

## this is Jack

as told by mom Sarah



Jack with mom and dad

**H**E WAS DIAGNOSED with Spinal Muscular Atrophy. Never heard of it? Neither had I until I was sitting in the emergency room with my 6-week old, Jack, who was having breathing problems. After he was diagnosed, doctors told us he had approximately 3 months to live. Our world fell apart. How could this happen? How could we say goodbye to the baby we fell in love with at first sight? We have never felt so much pain. SMA causes a degeneration of the

“It was like a little bit of my world stopped crumbling around me. I could focus on my child, I could focus on his comfort, I could focus on making memories.”

motor neurons in the brain stem and spinal cord. The signals from the neurons to the muscles are lost, and muscles can't function. It is a terminal disease that would hinder his ability to sit up, crawl and walk. Eventually he would be unable to eat, speak, cough, swallow and even breathe.

We should be able to watch Jack grow up. We should be able to dream about his future. But instead we were left waiting, waiting for the inevitable.

Doctors told us Jack would eventually need to be on oxygen 24 hours a day; he would need a feeding tube since he would lose the ability to swallow. He would also need a suction machine as well as a machine that would mimic a cough for him.

Knowing that Jack's care would be very demanding, my husband and I moved to Colorado from our home in Arizona to live with my mom.

**IT ALL SEEMED SO OVERWHELMING.** Each day, my world revolved around Jack's care. I was lucky if I got to shower. I remember the day I got a call from a woman named Adrienne. She explained that she was from an organization called, "There With Care." She asked me what they could do to help. I will never forget that feeling, like a little bit of weight had been lifted. I felt a little hesitant at first. Like other families may be more in need than us. She assured me that each family has different needs in many different circumstances and that they helped each of them in their own unique way. She asked me to tell her a little bit about our situation. I couldn't believe how helpful and thoughtful this complete stranger was. She explained that they could deliver food so that we would not have to stress about grocery shopping. It was like a little bit of my world stopped crumbling around me. I could focus on my child, I could focus on his comfort, I could focus on making memories.

*(Continued on page 3)*

## the magic of care

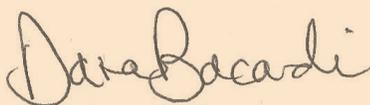
Every day the phones ring at There With Care with calls from social workers for families who need our help. Every hour we are reminded how important it is to be able to be there for a family with a critically ill child. In 2012, we will help more than 250 families - more than any other year in our history. We continue to provide this support to each and every family who call on us through the magic of care that you help us provide.

Did you know that There With Care is able leverage \$1 into \$4 worth of products and services for our families? Some of the ways we do this are by working with food banks and other local and national food resources, and by collecting gently used baby items. We also partner with local businesses to provide discounted services such as auto repairs, housecleaning, therapy and hold diaper drives and many other collaborations. This all works thanks to so many inspiring people, like you!

Thank you for reaching out into your own communities and engaging your families, your employers, your book clubs, your co-workers, your neighbors, your kids, your friends.

So many of you connect the work of There With Care to your communities, wave your wands and help turn every dollar into four. This magic directly impacts the services we provide to families.

Amazed. Inspired. Grateful. That's how your generosity makes us feel. Thank you for being There With Care.



Dana Bacardi  
Development Director



Cindy Davis and Melissa Koester from Crocs deliver diapers to TWC from the Crocs Cares Diaper Drive

## this is Jack (Continued from page 1)

Our goals were to keep Jack as comfortable as possible and to cherish the moments with him that we were fortunate to have. Chris and I decided we had a choice of how we spent our final weeks or months with our baby boy. We could either spend every day crying, locked in a room, or we could enjoy every single moment, making beautiful memories along the way. We created Jack's bucket list. It included blowing bubbles, catching raindrops in the palm of his hand, touching the grass with his bare feet, finger-painting, going to the aquarium and the zoo, swinging in a park, and making a snow angel. We were determined to have the short time we had together be filled with love and true living.

Over the months, Adrienne became much more than a stranger. She let me know that we could receive meals donated from a local restaurant, 4580. Since Jack had to travel with so much equipment, going out to a restaurant was very difficult. Having a special meal one night a week uplifted our spirits.

AS THE HOLIDAYS APPROACHED, Jack was getting worse and was having a lot of trouble breathing and digesting food. Adrienne called our family to ask us if we would like

Thanksgiving and Christmas dinner delivered. We hadn't even thought about the holidays. She explained that they had volunteers who donated presents to families in the There With Care community.

Our family decided to celebrate Christmas early. We bought Jack some reindeer pajamas and a few small presents. The next morning we all stayed in our pajamas, opening presents with our baby.

Jack took his last breath in my arms at just 6 ½ months old, two days before Christmas. That night, there was a knock at the door. It was one of the There With Care volunteers with our Christmas gifts and dinner. We opened the gifts that were meant for Jack on Christmas Eve. They were so thoughtful to think of him.

Jack is the strongest person I know. Not a day goes by that I don't think of him and the love he gave us. He has touched so many lives in his little time here. Having Jack has taught Chris and me that moments are made to be forever memories and that life is too fragile to not enjoy to the fullest.

We love our baby more than we ever thought we could and wish nothing more than to have him with us here today. We are forever grateful for this amazing organization that brought a little sunshine into our world when we needed it most.