

# PREEMIES TODAY

## *Families Helping Families*

### PREEMIE OF THE MONTH:

*This month's featured preemie is Nico Sanna. There is a family history of preemies in Nico's family, but he is not just a face in the crowd. Here is his story, as told by mom, Sandra.*

I always knew I'd have a preemie. Why? As I've told numerous doctors, both my sister and I are preemies, and many of the women in my family had miscarriages or pregnancy complications. They all reassured me that prematurity is not linked to genetics. "Are you sure?," I would ask. Okay, fine... so we went along with the pregnancy as if I was going to carry fully term. And then AFP test came back showing an increased chance of Down's Syndrome. That was a whole other worry for us, but we took it in stride and knew that either way, we would deal with the hand the life has dealt us.

Since I was still so paranoid about having a premature baby, I ensured that the nursery was already semi-prepared 3 months prior to our due date... the crib was up... sheets were on... hand-me-down clothes were already received and we already had a car seat -- just in case.

So, at 7 months – approximately 32 weeks gestation, I had "indigestion" from having spaghetti for dinner with red sauce -- the next morning, I still had what I thought was indigestion/heartburn. Wow this is weird. It was my first pregnancy and I didn't know what contractions felt like. So I called a friend and asked her... she recommended that I go to the doctor's "just in case". I went to the hospital and they said that I had a UTI, I was a bit dehydrated (which caused contractions), gave me some antibiotics and sent me home.

I assumed it would take a while for the contractions to recede since I needed to get re-hydrated. Several days later, I went back in because the contractions hadn't stopped... they were actually getting closer together. I thought they were going to

give me something to stop the contractions. They did a sonogram to find out if Nico was breathing on his own – and he was. They said I had preeclampsia and they needed to take Nico immediately via emergency c-section before the womb became inhospitable. We had 10 minutes to make phone calls and off to the O.R. I went.

It's a boy! Wahhhhhhhhhhh! What a beautiful sound! He was fine. Nicholas Anthony Sanna – born at a whopping and hefty 3 pounds 14.6 ounces – and perfect! Breathing fine. No signs of Downs Syndrome. All his fingers and toes! Perfect! What a miracle! Not too bad for 7 weeks early! We are truly blessed.



Nico did a lot better than I did. For the first 24 hours my husband took care of Nico, I was asleep, thanks to the notorious Magnesium Sulfate. They were afraid that I would stroke out so I couldn't be stimulated. The next few days seems like they lasted forever -- I remember feeling terrible about not being able to go full-term. What kind of mother's body rejects it's baby? I would cry and my husband would say – "you're the reason he's doing so well. You quit smoking, you quit drinking... he's healthy!

He's just small." And I would try to feel better. Then, I would cry because doctor's didn't think Nico would hit the 4 pound mark to go home before Christmas. They were wrong... 9 days later we were home.

That seems like forever ago now. Nico just celebrated his first birthday and has hit all his milestones. The doctor often times forgets he's a preemie... he's a whopping 20 lbs, with four little chicklet teeth, and trying to walk. We know that we are among the blessed – as are all of you. Never underestimate the power of a preemie!

## “The Latest Cure”: How to Interpret the Hype

We are constantly bombarded in the news by the latest cure for this, or the newest cause of that. Every other day we are told the new thing we shouldn't eat or the next thing we should. When it comes to diet, the latest studies might affect your choices at the supermarket and even if the study is flawed, the recommendations are usually benign. But when it comes to treating disease, how should the latest study affect patient care? These are complex questions, which are not easily answered by doctors or scientists. So, as a patient or parent of a patient, it can be even more difficult to decipher. When the latest study is published in the New York Times, it isn't necessarily because of scientific merit, but rather because it has a headline that will grab readers. Furthermore, the journalist who writes the article is almost never a scientist, and may provide an unbalanced, albeit catchy, interpretation of the study. Therefore, to begin to understand how to evaluate media reports of studies, it is necessary to understand how scientists, themselves, interpret scientific articles.

Scientific articles are written for an audience of scientists. Remember, although scientists are well-trained individuals, they are highly specialized in a very particular part of a scientific field. They know a lot about a very small area. So, how is it even possible for a scientist to interpret studies outside of their field? It is actually extremely difficult; however, a general principle to scientific study, that anyone can apply, is skepticism. Every scientist knows that a single article, no matter how convincing, does not hold the answer to basic scientific questions. Instead, it is the entire body literature that must be used to understand a specific question. It takes multiple studies performed by multiple researchers to truly show that a particular finding is valid.

Another important thing to understand is the limitations that all medical researchers face. First, the human body itself is extremely complex, containing many systems and interconnections between those systems. Also, it is difficult to study human physiology and drug response in an ethical way because it is unacceptable to put anyone at risk for the sake of a study. We circumvent this problem by studying model systems, such as lab mice, or by studying human cells in culture dishes. Eventually it is necessary to go back to the source, human beings, and then we rely on small scale studies and statistics to determine the effects of treatments. Even in these studies, it is difficult to determine whether the benefits of a drug outweigh the side effects. When a drug does seem beneficial, it may take years to determine the effects on all biological systems. In fact, often a drug is found to be useful not for the condition it was intended to treat, but for some beneficial side effect. For example, Viagra was originally developed to treat high blood pressure. Although we may have basic knowledge about a particular body system, it can take many years for an adequate therapy to be developed. Pulmonary surfactants, which coat the lungs to keep them open, were found by the 1960's, however, it was not until 1980 that clinical studies began, using surfactants to treat pulmonary distress in premature infants. Additionally, we still do not understand how many current treatments work. Steroids are given to pregnant mothers in distress to induce surfactant production in a premature infant, but how this works remains unclear.

There are several things to keep in mind when coming across a new study that may affect you or your child. First, mind the source. Just like newspapers have credibility, so do scientific journals. In the field, we call this the “journal impact factor”. A credible and exciting study will be published in a journal with a high impact factor. In medicine two of the most respected journals are the Journal of the American Medical Association and the New England Journal of Medicine. But there are many different medical research journals. You can ask the reference librarian at your local library or a medical professional about the credibility of a particular journal.

Another important factor in evaluating research is whether or not another scientist can duplicate a particular study. When a new study comes out, wait a few months and then search for recent articles to determine if the result holds up over time. Sometimes what looks to be promising results are really just a lucky fluke.

Most importantly, be a skeptic when reading an article and know that it is written to convince you of the results. If you believe that the study may impact you, ask your doctor directly about the quality and importance of the results. Do not rely on your ability to relay the results to your doctor, rather bring the article with you to discuss. Your doctor may pick up on something in the study that you missed or didn't think was important. Remember, Scientific advancement is a slow and meticulous process. It is important to be aware of the latest advancements, but do not get caught up in media hype.

*This month's contributor is Abigail Kroch, PhD. Abigail has her doctorate in biophysics and is currently working as a researcher in cell biology at the University of California, San Francisco. She is also the aunt of a preemie nephew, as well as three full term nieces.*

## Local News:

### Announcements:

#### Preemies Today Receives Generous Grant from The March of Dimes

The March of Dimes has awarded a \$15,000 grant to Preemies Today for 2007. This is third year that Preemies Today has received a grant from the March of Dimes. The grant will allow us to continue to publish our monthly newsletter in a new expanded format. It will also fund our Premie Care Kits for families with infants in the NICU and our Spanish outreach programs.

#### The Premie Bill Passed: March of Dimes Thanks President Bush for Signing Bill Calling for Public-Private Effort to Prevent Preterm Births

Dr. Jennifer L. Howse, president of the March of Dimes, made the following statement as President Bush signed the "PREEMIE" Act (S. 707) into law:

"Today President Bush responded to the growing crisis of premature birth by signing into law a bill that authorizes increased federal support for research and education on prematurity. Millions of active March of Dimes volunteers and staff across the nation have worked toward this day for more than 3 years. On their behalf, I thank the President and members of Congress for their willingness to work with us to put prematurity on the national health agenda.

"Premature birth, one of the most common, serious, and costly problems facing America's infants, affects more than 500,000 babies in the U.S. each year and causes disability and death in too many cases. A key provision of the "PREEMIE" Act sets the stage for a Surgeon General's conference at which scientific and clinical experts from the public and private sectors will sit down together to formulate a national action agenda designed to speed development of preven-

tion strategies to reduce occurrences of preterm labor and delivery.

As the New Year begins, we look forward to working with the Administration and the 110th Congress to appropriate the funding needed to implement the provisions of this most important initiative."

*Preemies Today would also like to thank our members, Susan Boucher and Deb Discenza for all their hard work lobbying on Capital Hill for the Premie Bill.*

### Support Groups:

#### *"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.

#### *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).

#### *Local Support Groups*

Local support groups are going strong! On every 2nd Wednesday at 7:30 pm we hold our local support group meetings at the Barnes and Noble, Fair Lakes. 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:

#### 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

[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

Arlington County- (703) 228-1630

Loudoun County- (703)-777-0561

Washington DC- (202)727-8300

Montgomery County- (240) 777-3997

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

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

### **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.*

### **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@premiesto-day.org](mailto:info@premiesto-day.org) or you may go to our website at [www.PremiesToday.org](http://www.PremiesToday.org) and click on "Join us."

### **In this Issue:**

Preemie of the Month:  
Nico Sanna

Focus on:  
Research

Local News:  
March of Dimes Grant

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.

Premies 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**