

Time for Kids' Health



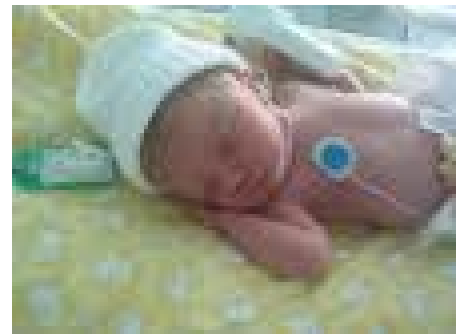
Supportive Care for Premature Babies

It is estimated that about 12.8 percent of babies in the United States are born prematurely, i.e. before the 37th week of pregnancy. Viability of the fetus generally occurs around 24 weeks. The rate of premature birth has increased by 36 percent since the early 1980s, in part due to increased C-section rates. All premature babies are at risk for health problems, but the earlier a baby is born, the greater the risk for serious complications. Premature babies are also at increased risk of developmental disabilities, cerebral palsy, learning problems, vision and hearing loss.

activity present in the NICU, but simple measures to modify the NICU environment can help babies cope. Minimizing unnecessary noise and light can reduce the amount of disruptive stimulation a baby receives. Closing incubator doors quietly instead of snapping them shut is less likely to startle a baby. Placing a blanket over the baby's incubator will shield the baby's eyes from light shining directly on him or her. Positioning the baby away from foot traffic and keeping voices low around his/her incubator can help the baby rest. Medical and caregiving procedures can be clustered to maximize the hours the baby can sleep undisturbed.

Over the last decade, researchers have developed ways to lessen the negative effects of hospital care and minimize the stress premature babies experience in a Neonatal Intensive Care Unit (NICU). The Neonatal Individualized Developmental Care & Assessment Program (NIDCAP) is an approach that is designed to meet an individual baby's needs and help that baby develop as normally as possible despite his/her early birth. NIDCAP is a comprehensive approach to care that is developmentally supportive and individualized to a baby's level of stability. Care recommendations are made after direct observations of the baby. Research indicates that using this approach decreases medical complications, increases weight gain, decreases days spent on a respirator and improves early developmental milestones.

Premature babies tend to need more sleep than their newborn peers; however, their sleep is often disturbed by the activity in the NICU. Babies sleep better when they are in a flexed position and have boundaries. This curled position, called flexion, is the position babies assume naturally in the womb. Premies, with their lack of muscle strength, have a hard time maintaining this position by themselves. Caregivers can help babies maintain flexion by



Babies tend to be stressed by all of the

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Children with Special Health Care Needs (CSHCN)

- CSHCN are those children ages 0-21 who have a chronic physical, developmental, behavioral or emotional condition.
- If you have suggestions for topics or would like to share a story for "Reflections," please contact us. We'd like to hear your point of view.
- Sue Wegman shares her insights in this issue of "Reflections."
- Sue Wegman, Editor & CSHCN Coordinator
478-1462 ext. 336
E-mail: swegman@contactefr.org

swaddling them in a blanket with their arms and legs bent, and their hands brought forward in front. Another method of maintaining flexion is to create a nest with rolls of blankets or cloth diapers around the baby's head and sides, and under his/her knees to keep them bent. In the hospital, babies sometimes sleep on artificial lambskins or water beds. However, because of the risk of Sudden Infant Death Syndrome, lambskins and waterbeds should never be used at home unless the baby is constantly monitored.

Preemies tend to express themselves through physical changes and behavior. It is important to learn a premature baby's cues and to pace activities accordingly. Most preemies can handle only one form of stimulation at a time. For example, rocking a baby should be done separately from talking to a baby. Placing a hand

on a baby's back or chest and applying firm pressure can help a baby calm down and organize him or herself by blocking out other stimuli. If a baby's medical treatment includes invasive or uncomfortable procedures, soothing measures such as swaddling, giving the baby something to grasp or a pacifier to suck on may offer him or her some degree of comfort.

Improving conditions in the NICU have shown to improve outcomes for premature babies. Babies 26 weeks and older have an 80% survival rate. The survival rate of babies as young as 24 weeks gestation has also improved. Still, only 20% of truly premature babies will have no long-term health or developmental problems. The remaining 80% demonstrate some degree of learning and/or health problems for most of their lives.

Information for this article taken from www.prematurity.org and www.miscarriage.about.com

AMCHP Celebrates 75 Years of Title V Programs

This year, the Association of Maternal and Child Health Programs (AMCHP) celebrates the 75th anniversary of the Title V Maternal and Child Health (MCH) Block Grant. Through Title V of the Social Security Act, the federal government established the MCH Services Block Grant to support the development of state programs dedicated to caring for the health and welfare of mothers and children. State money must be used to match 75% of each dollar received from the federal government. In other words, for each \$4.00 received, a state would need to contribute \$3.00 resulting in a program having \$7.00 to spend.

The Title V MCH Block Grant includes a wide range of maternal and child health programs; however, all programs developed by the states endeavor to:

- Reduce infant mortality and incidence of disabling conditions among children.
- Increase the number of children immunized against disease.
- Increase the number of children in low-income households who are assessed and receive follow-up diagnostic and treatment services.
- Provide and ensure access to comprehensive perinatal care for women; preventative and child care

services; comprehensive care, including long-term care services, for children with special health care needs; and rehabilitation services for blind and disabled children under 16 years of age who are eligible for Supplemental Security Income.

- Facilitate the development of comprehensive, family-centered, community-based, culturally competent and coordinated systems of care for children and youth with special health care needs.

In the coming years, most state-based MCH programs will be revisiting needs assessments and reviewing evidence-based research to identify unmet needs and opportunities for prevention and intervention. Areas receiving increased attention include: adolescent health, care coordination, early childhood development, home-visiting, mental health, newborn screening, oral health, school health and transition services to bridge child and adult health systems.

AMCHP has put out a commemorative booklet, *Celebrating the Legacy, Shaping the Future*, which includes information about the history of Title V, the role of AMCHP and future goals of state MCH programs.

For more information about AMCHP and Title V visit: www.amchp.org



Reflections

by Sue Wegman

It has been over twenty-five years since I gave birth to a premature baby. Since then advances in medical care have greatly improved outcomes for premature babies and their families. Still, it is always difficult to have a baby born prematurely. No one expects it. Doctors do everything possible to prevent it. As parents, we are thrown into a world we know little about. It is also a world few of us would choose. We find ourselves in a traumatic situation where we must make critical decisions with very little preparation.

My son, Brendan, was born at 29 weeks gestation. I had gone into labor unexpectedly, and he was born while I was on the phone to the doctor. He was quickly taken by ambulance to the hospital and immediately transferred to the NICU, where he was barely stable. The doctors worked on him for hours, inserting tubes and IVs. No one expected that he would live very long. He was “cold,” and the doctors doubted that he could regain, much less maintain, a normal body temperature.

I saw Brendan just once before I was discharged. I could find one leg that was free of medical equipment, and so I held onto that. Then I went home and cried, certain that my baby would not live through the night. Brendan, however, was tough. He not only made it through the night, but also made almost steady progress (every baby has setbacks) towards going home. Brendan was released slightly before his due date some 8 weeks later. His homecoming was an amazing accomplishment considering his condition when he first entered the hospital. Perhaps even more amazing is that he came home without the monitors and ventilator that had kept him alive for so long.

Anyone who thinks that Brendan made it through the trauma of being in the NICU unscathed would be

wrong. He had, and still continues to have, cutdown (a procedure that was used to measure blood gases) scars on both wrists and numerous scars on his scalp where IV lines were attached. He had difficulty eating and sleeping for months after coming home, and he was once given the diagnosis of “failure to thrive” because he grew so slowly. Brendan also had respiratory issues, and it seemed as if he was always sick. We discovered later that he had subglottic stenosis, a narrowing in his trachea right below the larynx, which required surgery. He had significant delays in early developmental milestones as well. Not surprisingly, he required frequent doctor visits. I once halfheartedly joked that I should have a reserved parking space.

As time passed, and Brendan got older, he got sick less and less. His pediatrician commented; “Just when you think a kid is never going to get well, he suddenly develops an immune system.” I was certainly glad of it.

Still, the trauma of being born prematurely showed in Brendan’s development. Brendan needed special education services from the time he was 8 months old until he left school as a 21 year old. He also received a full complement of related services. Even now -- though his health is greatly improved -- Brendan has significant support needs. This is certainly not the perfect ending I would have liked. Though Brendan experienced a better outcome than I could have hoped for years ago, his premature birth and the steps we took to save his life continue to affect him.

Mark your calendar

√ SUPAC Training

UNDERSTANDING YOUR CHILD'S IEP: SMART IEPs will be held on Tuesday, November 16th (6:30 to 8:00 p.m.). Come learn how to work with your child's team to develop goals that are specific, measurable, action-based, realistic and time-limited. This training will be held at the East Area Family YMCA, 200 Towne Drive, Fayetteville, NY. There is no charge and refreshments will be served. To reserve childcare, contact Kim Purcell at 637-2025 at least a week in advance. To register for the workshop, call SUPAC at 443-4336 or register online at

<http://www.supac.org/training/register-for-supac-trainings/>

√ EFR Advocacy Workshop

SPECIAL NEEDS TRUSTS will be presented by Rick Cote, Jr. from New England Financial on Tuesday, December 7, 2010 (6:00 to 8:00 p.m.). This workshop will be held in the 2nd floor Board Room at Exceptional Family Resources, 1820 Lemoyne Avenue, Syracuse, NY 13208. The registration fee for the workshop is \$5.00 and includes dinner. For more information and/or to register, call Sue Corcoran at (315) 478-1462 ext 327.

Sensory Garden



Arc of Onondaga created a Sensory Garden for individuals with disabilities to enjoy at its headquarters, 600 S. Wilbur Ave, Syracuse, NY. The garden includes a variety of plants chosen to ignite the senses. The plants also create a natural habitat for local wildlife such as birds and butterflies. The paths that meander through the garden are handicap accessible and designed to encourage individuals of all abilities to enjoy the tranquil beauty of nature.

Dental Toolkit Created by Autism Speaks

Oral health habits can be challenging for many children with autism. Autism Speaks has partnered with Colgate and Philips-Sonicare to create a dental guide and video to provide tips for improving children's oral hygiene at home. Information about how parents and dental professionals can make a visit to the dentist's office less stressful and more productive is also included. The video demonstrates a visit to the dentist's office by a child with autism along with tips on how to make the experience more successful. The dental guide includes a visual schedule that can be used to help the child understand the steps involved in a routine dental appointment. The video and dental guide can be accessed at:

http://www.autismspeaks.org/community/family_services/dental.php

Children with Special Health Care Needs

is located at:
Exceptional Family Resources
1820 Lemoyne Ave
Syracuse, NY 13208

Phone: 315-478-1462 ext 336
Fax: 315-478-1467

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is published four times yearly
Sue Wegman, Editor
478-1462 ext 336
Email:
swegman@contactefr.org

Exceptional Family Resources
1820 Lemoyne Ave
Syracuse, NY 13208



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