

# PREEMIES TODAY

## *Families Helping Families*

### PREEMIE OF THE MONTH:

*This month's preemie is Carla Bournigal. Carla is one of our international preemies, born in the Dominican Republic and proof that NICU miracles are happening all over the world. Here is her story as told by mom, Yokaira.*

My story began when I got pregnant with my princess, Carla. I found out that I was pregnant in May of 2005 and my due date was January 31, 2006. I was told that it was a girl at 15 weeks, and she was just perfect. This was my first pregnancy and the first grandchild in my family. Everyone was very excited and my pregnancy went smoothly until I reached 24 weeks.

I went to the bathroom and felt something strange. I told my husband, who called my doctor. The doctor said he was sure it was nothing, but to come in to be checked anyway. I was not concerned at all because I truly trusted my doctor. I knew that he would take care of me like I was his own daughter. It turns out that I had PROM and that I was having contractions. I already was dilated 4 cm and was immediately admitted to the hospital and put on bed rest. I was given medication to stop the contractions and steroids for Carla's lungs. My doctor thought I was going to have Carla that day so each day that she stayed in was a big milestone for us. I kept praying everyday to keep baby inside of me, but God had a different plan for us.

Carla was born on October 22, 2005, at 25 weeks. She was only 1 lb, 3 oz and the doctors told us that she was not going to make it. She was just too small. But my husband said "No! She is going to be okay." I didn't see her until the next day because I was on too much medication to leave my room. I felt a lot of blame, and I just wanted Carla to forgive me for not giving her a perfect home inside of me.

When I finally saw her, it was something that only a mother of preemie can understand. The doctor kept telling me to touch her and to talk to her, but I could not do it. No voice came out of my mouth, for she was surely the most beautiful baby in the world.

Many things happened in the NICU, a



PDA (resolved with medications), NEC (resolved with antibiotics), grade III and IV brain bleeds, ROP (2 laser surgeries), sepsis, anemia, and transfusions. It seemed like everything that could happen in the NICU, did happen. There were a lot of bad days, and also some good. There were many miracles during her NICU stay, things that not even the doctors could explain. Even they knew that she was special and a gift from God. I can surely say miracles do happen and that she is here for a reason.

I still remember the first bottle, the day she

came off of the ventilator, and the first time I held her in my arms. Everybody was praying and for me it was the only thing I could do to help to save my baby. My mom had never let that anything bad happen to me and I felt so helpless not to be able to do the same for my baby. My mom felt the same way because the only thing that she couldn't do for me was to heal my heart.

One day the doctor told me that Carla was going home before Christmas, but every time the doctor said she was going home, something happened. It was as if she didn't want it to go. Even though she was still very small, in the Dominican Republic if the baby is eating and breathing they have to go home, no matter the weight or the gestational age. She was supposed to go home on a Monday, just a special December 26, but nobody said anything because they didn't want to jinx her.

On Christmas Eve I was at the NICU and I was very depressed that she was not at home. I called the doctor that night to ask him if I was ever going to take her home. He said of course, she was going home on Monday, but he added that I could take her home the next morning. Not only was that a day early, but it was December 25, CHRISTMAS! So, I went home and cleaned all evening. Then, we woke up very early and cleaned some more. At 9 am we were at the NICU and Carla was not in her incubator, she was with the healthy babies in the nursery. She was clean and ready to go home. At first I was afraid because I did not know what we were going to do with her at home. I called the doctor and said I don't know what to do.... can she stay here for a few days? Can you imagine that? And he said "NO, she is going home. You are more than ready, I have never seen a mother doing all the things you do for her. She is going." Then

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**Mission of Preemies Today:**

*Preemies Today is a 501(c)(3) nonprofit organization whose mission is to reach out and provide support to families of infants born prematurely beginning at birth and throughout childhood.*

**Vision:** *We will reduce the stress of caring for a child born prematurely by creating a network of families who offer help, comfort, and understanding to one another.*

**Values:** *We strive to promote compassion, inclusiveness, understanding and patience.*

**What We Do**

We offer local in-person support to families of preemies in the extended Washington DC metropolitan area. We provide on-line support to families of preemies located across the country and internationally. Preemies Today is made up mostly of parents of children born prematurely. We network with other parents groups, healthcare providers, therapists, and people providing community resources to obtain information for our members.

**Our Programs**

Monthly Newsletter

Parent support groups

Online Chats

Preemie Play groups

Family Outings

Preemie Care Packages for NICU families

“Take a Break” program for families in need

“Friend to Talk To” support hotline

Resource Brochures

Online Yahoo group

Do you need

A FRIEND TO TALK TO?



If you are stressed or have questions only  
another preemie parent can answer, call us at  
1-888-712-3208

## The Individuals with Disabilities Education Act

Children born prematurely often require specialized attention to assist them in achieving developmental, functional and educational goals. Fortunately, the Individuals with Disabilities Education Act (IDEA) was created to address the needs of children with disabilities from birth to age 21 and many premature children have benefited greatly from services provided by this law.

IDEA was originally enacted in 1975 under the title “Education for All Handicapped Children Act” (Public Law 94-142). Throughout the years it has been re-authorized and amended to meet the changing and prevalent needs of children with special needs. The most recent changes took place in 2004 (Public Law 108-446). The law covers a wide range of topics, from access to early intervention for infants and toddlers to provisions for compliance with No Child Left Behind legislation. Below is a brief outline of basic rights sanctioned by IDEA for children with special needs and their families.

### Early Intervention

Part C of IDEA: Infants and Toddlers from birth to age 3 are entitled to receive related services for identified areas of need. An Individualized Family Service Plan (IFSP) is developed for children determined eligible by an evaluation. The IFSP is a legal document between the early intervention service agency and the child/family.

Services are to be provided in the “natural” environment, such as at home or in a community setting.

Helpful Hints: Children learn the most from birth to age 3 and early intervention has been proven to increase a child’s outcomes when a disability is present. If you suspect your child has any difficulties or disabilities, call your local early intervention agency immediately to schedule an evaluation. Agencies have up to 45 days to conduct the assessment.

Clarification: Infants and toddlers with minor delays may not qualify for early intervention services. Agencies and states have differing requirements to meet eligibility. For example, an agency may require a child be 25% delayed in certain categories to be eligible for services. In this case, a 16-month-old child must function as a 12 month old, or less, in a functional category in order to qualify for services.

The main purpose and goal of early intervention services is to educate and change the way parents and caregivers interact and work with the child’s needs. This differs from therapies provided by the medical and private model of service delivery. For example, a physical therapist from early intervention may instruct parents/caregivers on methods to use in daily life to promote walking. In private physical therapy, the therapist works

directly with the child and performs a variety of exercises specific to the child’s needs.

### Children and Students Ages 3-21

The primary purpose of IDEA for school aged children is to ensure equal access to a Free and Appropriate Public Education (FAPE) regardless of disability. School systems are held accountable to certain standards for teaching students with disabilities and are required to provide equal education to all students. Below are key components of IDEA that provide students with special needs access to education:

Individualized Education Program (IEP): A legal document detailing a student’s areas of needs, service delivery methods, goals and objectives, accommodations, adaptations, modifications, related services and a variety of other relevant information pertinent to the child’s disability.

The Least Restrictive Environment (LRE): Inclusion, or mainstreaming, is the practice of educating students with special needs in the general education classroom with non-disabled peers to the greatest extent possible. A significant effort throughout the past several years has pushed for greater inclusion to ensure children with disabilities are in the least restrictive environment as much as possible.

Preschool aged children, beginning at 2, may receive special services and have an IEP from their local school district if found eligible.

Students with special needs may remain in public education until the age of 21. This is helpful for those who wish to obtain a general diploma, but have difficulty completing the required number of high school credits within four years. Students with multiple, moderate or severe needs may use the extra time to take advantage of school sponsored education or work training programs and transition preparation services.

Mediation and Due Process: IDEA makes provisions if an irreconcilable dispute occurs between a family and the school district’s special education services.

Helpful Hints: Some students with special needs learn best in the general education classroom while others benefit from being in a special education setting part or all of the day. It is important to have a clear understanding of your child’s learning style so you and the IEP team can determine the most effective placement or combination of services for your child.

Make sure your child’s needs and accommodations are well outlined in the IEP. If your child requires extra time on tests or an adaptive device in class, make certain these provisions are listed

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## Preemie of the Month Update: Katelyn's Journey

I first told you Katelyn's story on her first birthday in the November 2004 newsletter. Katelyn has made a lot of progress since then. For those that haven't heard Katelyn's story, she was born on November 16, 2003 at 25 weeks gestation via emergency C-section. She came into this world at such an early gestational age because I developed a life threatening condition known as HELLP Syndrome (Hemolysis Elevated Liver enzymes and Low Platelets) and they had to quickly deliver her to save my life. She weighed 15.5 oz and was 11 1/2 inches long. She had IUGR (Intra-Uterine Growth Restriction) and was the equivalent of a 21 weeker when she was born. We were told she had about a 5% chance of surviving, but she had a different plan. After 159 days (over 5 months) in the NICU at Georgetown University Hospital, she came home.

For the first year after she came home we had 16 hour a day nursing care. She came home on oxygen, an NG tube, an apnea monitor, a pulse ox monitor, neb treatments 4 times a day, and on 10 different medications. She got rid of the NG tube at 9 months of age and the oxygen at 20 months of age. Today she is on 4 different medications and still gets neb treatments every other day. In the summer 2005 she underwent spinal surgery to correct a tethered spinal cord (TCS) and will need follow-up MRI's periodically to make sure it does not re-tether.

The most significant impact from her prematurity is due to her brain injury – she is missing her left cerebellum, which is the part of the brain that controls muscle coordination and motor control. She also had a Grade I IVH (intraventricular hemorrhage). As a result she is behind in her motor skills and speech. She started crawling in June 2006 and cruising about 3 months later. She took her first step at the March of Dimes Prematurity Awareness Day Celebration at Fairfax Hospital this past November. She can now walk on her own. She is not talking yet, but she says four or five words and has learned quite a bit of sign language. She goes to pre-school 3 days a week for 4 hours each day and just loves interacting with other kids. She amazes us each and every day and we are very proud of her progress. She is a very social kid and loves to be around people. I invite you to see more pictures of her and learn more about her at [www.katelynsjourney.com](http://www.katelynsjourney.com).



*Ashley Hall is mom to Katelyn, a business owner and a member of the Premies Today Board of Directors. Katelyn was first featured as Preemie of the Month in the November, 2004 issue.*

## Walk America 2007

Spring is in the air and that can only mean one thing. It is time for the March of Dimes Walk America!

Many of us at Premies Today remember Walk America vaguely from our elementary school days. Going door to door to get our neighbors to sponsor us and earning a t-shirt or poncho if we raised enough money. We felt good about helping, but it was more about hanging out with our friends for an afternoon than raising money. We quickly forgot the reason for the walk and the importance of the March of Dimes. It wasn't until years later when faced with the birth of a premature baby that we fully appreciated what the March of Dimes has done and does for millions of babies for over a half century.

The March of Dimes was established in 1938 to battle polio and in 1952 that battle was won with the development of the polio vaccine by Jonas Salk. This was just the beginning of the March of Dimes fight to save babies through research and education. The March of Dimes has now turned its efforts toward preventing premature birth as well as other causes of infant mortality and birth defects. Since 1984, the March of Dimes has funded at least 200 grants related to low birthweight and prematurity totaling more than thirteen million dollars.

In addition to funding medical research, the March of Dimes also is committed to funding projects in the community. The March of Dimes, National Capital Chapter, has generously funded the Premies Today Newsletter since soon after its inception in 2003.

Walk America is the March of Dimes largest fundraising effort and support from all of us is critical to its success. Now is the time that we can help the March of Dimes in their mission to save babies by walking or sponsoring a Walk America walker.

For more information about Walk America, or to join the Premies Today family team please go to [www.WalkAmerica.org](http://www.WalkAmerica.org).

*All static information and the full history of the March of Dimes can be found at their website, [www.marchofdimes.com](http://www.marchofdimes.com).*

## Fundraising Strategies for Walk America

Since Katelyn's birth, our family has gotten really involved with the March of Dimes, who has launched a national campaign to raise money for prematurity research to help other babies like Katelyn. Katelyn is alive today because they funded research that resulted in the development of surfactant, a substance that helped her immature lungs to develop. Somehow, we have managed to raise over \$35,000 for the March of Dimes over the last two years. As a result, Premies Today has invited me to share with you some of our fundraising strategies. These are the strategies that we have used to make our fundraising results so successful. For Walk America 2005, we concentrated on encouraging every one we knew to contribute. We set up a web page on walkamerica.org and used their on-line fundraising tool (OFT). We sent out thousands of e-mails to co-workers, friends, and family asking for donations. We asked our friends and family to do the same. We raised \$10,500 that year. Last year, we decided to host the Team Katelyn Walk America 1st Annual Golf Tournament. We printed up packets and distributed them to business all around Loudoun County. It was a huge success and we ended up with 136 golfers (144 is a full course) and over 30 sponsors. The tournament raised \$16,000. We raised another \$8,000 through personal donations and a bar in our community sold shamrocks during March and gave all the proceeds to Team Katelyn. We cut out hundreds of green shamrocks and Katelyn's story with now and then pictures that they showed their customers. This year we are partnering with Premies Today for the Team Katelyn Walk America 2nd Annual Golf Tournament. We also asked the same bar to sell shamrocks again this year. In addition, we have a local pizza restaurant selling pizzas (small paper pizzas) to their customers. It's a great way for local businesses to support your cause since they are soliciting money from their customers and then giving it to the March of Dimes for Team Katelyn – it's a great tax write off for them. So, our success has been from e-mailing solicitations, holding a fundraising event (in our case a golf tournament, but other ideas include a skate-a-thon, walk-a-thon, bike-a-thon to name a few), and asking local businesses solicit their customers. We provide them with paper cutouts that people can buy and they post them on their wall. We also give them a story of Katelyn for people to read so everyone can see whom they are donating for.

*Ashley Hall and her husband, Michael, have made Team Katelyn one of the most successful MOD Family Teams in the Metro area. They plan to continue this tradition for Walk America 2007*

*continued from cover; Carla's Story*

he called the nurses and told them that I have to take her home. I don't think is a coincidence that she came home that day. For me it was a sign from God that she was going to be okay. After all, it was Christmas.

I have to give thanks to all the doctors, and nurses that took care of Carla in her NICU stay in the Dominican Republic, they were more than great. They not only took great care of Carla, they took care of me too.

So we went home, without monitors and Carla weighing only 2 pounds and 7 ounces. We were instructed to count her heartbeat and breaths, take her temperature, look at the color of her nails and lips to see how her oxygen saturation was and the color of her feet to monitor for anemia.

We decided to move from the Dominican Republic to Boston, MA to give our baby the best services possible. We knew because of the brain bleeds that she will need a lot therapy.

It has now been almost a year since we moved to Boston. She was not even moving her head when we moved here, but now she is crawling, saying more than 6 words, and trying so hard everyday. She continues to amaze everybody because she was not suppose to do all the things she is doing. Because of her brain damage she had a VP Shunt placed three months ago. But God has always been with us, always by my side, in every tear, every night and every second of her life.

Carla is my inspiration everyday, I am so blessed that my baby is here with me. She is conquering all the obstacles put in front of her and trying so hard to achieve every milestone. I have a lot of hopes for her and I know she is going to be fine. Maybe she will no got to Harvard, but then again, who knows? Only God has the plan for her life, and I know that it is a perfect one.

*continued from page 3, IDEA*

in the IEP so the accommodation can also be used during state and national testing.

A child's needs may change rapidly and you have the right to request an addendum be made to your child's IEP at any time to reflect these changes.

IDEA has made a significant impact for millions of children with varying degrees of disabilities. However, parental involvement and advocacy are key to making sure a child's needs are being met. Understanding IDEA and IFSP's or IEP's can be overwhelming for parents new to the field of special education, but fortunately, many resources exist to assist parents in learning about the process.

**For more information, contact the following:**

[Parent Educational Advocacy Training Center](http://peatc.org)  
<http://peatc.org>

[National Dissemination Center for Children with Disabilities](http://www.nichcy.org)  
<http://www.nichcy.org>

*This month's contributor is Kimberly Avila M.A., COMS. Ms Avila has worked in the public schools as a vision specialist and is the mom to a preemie.*

## Local News:

### Preemies Today Walk America Team

Preemies Today is proud to support the March of Dimes WalkAmerica. WalkAmerica is a great way to celebrate and remember all babies, particularly those born prematurely. This year, the main Preemies Today group will walk in Washington, DC on Sunday, April 29. But you and your family can walk at any of the 1,100 walk sites across the country and still be part of the Preemies Today team!

To join our team, go to [www.walkamerica.org/335801](http://www.walkamerica.org/335801). If you have a Family Team, you can still be a part of the Preemies Today team. Just email [susan.boucher@gmail.com](mailto:susan.boucher@gmail.com).

All families touched by prematurity are asked to create a scrapbook page. The pages will be collected and bound. The scrapbooks will travel to the local WalkAmerica sites for walkers to see.

Two local WalkAmerica sites, Washington, DC, and Reston, VA, are having a very special program when the walk is complete. Families who have experienced the birth of a premature baby are asked to participate in a mini-parade, set to music. Families will have the opportunity to take a few minutes to share their stories, both to celebrate and remember their children but also to show walkers what prematurity looks like.

For more information on Family Teams contact Dona Dei, Program Director at the March of Dimes National Capitol Office at 703-824-0111 or [ddei@marchofdimes.com](mailto:ddei@marchofdimes.com).

### Walk America Sites for 2007

#### **Virginia-**

Springfield- 4/22

Reston- 4/22

Manassas- 4/22

Leesburg- 4/29

#### **Maryland-**

Prince George's County- 4/21

Charles County- 4/29

Rockville- 5/6

#### **Washington, DC- 4/29**

### Health Professional of the Year: Call for Nominations

Preemies Today is currently accepting nominations for our annual Health Professional of the Year Award. This is a great way to thank someone who went above and beyond for you and your preemie. Please submit an essay of no more than 500 words about your nominee. The nominee can be a nurse, doctor, therapist, or any other health professional that cared for your child in the NICU or after discharge. Just let us know why they are special and how they help preemies and preemie families. All submissions must be received by April 1, 2007 to be considered. Please submit your entry to [DeborahLeaf@preemiestoday.org](mailto:DeborahLeaf@preemiestoday.org).

### Team Katelyn/Preemies Today Golf Tournament

The Team Katelyn/ PreemiesToday golf tournament will take place on April 4, 2007. As of April 1, the tournament has raised over \$20,000 through tournament sponsorship for the March of Dimes and Preemies Today. It has been so popular that there is a waiting list for golfers, who look forward to playing at the Lansdowne golf club. All proceeds will go to March of Dimes Walk America 2007 and to Preemies Today to help support its programs such as the telephone-support line, support groups, and the Premie Care Package Program. Look for the final tally and a list of sponsors in the May newsletter.

## **Preemies Today Support Programs:**

### *"A Friend to Talk to"*

Our "Friend to Talk to" support line is up and running. Please feel free to give us a call and one of our preemie parent volunteers can offer you some much needed support. The support line telephone number is 703-552-0163, or toll free number at 1-888-712-3208.

### *NICU Support Group*

INOVA Healthsource is continuing to offer a NICU Support group for NICU families at INOVA Fairfax. The meetings are held on the unit and vary month to month. The group is led by Lynn Kuba, RN and is a great opportunity to talk about your experience in the NICU. For more information contact INOVA Healthsource at 703-204-3366.

### *Take a Break*

Preemies Today offers meal preparation assistance and additional support for preemie families in crisis. If you are in need

of assistance or would like to volunteer to help others, please contact Susan at [susan.boucher@starpower.net](mailto:susan.boucher@starpower.net).

### *Preemies Today Online Chat*

Join us for our monthly online chats. This is a great outlet for new parents who still can't get out for our support groups. For more information contact Julie at [jkipers@lmi.org](mailto:jkipers@lmi.org)

### *Local Support Groups*

Local support groups are going strong! On every 2nd Wednesday at 7:30 pm we hold our local support group meetings. For more information email Deborah at [deborah\\_leaf@yahoo.com](mailto:deborah_leaf@yahoo.com).

### *Yahoogroup!*

Come and join our yahoogroup and meet some of our wonderful parents where you can exchange information on preemie parenting. You can subscribe at <http://groups.yahoo.com/group/PreemiesToday/>

## **Helpful Resources:**

### **National Resources**

#### **Social Security Administration:**

1-800-772-1213

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

*Many premature infants qualify for Social Security Disability, regardless of parents income. Ask your NICU social worker or contact the SSA to see if your child qualifies.*

#### **March of Dimes**

1-800-326-BABY

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

*The March of Dimes has a wealth of information about preterm labor and premature birth. It is also a great place to start in looking for support in your area.*

#### **Sidelines National Support**

1-888-447-4754

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

*Sidelines provides support for pregnant women on bed rest and those dealing with the after effects of bed rest.*

#### **SIDS Mid-Atlantic**

(703) 933-9100

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

*Look here for information on how to prevent Sudden Infant Death Syndrome.*

### **Metro Washington, DC Resources**

#### **Social Services- Virginia**

Alexandria- (703) 838-0700

Arlington County - (703) 228-1550

Fairfax County- (703) 324-7500

Fauquier County- (540) 347-2316

Loudoun County- (703) 777-0353

Manassas City- (703) 361-8277

Manassas Park - (703) 335-8898

Prince William County- (703) 792-7500

#### **Social Services, Maryland**

Montgomery County- (240) 777-1245

Prince George's County- (301) 909-7025

#### **Social Services, Washington, DC**

Department of Human Services- (202) 671-4200

### **Early Intervention/ Infant Toddler Connection**

*This is a federally mandated program available in every state to screen and treat children under the age of 3 for developmental disabilities and delays. If you have any concerns about your preemie's development, contact your local office to have your child tested. Services are covered by most insurances and are billed on a sliding scale.*

#### **Virginia**

Alexandria- (703) 838-5060

Arlington County- (703) 228-1630

Fairfax County/Falls Church City- (703) 246-7121

Loudoun County- (703)-777-0561

Prince William- (703) 792-7879

**Washington, DC-** (202)727-8300

#### **Maryland**

Montgomery County- (240) 777-3997

Prince George's County-(301) 265-8415

#### **WIC**

*Provides food, nutrition counseling, and access to health services to low-income women, infants, and children under the Special Supplemental Nutrition Program for Women, Infants, and Children, popularly known as WIC.*

#### **Virginia**

Manassas- (703) 792-4703

Woodbridge- (703) 792-7319

Springfield (703) 569-1031

Mount Vernon (703) 660-7100

Fairfax- (703) 246-7100

**Washington, DC-** (202) 645-5662

#### **Maryland**

Montgomery County- (301) 762-9426

Prince George's County- (301)856-9600

**For a more complete listing of resources please go to:  
[www.PremiesToday.org](http://www.PremiesToday.org)**

**Membership/Subscription Information:**

We offer the Premies Today newsletter, family outings, parent support groups, preemie playgroups, 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 Premies Today please email us at [info@preemiestoday.org](mailto:info@preemiestoday.org) or you may go to our website at [www.PremiesToday.org](http://www.PremiesToday.org) and click on "Join us."

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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.



*P.O. Box 523525  
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Do you need to talk to someone who understands the preemie experience? If so, call the "Friend to Talk to" line at **1-888-712-3208**