

# Preemies Today

## *Families Helping Families*

### PREEMIE OF THE MONTH:

*This month's preemie is Katelyn Elizabeth Avila. Born on National Prematurity Day last year, Katelyn survived a tough start in life through the miracle of modern medicine and the love and faith of her parents. Here is her story as told by mom, Kim.*

Katelyn Elizabeth arrived at just 26 weeks gestation on November 16, 2004; National Prematurity Day. The couple of hours I spent in the hospital before Katelyn was born, I reflected on my career as a teacher for the blind and visually impaired and all of the students I knew who have Retinopathy of Prematurity (ROP). Despite my anxiety, remembering my students gave me hope that my daughter would lead a healthy life.

Yet, when the obstetrician told me I had to deliver immediately, my heart sank and the tears poured from my eyes. Even though many of my students were born earlier than Katelyn, I still feared for her life. I knew the chances of healthy survival were in our favor with medical advances to treat premature infants, but it was still devastating. My husband, our pastor, a neonatologist and I all prayed for Katelyn's well being.

Katelyn came into the world weighing 1 pound 14 ounces and was 13 \_ inches long. The first minutes of her life progressed as expected for a 26 weeker; later, this would not be the case. As my husband and I made our way to the Neonatal Intensive Care Unit (NICU), the neonatologist, who prayed with us earlier, met us at the door to deliver the news. Katelyn had a very rare and life threatening pulmonary condition, her blood pressure was barely registering and about thirty other things were wrong that I couldn't comprehend. The doctor explained all of their efforts to save her precious life were failing and one final attempt with an experimental nitric oxide therapy would be made. If the treatment did not work, Katelyn would not survive. They let us see her for a few minutes

before making us leave. For the next two excruciating hours we were not permitted back in the NICU. Once we were allowed back in, another physician met with us and explained that Katelyn started to slowly respond to the nitric oxide. He listed many concerns about her health and the very prominent threat of her not surviving, but she was fighting very hard to live.

Minute by minute, and after countless



prayers, Katelyn began to improve. Within six days the oscillating ventilator and nitric oxide were removed. Her blood pressure began to stabilize without the help of medication and all other ailments were showing signs of improvement. Later, head and heart sonograms revealed no sign of hemorrhaging or damage, she passed her hearing test and she does not have ROP.

Throughout the 70 days we spent in the NICU, Katelyn's doctors and nurses warned us that Katelyn would be in the hospital for months, but she surprised all of us. On January 25, 2005, we took our precious miracle home, just ten weeks after she was born.

She was not even due for another 4 weeks! Bringing Katelyn home was incredible. She was still on oxygen, an apnea/bradycardia monitor and a pulse ox; it took three of us to load a five-pound baby in the car! The next several weeks were exhausting, tiring, exhilarating and wonderful. I learned so much about my daughter in one night that I never knew while she was in the NICU. Katelyn talked in her sleep, she sang when she was awake and she loved to eat! Katelyn ate constantly from the second she came home until she reached 10 pounds two months later.

Week by week, Katelyn got stronger and the need for monitors and oxygen decreased. By mid April, all of Katelyn's equipment had been removed, the kidney fluid and spots she had from birth were gone and we rejoiced that our beautiful, wireless, happy baby girl was healthy.

Everyday Katelyn does something new. She gets very excited to hear and play the piano and absolutely loves swing music. She gets sad when things are too loud, but laughs hysterically at Daddy's silly faces.

Over the summer I enlisted the help of early intervention services to assess and help Katelyn with fine motor skills. She currently receives Occupational Therapy once a week. As a special education teacher, I know the benefits of early intervention are crucial for child development. As a mother, I know my job is to let my colleagues help Katelyn reach all of those milestones that may be a little more challenging since she had a rough start. Katelyn is making good progress with her fine motor skills and the gap I noticed in her development months ago is getting much smaller now. I remember telling many of my student's parents to be patient with their children, do not compare and not to be anxious for the future because we just don't know if

## Focus of the Month:

# National Prematurity Day

During November – Prematurity Awareness Month – Help Send a Message of Hope for Premature Babies

Babies are in crisis today. Nearly half a million are born prematurely every year and the number is rising. Premature birth is the number one killer of newborns and a major cause of serious health problems. It costs society billions of dollars every year. That is why the March of Dimes has designated November as Prematurity Awareness Month - to let us know that premature birth is a crisis in our country and to bring people together to help give all babies their 9 months.

The March of Dimes is leading a national effort to save babies from premature birth by funding research to find the causes and by supporting local programs that offer hope and help to families with a baby in intensive care.

In November, visit [marchofdimes.com](http://marchofdimes.com) and find out what you can do for pink and blue to help prevent premature birth. You can show your care by wearing pink and blue, raising awareness with wristbands, car magnets and ribbons. You can spread the word about the problem of prematurity by sending e-mails and letters. You can help pink & blue sweep the nation by organizing local events like Pink + Blue Jeans for Babies®. Visit [marchofdimes.com](http://marchofdimes.com) for more ways to help give all babies their 9 months during November – Prematurity Awareness Month – and any time of year.

Help Give All Babies Their 9 Months; The Fight Against Premature Birth Begins Before Pregnancy

The March of Dimes wants women to know that there are steps they can take to reduce their risk of premature birth. One of the best things a woman can do for her baby is to get a medical check up before she gets pregnant. If she's healthy, her baby has a better chance of being born healthy and on time. Babies born too early may have serious health problems. Even if a woman is already pregnant, it is never too late to find out what to do to have a healthy baby. Follow these 9 steps for a healthy pregnancy:

March of Dimes “I Want My 9 Months” List

Women should talk to their doctor or nurse about:

Any health conditions she may have such as diabetes, high blood pressure, or being overweight

Any illness or infections she may have

Any family or personal history of having a baby before the full 9 months (Premature Birth)

Any medications she may be taking

How to stay away from smoking, drinking alcohol, or using illegal drugs

How to lower stress

How to maintain a healthy weight with healthy foods

Taking a multivitamin pill with 400 micrograms of folic acid each day

The signs of having a baby too early (preterm Labor), and what to do about it

Visit [marchofdimes.com](http://marchofdimes.com) and click on “I want my 9 months” or email [askus@marchofdimes.com](mailto:askus@marchofdimes.com) to learn more about each of these steps. Everyone can visit [marchofdimes.com](http://marchofdimes.com) to find out what to do to give all babies their 9 months during November – Prematurity Awareness Month – and any time of year.

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*The March of Dimes Prematurity Campaign has produced this article to be published in newsletters during National Prematurity Month, November, 2005.*

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*continued from page 1, Katelyn's Story*

there is anything to be anxious about. Now I am following my own advice for my own daughter.

Katelyn reached one of her preemie milestones this fall; she got her first cold. Even though she was sick, she still managed to learn new things, play and be just as fun loving as ever. Doctors are still monitoring her for other health issues that may arise from her prematurity and pulmonary condition. However, we are not going to be anxious because we don't know if there is anything to be anxious about.

Katelyn still loves to eat, but her weight gain has slowed down. At 8 months corrected age (11 months chronological) she is 15 pounds 10 ounces and is 26 \_ inches long. She enjoys some solid foods and seems to like eating from a spoon more than nursing from a bottle.

Katelyn is on the brink of crawling; she loves to roll over, scooch, sit and is quite the wiggle worm. Katelyn has great language skills and is two months ahead in this area.

As I hold Katelyn while she sleeps, I can still see that tiny little preemie I held for the first time when she was barely 2 pounds. Except for some cubby cheeks, it's amazing how her facial expressions and mannerisms are just the same.

Katelyn will turn one this November! The past year has been a journey, but the ten weeks in the NICU now seem like a small wrinkle in time. Katelyn has come such a long way and is a happy little girl with a big heart from God.

## Local News:

### National Prematurity Day

National Prematurity day takes place on the second Tuesday in November. This year's day will take place on November 15, 2005. Please go to the March of Dimes website [www.marchofdimes.com](http://www.marchofdimes.com) and click on Pink and Blue to find out how you can promote prematurity awareness in your community. Every time someone clicks on the Pink and Blue Medimmune will give the March of Dimes \$1 per email address. Premies Today will be promoting National Prematurity Day by organizing an email campaign to promote prematurity awareness as well as sending out public service announcements to various local radio stations.

### November Outing

Premies Today will be participating in the Simon Youth Foundation "Day of Giving" fundraiser at Pentagon City Mall on Sunday, November 20th from 11am-6pm. You can beat the rush and get a jump on your holiday shopping. This year's event will take place during normal mall hours! There will be exclusive sales, a fashion show, celebrities, makeovers, food, and Santa Claus. You will find store discounts from 15-75% off retail products. Some of the participating stores are Aveda, Baby Gap, Banana Republic, The Body Shop, Eddie Bauer, Macy's, Gymboree, Guess, and many more! 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 Premies Today to help fund our programs which directly help families affected by prematurity.

To find out more information, or to buy tickets, please contact Elaine Noto at [ejcbrit@aol.com](mailto:ejcbrit@aol.com)

We will be meeting at 11:30 am at the McDonalds in the mall. We fill up for a little energy before a day of shopping!

### Support Resources:

#### *"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 premie 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.

#### *Premies Today Online Chat*

Join us every 1st and 3rd Thursday of every month at 8:30 pm for an online chat. For more information contact Julie at [jkipers@lmi.org](mailto:jkipers@lmi.org).

#### *Local Support Groups*

Local support groups are going strong! On the 2nd and 4th Wednesdays at 7:30 pm we hold our local support group meetings. For more information contact us at [premiestoday@yahoo.com](mailto:premiestoday@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/programsandservices/](http://www.co.prince-william.va.us/csb/programsandservices/)

#### 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

Arlington County- (703) 228-1630

#### WIC

Manassas- (703) 792-4703

Woodbridge- (703) 792-7319

Springfield (703) 569-1031

Mount Vernon (703) 660-7100

Fairfax- (703) 246-7100

**For a list of online resources please go to:**

**[www.PremiesToday.com](http://www.PremiesToday.com)**

## Mission of Premies Today:

*The birth of a premature infant is an extremely frightening and life altering time. Premies 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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Premies Today  
P.O. Box 523525  
Springfield, VA 22152