

October 2009

In this Issue:

- Premature Infant Spotlight
- Network News
- National News

National *preemie* Network News

Florida | Georgia | Illinois | Maryland | Minnesota | New York | Ohio | Oklahoma | Pennsylvania | Texas

Not a member yet? Join your state's network!

As a thought leader on prematurity issues, we hope you will join us to help preserve and improve the health of the nation's babies. For more information about your state's preemie network, please reference the state network contact information below.

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Premature Infant Spotlight

Tyler Bolyard



Tyler was born in 1996 at 31 weeks gestation age. Following his birth, he spent about a month in St. Vincent Mercy Children's Hospital's Neonatal Intensive Care Unit in Toledo, Ohio. After a brief time at home with his birth parents, Tyler returned to St. Vincent Children's with RSV. He spent a month-and-a-half on a ventilator, and then returned home only to contract RSV again two weeks later.

Tyler was transferred to the University of Michigan and spent approximately 20 days on Extra Corporeal Membrane Oxygenation (ECHMO), a miniature heart lung bypass machine. Tyler was sent back to St. Vincent Children's where he continued to have problems. After another visit to the University of Michigan for cardiac surgery, they sent Tyler back to St. Vincent's. He was four months old and was not expected to make it to his first birthday.

In April 1998, Tyler, 18 months old, was reunited with his family. However, a short time later, he was removed from his family due to their inability to provide for Tyler's special needs. Realizing his potential, Dawn Bolyard, a clinical nurse specialist in St. Vincent's Children's Pediatric Pulmonary Center, and her husband adopted Tyler.

Today, Tyler is doing quite well. He still has respiratory issues and was recently diagnosed with asthma. Tyler also was diagnosed with scoliosis and is back in therapy to help with this condition. He continues to receive speech and occupational therapy in school. Tyler has far surpassed the expectations of his physicians. While he still struggles daily with the issues from the beginning of his life, Tyler is a happy, enthusiastic and loving 13-year-old boy.

Network News

Florida Alliance for Healthy Babies

Following the 2009 Florida legislative session, the Florida Alliance for Healthy Babies celebrated the success of its three key legislative priorities, which included increasing the number of eligible families for Florida's SCHIP, increasing the state's cigarette tax, and securing funding for Florida's medically needy program.

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MedImmune strives to cultivate long-term sustainable relationships with national and state organizations to optimize health outcomes for premature babies and their families. That's why MedImmune supports regional prematurity networks. These networks bring together interested parties focused on the health and well-being of premature babies.

**Prematurity networks located in Florida, Illinois, Maryland, Minnesota, New York, Ohio and Pennsylvania are funded and supported by MedImmune. Network contacts listed at each of these organizations are paid consultants of MedImmune.*

In preparation for the 2010 session, the Alliance has already met to identify key legislative priorities and discuss upcoming NICU tours to reach key community leaders and policymakers. Key issues identified include changes in immunization scheduling, Medicaid coverage for smoking cessation, funding for the birth defects registry, and expanding Medicaid eligibility for pregnant women.

The Alliance also is focusing on recruitment efforts for physicians, as well as members in the healthcare, business and education sectors. A new key member, Children's Future Hillsborough, is a group that represents 20 organizations in the Tampa area, one of Florida's largest metropolitan areas.

Georgia Preemie Network

Recently, several passionate individuals met to discuss forming a coalition that would address the issues surrounding premature infants in the state of Georgia. As a result, a formal coalition was created. Members include: the Georgia Academy of Family Physicians, the Zoe Rose Memorial Foundation, the Atlanta Healthy Start and the American Lung Association of the Southeast.

At the meeting, members discussed the key areas of concern they would like the coalition to address. These concerns include early intervention, increasing access to care and expanding Medicaid for women (particularly pregnant mothers) and children, wellness education for women and expecting mothers and increasing awareness of existing programs and services for pregnant women and new mothers. The group held their second meeting on July 29 to determine key aspects of this effort, including a coalition name, key goals and priorities to be accomplished in 2009.

Illinois Premature Infant Health Network

The Illinois Premature Infant Health Network (IPIHN) recently supported the Illinois Chapter of the American Academy of Pediatrics (ICAAP) in conducting a survey examining Level III NICU follow-up programs across Illinois. The primary goal of the survey was to provide a comprehensive picture of the current NICU follow-up services available across the state and identify areas for improvement.

The survey results were varied and diverse across the Level III NICU programs, underscoring the need for improvements including: increased funding, increased access to services, research on outcomes of Early Intervention (EI), a better understanding of the roles of follow-up programs and EI to avoid duplication, and more education for physicians on the role of follow-up programs. IPIHN is currently working on next steps with ICAAP, including the distribution of the results to key stakeholders as well as a follow-up "best practices" conference call with survey respondents.

Maryland Premature Infant Health Network

The Maryland Premature Infant Health Network met for its fifth meeting in May 2009 to continue advances in advocacy, education and collaboration for premature infants across the state. Network members are proactively working with the Maryland Patient Safety Center — Neonatal Collaborative to address network priorities

Best Practices *Story*



Brenda Hussey-Gardner, PhD, MPH, from the University of Maryland School of Medicine, recently presented a study titled, “Part C Early Intervention Programs: A State-by-State Breakdown of Eligibility & Cost to Families of Preterm Infants” to members of the Maryland Premature Infant Health Network.

The objective of the study was to survey state Part C programs to identify (1) eligibility criterion related to gestational age and birth weight, (2) developmental delay eligibility criteria for states not automatically serving preterm infants, and (3) cost to families for program participation.

All 50 Part C state lead agencies were contacted by phone and/or email to determine (1) high probability eligibility criteria related to birth weight and gestational age, (2) percent delay required for program eligibility if preterm infants are not automatically eligible, and (3) cost of participation for families.

As criteria vary greatly, neonatologists and pediatricians need to be aware of the specific criteria for the state in which they practice. In addition, they need to know whether or not there will be any direct costs to families who participate in early intervention. Currently, 29 (56.86%) states provide services at no cost to families. For more specific information about the study, please contact Kari Lato at (920) 206-9611.

around the issue of NICU discharge. The Collaborative has more than 200 individual members and approximately 28 hospitals involved.

In partnership with key county health departments, the Network is working on a project with physicians to encourage referrals to state-based services for premature infants. Project execution will involve development and distribution of prescription pads to providers that contain county specific resources. This information will then be distributed to parents of premature infants.

The Network also is working with Preemies Today, a preemie parent support group, on a resource guide for families and providers.

Minnesota Premature Infant Health Network

Since its inception, the Minnesota Premature Infant Health Network has grown to nearly 100 members. The Network’s newest member, Alexa Stevenson, freelance writer and parent of a premature baby, puts a real face on prematurity. Alexa’s daughter, Simone, was born more than three months early, weighing just more than a pound and a half. Simone spent 96 days at the NICU at Children’s Hospital in St. Paul.

Minnesota state legislators are becoming more interested in what the Network is doing and Assistant Majority Leader Representative Erin Murphy spoke at the Network’s most recent meeting. The Public Policy group plans to continue their work with Rep. Murphy to bring more state legislators to network meetings and to work toward implementing a Legislative Prematurity Caucus during the 2010 legislative session.

In addition to recruiting state legislators, members are beginning to actively recruit more physicians to the Network.

New York Premature Infant Health Network

On June 10, the New York Premature Infant Health Network hosted a legislative reception during the New York State Perinatal Association conference held in Albany. Janet Press, RNC, BSN, CT, perinatal/obstetrical coordinator, perinatal bereavement services coordinator for Crouse Hospital in Syracuse, NY, and mother of premature infant boys, was invited to share her amazing journey as a parent of premature twin boys – caring for one premature child while mourning the loss of her other son. Her story was inspiring and insightful.

In addition, Dr. Jordan Kase and Dr. Edmund F. LaGamma of the Neonatal Center Marai Fareri Children’s Hospital and Amanda Hill of the Children’s Hospital at Albany Medical Center, served as moderators of the “Living the NICU Experience” session. The attendees heard from Debra Randazzo and Donna Zion, founders of Hailey’s Hope Foundation, who shared their NICU experience and challenges of caring for a premature infant at home.

Premature Infant Health Network of Ohio

The Premature Infant Health Network of Ohio met on May 5 in Cleveland, Ohio, followed by conference calls for the three committees: Continuity of Care, Family Supports and Policy.

National News

Preventing Premies

July 22, 2009, Time

When a baby is born too soon, it's hard to imagine that the infant would do better anywhere else in the world than in America. The most fragile preterm infants are housed in specialized intensive-care units and cared for by world-class experts.

Are Outcomes and Care Processes for Preterm Neonates Influenced by Health Insurance Status?

July 2009, Pediatrics

Does health insurance status impact the health care received by preterm neonates? A study in the July 2009 edition of the journal Pediatrics compares the processes of care and evaluates the outcomes of premature neonates delivered to women with Medicaid managed care versus private insurance.

The Continuity of Care committee is currently working on brainstorming ways to create standardizations of NICU discharge procedures. In addition, Network members will be sharing education pieces used throughout the state at the next meeting to determine similarities and differences.

The Family Supports committee has developed a survey to be distributed one month post-discharge to parents of premature infants. The goal of the survey is to determine where the gaps are for access to care.

The Policy committee is planning a legislator NICU tour and home care visit targeting the southwest region of the state. In addition, the Network is working to support the efforts of the Ohio Prematurity Caucus and the Governor's Infant Mortality Task Force.

Oklahoma Infant Alliance

The Oklahoma Infant Alliance held its first meeting on March 31 with 21 diverse groups in attendance. The purpose of the meeting was to announce the Alliance and begin developing partnerships with other state leaders and organizations interested in improving the health of Oklahoma's late preterm infants. The Alliance began their efforts in early March looking at national data and issues related to caring for late preterm infants.

Oklahoma hosted a subsequent meeting on August 27. Several members provided local data that supported the need for the creation of this group in Oklahoma. As the group moves forward, members will look at data available from the Oklahoma State Department of Health and the Pregnancy Risk Assessment and Monitoring System, which is preparing to release a report on late preterm infants. Many Alliance members will participate in the development of the report.

Pennsylvania Premature Infant Health Network

In May 2009, House Resolution 229 (HR 229) was successfully passed in the House of Representatives. HR 229 introduced by Representative Roebuck and 30 legislative sponsors from across the state, urges the Department of Health to prepare and distribute educational information about premature infants' risks and health care needs.

The Network will be working in conjunction with Representative Roebuck to provide recommendations for successful implementation of HR 229 to the Department of Health. The Network recommends four specific areas of focus – early intervention, consequences of late preterm birth, late preterm infants, and a statewide resource guide.

The Pennsylvania Premature Infant Health Network is excited for the increased visibility and educational opportunities for the State's premature infants.

In addition to work on HR 229, the Network is addressing the importance of early intervention referrals, recognition of the needs of late-preterm infants, and standardizations and implementation of NICU discharge procedures.

Great Web Resource for Parents of Premies



The American Academy of Pediatrics (AAP) has recently launched a Web page designed specifically for parents of premature babies. The page includes articles, links, free brochures and recommended reading.

Texas Infant Health Alliance

Texas ranks last in the U.S. in the number of children with health insurance, 49th in preventing teen births, 37th in prenatal care, and 21st in infant mortality. In the face of such dire statistics and the human hardship behind them, there is an urgent need for broad-based leadership among cross-interest groups and a consensus to advance an infant health agenda for Texas.

To meet this need, the Texas Infant Health Alliance has recently formed so that organizations and individuals with an interest in infant health can build a common knowledge base, exchange timely information and resources, and track administrative and legislative activities related to infant health. Since its formation in April, the group has grown to more than 100 members, including advocates, healthcare providers, community organizations, parents and state agency partners. Speakers at the monthly Alliance meetings have included researchers, the state epidemiologist and healthcare providers working directly with infants. Focus areas have been both best practices in care for infants and recommended policy changes for improving state outcomes.

National Preemie Network News, funded and sponsored by MedImmune, is a quarterly resource for sharing information about advocacy efforts across the nation focused on increasing quality health care access for premature infants.

