

PREEMIES TODAY

Families Helping Families

PREEMIE OF THE MONTH:

This month's preemie hails all the way from South Africa. Conner Benvie is proof that NICU miracles happen everywhere. Here is his story, as told by his mom, Adele.

Greg and I had been married for four years before we felt ready to take on the awesome responsibility of a family. I loved being pregnant. Every day of my textbook pregnancy was so exciting as we would read on our pregnancy diary what was happening with our baby week by week.

At 30 weeks, my obstetrician detected that my amniotic fluid was very low. After many tests it was determined that I was somehow losing amniotic fluid. The only explanation for this was stress from a hectic lifestyle. I was told to take it easy and see the OB more frequently. It felt so wrong that my pregnancy was not going 'according to the book'.

On the Tuesday before Connor was born, I had an uneasy feeling and went to see my OB. He was concerned and sent me for steroid injections for Connor's lungs, just in case our baby came early. I am so glad we did this! He warned us to monitor Connor's movements and make sure that I felt him moving at least once every three hours. Thursday, February 10 2005, I woke up at 3am and could not sleep. I made a cup of coffee and sat in the dark in our 14th floor apartment, just thinking. It was strange that coffee did not make Connor move. Usually drinking coffee would get some reaction from him. Once Greg was awake, I had a bath where I splashed my belly and sang to Connor, still no movement. I was not panicking, but it had been four hours and I had felt nothing.

Despite having a day planned with back-to-back appointments, I canceled my first appointment and went to the hospital instead. There they detected that Connor's heart rate was dipping frequently and I was sent straight to my OB. Connor's heart rate was monitored once again. I was told to phone Greg, Connor was making his debut at 32 weeks! Half an hour later I was officially a mom to a

three pound baby boy by emergency C-section. Everything happened so quickly! Lying on that operating table I had such mixed emotions. Delight at being a mom, but so confused at how everything could have been so different to how I had rehearsed it in my mind so many times. Waiting to hear Connor cry for the first time felt like a lifetime! Then he made a small noise, and then no more noise. I could feel that something was wrong, but knew that our Lord would take care of whatever was happening with Connor. Greg was wonderful. He was with Connor, helping the doctors as they resuscitated our precious son.



I did not see Connor that evening. In the early hours of the next morning, our pediatrician came and woke me up saying, "You need to pray. Your son is very sick." I was so drugged by all the painkillers that I did not even register what was happening. Only later, when I woke up and the drugs had worn off did the full reality of the situation hit me. Before they could bring me a wheel chair to take me to my son, I was walking there. It is amazing how you forget about yourself and your pain when your child is in need.

Two things may have been wrong: it could have been that Connor had a hole in his heart or that he had Persistent Fetal Syndrome. We were transferred to another hospital where it was confirmed that Connor had Persistent Fetal Syndrome. In the womb the oxygenat-

ed and deoxygenated blood mixes. With the first breath after birth, the body recognizes that it is out of the womb and the O2 and CO2 blood no longer mixes. Well, Connor's body did not realize that it was out of the safety of mommy's body and his blood continued to mix. This is very dangerous as no organs can function for long with the body in this state.

From day one, we called Connor 'our little warrior' and that is exactly what he is! Connor was on a ventilator for just under a week, after which he had had enough of the tube and extubated himself. He was in NICU for four weeks to the day. In that time, Greg and I saw miracle after miracle with Connor and the other babies. We made many friends with other NICU parents as we shared our fears and rejoiced with each other as our champions took tiny steps toward recovery that felt like giant leaps for mankind! Connor surprised us every day as we would arrive at the NICU and be greeted with his progress.

Today, Connor is a happy, fun-loving, healthy one year old boy who loves life and just wants to have fun and enjoy every moment. He is the delight of Greg and my life and brings so much joy to us and our entire family. You barely have to look at him and he is laughing. He is very busy and loves to discover new things. Every day is a pleasure with him, for which we are so grateful.

We were so blessed to be surrounded by an amazing family, wonderful friends, incredible doctors and NICU personnel! More than that, we are so grateful for the hand of our Lord on our son. He is the reason that our little one is with us today. Not only did He perform a miracle in Connor's life, but He gave all those caring for Connor in NICU extra wisdom to know what to do. Still today, we as a family pray for all those families in NICU as well as the NICU staff, that they would be filled with complete peace and heavenly wisdom to be able to love and care for the true heroes ... our preemie babies!

Each year between 14,000 and 16,000 premature infants experience some degree of retinopathy of prematurity (ROP). About 1,500 of these infants will develop severe ROP and will require treatment. Of those, 400 to 600 may eventually be classified as legally blind (NEI, 2003). To understand what ROP is, you first must understand the normal development of the retina. The retina is the layer of nerve-like cells at the back of the eye that allow us to see. As the fetus develops, the blood vessels that supply oxygen and nutrients to the retina grow slowly toward the edges of the new forming retina. In the last 12 weeks of development the eyes develop rapidly and continue to develop up to a month after birth. A premature infant usually has incomplete retinal development and can have abnormal growth of the blood vessels. This abnormal vessel growth is ROP and can result in bleeding, scarring, and eventually retinal detachment, which is when the layers of the retina separate.

There are five stages of ROP measured by the extent of abnormal vessel growth and retinal detachment. Stages 1 and 2 includes mild to moderate abnormal blood vessel growth, which may resolve on its own. Stage 3 is when there is severely abnormal blood vessel growth toward the center of the eye. Treatment may be necessary to prevent retinal detachment. Stage 4 involves a partially detached retina and treatment may be necessary to stop further progression. Stage 5 involves total detachment of the retina. Treatment, including cryotherapy and laser therapy, may be necessary to avoid severe visual impairment or complete blindness. These treatments can prevent retinal detachment and save the central vision, which is used to read, perform eye-hand tasks, and see faces.

Visual Implications

There are other visual impairments that can also occur with ROP, including: nearsightedness (myopia), lazy eye (amblyopia), rapid eye movements (nystagmus), loss of part of the field of vision and glaucoma. With Stage 1 and 2 ROP, retinal detachment may resolve on its own, but because of changes in the retina, the child may be nearsighted. Although corrective lenses may improve eyesight, the child may still have problems seeing things far away. If an eye has reduced vision or is very nearsighted, it is difficult for the brain to

process both images, resulting in a lazy eye (amblyopia). The brain may then ignore or suppress the image from the weak or "lazy" eye. Treatment involves patching the good eye so that the brain is forced to use the weak eye. If treatment does not occur at an early age, the vision in the weak eye may be lost. Nystagmus, the involuntary shaking of the eye, is associated with vision loss and may develop as early as 6 to 8 weeks after birth. Although there is no specific treatment, there are techniques to decrease the rapid eye movements. Loss of part of the field of vision can be caused by retinal detachment, or even from treatments such as cryotherapy or laser surgery. There is no specific treatment, but there are skills that a child can learn to adapt. Glaucoma is an increased pressure in the eye and should be monitored carefully. Normal eye pressure can be maintained with eye drops to prevent vision loss. Advanced stages of ROP can cause other more serious vision problems including total blindness.

Interventions

The federal Infant and Toddler Law requires all states to provide vision services starting from birth through 3 years of age. These services are provided through the Infant and Toddler Connection and may also be called Early Intervention. Many premature infants qualify for these services because of developmental delays but will also receive services for vision problems if needed. Often a hospital or family pediatrician will refer a family of a premature infant to early intervention services providers. An Early Intervention Specialist assesses and determines the needs of the infant and family and an Individual Family Service Plan (IFSP) is developed. The IFSP is a plan that is developed with the parents for the child and family.

An Early Intervention Specialist will begin preparing a child for entering the public school system before the child is 3 years old. The child will be tested to see if they qualify for the special education preschool program. If a child is eligible they will receive services in the school similar to those they received through early intervention. The child transitions from an IFSP to an Individualized Educational Plan (IEP) upon entering public school. An IEP is the document that focuses on the codes, placement, goals, accommodations, adaptations, and related support services for the child at school.

Related services available to a visually impaired student may involve interaction with a Teacher of the Visually Impaired (TVI) and/or an Orientation and Mobility Specialist (O&M). The TVI may work directly with the student and/or consult with staff to adapt the curriculum and assist with learning strategies. Some strategies may involve adaptations to best view material, such as slant boards or bold lined paper, as well as, accommodation for learning material, such as in large print or Braille. The TVI can teach Braille skills and promote assistive technology that may be helpful in accessing the curriculum. An O&M Specialist works with a visually impaired student to develop skills that will enable him/her to travel independently. Travel skills vary from learning to maneuver around their school through traveling in the community, crossing streets, and riding public buses. The O&M Specialist will also assist the student in using his residual vision, which may involve scanning and looking for informational cues. Other skills may involve using monoculars and long canes to travel safely and efficiently. Both a TVI and an O&M Specialist develop goals and objectives to meet the student's current needs by considering his present skills and abilities.

As discussed, there are a variety of outcomes for premies that have experienced ROP. It is important for parents to be active in their child's future by asking questions and participating with intervention specialists to plan goals for future skills and accomplishments.

Resources:

Levack, N. (1999). *Low Vision*. Texas: Texas School for the Blind and Visually Impaired.

National Eye Institute (December 8, 2003). *Early Treatment of Blinding Eye Disease in Infants Can Prevent Severe Vision Loss*; National Institutes of Health.

Steinweg, S. B., Griffen, H. C., Griffin, L. W., & Gingras, H. (Spring, 2005). *Retinopathy of Prematurity*, RE:View, 27, 32- 41.

Upshur, Beverley J., M. Ed. (Interview on December 6, 2005). She is an Infant and Toddler Teacher of the Visually Impaired.

This month's contributor is Gina Schmid. Gina has a Masters of Arts in Special Education and is an Orientation and Movement Specialist.

Local News:

Announcements:

Preemies Today Receives March of Dimes Grant

Preemies Today is proud to announce that for the second year we have received a grant from the March of Dimes. The grant is in the amount of \$6,325.00 and will be used to fund our newsletter, website, and other publications. "This project has been so successful that we are indeed willing to fund your efforts," says Dona Dei from the March of Dimes staff. Preemies Today thanks the March of Dimes for their generous support of our organization and their faith in our mission to help families with infants born prematurely.

Valentine's Day Party

Preemies Today is organizing a potluck on Sunday, February 12th from 3:30-5:30 in the conference room at the Sherwood Regional Library. Please bring a side dish to share. Preemies Today will provide drinks and a main dish. We will also have a Valentines craft activity and the children will be exchanging valentines! You can RSVP to Elaine Noto at ejcbrit@aol.com. Please be advised and follow the Preemies Today Illness Guidelines when bringing your preemie (especially during cold and flu season.)

Fairfax County Transitions Fair

The Infant Toddler Connection, the Fairfax County early intervention office, is offering a Transition Fair on Saturday, February 11, 2006 from 10 until noon at the Fairfax County Government Center—Alexandria. This fair will provide families the opportunity to meet with different groups or organizations that can help your child once he or she has transitioned out of the early intervention program. For more information contact Paula Gorman at 703-246-5313 or at paula.gorman@fairfaxcounty.gov.

Support Groups:

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 or would like to volunteer to help others, please contact Sara at 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 703-552-0163 or if you are out of the area, our toll free number is 1-888-712-3208.

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.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 preemiestoday@yahoo.com.

Yahogroup!

Come and join our yahogroup 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:

The following are some helpful resources available by phone and online:

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
(703) 425-BABY(Metro DC)
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
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.PreemiesToday.com

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.

To subscribe 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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Premies Today
P.O. Box 523525
Springfield, VA 22152