

PREEMIES TODAY

Families Helping Families

PREEMIE OF THE MONTH:

Sometimes the term preemie is based on more than gestational age at birth. Zander Macri is proof that even term babies can have "preemie issues". Here is his story, as told by mom, Melissa.

It may seem odd that I am writing about my 38 week baby in a preemie newsletter. Zander was born at 37.6 weeks.....not a preemie, not extremely sick, and did not stay in NICU for very long. We count our blessings everyday and realize how lucky we are; here is Zander's story.

I was already 37 weeks pregnant so I had my closest friends over for our last child free dinner with them since I knew D-day was only weeks away. I was almost 38 weeks pregnant so the chance of a preemie was gone and at this point of pregnancy I could be comforted knowing that I would be having a healthy baby in a few weeks. I had noticed all day that Zander wasn't moving very much. My friends were due to arrive for dinner and I hadn't felt Zander move in hours and was very concerned so I called the OB to run it by them; I had some bright red spotting & had a feeling something was very wrong. I had an appointment scheduled for Friday that week, but knew I needed to be seen as soon as possible, if nothing more then to set my mind at ease. I called the OB and told him my concerns and he felt Friday was soon enough to be seen. The next morning I still felt no movement and called the OB again, and again, and again until they decided to see me. I insisted the doctor see me immediately or I was going to the ER- I knew something was wrong.

When I arrived at the office I met with the nurse and I was very insistent the OB hurry up and see me. The doctor was sent in and tried for a heart beat, that's when things got scary. The doctor was unable to hear a heart beat and kept trying to initiate one by having me drink juice and using the buzzer. After

several attempts to hear the heartbeat he conducted a non-stress test and a biophysical profile and it was determined Zander was in trouble. The OB brought the sonogram machine in and explained to me that my insurance would not cover the sono in the office, BUT if I were to go to a lab, my baby might not make it. As they reviewed the results they found that most of my amniotic fluid was gone and the baby was small and his heart



was weak. It was determined that I would need to deliver immediately and they hoped my husband would make it to see the birth of his son. I was sent to L&D with my file in hand and I was to tell them it was an emergency.

I was brought to a deliver room and was met there by my OB, the anesthesiologist, the nurses, and an NICU nurse. We spoke about what was about to happen. They broke my water and gave me pitocin in hope I could try

to deliver Zander if his heart held on. When they broke my water nothing came out! They connected an internal heart rate monitor to Zander's head, and began flushing fluid inside me, and the epidural was given. I was only connected to the internal heart rate monitor for about 15 minutes when the OB came rushing in to tell me they needed to do an emergency c-section because Zander's heart kept stopping and my blood pressure was very high. I was told that Zander was in grave trouble and they would do everything they could to save him. I was rushed into the OR and it was time to get Zander out. Upon arriving in the OR everything moved quickly and my husband arrived just in time. Just as they were preparing to get started I had to make a decision to get put out or have them start even though I was not numb yet from the epidural. I wanted to see my son be born so they started (OUCH). After the first cut, Zander was here in less than two minutes. Zander was born January 21, 2004 at 2:10 PM weighing 4.7 pounds, at 37.6 weeks gestation. Zander was born dead, he didn't have a heart beat, didn't breathe for almost a minute, he was purple from head to toe, had meconium in his windpipe, was hypoglycemic and had hypothermia. After they revived him he still had a very weak heart-beat and was fighting for survival. Zander had to be intubated and wasn't able to maintain his body temperature. He was on heart monitors, apnea monitors, had an IV in his head, and so many wires I can't even name them all. He progressed into the close incubator rather quickly on day 3, and I was able to hold him for the first time when he was 74 hours old! Zander was diagnosed as IUGR and FTT. Zander suffered from fetal distress and only scored a 1 on his APGAR test.

Zander's brief stay in the NICU was only 2 weeks. Somehow 2 weeks seemed like 2 years at the time. We didn't get to cut the cord or hold him or spend any time with him during those initial moments. The first few days

Focus of the Month:

As parents of children who were born prematurely, we are acutely aware of the potential for developmental delays and long-term disabilities. While not all children who are born prematurely will have developmental delays or disabilities, those who do can benefit from Early Intervention services. These services can greatly reduce the severity of disabilities and delays and help prepare children for school and the world beyond. Accepting that your child may have a disability or developmental delay comes with a range of emotions similar to those felt by parents after the initial shock of her early birth. Once again, life is not as you had expected it to be. Instead of the neighborhood playgroup, you may work with a physical therapist twice a week.

Early Intervention addresses the following five areas of development:

Physical development
Cognitive development
Communication
Social or Emotional development
Adaptive development

Early Intervention is made possible under the Individuals with Disabilities Education Act (IDEA) and is available for children from birth to three years old. IDEA sets the federal guidelines for Early Intervention services. Each state and territory then develops its own policies for carrying out the law. For this, each state has a lead agency responsible for carrying out Early Intervention Services. See the table for the lead agencies in the DC Metro Area. You can also call NICHCY, The National Dissemination Center for Children with Disabilities, at 1.800.695.0285 and ask for the early intervention services in your state. Your pediatrician is another source for information on Early Intervention services.

Once parents recognize that their child may need early intervention services, the question becomes: How do I get these services? The process, with its paperwork, assessments, and meetings, is a bit overwhelming. While there are laws to guarantee that your child receives the services

The Early Intervention Process

she needs, the process is not fluid and certainly not without flaw. But being an advocate for your child, just as you were in the NICU, will help your family get the services that you need. It is important to keep good records. Write down the dates of your phone calls and the names of the people you speak with.

After locating the local agency responsible for early intervention in your area, you will be provided with a service coordinator who will help you through the evaluation and assessment process done to determine whether or not your child is eligible for Early Intervention Services. The assessment is free of charge for all families. Your service coordinator will know the specific policies for Early Intervention in your state.

The evaluation and assessment are conducted by a multidisciplinary team in order to assess your child's speech and language skills, physical abilities, hearing and vision, and other important areas of development. The team will assess your child's physical development, cognitive development, communication, social-emotional development, and adaptive development. This is done through: doctor's reports, results from developmental tests and performance assessments, direct observation – including that of the parents, medical and developmental history, and interviews with you and other family members or caretakers.

After the evaluation, you and the team will meet to discuss the information. The members of the team will determine if your child qualifies for Early Intervention services under IDEA and State policy.

If your child is found eligible, an assessment is performed. This consists of members of the team identifying your child's strengths and needs and determining what services can help your child best meet those needs. The team will write up an Individual Family Service Plan, or IFSP. The IFSP is an important legal document that outlines the services your child receives, the frequency of those services, the provider of services, and the goals for

your child. Be prepared to play an active role in ensuring that these services are provided in a timely manner. This may, at various times, require contacting your service coordinator to make sure the process is moving forward as it should.

The IFSP also states who pays for the services, such as physical therapy. Each state has a different formula for calculating the cost of services. Many have sliding-scale fees and bill private insurance or Medicaid. Services cannot be denied because a family cannot pay.

The period of time from referral to IFSP creation is 45 days. When contacting the lead agency in your state, be sure to ask when your 45-day period begins. It is again important to document the steps in this process so that your child is assessed and evaluated in a timely manner. One of the keys of Early Intervention is "Early." Research shows that Early Intervention increases developmental and educational gains for children, which can greatly impact their lives and the lives of their families.

Below is the contact information for the local providers of Early Intervention:

Virginia: *The Infant & Toddler Connection of Virginia*
<http://www.earlyintervention-va.com>

Maryland: *Division of Special Education/Early Intervention Services*
http://www.marylandpublicschools.org/M_SDE/divisions/earlyinterv/

District of Columbia: *Infants and Toddlers with Disabilities Office*
DC Child Find Hotline: 202-727-8300
www.k12.dc.us Click on "Child Find" under Special Education

*See Helpful Resources on page 3 for local listings of Early Intervention programs.

This month's contributor is Susan Boucher. Susan is a Special Education teacher and mom to preemie twins, John and Eleanor.

Local News:

Announcements:

Holiday Party: Yoga Tales

The Preemies Today's Holiday party will take place at Yoga Tales studio in Bethesda, Maryland. Yoga Tales teaches yoga poses to children using props and a unique storytelling approach. Yoga is wonderful for children of all abilities but can be particularly helpful to children with low muscle tone and attention issues. Following the class, we will serve food and refreshments and have a visit from Santa Claus. Children of all ages are invited. Cost is free.

Date: Saturday, December 16, 2006

Time: 11:30am-1pm

Location: 8020 Norfolk Avenue, Bethesda, Maryland 20814

RSVP to marybethhazelgrove@yahoo.com

Celebration of Remembrance

The annual SIDS Mid-Atlantic and MIS Celebration of Remembrance will be held Saturday, November 18 from 6 to 9 P.M. Family and friends of babies who have died from any cause are welcome to attend, and there will be baby sitting available. It will be held at:

The Unitarian Universalist Church of Arlington
4444 Arlington Boulevard
Arlington, Virginia

Please contact Betty Connal at 703-933-9100 or bconnal@aol.com for more information.

Preemies Today Survey

Preemies Today needs your input! We are looking for families to participate in our online survey. All responses are anonymous. This survey

continued from cover, Zander

we waited to see if he'd survive and then after 72 hours I was allowed to hold him. They found that my placenta was almost completely dead and that I had no amniotic fluid. Zander was just over 3 pounds when he came home with us and by 3 months was finally strong enough to latch on to breast feed.

Zander is now very healthy and active at 2 years & 9 months. He attends preschool through the county's special education program and absolutely loves going to school where he continues to receive therapy for speech delays, occupational therapy, among other things. Zander was diagnosed with sensory integration dysfunction and remains labeled as failure to thrive. We were very excited that at his 28 month check up he almost reached 3% for weight. Zander still suffers from acid reflux and sleep problems but is doing fantastic. We will never know why my 38 week baby was only 4.7 pounds, but we will always know how lucky we are to have him with us.

will let us know how well our programs are reaching families and what we can do better. Please log onto www.advancedsurvey.com and type in survey number 43558 in the "Take a Survey" box.

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.

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.

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/

Fairfax County Department of Family

Services:

(703) 324-7500

www.co.fairfax.va.us/services/dfs/

Social Security Administration:

1-800-772-1213

www.ssa.org

SIDS Mid-Atlantic

(703) 933-9100

www.sidsma.org

March of Dimes

1-800-326-BABY

www.marchofdimes.com

Sidelines National Support

1-888-447-4754

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

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 the newsletter please email us at premienewsletter@yahoo.com. If you would like to become a member of Premies Today please email us at premiemembership@yahoo.com. Our website is **www.PremiesToday.com**

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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.

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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**