

PREEMIES TODAY

Families Helping Families

Preemie of the Month: Christian

A Four-Year Old that Will Steal Your Heart

by Lisa Hollaender

I used to be a champion planner. My life revolved around calendars, schedules, and time, all of which I would keep track of in my oversized planner. For most of my life, my plans followed through as expected. Things changed that chilly January morning five years ago when my son was born. He surprised us by arriving nine weeks earlier than “planned”.

That morning, just after sunrise, I awoke hemorrhaging at 31-and-a-half-weeks pregnant. My first instinct was to panic. My next was to awaken my husband and then call 911. As the paramedics carried me out on a stretcher, I glanced back at our blood-soaked bed and thought there was no way our baby could survive. I did not feel the usual nonstop somersaults and kicks that I had grown to love from the little guy in my womb. However, much to our surprise, we were blessed that morning. After assuring us that there was indeed a strong heartbeat, our doctor delivered my beautiful 4 lbs., 7 ounces son via c-section at 12:31 pm that afternoon.

He came into our world with a head full of ebony hair, rosy cheeks, inquisitive eyes, and long, dark lashes. The nurses nicknamed him, “The Heartbreaker”. We named him Christian, a name that would be familiar in my American culture my husband’s French one. Although my first look at my son



was through the plastic of his isolette, I swear that I saw a fighting little spirit in his eyes. He would survive all of this, I assured myself.

Christian was released after only three weeks due to his incredible progress and as I truly believe, his “fighting spirit”. Christian never required full oxygen and was breathing on his own by day two. His bradycardia and jaundice were managed quickly and he amazed the NICU staff by learning to suck/swallow/breathe in just a few days. He gained weight and seemingly had no residual effects of his prematurity, other than a bit of reflux.

As soon as I was released from the hospital, I dove into planning mode. I planned for Christian to come home from the NICU nine weeks later. I planned to return to work in three months and began to make day-care plans for Christian.

Thanks to my mother, we were able to keep Christian at home during his early months as I tried to return to work part-time. After only a few months of working, I felt I should be with Christian more. With my husband’s full support, I decided to stay at home full-time with my preemie boy. It is a decision that I will never regret.

We noticed Christian was not meeting all of his motor milestones when he was six months old. A physiatrist and developmental pediatrician confirmed that Christian had gross and fine motor developmental delays due to his prematurity. We eagerly immersed ourselves into the world of physical and occupational therapy. As you might imagine, we met some of the country’s most respected and recognized medical specialists.

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Preemies Today
P.O. Box 523525
Springfield, VA 22152

Founded:
March 2003

web:
www.preemiestoday.org

email:
info@preemiestoday.org

Preemies Today is a 501(c)3 non-profit organization whose mission is to provide outreach and support programs to families of infants born prematurely beginning at birth and throughout childhood.

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Calendar of Events

January

Parent Support Meeting

January 9th, 7:30 pm

Barnes and Nobles, Fair Lakes, VA

February

Parent Support Meeting

February 13th, 7:30 pm

Barnes and Nobles, Fair Lakes, VA

Dream Dinners

February 26th, 5:00 pm -8:00 pm

two locations:

Richland Business Center on Route 7

21430 Cedar Drive #107

Sterling, VA 20164

and

1701 Rockville Pike, Space B-7

Rockville, MD 20852

(See advertisement page three for more information)

 **Mailbox:**

Please send us your feedback, suggestions, or contributions for future articles by the 15th of each month to:

info@preemiestoday.org

Preemies Today
PO Box 523525
Springfield, VA 22152

Would you like to talk to another preemie parent that has had a similar experience?



Call 1-888-712-3208
or 703-552-0163

A Special Thank you...

Preemies Today is grateful to its supporters for their generosity. We extend our deepest thanks to the contributors listed below who have donated during the past few months.

Connie Bezanson
Al and Stephanie Miller
Janet Remier
Maureen Brookbank
Ann Hall
Exxon Mobile's Favorite Charity Campaign
Kenneth Noto

Thank you also to all of those that bought or sold White House Ornaments this year. We sold 200 ornaments which purchased 450 holiday gifts that were delivered to 18 different NICUs. A special thank you to Heather Hall for selling 55 ornaments!

Thank you to those that volunteered their time during the holidays to help deliver the holiday gifts to the local NICUs and assisted with the NICU Pizza Dinners at Holy Cross Hospital and INOVA Fairfax Hospital.

| | | |
|---------------------|------------------|-------------------|
| Patricia Lira | Lauren Greenberg | Shelby Arnold |
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What We Do:

We offer local in-person support to families of preemies in the extended Washington DC metropolitan area. We provide on-line support to families of preemies located across the country and internationally.

Programs:

Monthly Newsletter
Parent Support Meetings
NICU Premie Care Packages
Telephone Hotline
Play Groups
Family Outings
Parent Education
Resources Brochures
Yahoo Group
Online Chat

Join Our Yahogroup!

Subscribe:

<http://groups.yahoo.com/group/PreemiesToday/>

Meet wonderful parents from the DC metropolitan area as well as elsewhere in the United States.

Help Spread the Word and Join Us In Support of Preemies Today at Dream Dinners



Dream Dinners is one of the area's leading meal preparation companies which prides itself on healthy menu options.

When: February 26, 2008

Time: 5:00 pm - 8:00 pm

Cost: \$25.00*

*Price includes the cost of one meal for a family of four. Proceeds from the event will help support Preemies Today Programs

RSVP by February 23, 2008

Menu Options will be available mid-January. www.dreamdinners.com

Joanne Hanson is a speech pathologist at Building Blocks Therapy Center located in Falls Church, VA. In February, Joanne will be moving to New Hampshire and starting a new practice there called "Miracle Farm Speech Therapy" in Hampton Falls, New Hampshire. Joanne has graciously agreed to share an excerpt from her recently published book, Lip Prints, for our Premies Today readers.

Babies in the Neonatal Intensive Care Unit

The Neonatal Intensive Care Unit (NICU) is a section of the labor and delivery ward in hospitals. It is equipped to handle premature infants or infants with significant complications. Common reasons why a child may need to be in the NICU include cleft lip or palate, respiratory distress, syndromes, birth defects, jaundice, complications during birth, and complications with nursing or taking in nutrition. No one wants to have a child in the NICU, but if circumstances arise in which your baby needs special care, the NICU is the best place to be. A baby who has a prolonged stay in the NICU may be at higher risk of having feeding and oral-motor difficulties due to a rocky start.

A neonatologist is a doctor who specializes in the care of neonates, or premature infants. Often this physician is in charge of care in the NICU, making rounds to check all the children in the NICU and working closely with the special nurses who care for the babies there.

The goals for infants in the NICU include attaining successful feeding skills, adequate weight gain, stable respiratory and gastrointestinal function, competence of the caregivers in feeding and caring for the baby, competence in operating any equipment or handling any medication needs their baby may have and general stable health. Many NICUs have what is called a "step down" unit that the child is transferred to when he is improving and being prepared to go home. The focus in these units is often on providing comfort for the parent and developing her competence in caring for her baby.

If your baby is in the NICU, the following tips are offered to help make his stay and your participation in the process easier. If the caregiver feels more comfortable with her premature or special needs baby, the baby is more likely to be relaxed, and this will improve the feeding and communication process from the very beginning.

Tube feeding. It is important to know that the ability to suck and swallow is not even expected until the 34th week of gestation. Therefore, premature infants who are born

prior to 34 weeks gestation may require alternative methods for nutrition intake, most commonly a feeding tube. There are many types of feeding tubes, but in a NICU the most common type you will find is a nasogastric or orogastric tube. A feeding tube is inserted into the nose (nasogastric) or through the mouth (orogastric) and goes from the nose or mouth to the stomach. If your child needs to be fed through a tube, one thing you can do is offer a pacifier for him to suck on during feeding time. This will allow your baby to begin the process of associating the oral sensation of sucking with the feeling of being full. Ask your nurse, neonatologist, or feeding specialist if this strategy is appropriate for your child. It is often beneficial to work with a feeding specialist who can show you specific strategies to help transition your child to oral feedings when he is ready.

Protecting your baby's skin. When infants in the NICU are tube fed or receiving medications or nutrients intravenously, taping is used to keep the tubes in place. This tape, whether it is on the hands, legs, or face, can have a sensory impact that is long lasting. Many specialists in the area of sensory integration theorize that the association of touch for the purpose of taping, drawing blood, or even putting a tube through the nasal or oral passage leaves a sort of "sensory memory" with negative associations. To help limit the discomfort associated with the medical necessities of the special care unit, caregivers are encouraged to touch, massage, and hold the child as much as is allowed. Patting the baby's back gently or stroking the head or cheeks is also a great way to provide a pleasant touch sensation. You can also ask the nurses or doctors to use a minimal amount of taping.

Positioning. Be sure your baby is given the opportunity to change positions when allowed. It is helpful to have baby switch from lying on the left to the right and onto his back. Because infants in the NICU spend so much time sleeping and also in the isolettes just regulating their body temperature, breathing, and digestion, it is important to put them in different positions to promote better head movement, muscle tone, and body awareness. NICU nurses will also put babies on their tummies, especially babies who have reflux, because that position is often more comfortable for them. In all cases, you should consult with your pediatrician about alternative positioning options when your child has reflux.

Environment. With all the horns, bells, whistles, buzzers, and lights in the NICU, these tiny babies are thrust from the womb into a situation of near overload. Personnel working in the NICU are becoming increasingly aware of the importance of a calm environment to help babies fall into a more relaxed, organized state in which they

See Lip Prints, page 6...

A parent recently asked why I recommended that her child be examined by an optometrist rather than an ophthalmologist. The answer comes from my understanding of these two eye care professions and my personal experience.

Both types of eye doctors examine and prescribe glasses, diagnose and treat eye disease, and can evaluate how well a person uses the eyes together. However, each profession is unique.

Ophthalmologists are trained to do surgery. I credit one with saving the eyesight of my daughter, who at age five, sustained an eye injury. Optometrists are schooled in the behavioral (or functional) aspects of vision. They are more apt to use lenses, prisms and vision therapy to enhance and improve function. These interventions often improve children's academic and other abilities.

Eyesight vs. Vision

Eyesight and vision are not synonymous. Eyesight is the sharpness of the image seen by the eye. Vision is the ability to focus on and comprehend that which is seen. Research has shown that most children with special needs do not have eyesight problems, while many have visual dysfunction. If a child has motor delays, vestibular difficulties, or health problems, vision is often compromised.

The American Optometric Association (AOA) recommends that children have vision examinations by six months. A good eye doctor can test many aspects of function at this young age and quickly effect changes with intervention.

Most school vision screenings check only eyesight only at twenty feet, not at reading distance. They rarely tell us whether a child has a clear image at nearpoint or how the eyes work together. The only information they provide is whether a child can see the blackboard. Many vision problems thus go undetected when parents have false security and brag, "My kid's eyes are 20/20!"

Vision is Learned

Vision, like reading, mathematics, and language, is learned. Giving meaning to what is seen begins at birth. In the developmental hierarchy, infants move without purpose, while their eyes learn how to work as a team, to sustain focus. Toddlers use movement to drive vision, such as shaking a rattle for its sound before looking at it. Finally, children can visualize without movement. Thus, for children to be successful in school, vision must purposefully direct their actions.

Vision Must Become the Primary Sense

We hear a great deal about individual learning styles. "My child is a kinesthetic learner," a mother told me. She meant

that her child is still using touch and movement to get information about the world. This learning style is more primitive than getting information visually.

Well-functioning individuals store all types of sensory images and can visualize and retrieve them upon demand. They no longer need to touch and move to experience their

Eyesight and vision are not synonymous. Eyesight is the sharpness of the image seen by the eye. Vision is the ability to focus on and comprehend that which is seen.

world. Vision directs their thinking, organization, listening and actions.

Vision Lays the Foundation for Language & Relationships

Vision plays a major role in language and social-emotional development. Children with language delays, attention deficits, pervasive developmental disorders and autism all have inefficient visual systems. If a toddler is not speaking or relating to others, a vision evaluation is essential.

A developmental optometrist can prescribe therapeutic and pleasurable activities to be done at home, during floor time, occupational and language therapy, or at day care. Combining the visual system with touch, movement, audition and social experiences benefits all areas. *Begin Where They Are*, a workbook designed by vision therapists and available through the Developmental Delay Resources (DDR), has good ideas for pre-verbal children and toddlers.

Making the Right Choice

Scientific evidence indicates that interventions such as vision therapy, used by behavioral optometrists, work. The Optometric Extension Program Foundation (OEPF) offers a CD entitled *The Efficacy of Optometric Vision Therapy*, containing 238 references; it is available on their website www.oep.org. They dispense free information and can also help locate eye care professionals qualified to evaluate even the most difficult, non-verbal children. They offer post-graduate education to optometrists and educate the public about vision. The College of Optometrists in Vision Development (COVD) certifies behavioral optometrists who satisfy strict criteria.

If your child was premature or has developmental delays of any kind, choose to have all aspects of vision evaluated.

Patricia Lemer is the Executive Director of Developmental Delay Resources, www.devdelay.org

Christian continued from page 1...

Most importantly, we had the privilege of getting to know some of the most incredible kids and parents who were going through similar struggles and triumphs. These families remain some of our closest friends. These dear friends, along with our own family, have provided us with a supportive network in times when all of the planning in the world has failed us.

Five years later, Christian still struggles with gross and fine motor tasks. He is what we call a part-time independent walker; Christian can walk alone, but prefers and does better using forearm crutches. His fine motor skills are catching up and he is doing surprisingly well learning to write. Christian's long term, gross motor goal is to walk independently without any assistive devices. He receives both county-based and private PT and OT. He will never be the fastest kid on the playground or win the "penmanship" award; however, where he struggles with motor skills, he excels in the cognitive and speech language areas.

Christian spoke in full sentences by age 2, miraculously taught himself to read at 3 ½, and is currently learning two foreign languages. He attends a typical preschool where he enjoys circle time, outdoor play, art, music, and reading. Needless to say, we are proud. He is and will always be the

"Christian spoke in full sentences by age 2, miraculously taught himself to read at 3 ½, and is currently learning two foreign languages."

person I admire most in the world due to his inner strength, his resiliency, his determination, his endless quest for knowledge and learning, and of course, his heartbreaking beauty. He is my little hero.

If my husband and I have learned anything during our preemie journey with our son, it's that each baby comes into our world with "special needs" and each one has his or her own path, schedule, and timeline to find and follow. There is no one prescription, procedure, or plan, for children; there certainly isn't for the preemie child. Though there are times to be proactive, to prepare, and to plan, there are going to be many moments when you have no choice but to let life take the lead.

I still hang onto my oversized planner. It's complete with dates, schedules, and appointments. The difference being that now the plans are only penciled in, with room left open for those unexpected twists and surprises that come with life; the difficult bumps in the road from which you must learn and grow as well as the ones that are simply a blessing—like my son.

Lip Prints continued from page 4...

can eat, grow, and heal better. This may include dimmed lights and soft classical music in the background. Ask the staff if you feel a change would help your baby.

Talking to your baby. Even though your child is going through some trying times, he is fully aware of your presence. If he can hear, he is able to learn the sounds of your voice. This is the initial starting point of communication.

Although it may seem easier to let the nurses to do the work, you need to remember that bonding with your baby means being with him through it all and caring for him as much as possible. Change the diapers, read the charts, feed you baby at each feeding allowed. If you don't know how to do something for your baby, have a nurse teach you. Learn about the equipment, the rules of the NICU, and the terminology that is used. Ask questions about everything that is being done to your child and be there as often as you can. If the staff says you may do so, it can help to bring in some baby clothes and blankets from home and dress and wrap you baby.

This article is taken from Lip Prints, Home Program for Oral-Motor Skills by Joanne Hanson. The book is available through Pro-Ed publishers at www.proedinc.com. The book provides articles and activities for children from birth through 5 years of age who are in need of oral-motor and feeding assistance.

For questions or to contact Joanne Hanson:

Joanne Hanson 703-402-1321

Miracle Farm Speech Therapy

joanne@miraclefarmtherapy.com (active as of Feb. 15th) or joanne@buildingblockstherapy.com

Helpful Resources

Websites and Numbers

March of Dimes.....www.marchofdimes.com
The March of Dimes offers a wealth of information about preterm labor and premature birth.

Social Security Administration.....www.ssa.org
Many premature infants qualify for Social Security Disability regardless of income. Go to the above website to find your state's program.

State Children Health Insurance Program (SCHIP).....www.insurekidsnow.gov
All states have a health insurance program for uninsured families that meet the income gap. Go to your state's program.

Sidelines National Support....www.sidelines.org
Sidelines provides support for pregnant women on bedrest and those dealing with the after effects of bedrest.

Social Services

Virginia

Alexandria- (703) 838-0700
Arlington- (703) 228-1550
Fairfax County- (703) 324-7500
Fauquier County- (540)347-2316
Loudoun County- (703)777-0353
Manassas City- (703)361-8277
Manassas Park-(703)335-8898
Prince William County- (703)792-7500

Washington DC

Department of Human Services
(202) 671-4200

Maryland

Montgomery County (240) 777-1245
Prince George's County- (301)909-7025

**For more resources
go to www.premiestoday.org**

Early Intervention

This is a federally mandated program available in every state to screen and treat children under the age of three for developmental disabilities and delays. If you have any concerns about your preemie's development, contact your local office to have your child tested. Services are covered by most insurances and are billed on a sliding scale.

Virginia

Infant and Toddler Connection
Alexandria- (703) 838-5060
Arlington County- (703) 228-1630
Fairfax County/Falls Church- (703) 246-7121
Loudoun County- (703)-777-0561
Prince William- (703) 792-7879

Washington, DC

Office of Infants and Toddlers With Disabilities
(202) 727-8300

Maryland

Infant and Toddlers
Montgomery County- (240) 777-3997
Prince George's County-(301) 265-8415

Child Find

Preschool Child Find is a part of every public school system and serves as a resource for preschool children and their families by providing therapy or educational services in the home or in various local elementary schools for children that qualify starting at age 3 through age 5. This program is provided at no cost.

Virginia

Alexandria (703) 824-6708
Arlington (703) 228-6042
Fairfax County
(703) 876-5244 Devonshire office,
(703) 446-2100 Lorton office
Falls Church City (703) 248-5655
Prince William County (703) 791-8857

Maryland

Montgomery County (301) 929-2222
Prince Georges County (301) 808-2719

Washington DC

(202) 727-8300

Membership/Subscription Information:

We offer the Preemies Today newsletter, family outings, parent support groups, preemie play-groups, 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 Preemies Today please email us at info@preemiestoday.org or you may go to our website at **www.PreemiesToday.org** and click on “Join Us.”

This newsletter was funded by a Community Grant from the March of Dimes. This material is for informational 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.

Don't Miss These Events!

Parent Support Meeting

January 9th, 7:30 pm, Barnes and Nobles
Fairfax, VA

Dream Dinners

February 26th, 5-8:00 pm
Rockville, MD and Sterling, VA

Please RSVP to events@preemiestoday.org

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TODAY**

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or
703-552-0163