

# Preemies Today



## *Families Helping Families*

### PREEMIE OF THE MONTH:

*This month's preemie is Rachel Kassis. Rachel is a sweet and fun loving little girl who continues to amaze her parents every day. Here is her story, as told by mom, Jenna.*

I always expected that my pregnancy would be perfect, or at least uneventful, and for the first several months that was the case. In fact I didn't even know I was pregnant until I was about 8 weeks because I never had any of the typical indicators such as nausea or fatigue! All that changed at 28 weeks into my pregnancy. I had horrible cramping through the whole night and the feeling that I had to urinate, combined with feeling that I had horrible gas. The following morning I went for a walk thinking that it would make me feel better. Instead, I started leaking fluid. Totally convinced by my own ignorance, I assumed that I had either some sort of digestion issue or a bladder infection. Later that afternoon, I went to the OB office "just in case." They sent me to the hospital for an ultrasound where it was determined that there was barely any fluid because my water had broken. They told me there was an 85% chance that Rachel would be born within 24 hours.

Over the next two weeks, the doctors were concerned about losing both of us because of a large infection, but somehow my baby never got infected. Miraculously, Rachel was not born until almost 6 weeks later when she arrived on July 7, 2004 at 33 weeks and 6 days gestation. She had an easy NICU stay and was discharged after 1 week. They probably assumed that since she was late-term preemie and was over 5 lbs. at birth, she would be fine. When she was discharged she was still not maintaining her temperature, fed orally but took about an hour to eat an ounce, and although she was still having apnea spells, was not sent home with a monitor. Since we were in the process of moving to Virginia when I was admitted to the hospital, we no longer had a home in Indiana where

she was born so we took her immediately from the hospital to my parents' house in St. Louis. I was assured by the NICU staff that probably no one would ever know she was a preemie and to just treat her like a full-term baby.

Unfortunately large size does not mean that her body systems were any more developed than other 33 weekers'. The day we brought



her home, she started having horrible apnea spells associated with severe reflux. We took her to the pediatrician who gave her some Zantac. In reality I probably should have taken her to the hospital because these spells of her refluxing and not breathing for a minute or more went on for 2 months. I did not leave the NICU with enough information about possible complications. Later I learned that these were called ALTE's (apparent life-threatening events) and require immediate medical attention. If they had kept her in the hospital a few more days, this would have been discovered.

I truly believe that the NICU was probably one of the easiest parts of my preemie's jour-

ney. When she was 6 months old (4.5 months adjusted) and not reaching for toys or holding her head up well, we were very concerned that she had cerebral palsy. Fortunately this was not the case as she soon started reaching milestones. She rolled at 8 months (6.5 months adjusted). Currently, she has surpassed her occupational therapist's expectations and started to crawl right before she turned one. Walking may take a while though because she still has increased tone in her leg muscles, although her hypertonia (increased tone) has dramatically improved. She recently got her first pair of shoes in an attempt to deter her standing on her toes. Most likely, she will need orthotics.

Since birth she has faced feeding issues. Even after she learned to feed from a bottle adequately, she leaked half of it from the sides of her mouth. This continued until she was about 8 months old. Her oral-motor control has improved but we are told her facial muscles are still weak and she may have speech problems later.

Currently, we are still battling issues regarding feeding and breathing. Even after we switched to Prevacid, she still screamed sometimes during feedings. Sometimes she would cough violently and start to wheeze. In May of this year, we went for a swallow study where it was determined that Rachel has a moderate to severe swallowing disorder. She aspirates (meaning the liquid or food goes into her lungs) on any liquid or puree thinner than pudding. Consequently, all her foods must be thickened with a starch thickener (since rice cereal constipates her). She probably also sometimes aspirates her refluxed stomach contents. The doctors are unsure when or if she will outgrow this. Just a couple weeks ago, she had two instances of turning bluish around the mouth and eyes after coughing fits. The starch thickeners also cause her to feel full so she has been strug-

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## Focus of the Month:

### “The Preemie Workout”- Tips From a Physical Therapist

Every child can benefit from physical activity. You don't need to have a fancy gym or buy expensive equipment for your child to improve their gross motor skills. Looking around your home and your child's natural environment you will be amazed at how many things work on strengthening, coordination, and development of gross motor skills. The key is that activities should be fun for the child. If a particular activity is difficult for the child, use a toy that the child likes, sing a song, or create a game for motivation. The key to encouraging gross motor activity and physical fitness in children is to tap into their interests and to make the activities fun.

One of the best places to encourage gross motor skills in your child is at the playground. It may seem that the playground is just a fun place for your child to play but every part of the playground addresses strengthening, coordination, and balance. Even children who are new walkers or are not yet walking can benefit from time at the playground.

**Wood trim:** The wood trim around the playground works great as a balance beam. First hold your child's hands and then as their balance and coordination improves, decrease your support. The wood trim also is an ideal place for new walkers to practice stepping up and down from one step.

**Ladders:** Climbing up the ladders addresses leg strength and coordination.

**Tunnels/Slides:** Crawling through the tunnels and up the small slides can help improve shoulder strength. Going down slides can work on trunk (abdominals/back) strengthening.

**Swings:** A trip on the swings is an opportunity to work on trunk strengthening. In addition, for some children who have difficulty with independent movement, swinging provides them sensory input.

**Uneven surfaces:** The mulch at the playground and the hills around playgrounds are perfect for improving balance and leg strength.

Your home is probably the one place where your child spends the most amount of time. Your home is full of things that can be used to work with your child to address their gross motor skills. Just look around your house and you will discover a wealth of materials that your child will love to play with.

**Stairs:** Stairs are great tools for strengthening and coordination. For prewalkers, encouraging your child to climb up and down the stairs works on shoulder strengthening and transitional movements to stand. For older children, you can have your child walk up sideways and backwards to focus on other leg muscle groups (I would encourage adult supervision while doing this activity).

**Couch Cushions/Pillows:** Soft surfaces such as pillows, comforters, and couch cushions can be used as uneven surfaces to address arm and leg strength as well as balance. Your child can roll, crawl, or walk over the pillows/couch cushions when placed on the floor.

**Step stool:** Stepping up and down from a step stool can work on leg strengthening.

**Laundry Basket:** To work on shoulder strength you can place objects in a laundry basket and have your child push or pull the basket. Even a pre or new walker may enjoy walking behind and pushing the laundry basket.

**Playground ball:** Balls are great to work on strengthening, balance, and coordination. For arm strengthening encourage your child to hold the ball over his/her head while walking or dancing. With larger balls, your child can lie on their stomachs over the ball and support their weight with their arms. Your child can also work on trunk strengthening by sitting on the ball with you holding their hips. Kicking a ball works on balancing on one foot, as well as coordination.

**Bubbles:** You can blow bubbles to encourage your child to reach high and push up onto their toes to catch the bubbles. To address balance skills, you can catch a

bubble on the wand and encourage your child to pop the bubble with their feet.

**Sidewalk chalk:** Make a hopscotch board to work on jumping with 2 feet or hopping with one foot. You can also use the chalk to draw a line as a balance beam.

**Blankets:** The blanket can be used as a tent or tunnel that your child can crawl underneath to address arm strength. This is also perfect for children who are bottom scooters, as they aren't able to go through the tunnel in sitting. Also for arm strengthening, you can place heavy objects on the blanket and have your child pull the blanket. Trunk strengthening can be addressed as your child sits on the blanket and you pull them across the floor.

**Swim Noodles:** You can cut up swim noodles into smaller pieces and place them a small distance apart and have your child walkover them as if they are walking through a ladder to address balance and coordination. (You can also use sticks or brooms to make a floor ladder). They also can be used for a game of tug of war to increase arm strength.

**Jump rope:** Use the jump rope as a rope for tug of war or tie it to the end of a laundry basket so your child can pull the basket for arm strengthening. You can also lay the rope down flat and encourage your child to jump over it.

These are just a few examples of activities that you can do with your child. So many things that are a part of your child's world can address strengthening, balance, and coordination. Outside play at a playground, in your backyard, or even walking around the block can be extremely beneficial. Just remember you don't need expensive equipment to provide your child with an opportunity to develop their gross motor skills.

*This month's contributor is Colleen Wood, MPT, Physical Therapist. Colleen is a Pediatric Physical Therapist, mom of two and the aunt of a preemie.*

## **Local News:**

### **Preemies Today Elections/August Outing-**

Preemies Today will be holding elections for new board members on August 21st. The election will take place during our August family event at the home of Elaine and Tom Noto. It will be a pool party with lots of fun games and activities for the kids. Hamburgers and hotdogs will be provided. Please bring a side dish to share. Please RSVP to Elaine at [ejcbrit@aol.com](mailto:ejcbrit@aol.com) or Mary Beth Hazelgrove at [marybethhazelgrove@yahoo.com](mailto:marybethhazelgrove@yahoo.com).

### **Pentagon City Fundraiser-**

Preemies Today will be participating in the Simon Youth Foundation "Day of Giving" fundraiser at Pentagon City Mall on Sunday, November 20th. You can beat the rush and get a jump on your holiday shopping. This year's event will take place during normal mall hours! Last year over 30 charities participated in this event. There will be exclusive sales, a fashion show, celebrities, makeovers, and food. Tickets are on sale for \$10. Three dollars of every ticket will go to the Simon Youth Foundation to help at-risk youths, and seven dollars of every ticket will go to Preemies Today to help fund our programs. To find out more information, or to buy tickets, please contact Elaine Noto at [ejcbrit@aol.com](mailto:ejcbrit@aol.com)

**Susan Torres Fund-** On Wednesday, June 29th, at Chevy's restaurant in Falls Church, Preemies Today held a fundraiser to support the Susan Torres Fund. Preemies Today is pleased to announce that we raised over \$700. Susan Torres is a 26 year old woman from

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gling with losing weight. On the positive side, her lungs sound good so far, despite the intermittent wheezing, so we have been able to avoid the surgical route.

Rachel also has sensory issues (such as sensitivity to some sounds) and possibly sleep apnea (for which we will soon be doing a sleep study).

Despite the issues, I am so thankful for how well she had done. Rachel is my little joy! She's such an active, happy, and social child who loves to smile at people just as much as

Alexandria who collapsed of a brain hemorrhage caused by a stage four melanoma. She is at the Virginia Hospital Center and, tragically, is brain dead with no hope of recovery. Doctors are fighting to keep her alive through artificial respiration through July to give her baby a fighting chance at life. The cost to her family, after insurance, is around \$1500 a day. For more information, got to her website: <http://www.susantorresfund.org>

### **Support Resources:**

#### "A Friend to Talk to"

Please call us on our "Friend to Talk to" support line and one of our preemie parent volunteers 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 and are 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](mailto: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](mailto:preemiestoday@yahoo.com)

she now loves to crawl up the stairs.

My purpose in sharing this is that I have been frustrated by doctors, even her current specialists (of which there are 4) and therapists (of which there are 3), assuming that 33 and 34 weekers will suffer none of the consequences of prematurity that face younger preemies. If you have a premature baby, you cannot treat them as a full-term child as I have often tried to do. Even late-term premature children are not necessarily immune to the impacts of being born too soon.

## **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/](http://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/](http://www.co.fairfax.va.us/services/dfs/)

#### Social Security Administration:

1-800-772-1213

[www.ssa.org](http://www.ssa.org)

#### SIDS Mid-Atlantic

(703) 933-9100

[www.sidsma.org](http://www.sidsma.org)

#### March of Dimes

1-800-326-BABY

(703) 425-BABY (Metro DC)

[www.marchofdimes.com](http://www.marchofdimes.com)

#### Sidelines National Support

1-888-447-4754

[www.sidelines.org](http://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.PremiesToday.com](http://www.PremiesToday.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 knowl - edge 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](mailto:mlundregan@strategicm.com) or call (703) 535-1421. Our website is **[www.PremiesToday.com](http://www.PremiesToday.com)**

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This newsletter was funded by a Community Grant from the March of Dimes. This material is for information purposes only and does not constitute medical advice. The opinions expressed in this material are those of the author(s) and do not necessarily reflect the views of the March of Dimes.

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