

remembering rhys

a pregnancy loss blog

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Our Story

☐ rememberingrhys . Pregnancy Loss ☐ March 22, 2018May 14, 2018 ☐ 4 Minutes



I started the D&E process on March 5th, 2018.

If you've been here yourself, you'll be able to guess the main details of my story. If you have not, let me start by explaining that D&E stands for dilation and evacuation. It is one option when medically terminating a pregnancy in the second trimester.

My story starts at 12 weeks with an abnormal ultrasound. The purpose of the 12th week ultrasound is to screen for potential genetic conditions. Our child, sadly, presented with a measurement (known as nuchal translucency) that was outside of the normal range. As a result, we were sent to see a genetic counselor and submitted a blood test for trisomy 13,18, 21 (aka Down's syndrome). We were relieved when the blood test came back negative for the main types of trisomy and we learned we were having a boy (I knew it!). Despite the good news, we proceeded with an amniocentesis at 16 weeks which also came back as negative for genetic abnormalities.

As far as we knew, our son had no chromosome abnormalities. When we went into the OB on February 12th for the 20 week anatomy ultrasound, my husband and I felt like we were out of the woods. We had finally started to decorate his room and had decided on a name we liked.

Sadly, during our 20 week anatomy scan, we learned that our baby boy had no amniotic fluid and short limbs. We were sent to a maternal fetal medicine practice for another ultrasound.

On February 16th, we heard the words I will never forget: “This baby is not compatible with life.”

We learned that our son had some sort of skeletal dysplasia (of which there are over 400 different types). I did not cry in front of the doctor, but I understood that we were now faced with the unthinkable: medical termination.

Back at the original OB’s office, we were shocked to learn that our OB did not do terminations and that no one else in the practice did either. We had been assured by another doctor from that same practice that they would make sure we got into the hospital ASAP. Our OB told us that most doctors don’t want people to know that they are willing to terminate pregnancies and she doubted that three shifts of nurses would want to work an induction/delivery. She handed us a slip of paper with two clinics to contact and sent us on our way. She assured us that the locations were very “discreet”. Unfortunately, these clinics do not accept insurance and suggested that we try Arizona or Colorado.

We felt like our OB had abandoned us. We started to get the sense that we had walked into a political issue. It never crossed our minds that a lethal diagnosis would be met with such hurdles.

Ultimately, we decided to reach out to a nurse at a specialized maternal fetal medicine group. We were lost and hoped that she could guide us in a way our OB had not. She took our case upon herself and connected us with the wonderful people at Ronald Reagan UCLA Medical Center.

The D&E was done over three days.

- Day 1 was the injection to stop our son’s heart.
- Day 2 involved inserting the laminaria sticks inserted into my cervix. This is how they dilate the cervix. It’s the most painful of the three days.
- Day 3 was the evacuation of our son’s body under anesthesia.

After surgery, one particularly thoughtful doctor gave us the sweetest prints of his hands and feet. These two slips of paper represent all that I will ever have of our baby’s physical form.

In terms of physical pain, I did not find the procedure all that bad. My husband was a little concerned by the volume of blood I lost, but it quickly slowed by that evening. I did experience some extremely painful cramping in the hours after the surgery, but that was the worst of it.

The pain that people are hesitant to ask you about is the emotional pain. This pain is unlike anything I have ever experienced. At moments you feel OK, back to normal even, and then you remember what you have lost.

My husband has occupied himself by taking care of me and all the various doctor visits. Now that we are left with the emptiness, all we can do is cry. We treasure the memory of the day I took the pregnancy test. We are so sad to have lost that innocent joy of first time parents. We ache for this person we will never know but for whom we have so much love.

This has been the most isolating experience of my life. I try to explain everything to my friends and family. I am grateful when they ask me questions. I also can't help but feel pissed off by people who haven't seemed to care. I get the sense they do not understand the gravity of the situation. I feel pissed off by the people who tell me things like "he couldn't have lived anyway," "everything happens for a reason," and "I know this one person who went through the same thing."

And yet, I am grateful for the 23.6 weeks we had. I am grateful for all of the joy and all of the life lessons that came from the pain. I am grateful to have learned so much about empathy for others. I am grateful to have learned so much about pregnancy. I am grateful for every kick and punch and wiggle I felt. I am grateful for the doctors and nurses who are willing to see the unpleasant side of childbearing. I am grateful for my best friend who came over every weekend for a month. I am grateful for my job which will have given me almost two months of time off. I am grateful for my husband who means more to me than words can describe. And, I am even grateful for our silly dog who snores and farts and burps as if nothing has happened.

We named him Rhys. He was due June 26th, 2018.



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2 thoughts on "Our Story"

Kathie says:

March 25, 2018 at 1:04 am

This is so sad to read. But I'm glad you put up this blog. We don't talk about the death of an unborn even though it's very real. My heart goes out to both of you. Please know that Mark

And I are thinking of you.

Reply

Jennifer says:

April 10, 2018 at 4:19 am

Rhys is a beautiful name! I love that the doctor provided you with your son's hand and footprints. Such a thoughtful gift.

Thank you for sharing your story.

Reply

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