

# PREEMIES TODAY

*Families Helping Families*

## I was a Premie for a Day!

NICU Nurses Learn What It Is Like To Be a Premie

*by Mary Beth Hazelgrove*

**T**his month, in honor of Prematurity Awareness Month, we are featuring the Premie for a Day in-service which will be sponsored again this year by the March of Dimes and in conjunction with the Perinatal Council and the INOVA Health System. The program will take place for INOVA hospital staff on November 12th. The program's purpose is to give NICU Nurses and staff a glimpse of how the NICU is experienced by premature infants and their families. Participants will also learn developmentally supportive and family-centered care which ultimately helps improve developmental outcomes of premature infants. I was invited to attend this event last year in order to share this experience with other parents and this is my story.



*A NICU nurse experiences what infants go through when they are born prematurely*

voice. Suddenly, my sense of security was quickly taken away. My immature organs were forced to function. Stress! I remember lots of bright lights, noise, and bitter coldness.

My nurses and doctors tried to comfort me by shielding my eyes. My eyes lids were simply too thin and could not adequately block the overhead lights. The medical team warmed their hands and the instruments before they touched my body. My nurses placed me in a side-lying position with my hands near my face. This gave me a feeling of security like when I was in the womb. It was important to tuck my legs, and keep my hips, shoulders, neck, head, and ankles flexed. These positions were comfortable for me and would make it easier for my muscles and body when I started crawling and walking. My nurses also tried to keep my head in midline and support the back of my

head with a gel-pillow to help with my development and the shape of my head. I was also placed in a snugly with bumpers around me to help me feel more contained. Whenever my little foot popped out from my blankets my nurses repositioned it back in the snugly and placed a blanket over top. I liked pushing my foot on something because it helped remind me of what it was like inside of my mother.

My NICU nurses and doctors cared for me with such compassion. They let me rest when they knew that I needed it. They draped a blanket over my isolette so that I would not be disturbed by too much light. They spoke to my parents with ease and away from my bedside. They repeated important information not just once or twice but sometimes up to seven times because they knew how overwhelming the NICU could be for them. They also encouraged my parents to help get involved with my care beginning with diaper changes and temperature checks. My special nurses comforted me by giv-

See **Premie for a Day**, page 5...

### Inside...

Preemie for a Day.....	1, 5
Calendar of Events.....	2
Program Updates.....	3
Rx for Hope.....	4
Prematurity, is it Hereditary?.....	5
RSV Survival Tips, Local News.....	6
Resources.....	7

warm place where I could hear the soft tone of my mother's

I was born too early, and I weighed less than either of my parents had ever expected. My mother likes to tell the story of one of her visits with her OB--when the doctor thought she would have a baby that would weigh between seven and ten pounds. Boy was he wrong!

I distinctly remember the day that I was born. I wasn't feeling quite right, but I was tucked in a nice

**Preemies Today**  
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**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.

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## Calendar of Events

### November

#### **Prematurity Awareness Day**

November 13th

Show your support of the March of Dimes and their fight against prematurity. Lawn Signs are available. Contact [marybethhazelgrove@preemiestoday.org](mailto:marybethhazelgrove@preemiestoday.org) to get yours today.

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#### **Parent Support Meeting**

November 14th, 7:30 pm

Barnes and Nobles, Fair Lakes, VA

### December

#### **Holiday Cookie Exchange**

Bring 5-6 dozen cookies to assemble for local NICU families.

December 15th, 7pm, Bethesda, Maryland

or

December 16th, 2 pm, Burke, VA

Contact: [laurengreenberg@preemiestoday.org](mailto:laurengreenberg@preemiestoday.org)

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#### **Preemies Today Holiday Party VA/MD**

December 2nd, 10:15 am

The Bannockburn Clubhouse, Bethesda, MD

December 9th, 3:30 pm

Reston Regional Library, Reston, VA

#### **Mailbox: A Special Request!**

Please send us your preemie milestones, special memories, or holiday wishes about your preemie to [info@preemiestoday.org](mailto:info@preemiestoday.org). All entries will have the chance to earn a stylish diaper bag that was donated especially to Preemies Today by Fleurville Inc. [www.fleurville.com](http://www.fleurville.com)

**All submissions must be received by November 15th for consideration and your chance to win!**

# Program Updates

## Holiday Giving/Celebrations

Preemies Today has a lot of exciting things going on during the months of November and December. The holidays in the NICU can be a difficult time and Preemies Today hopes to relieve some of the stress by providing Holiday cards and cookies for NICU families. We also offer a holiday gathering for families to meet one another.

✦**National Members:** You can participate in the Holiday card giving. Please contact your local NICU and speak to a social worker, head nurse, or clinical nurse specialist to see if a non-religious holiday card could be distributed by nurses to NICU families. Then, send us the contact name, address, and approximate number of cards needed. The number of cards we provide is in relation to the number of beds in each NICU.

**Local members:** If you are unsure if Holiday cards are distributed to your baby's NICU, then contact us at [info@premiestoday.org](mailto:info@premiestoday.org) or call 703-552-0163.

**Cookie Exchange** This has become an annual tradition. Not only do we get to sample great cookies, but we get to pass along holiday cheer to the local NICUs. If you are interested in participating in the VA or MD exchange please contact Lauren Greenberg at [laurengreenberg@premiestoday.org](mailto:laurengreenberg@premiestoday.org) for the details.

**Holiday Gathering:** For the first time this year we will be having two holiday gatherings. We will host one in Virginia and one in Maryland to help better support families in both areas. Everyone is welcome to attend. Please RSVP at [events@premiestoday.org](mailto:events@premiestoday.org)

**White House Ornaments:** We have sold 100 ornaments! We need to sell more in order to meet our financial goals and have sufficient funds to support the local NICUs during the Holidays. If you have any family or friends interested in purchasing these ornaments please contact Elaine Noto at [elainenoto@premiestoday.org](mailto:elainenoto@premiestoday.org).

## Play Groups--Interested in Joining?

Please contact Julie Kipers at [juliekipers@premiestoday.org](mailto:juliekipers@premiestoday.org)

### **Preemies Today Winter Holiday Party**

Reston Regional Library, Reston, VA  
December 9, 3:30-6 pm

With Special Guest:

Music Therapist Myra Parker Goodrich, LCSW, MT-BC  
**Therapeutic Rhythms, LLC**

**Music therapy can help attention, speech, & motor development**

### **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.

### **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.

## **Volunteer**

Email us at [info@premiestoday.org](mailto:info@premiestoday.org) for more information.

## *Take a Break*

We need your help to serve food and refreshments for local NICU families during the months of November and December. Please email Susan Boucher at [susanboucher@premiestoday.org](mailto:susanboucher@premiestoday.org) for more information.

## Rx for Hope By Suzanne Lago Authur

### A Special Message to NICU Nurses.

**W**hat can I say to help improve the performance of people who save lives every day? From my vantage point they are doing all the right things. There is very little that I could say. It would be like telling last year's NFL MVP and Super Bowl champion Peyton Manning how to best read the field. NICU nurses are my Super Bowl champions. I owe everyone who helped save my son Alexander, a 26 weeker who was born at just 1 lb, 2 ounces and spent 149 days in the NICU, never-ending gratitude. Because of their dedication to their jobs, I get to hold him everyday and tell him how much I love him. That is a gift beyond measure. However, if I were to offer them some advice it would be something along the lines of the following:

Forget what they told you in your training about preparing your patient's family for the worst. You have a tougher job ahead of you. You are the front line reinforcements. You are right there with these families in the trenches as they fight daily against all odds to save their precious babies. What they need to hear from you is as Dr. Baker puts it is "cautious optimism". Take a moment to look at your new patient's mother--I think you will find she is a lot like me. In one rapid moment her world has been turned inside out completely. She is still reeling from the loss of a perfect pregnancy, a dream every woman holds onto in the same way she dreams about her perfect wedding day. She is exhausted emotionally, physically and spiritually. Her marriage is strained and she may even be having a crisis of faith. She probably also blames herself for putting her baby in this precarious situation to begin with, even if there was nothing she could have done to prevent it. Desperately she struggles to understand all the machines tied up to her baby and in your face she scans for a look that will give her hope or ruin her day. Hope is the only thing she has going for her at this moment. And you my dear nurses, and I say this with all due respect, have no right to take this from her.

For the sake of your patient's well being, you must give his or her mother a reason to get out of bed every morning. I know you believe that you need to be realistic with mothers to avoid any future disappointments, and to a certain degree you are right. The problem arises when every single person this new mother encounters, every new nurse that signs on with each new shift, tells her his or her perspective of what the future holds. I can't tell you how many nights I cried myself to sleep worrying about things told to me, by well-meaning nurses, which never came to pass. A woman in this position, with such a huge learning curve ahead of her, can only deal with so much at one time. Give her a chance to digest what she can and to go at her own pace in understanding the medical complications that may lie ahead. Even if the unthinkable is her child's fate, do not rob her of hope in the present moment. Miracles happen so please allow her to live with that possibility on one. I know of one child who was given his last rites and is crawling around today as if nothing ever happened.

Only offer your opinions if she directly asks for it. When you do answer her be as clear as possible but do not linger on the negative. Help her to refocus her energy onto the positive so that she can be there for her baby. A happy mother will be more attentive to her child and will be able to produce more milk. By helping the mothers you are indirectly helping your patients. And although you may be able to still remember the patients who did not make it, I am willing to bet that you have seen many more happy endings than not. Share these happy endings with mothers and if you want, you can start with ours.

*Suzanne originally wrote this for a NICU nurses' newsletter and has given us permission to print it here for preemie parents.*

**\$15 OFF our Winter Session with this ad if enrolled by Nov. 15th!**

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**Bethesda, Potomac, Rockville & Kentlands!**



**COME CELEBRATE THE WINTER HOLIDAYS WITH PREMIES TODAY AND SPECIAL GUEST:**

**Sing Along with Karen**

Sing holiday songs and meet preemie families from **Maryland**

The Bannockburn Clubhouse  
6314 Bannockburn Drive  
Bethesda, Maryland 20817  
10:15 am

RSVP [events@premiestoday.org](mailto:events@premiestoday.org)

## Prematurity, is it Hereditary? by Maria Zirpoli



My mother was carrying twins, but she didn't know it at the time. Then, suddenly, at 25 weeks she gave birth to me and my twin brother. She was having mild cramps and went in for a check up. Much to her surprise, she was fully dilated. Her pre-term delivery was a result of what I believe was an incompetent

cervix. After she gave birth to me and delivered the placenta, she still felt like pushing. Low and behold to everyone's surprise out came my brother! I get such a kick out of this part of the story.

My brother and I were in the NICU for four months. No one was allowed to touch or hold us. My mother said that her visits consisted of the NICU staff showing my brother and me to her through a glass door. I can only imagine how painful it must have been for her. From the start, the doctor warned my mother not to fall in love with us because we were not going to survive. Can you imagine that? She must have been afraid for us, but was unable to draw even the slightest bit of

comfort from direct contact with her newborn babies.

This delivery happened 38 years ago, before premature babies received treatments which are considered standard for today such as physical therapy, early intervention, new and more specialized surgeries, and surfactant therapy. All things considered, we did remarkably well. I'm very happy to report that I feel no ill effects from the prematurity and neither does my twin brother.

Oddly enough my mother went on to have three more full-term pregnancies, which gives me a bit of hope for my next one. I did read somewhere that the tendency to have pre-term birth can be hereditary, but I have not read anything more substantial, such as a medical journal, to confirm it. It is interesting to note that my birth weight was the same as my Giovanni's, 11lb, 15 ounces. One can speculate about the causes of our pre-term births in terms of coincidence or genetics, but regardless of how the end result came to be my son, my brother, my mom and I share a unique bond--the premie connection.

*Maria and her twin brother Mario shown pictured at a year old.*

### Preemie for a Day continued from page 1...

ing me a pacifier to suck on. They also monitored the noise in the room and talked in low voices to help protect my ears.

One of my favorite memories of the NICU was of my swaddle bath. My nurse showed my mom how to do this and she soon started giving me one too. During my bath a blanket would be placed around me in a loose swaddle. I would be gently lowered into the warm water that was held by a tub just my size. The water would then be almost at my neck level. It felt so nice. One side was gently exposed to the water and washed nice and clean and then recovered. The next side would then be uncovered, washed, and recovered. My body would stay nice and warm and then I would be transferred to nice warm blankets and I never felt the cool air. Afterwards, I eagerly awaited my bottle before I would begin a restful sleep.

Eating was always challenging for me, but my nurses took great care to make sure my parents were involved whenever they were visiting. I would give everyone cues to let them know that I was hungry. Sometimes I would be drowsy other times alert. I showed I was ready to eat when I started rooting and placed my hands to my mouth. It took a long time for me to take all my food by bottle. For many weeks I had a tube that went up my nose and down into my stomach. My nurses adapted my feeding routine to suit my needs, as a result I started eating and gaining more weight. They always put me in a secure position and gave me facial support when-

ever I needed it. They taught both my parents these techniques as well so they were always involved in my care.

Before I transitioned home the nurses went over so many instructions with both of my parents. There was so much to learn. Being at home is very different than being in the hospital. They taught my parents that I was to sleep only on my back and told them I needed plenty of time on my tummy when I was awake. This is an important position to help me develop my muscles. I was also not allowed to have anything in my new bed at home. My parents soon learned that blankets, toys, and positioning aids could put me at risk for Sudden Infant Death Syndrome (SIDS). Premies have an increased risk for SIDS and parents have to be aware of the dangers of having these items in the bed. It was different but I didn't mind, because I was too busy enjoying the peacefulness of what I now knew as home. As for the blankets I did not miss them one bit since I was introduced to a sleep sack.

***"My parents learned that blankets, toys, and positioning aids put me at risk for SIDS"***

My parents will be forever grateful for the level of care that I received while I was in the NICU. My mom says that the nurses and the doctors are all heroes. They not only saved my life, but they showed me and my family compassion. They also cared for me in a way that gave me the best chance of reaching developmental milestones! Thank you to the entire NICU staff and to the hospitals that continually train and educate their healthcare professionals to offer the best quality care to infants born prematurely.

# RSV Season Survival Tips for Parents

**T**his is the season that so many preemie parents dread. For many the isolation of RSV season is difficult but just lasts one year. For others it continues on into the second year. How do you make it through this difficult time? Here are a few tips sent in by some veteran preemie parents to help you relax and relieve the stress of day-to-day life while caring for your premature infant.

- **Order take-out** Eating out was part of our weekly routine. During RSV season we still ate restaurant food once a week but we did so at our kitchen table and ate on paper plates. There was no cleanup and it was a nice change of pace.

- **Bathe them often!** Our oldest child was still allowed to attend preschool as long as she had a bath first thing after she came home, and all her clothes worn to preschool were laundered right away. Lots of germs are spread via clothing. At that age, kids need more than just handwashing -- they need a bath.

- **Don't forget the siblings.** We gave our preschooler a puppet theater for her birthday that winter. It was something she could do with fairly minimal supervision. I'd be folding laundry or emptying the dishwasher while she was performing for her baby brother. She loved the creative play and our son loved watching his big sister.

- **Turn the TV off and play music.** I tried to stay away from anything too emotional. The stable rhythm of Mozart, Bach, or even Madonna definitely helped structure my day and calmed my emotions.

- **Exercise at least a half hour a day.** I would do step aerobics as I watched TV shows such as Dr. Phil or all shows--don't laugh, he's strong and stable. Sometimes I stepped to disco music and then I would stretch and do yoga.

- **Call a friend.** A good conversation with a friend was always helpful.

- **Make time for your hobbies.** I would practice my violin, my hobby, and my profession, daily for an hour or so in the wee hours of the night.

- **Go for a walk.** When the weather was nice I was able to take my daughter and son out for a walk.

- **Get Connected.** Get involved in online communities where you can share stories about your life or take an online class.

- **Keep a list** of fun things to do with your baby or child in a very visible place. That way when you are climbing the walls, you can just select an activity off the list.

- **Use your stroller as a safety guard.** If you do need to go to the store with your child, use your child's stroller basket as your cart. My motto is, "If it doesn't fit in the stroller I don't need it now."

- **Visit a few safe friends.** Refer to yourself as "bubble people" to family and friends when you ask them for the 100th time if anyone is sick before making visits.

- **Do what makes you feel good.** Map out where your local Starbucks drive-through is and use it often--this tip alone kept me sane whenever I just wanted to get out of the house with the baby.

- **Don't forget your spouse!** Most importantly, my husband was there for me, and we were surviving together.

*All of our babies are very special to us, but we certainly need to remember to take care of our own needs and the needs of the rest of the family, too! A special thanks to Natalie Trainer, Suzanne Lago Authur, Margaret Behrns, and Debra Stepel for contributing their survival tips.*



## Local News...



### SIDS Mid-Atlantic and MIS Celebration of Remembrance

Sunday, November 11th, 5 to 8 P.M.

The Unitarian Universalist Church of Arlington

4444 Arlington Boulevard, Arlington, Virginia

**Family and friends of babies who have died from any cause are welcome to attend.**

# Helpful Resources

## Websites and Numbers

**March of Dimes**.....[www.marchofdimes.com](http://www.marchofdimes.com)  
The March of Dimes offers a wealth of information about preterm labor and premature birth.

**Social Security Administration**.....[www.ssa.org](http://www.ssa.org)  
Many premature infants qualify for Social Security Disability regardless of income. Go to the above website to find your state's program.

**State Children Health Insurance Program (SCHIP)**.....[www.insurekidsnow.gov](http://www.insurekidsnow.gov)  
All states have a health insurance program for uninsured families that meet the income gap. Go to your state's program.

**Sidelines National Support**....[www.sidelines.org](http://www.sidelines.org)  
Sidelines provides support for pregnant women on bedrest and those dealing with the after effects of bedrest.

### Social Services

#### Virginia

Alexandria- (703) 838-0700  
Arlington- (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

#### Washington DC

Department of Human Services  
(202) 671-4200

#### Maryland

Montgomery County (240) 777-1245  
Prince George's County- (301)909-7025

**For more resources  
go to [www.preemiestoday.org](http://www.preemiestoday.org)**

## Early Intervention

*This is a federally mandated program available in every state to screen and treat children under the age of three 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

Infant and Toddler Connection  
Alexandria- (703) 838-5060  
Arlington County- (703) 228-1630  
Fairfax County/Falls Church- (703) 246-7121  
Loudoun County- (703)-777-0561  
Prince William- (703) 792-7879

### Washington, DC

Office of Infants and Toddlers With Disabilities  
(202) 727-8300

### Maryland

Infant and Toddlers  
Montgomery County- (240) 777-3997  
Prince George's County-(301) 265-8415

## Women Infants & Children (WIC)

*The WIC program provides food vouchers and nutrition counseling services to low-income women and children.*

### Virginia

Arlington- (703) 228-1260  
Alexandria- (703) 838-4879  
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

## **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 email 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**

November 14, 7:30 pm, Barnes and Nobles  
Fairfax, VA

### **Winter Holiday Parties**

December 2, 10:15 am  
The Bannockburn Clubhouse, Bethesda, Maryland

December 9, 3:30 pm  
Reston Regional Library, Reston, Virginia

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

**PREEMIES  
TODAY**

P. O. Box 523525  
Springfield, VA 22152

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**  
or  
**703-552-0163**