March of Dimes
NICU Family Support®

Supporting Families and Staff in the NICU
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Our Mission
To improve the health of babies by preventing birth defects, premature birth and infant mortality.

- Fund Research to understand the problem and discover answers.
- Help Moms have full-term pregnancies and healthy babies.
- Support Families comforting them when their baby needs help to survive and thrive.

March of Dimes: Champion for All Babies
March of Dimes helps moms have full-term pregnancies and healthy babies. And if something goes wrong, we offer information and comfort to families. We research the problems that threaten our babies and work on preventing them.

March of Dimes NICU Family Support "changed our NICU culture"
-- Hospital Administrator Interview

NICU Family Support: Core Program Goals

- Providing information and comfort to families during the NICU hospitalization of their newborn, during the transition home, and in the event of a newborn death
- Contributing to NICU staff professional development
- Promoting the philosophy of family-centered care in NICUs
81% of staff said that NICU Family Support resulted in more informed NICU parents.

79% of staff said NICU Family Support resulted in less stress on parents.

75% of staff said that NICU Family Support resulted in increased confidence of parents at discharge.

Changes after Implementation of NICU Family Support:
- Open and honest communication between parents and staff
- Involvement of parents in decision-making
- Sharing information and the meaning of information with parents
- A partnership between professionals and parents in the provision of care
- The development of policies and programs to promote parenting skills and family involvement

95% reported that NFS Specialist was the source to go to in transition to home from NICU...above all other staff.

Respondents from the fully implemented project sites consistently reported a high percentage of opportunities for involvement in the direct care of their baby.

80% of families at fully implemented sites reported obtaining comfort from NICU Family Support materials.
Families highly valued Sibling Education, Photography and Scrapbooking.

Parent Education Hours were rated as highest for comfort and information.

When asked what brought the highest levels of comfort and parenting confidence to parents, it was an overwhelming vote for “holding my baby.”

March of Dimes NICU Family Support® has had a positive impact on:
- Stress level
- Comfort level and
- Parenting confidence of NICU families
- Receptivity of staff to family-centered principles

Key Learnings

Areas Parents Identified (Cooper, et al, 2007)
- Promote holding and skin-to-skin
- Involve Parents Early and Often/Transition to Home

Percent of NICU staff who stated that skin-to-skin care was routinely performed in their units:

Close to Me

The power, benefits and impact of skin-to-skin holding for newborns, parents and families
What are some obstacles stopping you from suggesting skin-to-skin holding to a parent?

- Inconsistent criteria/standards
- Difficulty assessing newborn readiness
- Staff concern about adverse events (extubation, etc.)
- Lack of knowledge about depth of benefits
- Staff concern about workload, time, space, multiple staff needed

(Engler, A.J., et al., 2002)

Kangaroo care enables moms to regain the temporarily lost relationship with their child, and enables fathers to experience the beginning of a new relationship.

(Fegran, L., Helseth, S. & Fagermoen, M.S., 2008)

Improving practice

- Develop guidelines
- Develop teaching plan for family
- Develop ongoing teaching plan for staff
- Develop teaching plan for mothers on the antepartum unit before NICU admission
- Continue to encourage skin-to-skin holding even after a baby graduates to wearing clothes
- Encourage families to hold skin-to-skin at home after discharge.

What We Say Can Help, Hurt or Heal

“Your baby’s heart rate is dropping. It’s time to put her back.”

“He looks so peaceful in your arms.”

“You’re doing such a great job.”

“You are not holding him right. He’s not comfortable.”

“I will never forget the first time my newborn was placed on my chest. She was so tiny, so fragile, but she curled right up into me, as if she instinctively knew that’s where she belonged. It was the closest I’d been to her since she’d been inside me. In that moment, I finally felt like a mother. This child was mine. Those moments (when we kangarooed) would fast become my favorite NICU moments. In those moments, nothing else existed but my daughter and me.”

Denise R, NICU mother
Taking Baby Home

1. You can never spoil your baby with too much attention.
2. Never let anyone shake your baby.
3. Keep germs away from your baby.
4. Put your baby to sleep on her back.
5. When home with your baby, give him “tummy time.”
6. If your baby was premature, talk to your doctor about ways to decrease the chance your next baby will be born early.
7. Take a multivitamin with 400 mcg of folic acid every day.
8. Be sure to eat right. It’s important for you and your baby.
9. Keep your baby away from cigarette smoke.
10. Get support from others who understand at shareyourstory.org

NICU Family Support®

Different Services, Same Goals
- Providing information and comfort to families during the NICU hospitalization of their newborn, during the transition home, and in the event of a newborn death
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- Promoting the philosophy of family-centered care in NICUs

Components and Services

NICU Family Support Specialist
Parent/Staff Committee
NICU Staff Professional Development
Customized Programs
24/7 Computer Connection
Parent Care Kits, Educational Material
Direct Services
Parent-to-Parent Support/Mentor
www.ShareYourStory.org
Promotion
Evaluation Assessment

NICU Family Support Hospital Licensing

- Extensive assessment of family support in your NICU
- Innovative, on-site family-centered training for all NICU staff
- Guidance and technical assistance for implementation
- March of Dimes NFS materials and resources
- Access to special products, offers and vendors to enhance family support
- Membership in national network of NICU Family Support sites to exchange best practices, ideas and expertise
- Quality assurance from March of Dimes team, working in concert with NICU

NICU Family Support Center

- Provides a tangible service that hospital can offer to families and promote in their community
- Provides supportive information

“Thanks for helping me find more information about (my child’s condition). Now I know what lies ahead for my baby.”
... a NICU parent at a Georgia hospital
NICU Family Support Center

- Helps minimize stress
  "(The Center) tells you a lot about what you should do before and after the baby comes home."
  — a NICU parent at a Florida hospital
- Connects families to others
  "After visiting Share, I know I’m not alone."
  — a NICU parent at a Florida hospital

March of Dimes Nursing Modules

- Abuse During Pregnancy: A Protocol for Prevention and Intervention
- Breastfeeding the Infant with Special Needs
- Care of the Multiple-Birth Family: Postpartum Through Infancy
- Care of the Multiple-Birth Family: Pregnancy and Birth
- Discharge and Follow-Up of the High-Risk Preterm Infant
- Loss and Grieving in Pregnancy and the First Year of Life: A Caring Resource for Nurses

March of Dimes Nursing Modules

- Perinatal and Neonatal Ethics: Facing Contemporary Challenges
- The Premature Infant: Nursing Assessment and Management
- Tobacco, Alcohol and Drug Use in Childbearing Families
- Late Preterm Infant Assessment Guide
- Neonatal Skin Care, Evidence-Based Clinical Practice Guideline

2009 Statistics

- 34,000 members
- 3,000 active at any given time
- Over 100,000 posts

www.shareyourstory.org

Almost 500,000 unique visitors
Over 3,600,000 page views

"Share Your Story has changed my life. I had never met anyone who had been through what I had. I not only found one person who had...I found thousands. I could say thank you a thousand times over - and it wouldn’t be nearly enough."

- Denise (weerock)
Community Center - social and site help
Share Your Story - stories through blogs, short stories & comments
Parent to Parent - topical, informational, useful
Get Involved - local and national action, timely

Share Your Story is maintained and managed 24 hours a day/7 days a week.

- Community host - full coverage
- Health education staff and resources
- Licensed social worker
- Technical support
- Volunteer leadership

“I am glad that one of the nurses told me about this site. Because when I come in here and read some of the stories they give me inspiration and hope and faith that we are going to make it through. So to each and every one of you who share your experience on here thank you so much. I will keep all of you in my prayers. And I appreciate all of the support I get from everyone who surrounds me.”

- Savannah (Ilove4)

Safe Place to Land

What You Can Do

- Promote skin-to-skin holding - early and often
- Build parents’ confidence in the transition to home, starting at admission
- Encourage families to connect to each other: www.shareyourstory.org
- Utilize March of Dimes online continuing education: nursing modules for the NICU
- Find information for NICU professionals and families at www.marchofdimes.com

March of Dimes NICU Family Support® Locations

March 2010
In their words

Sponsors and Supporters

Ther-Rx Corporation
MedImmune
Scholastic Books
Farmers
PerkinElmer

References