic needle.
JUMPER	Sweater
KNACKERED	Tired out, needing a rest. "The walk up the hill left me completely knackered."
LOO	British slang term to describe a room with a toilet, or sometimes just the toilet fixture.
MILTON SOLUTION	A mild chlorine bleach solution made by dropping a Milton tablet into clean water. Used to disinfect.
MP	Member of Parliament. An MP is an elected official.
NAFF	Uncool, not in style.
NAPPY	Diaper.
NUTTER	A foolishly insane person, but one who is generally harmless. Also, a person may be called a nutter if they have done or are planning to do something exceptionally silly.
ONE OFF	An event that takes place only once or a task one has to do or is able to perform only one time.
PennDot Worker/Engineer	American (Pennsylvania) term for a person who works on a road crew repairing and maintaining the public highways. As with most figures in the public eye, often the unfair subject of jokes about inefficiency or sloth.
(feeling) POORLY	Sick, ill, under the weather. "I'd have come to work today but I was poorly."

PUSHCHAIR	Stroller
RAILTRACK	British company in charge of maintaining all the railways in the UK. Regulated by the government.
ROP	Retinopathy of Prematurity, a common eye disease for premature infants. It is caused when the blood vessels in the eye grow uncommonly fast and into parts of the eye they should not. Typically this growth occurs in the womb during the last few weeks of pregnancy where the anaerobic environment keeps the growth in check. Fortunately for most infants it is mild and heals without intervention but in some cases can lead to severe scarring and even blindness.
SATURATION POINT	The point at which blood is considered “full” of oxygen or at which life can be sustained. In premature infants the SpO2 monitor keeps track of how much oxygen is present in the blood. Curiously, full saturation is present at 97% and beyond that level sustained exposure causes health problems. For this reason it is monitored closely in SCBU’s.
SCBU	Special Care Baby Unit, the same as a Neonatal Intensive Care Unit (NICU) in the United States.
SHATTERED	British slang term meaning extremely tired, totally exhausted. “I didn’t get a wink of sleep last night and now I’m shattered.”
SISTER	British medical term for a nurse.
STRAIGHT AWAY	British slang term meaning to do something immediately. “I’ll take care of that flat tyre straight away.”
SURGERY	British term for a doctor’s office.
TEA	Besides the obvious reference to a drink made with leaves, this is a British slang term for the evening meal. “We had beef and Yorkshire pudding for tea.” Or, “The Kovach’s had us over for tea.”
TIDAL BORE	Referenced in this book as the “Severn Bore”, this is a standing wave that is generated on a coastal river. It must have a funnel shaped estuary with a large difference in the height between high and low tide. When an especially high tide comes in, such a wave can be generated in a few select locations in the world. The Severn estuary is one such place where waves up

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	to five feet can be seen several times a year.
TORCH	Flashlight
TPN	Total Parenteral Nutrition. A substance that is given intravenously and which supplies 99.9% of a person's nutritional needs. In the case of a premature infant, this can supply nutrition until the child can begin to tolerate food by mouth.
TRANSIENT	In British SCBU terms, this is an infant who is not expected to stay in the SCBU longer than 24-48 hours. They are placed in the SCBU due to the possibility of birth complications or a low APGAR score.
VEST	British term for a one piece baby outfit without feet.
WANKER	British slang term meaning literally a man who constantly masturbates, but is also commonly applied to a man who goofs off frequently or who has a careless attitude. In Pittsburgh we call these people "jagoffs".
WELLIES	Rubber or plastic waterproof ankle height boots.
WONKY	Something that is wobbling or not performing exactly as expected. "My car was shaking badly because I had a wonky wheel."





Steve is originally from western Pennsylvania, and after the short stay in England he returned to the area where he grew up. Steve is employed as a computer consultant with a large Pittsburgh area food retailer. When not writing, he loves to spend time with his family and enjoys playing the guitar, singing with his folk group The Heartland Singers, being a Cub Scout leader and just about any activity outdoors or history related.

Steve attended Catholic elementary school in Ford City, PA and graduated in 1982 from Ford City High School. He went on to study at Penn State and graduated with an Associates Degree in Computer Science and business.

The Kovach family lives in a 1901 old Victorian farm house located in a rural area near Freeport, PA.