

Preemies Today



Families Helping Families

PREEMIE OF THE MONTH:

Our Premie of the Month is Lucy Coleman. This is her story, as told by her mother, Rachel Coleman, in a phone interview to Kathy Paz, President of Preemies Today and Mary Beth Hazelgrove, Vice President. Her story is a special story that begins with the birth of her sister, Leah who is deaf, the emergence of her mother's desire to share Leah's language with the world, and then her own premature birth and how sign language opened a whole new world for her too.

We went for the 18 week ultrasound and they discussed the AFP test (Alpha-FetoProtein) and we decided that we did not want to do it because if any of my children had a disability we did not care.

So, I went down for my ultrasound which I also did not want and I also almost walked out on because they would not let Aaron in with me because we had Leah, my first born who was 3, with us at the time. I was in there, by myself, with the technician and I was looking at the picture, and I watch enough Discovery Health to know what an ultrasound should look like. I asked, "Is that my baby's head?" I then thought to myself, "Isn't that weird in this day and age in which technology is the way it is that they do not have their little circle, the little circle that measures the baby's head, the right shape." My baby's head was sticking out the circle. So I thought, "This is weird you would think by now there little circle would match what a baby's head looked like." No one was saying anything. Everyone was disappearing and people were coming in doing the ultrasound. Someone kept saying you need to get the baby's back. I thought to myself, "Either this guy does not know what he's doing or there is a problem."

Then, they finally told me to get dressed. The doctor came in and told me there was something wrong with the baby's head and we needed to go to a genetics counselor right away. I burst into tears and I yelled "Get my husband!"

We went to see the genetics counselor who said, "The baby has hydrocephalus and we believe it is caused by spina bifida, but they



could not get a really good picture of her back." Then, we locked into an amniocentesis, c-section, and at 22 weeks Lucy had fetal surgery to repair the lesion in her back. They actually did a c-section on me, delivered my uterus, and then operated on her, and then put everything back in.

The number one complication would be prematurity, because of a hole in your uterus would cause your uterus to become weak

and it would want to contract. So, we did this knowing it and after weeks of strict bed rest I went into unstoppable labor at 32 weeks and Lucy was born.

Thirty-two weeks is not that premature. There are a lot of preemies who do well at 32 weeks. I don't know with the other stuff that she went through, or whatever, but her first nine months she just screamed all the time. She either screamed or cried or she was blank. She didn't cry when she was hungry-nothing. She didn't smile when I came into the room, nothing. The only person who could get a smile or a laugh out of her was Leah. I had to remind myself if it had been 2 hours and I had to feed her I realized how much of that relationship was a reciprocal relationship. When your baby smiles you smile. When your baby giggles you giggle. You feed off each other in that way and it was so hard to have this blank baby who didn't give

At nine months we almost lost her. We took her into the hospital because she was basically nonresponsive, and we learned something about what the rest of our lives would be like. We had to start catheterizing her every four hours but she kept getting sick so now we do it every four and half hours. So, since she was 9 months until now we have had to catheterize her every time she has had to go pee.

When she was in the hospital the doctors told us that they really thought that she had cerebral palsy and so we started learning about that and we tried to look at it as we looked at Leah's experience. Wow, this is new. We know nothing about it and it sounds really scary. Let's assume like we did with Leah, if we are willing to educate ourselves, and that we love her that we all are going to be fine and you know, we are.

Product Review: Signing Time! Videos, Volumes 1-6

Signing Time! is a series of videos that teaches hearing infants to children how to sign in a fun way. The videos cover a range of signs from first signs and the alphabet, to playtime signs and feelings. These videos are a great way to get your child interested in communication before they are ready to vocalize.

The Signing Time! video series helps to create another avenue of communication for children. Children that experience significant delays in speech and other areas, can really be helped by sign language to continue to develop, decrease the frustration of not being able to vocalize, and increase their fine motor skills with hand and finger manipulation. As they continue to hear and see words, they can begin to associate signs to vocal words and use them in concert. It in turn enables the child to learn to communicate visually while also affording them the opportunity learn a wider range of words at a much earlier developmental age.

When my former 25 weeker, Alex, was 18 months old, he still had no vocal words. He became increasingly frustrated and his behavior really began to take a turn for the worst. Having taken years of sign language myself, I began to teach Alex some basic signs to communicate. He picked them up very quickly, and though he was not ready to vocalize, he was able to communicate with me in sign. Each word that Alex learned in the following six months he learned to sign, and then he learned to vocalize. We always used the sign with the vocal word so that he would learn the associate between the word and the sign. Eventually he began to use both sign and vocal word, and even creating sentences with signs and words.

When Alex was 2 years old, he got his first Signing Time! Video- My First Signs. He was immediately drawn to the animation and the small children playing and signing. It seemed to make much more sense to him when he saw other children using signs. His vocabulary continued to grow, and he picked

up words very quickly while watching the videos.

Alex's sister, born full term, also loves to sign and watch the Signing Time! videos. When she was six months old, she used her first sign, milk. Now Lily is advanced in speech and communication. She makes full sentences combining both signs and vocal words at 19 months. Together she and her brother are thriving in language development from using signs that they have learned by Signing Time!

The Signing Time! series of videos and music, are not sold in stores. You can find Signing Time! at their web site SigningTime.com which includes a very comprehensive store with their entire collection and some extras, the Signing Time! history, benefits of singing to your child and much more. You can also join the Signing Time! yahoo group to keep in the loop about Signing Time! happenings and to talk with other parents who sign with their children.

Continued from cover, Lucy's Story

At two years old, her neurologist said that she was mentally retarded and she had no signs, no words and she probably never will. Her hands were in little fists real tight and we had to pry them open to clean them. Her arms were bent tight next to her body and her head thrown back. Her back was arched and this is how she was for two years. I didn't believe them. I said to myself that I know that she is smart. I know she is in there, but she is in a very uncooperative body. I said to the doctors, "I understand why you came to that conclusion, but as her mother I feel differently and I don't accept it."

Well, my sister Emilie called me around that same time and asked if I wanted to make a video series for kids. "Of course," I said, because that is what you say when your sister asks you that. She said, "What do you think about music?" "Great idea," I said. "Right idea, but wrong concept. We need to do this about sign language."

So we started making Signing Time. I think we must have started when Lucy was around

one. By the time we got it out she was two and we just heard that she was mentally retarded. But she was watching the demo tapes all the time and soon she started signing. It was an approximation of the sign, for sure, because she didn't have the fine motor skills. If you take your fists and put them by your shoulder like you have CP and move your left fist in just slightly. That was her sign for "more".

She'd been watching the videos daily but she had the will to communicate and our doctor said that CP doesn't get better it doesn't get worse it stays the same. What you see is what you get. Well, her CP has changed. She can finger spell her name and her sister's name. She knows the entire manual alphabet. She is fluent in sign and when she started signing is when she started talking, but the speech came a lot later.

When I look at what we experienced and think if Lucy had been born first, would I have thought this baby has spina bifida, and CP, and we should sign with her? Would I have believed that she was not even in there and she is mentally retarded and she will

never communicate? I hope not. I would like to think that I would have taken the same attitude. I feel so fortunate that I had Leah and who would have guessed that she put her sister in a sign language immersion program since the day she was born. Leah's language opened the doors for communication for Lucy. Lucy started signing and she said, Hey, look I can express myself and I am valuable and I have things that I want to share." Now Lucy's speech is like "Come on mom. Look at what I just discovered. This looks familiar." This is at 4_ and she is fluent in sign.

Yesterday, I recorded 12 new song demos and Lucy is always an underlying theme. Lucy is also my test audience for everything. She is a lyrical genius. I can sing her a song and she can sing it right back. She can hear an entire CD and she can sing it right back. It is creepy but in a really cool way. She loves John Mayer. She LOVES him. "He is my boyfriend," she says. She loves music. So I bounce ideas off of her all the time. I sing her a song and if she is still singing it later that day I know it is a hit with a four-year-old.

Focus of the Month:

Signing Time!: An Interview with Rachel Coleman

The story of Signing Time! begins with Rachel Coleman's sister, Emilie, who began signing with her son Alex to help him communicate with his deaf cousin, Rachel's daughter, Leah. Soon Rachel and Emilie began to see the benefits of signing with a hearing child. Some of these benefits include a larger vocabulary, less frustration, and earlier communication. Coming from a musical family and performing background, Rachel and Emilie have created a fun and easy to learn sign language video series for children of all ages and abilities. My First Signs: Volume 1, Playtime Signs: Volume 2, Everyday Signs: Volume 3 are the first three videos in the six video series. The next three videos were released in December 2004 were Feelings and Fun: Volume 4, ABC Signs: Volume 5, and My Favorite Things: Volume 6.

Rachel Coleman is a mother of two and resides in Salt Lake City, Utah. She began Signing Time! to share her daughter Leah's language with others. Rachel spoke to us in an inclusive interview about her experiences and Signing Time! To learn more about Signing Time! and their products visit them at www.signingtime.com.

This interview was conducted by Kathy Paz and Mary Beth Hazelgrove

Preemies Today (PT): I know you said that you just finished recording a series of songs. We were just wondering what to expect for the future in Signing Time?

Rachel: We are looking at doing Volumes 7, 8, and 9 this year. We will be doing Animals, My Home, and The Places I Go. Then, we will get more specific like Alex and Leah Go to the Park or Alex and Leah Go to the Library.

PT: Do you plan on keeping the videos from a 0-5 kind of age group?

Rachel: Our customer range is really hard. We have infants watching it up to grandmas. We have teenagers watching it. We have people that don't even have kids yet, but have realized this is the easiest way to learn ASL. There is a secret spin-off for the two years and under coming out soon. When does your newsletter come out?

PT: April or May?

Rachel: Oh, good. The entire series will be geared to two and under. It is called Baby Signing Time! The entire series will be similar to Volume 1 where it is one sign at a time and more music. It is also a way to preserve Alex and Leah when they get

older. We are doing 3D computer graphics of Alex, Leah and Hopkins (the Signing Time mascot) as infants. Alex will probably be a crawler, Leah a toddler, and Hopkins will be a tadpole. This is something that I am very excited about. We are thinking it will be videos, music CDs, and board books of the signs.

PT: You are going to change the face of parenting and early childhood education.

Rachel: It really is. It is going to revolutionize parenting. Whenever I do seminars or do presentations my story is using American Sign Language for children of all abilities. It is not just for deaf kids. It is not just for hearing kids or for kids with Down Syndrome. It can benefit every single child.

PT: What is the Signing Time Foundation?

Rachel: We started Signing Time! for Leah to share her language with others and we started the Signing Time Foundation for Lucy. The Signing Time Foundation is going to create universally accessible playgrounds for children across the United States in their communities and their areas. The first one we are going to do is Lucy's Garden here in Salt Lake City. Basically, we are building tributes to these amazing little people and their amazing lives.

PT: With all that you have gone through—the bed rest, the hospitalizations, how do you find the strength to cope with every thing and then help other people?

Rachel: I am a totally normal mom. I try to run three times a week on my treadmill, but I am not the type of person that says, "Oh, look at me. What am I going to do now?" That is not me. We have this pattern from the time that we found out that Leah was deaf to educate ourselves and let's get on with it. I don't want people too feel sorry for my girls or for me. I don't need pity. I want people to understand. I would rather have someone ask a question rather than someone stare at us.

What we are doing is education. In the new upcoming videos you will see more children with disabilities, because I want children to feel comfortable with kids who are different. We bring that into your home and show you that not everyone is blonde and blue-eyed and walking. We want to emphasize you are perfect just the way you are and you are important. You have something to share and I would love it if every parent took that attitude.



The cast of Signing Time! Rachel, Leah, and Alex

You know, I think the first two years when you have a child that is premature or has a disability are so difficult. You have no idea what to expect and nobody can tell you. We basically had to throw a way What to Expect When You're Expecting because they don't even cover fetal surgery. What to Expect in the First Year—burn this. Lucy taught us to throw out all of those timelines. Sometimes it doesn't happen for years and then she is four years old and she learns to sit up. I don't even know when kids are supposed to sit up, and I am like, "Yaah whooo," when she does.

We celebrate every day. That is the attitude that she has given us. She gives us the ability to celebrate every little thing, because it is always a major accomplishment. It is like a miracle in your mix to have a child with special needs.

The first two years I kept asking the doctors when she would reach certain milestones. That is why the song "Shine" was written. "Shine" came out because she was doing these incredible things. Then, we would go through these slumps and I tried not to get disappointed. I tried to support her even when she was in a slump, so to speak, and then all of a sudden, out of the blue, she would do something incredible. And Bam! I would say, "Lucy, look at you. You are shining." Things that we never even knew she could do. She just figured it out. That is why Lucy will do, what Lucy will do, when Lucy is ready to do it. That is what she has taught me and that wasn't even a lyric. That is just something I had been saying for four years.

PT: What advice would you give to parents who are dealing with speech delays to better help them to communicate with their children?

Rachel: Well, Lucy was two and had no words or signs and it didn't look like they would be coming any time soon. I don't know what our story would be if we weren't signing. I don't know how long it would have taken her to figure out how to form those words, but it seemed like sign language gave her something concrete. Then, she could take the time to learn how to pronounce that word.

If you think about it, we all know that people have different types of learning styles. There are visual learners, auditory learners, tactile, spatial and all these different things. Sign language is pretty much the only language that incorporates every single style of learning. It is spatial, visual, tactile and kinesthetic.

Every child has their whole life to learn how to pronounce words. You shouldn't be in a big hurry to get them to pronounce words especially when they have delays. They have their whole life to learn that skill but right now they need to communicate. And the only way they are going to communicate if they do not have speech is through sign. It is a real language used by millions of Americans including my own daughter, and not only is

it a second language but it is a true language. It is not like we just made up this language to communicate. They are using ASL signs and your child can communicate with Leah or the other 1 in 1000 babies that are born deaf every year.

PT: Some parents may be reluctant and give up after teaching their child only a few signs like "milk", "all done", and "more". Do you have any encouraging words for them?

Rachel: People feel overwhelmed or feel self-conscious. I did. When I first started I couldn't imagine sitting in front of anyone but my two-year-old daughter signing. I would be so self-conscious. When you are learning from a book you don't even know if you are doing it right. I hope the feeling people get from Signing Time! is that moms can do it, dads can do it, and grandmas and babies can do it. I can do it.

PT: Do you have any advice to parents who try one or two signs and they think that they just don't get it?

Rachel: The first sign takes a long time. You sign "more" and give them some more. Then, you take their little hands and sign "more". Next, you give them some more again of whatever they are eating, cheerios or milk. You say it at the same time and you really reinforce it. Even with Leah I thought, "I don't think she is getting this." Then all of a sudden she is signing "More, more, more."

More is really powerful. Then they will use it in other contexts like "more daddy." I want Daddy more than you [everyone laughs] More food, more drink more milk. Milk is usually one of the earliest ones. It is one of the easiest hand shapes for babies to do. So when you are nursing them or when you are pump feeding you should say, "Milk, milk, milk, milk. Here is your milk." I see six month old babies who are crying because they are hungry. Their parents sign milk and they stop crying because they know milk is coming.

PT: Why do you feel teaching children sign language continues to be so controversial?

Rachel: You will meet people who will say, "Oh, be careful. You don't want to sign with them too much." People said that about Leah and she was deaf. You don't want her to rely on sign too much and I was like she is DEAF. She can't hear anything and chances are she won't be talking for awhile. Not that we gave up on speech but we wanted to communicate with our child. That is your goal. You want to communicate with your child too. If you would like to do it as soon as possible it will be in sign language. If you want to learn it easy, quickly and in a fun way, then you will want to learn it in Signing Time!

Signing Resources:

Online Sign Language Resources:

www.signingtime.com
www.signbabies.com
www.weehand.com

Books:

Simple Signs by Cindy Wheeler
Signing for Kids by Mickey Flodin
Signs for Me: Basic Sign Vocabulary for Children, Parents, and Teachers by Ben Bahan and Joe Dannis
Teach Your Tot to Sign: the Parents Guide to American Sign Language by Stacy A. Thompson (Coming soon to Amazon.com)
Baby Signs: The Complete Starter Kit
Dancing with Words: Signing for Hearing Children's Literacy

Local News:

Preemies Today Second Annual Yard Sale— Come by and support Preemies Today on May 7th at 8255 George Washington Court in Vienna, Virginia starting at 8 am. (It is located right across from Tyson's Corner Mall.) You will be able to find unique baby items, children's clothes, toys, household items, and furniture. All proceeds from the yard sale will support Preemies Today programs.

May Family Outing— Please join us at 10:30 am on Saturday, May 28 at Kidwell Farms. It is located at 2709 West Ox Road, Herndon, Virginia. Kidwell Farms is a working farm sponsored by the Fairfax County Park Authority. Check out their website at www.fairfaxcounty.gov/parks/fpp/kidwell.htm. Admission is free, so come and join the fun and see the new baby animals. Following our farm yard tour we will be having an international potluck. So please bring your favorite international dish. There are picnic tables and some trees that can provide shade. RSVP to MaryBeth at marybethleightley@prodigy.net.

Support Resources:

"A Friend to Talk to"

Please call us on our "Friend to Talk to" support line and one of our preemie parent vol-

Local Sign Classes for Child and Caregiver:
Signing With Kids
www.signingwithkids.com
Classes in Gaithersburg, Falls Church, Tysons, and Annandale

Tiny Fingers
www.tinyfingers.com
Saturday classes and workshops are held near the Landmark area of Alexandria and weekday classes are held in Springfield

Local Parks and Recreation programs
Check with your local programs. Fairfax County currently offers a baby sign language class called Baby Basics.

unteers can offer you some much needed support. The support line telephone number is 703-994-6624.

NICU Support Group

INOVAHealthsource offers a NICU Support group for current INOVAFairfax NICU families. The meetings are held on the unit and vary month to month. The group is led by Lynn Kuba, RN. For more information contact INOVAHealthsource at 703-204-3366.

Preemies Today Online Chat

Join us every 1st and 3rd Thursday of every month at 8:30 pm for an online chat. For more information contact Julie at jkipers@lmi.org.

Local Support Groups

Local support groups are going strong! On the 2nd and 4th Wednesdays at 7:30 pm we hold our local support group meetings. For more information contact us at preemiestoday@yahoo.com

Preemies Today Playgroups

Preemies Today continues to offer monthly playgroups. Monthly playgroups offer our children a stress-free environment to play. Playgroups typically meet in a member's home or in a location of the group's choice. For more information contact Deborah at Deborah_Leaf@yahoo.com

Helpful Resources:

The following are some helpful resources available by phone and online:

Prince William County Social Services:

www.co.prince-william.va.us/csb/program-sandservices/

Fairfax County Department of Family Services:

(703) 324-7500
www.co.fairfax.va.us/services/dfs/

Social Security Administration:

1-800-772-1213
www.ssa.org

SIDS Mid-Atlantic

(703) 933-9100
www.sidsma.org

March of Dimes

1-800-326-BABY
(703) 425-BABY (Metro DC)
www.marchofdimes.com

Sidelines National Support

1-888-447-4754
www.sidelines.org

Early Intervention/ Infant Toddler Connection

Fairfax County- (703) 246-7121
Alexandria- (703) 838-5060
Prince William- (703) 792-7879
Calvert County- (410) 535-1955

WIC

Manassas- (703) 792-4703
Woodbridge- (703) 792-7319
Springfield (703) 569-1031
Mount Vernon (703) 660-7100
Fairfax- (703) 246-7100

For a list of online resources please go to:

www.PreemiesToday.com

Mission of Preemies Today:

The birth of a premature infant is an extremely frightening and life altering time. Preemies Today strives to form a network of families to offer help, comfort, and understanding to one another through their knowledge and personal experience.

Membership/Subscription

Information:

We offer the Premies Today newsletter, family outings, parent support groups, preemie play-groups, and “A Friend to Talk To”, our call-in line for parents and families of preemies.

To subscribe to the newsletter please contact us at (703) 944-6624. If you would like to become a member of Premies Today please contact Mary at mlundregan@strategicm.com or call (703) 535-1421. Our website is **www.PremiesToday.com**

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Premies Today
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