

# Preemies Today

## *Families Helping Families*

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### PREEMIE OF THE MONTH:

*This month's featured preemie is Morgan Guidetti. Despite her status as a "micro-preemie" she has blossomed into an energetic and fun loving toddler. Here is her story, as told by mom, Kristin.*

They say there is no such thing as the perfect pregnancy, right? Boy, were they right, I just didn't know how right! I was having an easy time of it, only a bit nauseous until week 12, but no true morning sickness. I had been an avid runner for several years, so my jogs had continued, weaned down and with my doctor's permission, until just a few weeks before my daughter was born. To look at me you would not have really known I was pregnant.

New Year's Eve 2003 came and went uneventfully. I rang in 2004 while simultaneously marking the beginning of my sixth month of pregnancy, week 24. I was in property management and at 10 pm on New Year's Day a fire broke out at my property. I was called in to help residents relocate homes, handle paperwork, direct potential media attention, the works. I returned home exhausted at 2 am.

January 2nd I awoke still exhausted. I knew something wasn't right. I noticed slight spotting and immediately called the OB. She took me right in and did the fetal heart monitor, the baby was fine. I had just had a normal sonogram 3 days before, but as a precaution, she decided to do an internal exam and she nearly passed out. She asked me who I was with (no one!) and said, "Do NOT move. Do NOT get dressed. Can someone come get you or do we need to call an ambulance? You are about 4-5 cm dilated!" At this gestation (24 3/7 weeks) that was almost enough to deliver! This was an utter shock. I laid there in disbelief as my friend came to get me and within 30 minutes I was admit-

ted to labor and delivery at Greater Baltimore Medical Center (GBMC) in Baltimore, MD. Within minutes of my arrival, I began having bad cramping in my lower back and contractions. I was catheterized, put into Trendelenburg position and told that I would be there on bed rest for the remaining 16 weeks of my pregnancy. I was still in disbelief. My membranes had not ruptured, I had no infections, no fever, nothing. Their hopes were to get the membranes to recede and then cerclage.

That was until the excruciating pain and contractions began. Steroids were administered and then magnesium sulfate, but it



never even touched the contractions. I began hemorrhaging before each contraction. At this time they asked me if I would like to resuscitate my daughter at birth because they didn't automatically resuscitate at GBMC then until 25 weeks (that has since been changed to 24 weeks). Stunned again, I replied yes.

A mere 2 hours after receiving the steroids, Morgan Marie Guidetti was born via emergency c-section weighing 635 grams or 1 lb. 6.4 oz and 13 inches long. Her Apgars were

6 at 1 minute and 7 at 5 minutes. She was immediately intubated, given 2 doses of surfactant, and all of the life saving medications she required. My OB said that the placenta was over half abrupted but her membranes had never ruptured, he had to break them at delivery. She was whisked away to the NICU where I first saw her 2 hours later when being wheeled to my room to recover. Her little body was spotted with multiple bruises from the delivery and covered in a cellophane-like blanket on a warmer bed. A team of doctors and nurses hovered over her.

Morgan's 85 days at the GBMC NICU were tedious and the biggest emotional roller coaster I could have ever imagined. Morgan was very fortunate and escaped without many of the typical problems that micro-preemies endure. She was ventilated for the first 7 days, extubated for 10, then back onto the ventilator until day of life 23. She remained on the CPAP for the next month and a half, and finally was weaned to the nasal cannula. She had a rough time with apnea and bradycardia, having her final episode requiring stimulation about seven days prior to discharge. She had no brain hemorrhages, no NEC, and has had no surgeries to date. She had Stage 1 ROP which resolved by 9 months, corrected age. She always tolerated her feeds but was slow to gain weight and required 30 cal formula at times. Morgan was discharged on March 25, 2004 at 5.0 lbs even and 19 inches!

Morgan came home with an apnea monitor only. She was subsequently diagnosed with GERD (Reflux) and took Zantac and Reglan until 1 year old, and now takes Prevacid and Zantac. She passed her 1 year eye exam with no abnormalities and passed her second hearing exam with flying colors. She is followed by The Infant and Toddler Connection (early intervention services) to

## Focus of the Month:

### Top Ten Ways to Keep Your Premie Healthy this Winter

The onset of cold and flu season can be a difficult time for the parents of premature infants. We all want to keep our preemies healthy and avoid a possible hospital admission due to infection. While there are no guarantees, by following some simple tips we can keep our preemies healthy throughout the winter months.

#### 1) Hand washing, Hand washing, Hand washing!

Hand washing cannot be emphasized enough. It is the single best way to avoid the spread of disease. Every single person who touches a preemie (or any baby) should first wash their hands. This includes friends, family, siblings, health care workers, and even parents. The CDC recommends the following technique for hand washing:

- First wet your hands and apply liquid or clean bar soap. Place the bar soap on a rack and allow it to drain.
- Next rub your hands vigorously together and scrub all surfaces.
- Continue for 10 - 15 seconds or about the length of a little tune. It is the soap combined with the scrubbing action that helps dislodge and remove germs.
- Rinse well and dry your hands.

#### 2) Stay away from sick people

This may seem obvious, but do not let sick people visit and do not visit them with your preemie.

#### 3) Avoid crowds

The grocery store and malls are full of people and germs this time of year. Even churches and synagogues can be a hazard, especially because everyone will want to admire your preemie up close. If you have to go out with your preemie pick a time of day when there will be minimal exposure to crowds and do not be afraid to ask people to step back.

#### 4) Hand Sanitizer

Recent studies have shown that the proper

use of hand sanitizer can decrease the transmission of disease in the home. It comes in large containers for home use and travel size bottles that fit right into the diaper bag. It is a great option when there is no sink available or when you have the baby on the changing table.

#### 5) Smart scheduling

When making doctors appointments ask for the first appointment of the day or the first appointment after lunch. This decreases the risk of exposure to other children in the office. Most offices will be happy to accommodate preemies any way they can and will put preemies into an exam room right away instead of leaving them in waiting rooms, if the parents ask.

#### 6) RSV and Flu Preventatives

RSV is a virus that presents as nothing more than a cold in most children, but it can be very serious for children at risk including many preemies. Ninety percent of the population is exposed to RSV before they reach two years old, which means it is very likely that your preemie will be exposed to RSV at some point. The drug Synagis is given as a monthly injection to protect against RSV. Synagis decreases the severity of RSV but it does not totally prevent children from contracting RSV. The flu is also a very serious illness in young children. The flu vaccine should be given to all children under the age of two but older children with chronic health issues may also qualify. Check with your pediatrician to see if your child qualifies for Synagis and/or the flu vaccine.

#### 7) Be the Gatekeeper for Your Child

One of the most important responsibilities any parent has is to be the gatekeeper for their child. This is especially true for preemies. Do not feel bad telling well meaning strangers that they cannot touch your child. Let family and friends know that they cannot come into your home with so much as a sniffle and do not feel guilty about not visiting an elderly relative in a nursing home with your preemie. These strict guidelines can be hard for some people to accept, so just remember to blame

the doctors and nurses. Stating, "The doctor told me I can't do X with the baby," to friends and relatives can take the pressure off you as the parent. Your child's health-care providers are happy to take the blame in order to keep your child healthy.

#### 8) No smoking

Smoking has been shown to increase the risk of RSV and other respiratory illness in preemies. Yet another good reason to quit and to ban smoking in your home.

#### 9) Limit Exposure from older siblings

If there are older siblings in school it is important to teach them how to prevent the spread of infection. Some parents may choose to keep preschoolers home from school during the winter months, but this is not necessary in every case. Emphasizing hand washing and limiting close contact as much as possible, especially if the sibling is sick, are the best ways to keep older siblings from spreading illness to your preemie.

#### 10) Stay Healthy

As a primary caregiver you need to stay healthy for yourself and your preemie. Aside from frequent hand washing you also should avoid touching your eyes, nose and face. Illness can also be avoided by practicing good health habits such as getting enough rest, eating nutritious foods and staying physically active. Although this may be difficult for anyone with children, it is important to try to do these things. Lastly, if you do happen to get sick try to stay away from your preemie and let another caregiver take over until you are no longer contagious.

For more information about preventing infection check out the CDC website at [www.cdc.gov](http://www.cdc.gov) and for more about RSV check out [www.rsvprevention.com](http://www.rsvprevention.com).

*This month's contributor is Deborah K Leaf, RN MSN FNP. Deborah is a member of the Premies Today board and the mom to former 27 weeker, Jake, and full termer, Sarah.*

## A Message from Preemies Today President, Kathy Paz

On August 21st, Preemies Today held its 2005-2006 board elections. We are excited to be welcoming in new members and know we are facing a new and exciting year. I wanted to offer my extreme gratitude for our outgoing board. Many of you served on the Preemies Today board from its inception over 2 years ago. You have helped this organization build its foundation and been dedicated contributors to its mission to help families. Your work and commitment will always be remembered.

Please join us in welcoming the new board members for 2005-2006. Below is a little information about each of them.

### **Mary Beth Hazelgrove**, Chairman of the Board

Mary Beth is a native of Northern Virginia. She attended Mary Washington College in Fredericksburg, VA where she studied History and received her license to teach elementary school. Following graduation Mary Beth joined the Peace Corps and taught in the former Soviet Republic of Moldova for three years. She is now a mother of two and has been married to her husband, Doug, for four years. She is excited about rejoining the Board for Preemies Today and is looking forward to an exciting year!

### **Jenna Kassis**

Jenna is mother to Rachel, a former 33 weeker, who is currently 15 months old. Rachel was born after almost 6 weeks of hospital bed rest after Preterm Premature Rupture of Membranes at almost 28 weeks. Jenna's background includes a BA in chemistry from University of Colorado and masters in teaching from University of Indianapolis. She is currently a domestic manager and sort-of medical case manager (ie stay at home mom of a young preemie). She moved to Northern Virginia in summer of 2004 with her baby daughter and husband Sami. This is her first year on the board of Preemies Today. She is looking forward to helping parents of preemies come together in compassionate community.

### **Deborah Leaf**, Treasurer

Deborah is originally from Philadelphia and has lived in Northern VA for four years. She attended the University of Pennsylvania where she received a BS in Nursing and a BA in Anthropology. She worked as a nurse in kidney and liver transplant for three years and then attended the University of California, San Francisco and received her Master's in Nursing as a Family Nurse Practitioner. She worked in women's health until the birth of her son, Jacob, at 27 weeks. He is now two years old. She has been married to her husband, Brian, for eight years and also has a newborn full term baby girl named Sarah. This is her second year on the board and she looks forward to another great year with Preemies Today.

### **Christine Miller**, Membership Chair

Christine is mother to Aidan, a 3 year-old, former 25 weeker, surviving twin born on August 2, 2002, and Avery, a full-term five month-old born April 18, 2005. She is originally from Long Island, New York, but has lived in Northern Virginia for the past 10 years. She holds a Bachelor degree in Art History from the State University of New York at Stony Brook and currently works in the membership accountability department at United Way of America in Alexandria. Christine has been married to Sean Miller for 9 years. She has been an active member of Preemies Today and this is her first year on the board.

### **Elaine Noto**, Secretary

Elaine is originally from Great Britain and moved to the United States in 2000. She married her husband, Tom, in 2001. After many IVF attempts, she became pregnant with identical twins. The twins were diagnosed with Twin To Transfusion Syndrome and were born at 26 weeks. One twin, Jennifer (11b3oz), born with Potters Syndrome, passed away after 2 days. Rebecca, (11b 9oz) came home after 163 days in Fairfax NICU. Shortly before Rebecca's release Elaine met a member of Preemies Today who told her about the organization, and she and Tom were thrilled to hear that support was available outside the NICU. Elaine is delighted to be on the board of Preemies Today and looks forward to helping the organization grow in order to satisfy the needs of many preemie parents.

### **Kathy Paz**, President

In March of 2002, while studying at the Corcoran College of Art and Design, Kathy prematurely went into labor with her son, Alex. He was born at 25 weeks gestation and spent 2 and a half months in the NICU. As new and young mother, she went looking for help and support and found little for families of preemies. In March of 2003 she started the Preemies Today newsletter and things took off from there. Today Kathy is mother to two, Alex and Lily, and wife to Adam. She works full time for SAIC and serves as President of Preemies Today. She continues her commitment to helping families understand that they are not alone in their struggles with children born too soon.

### **Susan Salguero**, Vice President

Susan majored in Computer Science at William & Mary. She has worked in Information Technology for past 10 years, specifically in healthcare for 6 years. Susan is the mother of three boys: Lucas, born full-term, now 9 years old; Aiden, born full-term, now 6 years old; and Ethan, born at 26 weeks, 1 lb 10 ounces, now 20 months old. She has been involved with the Preemies Today organization for the past year and this is her first year on the board.

## Book Review : Baby Steps: Exercises for Baby's First Year

Susan Fox, a pediatric neurodevelopmental therapist, has written a book with simple but fun exercises that help your baby from birth until they are walking. Although, I think the book is inappropriately titled since many of us know that few babies actually walk by 12 months. She does emphasize that all babies develop at their own rate, and many preemies and other special needs children may even take a little while longer to accomplish developmental milestones.

Each chapter starts by identifying the skills your baby needs to be able to accomplish the desired objective. She also includes lists of books, as well as, toys and equipment that are geared towards that particular stage of development. Each chapter then ends with some frequently asked questions and parent stories (Several stories are experiences shared by preemie parents!) The chapter titles include: Calm and Comfort; I Can Hold My Head Up; I Can Roll Over; I Can Crawl; I Can Stand Up; I Can Walk; Feet, Feet, Feet; and Special Babies, Special Parents (This includes a section on preemies).

I applaud Susan Fox for writing such an easy to read book. I think any parent of a preemie developmentally delayed child, or a parent just wanting to enhance their child's development should read this book. I enjoyed doing these exercises with my daughter who was born at 26 weeks gestation, and I continue to use the same types of exercises with my youngest daughter who was born at term. All the activities are fun and my babies all have enjoyed playing with me!

Mary Beth Hazelgrove



Ethan Salguero and Rebecca Noto at the March of Dimes Ride for Babies

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monitor her development and I am told she is functioning at an age appropriate level. She sees a Gastroenterologist for her reflux and failure to gain adequate weight and an Endocrinologist, also to find the answer to her weight issues. Morgan has some feeding issues, including an immature chew. This results, often times, in her storing food in her cheeks for long periods of time and then spitting it out. As a result, she is about 75% Pediasure dependent for her nutrition. She was also determined to have a gluten sensitivity (not prematurity related) so that makes food selections tough at times. I am a single parent and work from home so as to not have to put her into

daycare, but even so, Morgan was very sick over the winter of 2004 with multiple respiratory infections, and after a ton of doctor appointments and 2 trips to the ER, she now takes Pulmicort via nebulizer treatments daily to help alleviate her reactive airways.

In light of her potentially devastating entrance to this world, these issues are a drop in the bucket and I say Thank You for this, everyday. Morgan is a happy, healthy, beautiful, enlightening, inspiring, VERY active 21 month old. She is petite at 32 inches and 19 lbs.-- but that only makes her all the more squeezable to me!

## Local News:

### October Outing

Please join us as we go pumpkin and apple picking at Homestead Farm in Poolesville, Maryland on October 23 at 10:30 am. They are located at 15600 Sugarloaf Road, Poolesville (301)977-3761. Admission is free. They are located 20 minutes west of DC. You can find directions on their website <http://www.homestead-farm.net/> It is a beautiful drive! We will be meeting at the barn next to the main entrance. Please bring a Halloween-themed dish or your favorite picnic food to share and RSVP to Christine at [cmiller173@comcast.net](mailto:cmiller173@comcast.net).

### 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, food, and Santa Claus. 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 [ecbrit@aol.com](mailto:ecbrit@aol.com).

### Ride for Babies

On October 2nd Preemies Today participated in the March of Dimes Ride for Babies. Ride for Babies is an annual March of Dimes fundraiser where motorcyclists gather pledges and ride their bikes on a specified route. The event started at J. Koons Pontiac-GMC in Tyson's Corner. Our preemies

helped Lead the Way by riding their favorite bike, trike, or stroller. It was a fun event. All the kids were dressed in red, white, and blue.

### Support Resources:

#### *Take a Break*

Preemies Today offers meal preparation assistance, babysitting, and other additional support options for preemie families in crisis. If you are in need of assistance please contact Sara at [sara@teamchae.com](mailto:sara@teamchae.com)

#### *"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 703-994-6624.

#### *NICU Support Group*

INOVA Healthsource is continuing to offer a NICU Support group for current INOVA Fairfax NICU families. 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.

#### *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.com](mailto:jkipers@lmi.com).

#### *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).

## 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.PreemiesToday.com](http://www.PreemiesToday.com)**

## Mission of Preemies Today:

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

## **Membership/Subscription**

### **Information:**

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

To subscribe to the newsletter please email us at [premienewsletter@yahoo.com](mailto:premienewsletter@yahoo.com). If you would like to become a member of Premies Today please email us at [premiemembership@yahoo.com](mailto:premiemembership@yahoo.com). Our website is **[www.PremiesToday.com](http://www.PremiesToday.com)**

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