

# PREEMIES TODAY

*Families Helping Families*

## Preemie of the Month: Breeze

### A Four Year Old's Love of Anything Musical Keeps this Infectious Smile

*by Margaret Davis*



Every year on February 2nd we all eagerly anticipate the groundhog exiting his wintry burrow to determine how soon spring will appear. In 2004, the Davis family was surprised by an exit of a very different type when our daughter Breeze Elaine exited her burrow 8 weeks too early.

had built a stable and secure environment to raise a child. Although, I have heard it said before, "The best laid plans often go awry."

I began having horrible morning sickness six weeks after conception. At 12 weeks, I had the "quad-screen" which tested the various hormonal levels in my blood. Despite the fact that I was having intense discomfort, I believed nothing was wrong. I was very excited after learning the good news from my OB's office that the test was "positive". The nurse then explained that oddly enough a "positive" result was not the answer they were hoping for in this case. We would soon learn that we were facing a serious chromosomal abnormality with our child and embarking on a journey that would challenge us in ways we could not begin to imagine.

We had an appointment at the fetal high-risk clinic that afternoon. Before the appointment, I immediately began researching on the internet to try to find some answers to all of the questions that haunted me. I found a world of terrifying, yet enlightening information. I began reading stories from different families such as one expectant mother who was nervous about her quad screen results of a 1:750 chance of having a child with a serious chromosomal defect. I called

See Breeze, page 6...

When my husband Brett and I decided to have a baby, I made sure I was in the best physical shape possible. I had a complete exam from both an OB and general physician and was at a point in my career where I thought having a child would not disrupt our ambitions or plans. We had also reached a place in our lives where we

### *Inside...*

Preemie of the Month.....	1, 6
Calendar of Events.....	2
Dream Dinner Fundraiser.....	3
Children with Special Needs.....	4, 6
Preemie Update and She's Not Six Month's Old.....	5
In Memoriam.....	7

## **Preemies Today is Awarded a \$12,000 Grant from the March of Dimes**

Preemies Today accepts a \$12,000 grant from the Maryland-National Capital Area branch of the March of Dimes to help support its program, "Straight from the Source: Enhancing Parent Support." This grant will help fund the outsourcing of the distribution of the Preemies Today Newsletter, assist with enhancements to the Preemies Today website, and will assist with the expansion of the current Preemie Care Package program.

We are thrilled about the opportunities this grant will provide and we praise the March of Dimes for their continued support and dedication to families affected by prematurity.

**Preemies Today**  
P.O. Box 523525  
Springfield, VA 22152

**Founded:**  
March 2003

**web:**  
[www.preemiestoday.org](http://www.preemiestoday.org)

**email:**  
[info@preemiestoday.org](mailto:info@preemiestoday.org)

**Preemies Today** is a 501(c)3 non-profit organization whose mission is to provide outreach and support programs to families of infants born prematurely beginning at birth and throughout childhood.

**Board of Directors:**

**Chairman:**

Elaine Noto

**President:**

Mary Beth Hazelgrove

**Secretary:**

Heather Ablondi

**Treasurer:**

Vacant

**Board Members:**

Susan Boucher

Danette Cruthirds

Malou Gemeniano

Lauren Greenberg

Lisa Holleander

**Newsletter Editor-in-Chief:**

Mary Beth Hazelgrove

**Content Editor:**

Heather Hall

**Layout Editor:**

Susan Boucher

**Spanish Editor:**

Margaret Behrns

Copyright 2007 (c) All Rights Reserved

## Calendar of Events

### February

**Parent Support Meeting**

February 13th, 7:30 pm  
Barnes and Noble, Fair Lakes, VA

**Dream Dinners**

February 26th, 5:00 pm-8:00 pm  
two locations:

Richland Business Center on Route 7  
21430 Cedar Drive #107  
Sterling, VA 20164

and

1701 Rockville Pike, Space B-7  
Rockville, MD 20852

(See the advertisement on page 3 for more information)

### March

Preemies Today and  
Developmental Delay Resources ([www.devdelay.org](http://www.devdelay.org))  
present a parent lecture series for preemie parents with  
children of all ages beginning the end of March.

Inova Fair Oaks Hospital  
Conference Center  
Dates and Times TBA



In March  
Preemies Today will be celebrating  
It's  
5th Anniversary !!

If you'd like to send Anniversary wishes for the Organization to  
be printed in the March Newsletter, please send them to:

[info@preemiestoday.org](mailto:info@preemiestoday.org)

# Help Spread the Word and Join Us In Support of Premies Today at Dream Dinners

---

Dream Dinners is one of the area's leading meal preparation companies which prides itself on healthy menu options. Dream Dinners will do all the preparation and clean up. Participants will assemble tasty meals to take home and freeze.

When: Tuesday, February 26, 2008

Time: 5:00 pm - 8:00 pm

Cost: \$25.00

Price includes the cost of one meal which serves six people.

60% of proceeds from the event will help support Premies Today Programs

RSVP Menu Selection by February 23, 2008

## Dream Dinners Menu

Select from the following menu options:

### 1. Herbed Chicken & White Beans

Southern Living Magazine & Dream Dinners have joined hands in the test kitchen to create this tasty dish reminiscent of the dishes of Northern Italy.

### 2. Cantonese Pork Chops

Perk up the family's taste buds with this slightly sweet, magnificently savory offering and its divine sauce.

### 3. Tuscan Steak

A blend of herbs, balsamic vinegar, and sun-dried tomato pesto add incredible flavor to these melt in your mouth steaks.

### 4. Pesto Cheese Ravioli, Chicken & Walnuts

Italian cheese filled ravioli are tossed with diced chicken breast and basil pesto sauce.

**RSVP with Menu Selection by February 23, 2007 by contacting:**

**In Northern Virginia—Danette Cruthirds** (703) 430-4490 or [dcru3rds@yahoo.com](mailto:dcru3rds@yahoo.com)  
**In Maryland or DC area—Malou Gemeniano** at (301) 896-0214 or  
[mgemeniano@comcast.net](mailto:mgemeniano@comcast.net)

### What We Do:

We offer local in-person support to families of premies in the extended Washington DC metropolitan area. We provide on-line support to families of premies located across the country and internationally.

### Programs:

Monthly Newsletter  
Parent Support Meetings  
NICU Premie Care Packages  
Telephone Hotline  
Play Groups  
Family Outings  
Parent Education  
Resources Brochures  
Yahoo Group  
Online Chat

## Join Our Yahogroup!

### Subscribe:

<http://groups.yahoo.com/group/PreemiesToday/>

Meet wonderful parents from the DC metropolitan area as well as elsewhere in the United States.

*Walk America is now  
March for Babies*

*Join the Premies  
Today Team this spring  
as we support the  
March of Dimes in their  
continued efforts to  
fight premature birth.*

*[www.marchofdimes.com](http://www.marchofdimes.com)  
[info@premiestoday.org](mailto:info@premiestoday.org)*

## **Increasing Our Acceptance as Parents of Children With Special Needs- David Loewenstein PhD**



*This article was published by Dr. David Loewenstein in the December 2007 Issue of Exceptional Parent Magazine and has been reprinted by permission.*

I had always considered myself to be both a happy and accepting person. At 35 years of age and with a Ph.D. in clinical psychology, I had spent many years helping other people to cope with and to navigate the unfortunate twists and turns of life. On the faculty of a major medical school, my research on Alzheimer's disease and related brain disorders was increasingly gaining national recognition and I was on the fast track for promotion to Full Professor. More importantly, I had married the woman of my dreams who was finally pregnant. We were looking forward to the many exciting possibilities that lay before us. At 23 weeks gestation, my wife experienced a tear in her amniotic sac and gave birth to my daughter Rachel, born, four months premature with a collapsed lung and weighing a mere 18 ounces. Over the next several weeks her weight fell to 14 ounces as her life hung in the balance. For nine agonizing months, my daughter remained in the neonatal intensive care (NICU) unit, suffering a series of setbacks including the loss of several fingers on her right hand, removal of a significant part of her small intestine, bleeding within the brain and retinopathy of prematurity which threatened her eyesight. At a certain point in her hospitalization, Rachel's condition was deemed by her physicians to be hopeless and she was placed in "comfort care" with an order not to resuscitate, so that God could take her.

Rachel miraculously survived her ordeal and we were so excited and grateful to finally bring her home. In the past eleven years since she was born, my daughter has shown equal courage in dealing with subsequent developmental challenges including mild cerebral palsy, difficulties in chewing food, visual deficits and hearing impairment that necessitated bilateral hearing aids. In the process, I have learned more about love and acceptance than all of my years of advanced graduate training. As a psychologist and a father, I have also come to know the parents of other special needs children and what is expected of these courageous children and their families and to better appreciate that acceptance is frequently one of the most challenging aspects of parenting. Accepting the limitations of a child whose life was supposed to be imbued with endless possibilities requires us to come to terms with expectations of ourselves and the world around us. Below I share some specific strategies that can often be helpful in helping to foster acceptance and strengthening relationships within the family.

**1) Remembering that parenting is a marathon not a sprint-** No human being can be a perfect or ideal parent all of the time. Unfortunately, the parents of special needs children may sometimes demand more of themselves than is realistic. In professional sports, a quarterback in football who completes his passes to his receivers 80% of the time is considered stellar while a batter in baseball is considered very successful if he can safely reach base one third of the time. Perfection does not exist in the world of sports and it certainly doesn't exist in parenting. If I can be successful in my actions and decisions as a parent, a significant majority of the time, I can confidently say that I am working towards my goal of providing the optimal launch pad to help my child maximize her potential. Another thing to consider is the following: If we are overly perfectionistic and can not accept our own fallibility, how can we ever expect our children to accept their own limitations of being human?

**2) Nurturing ourselves -** To optimize our effectiveness as parents, we must accept the importance of being adequately able to nurture ourselves. Our lives and relationships are like gardens which must constantly be cared for and tended. We require both time alone as well as with spouses and/or friends to achieve necessary balance. It is also important for parents of special needs children to spend time pursuing specific hobbies or interests, particularly those that reduce feelings of isolation and enhance rewarding interactions with other adults. Finally, parents must remember to pay sufficient attention to the needs of other children and members of the family. As with most things in life, balance is important and helps to avoid unnecessary conflicts and resentments.

**3) Recognizing the importance of collaborative relationships-** The road to acceptance begins with being able to change the "what if" to "what is". It means listening to and accepting the input of others as well as attempting to understand their point of view. This openness is important so as not to overlook particular avenues that may be beneficial to one's child. It is helpful to start early in building both cooperative and working relationships with teachers, counselors, school staff and other professionals in our child's life. Connections with these individuals as well as educational, advocacy and support groups involving other parents of special needs children can be invaluable.

**4) Focusing on strengths-** It is not uncommon for parents to get so caught up with a child's challenges or limitations that they lose sight of the many things that a child is able to do. Successful learning and growth requires utilizing strengths to help overcome areas of weakness. Therefore, it is important to reflect on the strengths of our children and not merely emphasize their challenges. Focusing on strengths also fosters a sense of self-esteem and self-efficacy.

# Preemie Update: by Gregg Discenza



**M**any people meeting Becky for the first time and hearing of her early birth immediately exclaim, "You'd never know she was a preemie!" Our Becky, a former 30-weeker born in September, 2003 and now four years old, has truly defied the odds.

Becky spent 38 days in the NICU at Inova Fairfax Hospital and came home with an apnea monitor, oxygen, medications, and a team of specialists. Deb and I had no idea what to expect. A re-hospitalization five days after her homecoming shook us to the core and left us wondering if we could handle the uncertain future ahead of us. Would Becky walk and talk? Would we watch our daughter run and play with other kids? Would she say "Mommy" and "Daddy"? Would she live to see her first birthday? That first year was scary for us because life as we knew it had dramatically changed and we were forced to examine so many harsh unknowns with our newborn child. Life was anything but "normal".

Once the medical equipment disappeared and Becky shed some private specialists, we looked to the Fairfax County Health Department and the hospital Follow-Along Clinic for therapeutic evaluations. With the slightest gain that Becky made moving forward, we celebrated while keeping a vigilant watch on her development. When Becky entered into Early Intervention at 18 months for gross motor, fine motor, and speech/feeding delays, we were wowed by her speedy

---

## She's Not Six Months Old

By Margaret Behrns

**W**hen my beautiful daughter came home from the hospital she was 4 months old. People thought she was a newborn and remarked how well I was walking for having just had a baby.

She was 10 months old when the weather warmed up and we were able to take her out more. People would ask if she was 6 months old. I liked to tell people about her, that she was a preemie, that she had been really tiny, and that to us she was truly a big baby now.

progress throughout the program. In seven months Becky caught up faster than we had ever expected. She smiled and giggled her way through it all.

Despite all of her gains in therapy, Becky faced a rough second winter health wise that resulted in a diagnosis of Reactive Airway Disease and allergies. We were still amazed at the strength of our little girl as she fought to be a part of a bigger picture while taking medications and other remedies--she seemed determined to explore her world and socialize with anyone and everyone in her path.

Preschool was a whole new world for us. Deb and I found ourselves a bit emotional about this big step for Becky. Feeling both excited and nervous, we were clear with her teacher about wanting to be proactive and not reactive when it came to our daughter. At the first Parent/Teacher Conference the teacher noted a concern that Becky was not talking in school and felt that Child Find should evaluate her. We started the process of getting her evaluated by Child Find immediately. The testing results showed a severe gross motor delay, right hand weakness, and some fine motor issues. We were a bit surprised that her speech was not an issue. Becky entered into the Child Find program and quickly showed us that she loved to play with her preschool teacher as much as she liked to work with her EI therapists. She is in the Child Find preschool program again this year and is doing well.

While so many things appear to be more and more typical with Becky's development, we are aware that she still has some issues. For example, she has finicky eating habits, low muscle tone, a heart murmur, Reactive Airway Disease, and allergies. We may not know all that the future holds for Becky, but we find comfort in knowing that Becky is a sweet and joyful little girl that charms everyone around her. For us she is a symbol of hope and joy. It is an absolute honor and blessing to be her father.

---

Now, she is almost 14 months old. Out of nowhere, a woman asked me today if she was 6 months old. I managed to say "a bit more than that" and got passed the woman before I burst into tears.

I don't know why my emotion got the better of me today. There was nothing different about this woman's attempt to connect with the baby from anyone else who'd stopped to talk. My daughter has made so much progress and come so far. She is off most medications and oxygen. She is crawling, standing, and trying to walk. We feel very fortunate that she is doing so well. That woman meant no harm, but I guess I'm still healing in certain places. Her comment just went right through the heart.

Breeze continued from page 1...

the nurse back and found out that our results were much worse, and my unborn child had a 1:2 chance of a serious chromosomal abnormality.

My husband was in the office building next to me and, as far as I can remember, he carried me to the car and to the high-risk clinic. We were assigned a genetic counselor to discuss our situation. We were shocked to hear what we were up against with this chromosomal defect. The counselor explained to us in a very direct manner that our little girl, that we had already seen through sonograms and had come to love, either had already passed away in the womb or had some major chromosomal abnormality and would likely be a still birth. They were planning to give me an amniocentesis and a level 3 ultrasound, but I had an HCG level that was a record-breaker for that clinic. No one was optimistic. We were told that it was still early enough to terminate the pregnancy and that if she had passed away, they would admit me for surgery.

We completed further testing and to everyone's surprise nothing seemed to be wrong with our Breeze. She was quite small, but seemed fine. I was carefully observed with bi-weekly visits. On January 1st 2004, I was put on bed rest at the hospital as I had been diagnosed with severe preeclampsia. Our daughter Breeze was born on February 2nd in the evening. I wore glasses and during the labor someone had taken them off of me. I was not able to see her for the first thirty-six hours of her life. She was immediately placed on life-support and rushed immediately to the NICU. Her first Apgar score was a zero. She weighed 2 pounds, 15 ounces. My husband saw Breeze before she was taken to the NICU. He will always remind me of how beautiful she was the day she was born.

Special Needs continued from page 4...

**5) Contemplating what really is important-** It is an unfortunate fact that we live in a fast-paced, often superficial world where image and achievement is often over-emphasized. It is important to remember that a child's value and humanity transcends any cognitive or physical limitations. Our children are as unique, special and important as any human being in the universe. Unfortunately, children with special needs are particularly prone to being judged based on appearances. A child's ability to master certain skills such as walking, talking, problem-solving or interacting with others, that many take for granted may be in fact, more heroic than the feats of an Olympic or professional athlete. It is up to parents to appreciate the heroism of their children and themselves. Hopefully, an emphasis on the values of love, acceptance, integrity and cooperation can help to counteract more superficial but nonetheless constant societal pressures such as one's appearance, or how far one can throw a ball.

Breeze stayed in the NICU for eight weeks. She weighed 5 pounds and had a feeding tube in her nose when we were finally able to bring her home. The NICU nurses said that she was a little peanut and that nickname has stuck with her to this day.

Our first diagnosis was that Breeze had cerebral palsy based on the fact that all of her DNA testing came up with no conclusive evidence of any known syndromes. We immediately began speech, feeding, physical, and occupational therapy. We started feeling uncomfortable with her diagnosis as she did not appear similar to children her same age with cerebral palsy. Once again, I hit the internet in hopes of finding more answers to help Breeze.

Three years later and multiple DNA tests, including advanced testing of gene sequencing, we learned that Breeze has Cornelia DeLange Syndrome ([www.cdlsusa.org](http://www.cdlsusa.org)). Her diagnosis explains so many of the challenges she has faced in her four years with us.

Despite the hardships we have faced on this journey with Breeze, we consider ourselves truly blessed. Our daughter walks with the help of a reverse walker, and always has a big smile on her face. She loves music, especially reggae. She also enjoys playing the piano and any other musical instrument she can get her peanut hands on. She turns four this month and we are proud of all she has accomplished. Breeze is living evidence that miracles do indeed happen. Through Breeze we have learned to embrace living in the moment and have found great joy amidst the pain of our best laid plans gone awry.

**6) Living in the here and now-** Despite our best efforts and intentions, bad things happen to good human beings and the universe does not always unfold to meet our hopes, dreams, expectations and demands. Life is not fair and we often have far less control over our lives than we would like. Some parents spend much of their time stuck in the past or preoccupied with worries about the future. However, we only truly have the present moment to love, try to optimize our children's potential, enhance acceptance of ourselves and others and to experience gratitude for what we have rather than harbor bitterness about what might have been. It is these present moments that become the rich fabric of our lives.

*Dr. Loewenstein is Professor of Psychiatry and Behavioral Sciences at The University of Miami School of Medicine. For the Love of Rachel: A Father's Story is available on Amazon.com <http://www.amazon.com/LoveRachelFathersStory/dp/0979194342>.*

# In Memoriam

Phoebe Skye Bobko



Phoebe Skye was born on May 12th at 11:07 in the morning weighing 490 grams. Her gestational age was 27 weeks, but NICU doctors thought her to be 23-24 weeks. However, everyone agreed that Phoebe had the spirit of a full-term baby. She approached every day with more strength and determination than anyone could imagine. More importantly, she affected more people's lives than many of us ever will. For months, off-duty nurses and techs would call in on their days off to check on her. Family, friends, and friends-of-friends were all affected by our little angel. Phoebe was inspirational. The NICU team told us she renewed their spirit and said she made them more careful. Our family is now closer to each other and to God.

She fought valiantly for 126 days but in the end, succumbed to her many medical problems, and died quietly in her mother's arms. It is a terrible thing to lose a child, but I am bursting with pride knowing that my daughter was the bravest and most loving person I will ever know.

Throughout Phoebe's life, the stories of other families from Premies Today kept our hopes up. We are so grateful that we had your newsletter to look to, and the support of your hotline. We want to thank you all, and will keep you in our hearts.

Glenda Bobko, Phoebe's mother

## A Special Thank You to Those That Donated to Premies Today in Memory of Phoebe Skye Bobko

Diane Bobko

Tristan Lai

Jason Miller

Roxanne and Ryan Neuhaus

Debran McClean

Andrea Callanen

Maurice and Jeanette Sobajian

Aaron Westlake

Benjamin Allen

Friends and Coworkers at Wilmer Hale

## **Membership/Subscription Information:**

We offer the Preemies 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. Membership in our organization is free.

For a free subscription to our newsletter and to join Preemies Today please e-mail us at [info@preemiestoday.org](mailto:info@preemiestoday.org) or you may go to our website at **[www.PreemiesToday.org](http://www.PreemiesToday.org)** and click on "Join Us."

This newsletter was funded by a Community Grant from the March of Dimes. This material is for informational 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.

## **Don't Miss These Events!**

### **Parent Support Meeting**

February 13th, 7:30 pm, Barnes and Noble  
Fairfax, VA

### **Dream Dinners**

February 26th, 5:00 pm-8:00 pm  
Rockville, MD and Sterling, VA

***Please RSVP to [events@preemiestoday.org](mailto:events@preemiestoday.org)***

**PREEMIES  
TODAY**

P. O. Box 523525  
Springfield, VA 22152

Do you want to speak with one of our  
Parent-to-Parent volunteers? If so,  
call the "Friend to Talk to" line at

**1-888-712-3208**

or

**703-552-0163**