The Development and Dissemination of Written Informational Materials Regarding the Care and Support of Preterm Infants

Report Prepared by the House Joint Memorial 60 Task Force

Convened by the New Mexico Department of Health



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Introduction

House Joint Memorial 60 (HJM60) requested that the Department of Health convene a task force to develop and disseminate written informational materials regarding the necessary care and support of preterm infants with specific information about unique health issues, proper care, developmental screening, vaccinations, and the emotional and financial challenges faced by parents and families of preterm infants. Materials developed would be distributed to Medicaid providers, hospitals, maternal and child care providers, and others.

Based on this request, a task force was formed consisting of members from the Department of Health; Children, Youth and Families Department; the New Mexico Hospital Association; Human Services Department and an intern from the Governor's Office (See page 16 for a complete membership list).

Background

Preterm labor is defined as labor that occurs before completion of the 37th week of gestation. The 2006 New Mexico Selected Health Statistics Annual Report stated that in New Mexico, the percentage of preterm births increased in 2006 to 11.1% from 10.2% in 2002. There were a total of 29,918 births in New Mexico in 2006. Of those, 154 were under 28 weeks (0.5%), 368 births were from 28-31 weeks (1.2%), 1,619 were from 32-35 weeks (5.4%) and 1,204 births were at 36 weeks (4.0%). Preterm births in New Mexico were predominant among first-time mothers, moms over 34 years of age, African American mothers, and those with less than a high school education.

The exact causes of preterm labor are not known and the etiology is likely to be multifactorial. Maternal age is one factor in preterm labor, especially for women under 18 or over 40. Younger or older women should be offered education and/or intervention for family planning, smoking cessation, substance abuse prevention, adequate nutrition, treatment of sexually transmitted diseases, and improvement of adverse work conditions that could harm a fetus.

A study "Preterm Birth in New Mexico", written by Kimberly Leslie, MD, a professor and Chief of Obstetrics and Maternal-Fetal Medicine Department of UNM, concluded that a lack of prenatal care was a significant predictor of preterm birth in high risk patients. Prenatal care should be provided in underserved rural and urban areas to women at high risk for preterm birth.

Furthermore, pregnancy outcomes can be optimized by the treatment of pre-existing medical conditions, such as hypertension and diabetes. In addition, infections of the genitourinary tract are important and treatable factors associated with preterm labor. A maternal history of one or more second-trimester abortions or a previous history of preterm labor also increases the risk of subsequent preterm labor. At present, corticosteroid therapy is the only treatment shown to improve fetal survival and outcome. iv

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Preterm birth is a leading cause of infant death and is associated with congenital neurological defects. The earlier the baby is born, the greater the chance he or she will have health problems. Premature infants are at risk for low birth weight, respiratory problems due to underdeveloped lungs and organ systems, life-threatening infections, increased risk for respiratory distress syndrome, greater risk for cerebral palsy, hearing and vision problems, and a higher risk for learning and developmental disabilities.

Not only is premature birth emotionally difficult for families, it carries a tremendous financial toll as well. In 2005, the annual socio-economic cost (medical, educational, and lost productivity) of preterm birth in the United States was at least \$26.2 billion. The average first year medical costs were about 10 times greater for preterm than for full term babies. The cost for the medical care of a preterm infant averages \$51,600 as reported by Institute of Medicine in a 2006 Report Brief entitled "Preterm Birth: Causes, Consequences, and Prevention" (at www.cdc.gov).

Care for Premature Infants

Neonatal Intensive Care Unit (NICU)

Premature babies may need to stay in the hospital for several weeks or more, often in a Neonatal Intensive Care Unit (NICU). Hospital nurseries are categorized in the following way (www.rushcopley.com/consumer/services/nicu/index.aspx):

- Level I nurseries care for normal newborn infants only.
- Level II Neonatal Intensive Care Unit (NICU) nurseries may care for moderately ill or premature infants.
- Level II+ NICU nurseries (or with exception) treat babies born as early as 28 weeks gestation.
- Level III NICU nurseries are the most advanced with no restrictions on caring for babies of any gestation, weight or medical condition.

There are three NICUs in New Mexico, all in Albuquerque. They belong to University of New Mexico Hospital, Presbyterian Hospital, and Lovelace Women's Hospital. The hospitals collectively offer 163 beds to premature babies at any time. All three NICUs are Level III certified and dedicate themselves to the needs of their patients. During the research of this memorial, an onsite visit to the three NICUs was made to acquire the information given out to the families served by these hospitals.

Visits with the NICU personnel suggest that families are given adequate preparation and education about preterm infants. Each NICU provides the families of preterm babies with up-to-date information and opportunities to participate in their child's care. The NICUs do a great job of preparing parents for the responsibilities of having a preterm baby, and are committed to connecting families of preemies with early intervention services.

The NICU experience is unique, but not one that any parent really wants to have. Our representative found that New Mexico's NICUs create an atmosphere that is supportive for the parents of premature infants. Parent/family education materials and videos are readily available. Below are descriptions of each hospital and the services they provide.

University of New Mexico NICU – (505-272-5437)

Fifty-two beds with space for nurse educators, lactation specialists, developmental care specialists and research staff. A new 12-bed transitional and intermediate care nursery opened in January 2008. UNM's NICU offers different types of education to parents, including a booklet that they designed specifically for premature families. They also have an outreach program which aids families and they host a representative from Parents Reaching Out (PRO).

Contact: Jamie Robertson 505-272-2458 (fax 505-272-3556)

Lovelace Woman's Hospital NICU- (505-727-4725)

Fifty-three beds with 24/7 in-house neonatologist coverage, specialized respiratory therapist, neonatal nutrition care and dietary counseling, developmental rehabilitation, lactation consultants, infant CPR training, and family support services. Sixteen labor/delivery rooms and 41 beds in the Mother-Baby Unit. Online, they offer: Baby Care Basics, Breast Feeding Services, Childbirth Preparation and a New Mother Support Club.

A number of different informational sheets are given out by Lovelace. They offer two packets to families: a welcome to the NICU packet and a discharge packet that contains a variety of information that helps parents of premature infants navigate the system (visitation, regulations and insurance) and care for their baby while in the hospital (infant care and specific disease-oriented fact sheets) and upon discharge.

Contact: Johanna Ruby (Charge Nurse) 505-727-3437

Presbyterian Hospital NICU – (505-841-1280)

Sixty beds with multi-specialty teams, state of the art monitoring and therapeutics, and air or ground transportation services via specially trained neonatal transport teams. Similar to other hospitals, Presbyterian distributes packets of information that cover a variety of topics that are beneficial to the parents of a premature infant.

Contact: Jenny Miller 505-841-1280 jmiller 7@phs.org

Amy Bubbico abubbico@phs.org

Beyond NICUs

Due to the stresses of premature births, many families do not experience the long-awaited first moments of holding the child. Instead, the child is rushed away for care, leaving the family to worry and wonder what will happen in the days, weeks, months or years to come. Encouraging families to bond with the child could prevent some emotional problems seen later in life by both family and child. Various issues accompany such situations, but the fact is premature children need care beyond the NICU.

Additional resources are needed for parents to assist them in anticipating not only the physical, but the emotional needs following recovery and the return home of their premature babies. Mothers actually tend to indicate the most negativity some 4-5 weeks after their infant has reached recovery and returned home. Other descriptive studies found that mothers of premature infants reported two periods of emotional difficulty; the first being immediately after birth and the second being after the baby returned home. Many different organizations work with children that have delays and their families, but due to lack of information, some families may not be aware of these organizations.

Non-NICU Care

Many babies who are born only a few weeks premature may not need specialized treatment, such as that provided in NICUs, but their families would likely benefit from support and information about the consequences and challenges of being born slightly pre-term.

The National Institute of Child Health and Human Development has found that "mildly premature" infants are at risk for minor developmental delays. To avoid long-term consequences, they advise parents to have mildly premature children followed through early childhood to see if they will require specialized services to assist in their development.

Researcher Dr. Mary L. Hediger states that "a cumulative effect may result when a child who faces other risks for developmental delays is born prematurely. Being born to an older mother, being the youngest child in a large family, being born in poverty, being born to a family with a low educational level — are all risk factors for developmental delays." She continued, "A combination of these risk factors, together with the developmental risks of moderate prematurity, might have a noticeable affect on development and might hinder a child's academic and other achievements." (National Institutes of Health Eunice Kennedy Shriver National Institute of Child Health and Human Development, January 15, 2002.)

<u>**Information On-line Concerning Preterm Babies**</u>

The task force found many sites online that carry very similar information (see Appendix A). The power of the Internet and the ability to acquire large amounts of information quickly makes it possible for parents of premature infants to access answers to their questions in a way not possible in the past.

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Task Force Conclusions

The task force is confident that adequate information is available on the immediate care of the premature infant, but did have a concern about the amount of information available for parents of premature children that still require specialized care, especially as the child ages. Additional resources also are needed for parents to assist them in anticipating the physical and emotional needs following recovery and the return home of their premature babies.

The following gaps/barriers were identified regarding educational materials.

- Families' comprehension of materials depends upon their level of literacy and primary spoken language at home.
- With the variety of materials available, parents may be challenged by sorting through and getting the most important information regarding the care and development of their premature infant.
- Hospital care below the newborn intensive care units may not have sufficient resources or materials to inform parents with slightly premature infants.

The task force makes the following recommendations:

Materials

- Convene an Early Childhood Summit, with representatives from the private/public sector, to develop a standardized, cultural-relevant and user-friendly packet of materials on the care of premature infants after hospitalization and a website for parents providing resources for the care of preterm infants.
- Where available, use well written materials, like those from the March of Dimes, as part of the information to parents and providers of preterm infants.
- Review possible sources for a mini-grant funding (March of Dimes, Brindle, LANL) for obtaining materials.
- Make wider use of videos on preterm infants currently shown at the University of New Mexico's NICU for parents who have literacy and language barriers.
- Appoint a subcommittee to develop a training module on preterm infant care for Community Health Improvement Councils, *promotoras*, case managers, WIC personnel and others that interact with new parents.

Distribution

• Invite key stakeholders, including deputy directors of appropriate state departments, representatives from the NICUs, rural non-profit health clinics, and

the New Mexico Pediatric Society, to a meeting of the Multi-Agency Team from the Young Child Wellness Council for Project LAUNCH (Linking Actions for Unmet Needs in Children's Health) to develop a material distribution plan.

- Use existing early intervention and service providers to distribute materials to families with preterm infants (Family, Infant and Toddler providers, WIC offices, Community Health Improvement Councils, hospital discharge planners, as well as home visiting nurses and case management personnel).
- Provide showings of videos regarding premature infants to both parents during hospital stays at all NICUs and local hospitals.
- Use home visiting and case management services to educate parents of preterm infants and for detection of developmental delays and proper referrals.
- Create a mechanism to communicate information to communities and between agencies through the Community Health Improvement Councils.

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References

ⁱ New Mexico Selected Health Statistics Annual Report for 2006. Santa Fe, New Mexico: New Mexico Department of Health, Bureau of Vital Records and Health Statistics. 2008.

ii New Mexico Pregnancy Risk Assessment Monitoring System. Surveillance Report 2004-2005 births. New Mexico Department of Health, Public Health Division, Family Health Bureau, Maternal Child Health Epidemiology Program. 2008.

Leslie, Kimberly, M.D., Professor and Chief, Obstetrics and Maternal-Fetal Medicine, UNM, Preterm Birth in New Mexico. 2008.

^{iv} Trachtenbarg, David E., M.D. and Golemon, Thomas B., M.D., University of Illinois College of Medicine at Peoria and Methodist Medical Center Family Practice, Peoria, Illinois. Published by the American Family Physicians, May 1, 1998.

^v Gennaro, S.: Postpartum Anxiety and Depression in Mothers of Term and Preterm Infants"; Nursing Research, 37, 82-84. Quoted in Bell, Michelle, "The Effects of Prematurity on Development Process Studies: The Premature Birth"; www.prematurity.org

APPENDIX A

Internet Search Results:

GENERAL INFO

• http://children.webmd.com/tc/premature-infant-the-premature-newborn

A general overview of premature children, which briefly touches on gestational age, underdeveloped lungs, apnea, inability to maintain body heat, and inability to feed orally.

• http://www.thechildrenshospital.org/wellness/info/parents/21879.aspx (Bilingual)

A good overview of prematurity, which addresses what a premature baby is, the preemie's basic needs, common health problems of preemies, and health concerns after the NICU. It also has links to other articles that include: common diagnoses in the NICU, when your baby's in the NICU, and apnea of prematurity.

• http://www.keepkidshealthy.com/development/preemie_development.html

Speaks of premature development and whether or not a premature child is more likely to have premature delays.

http://www.evergreenhealthcare.org/ehkwa/Templates/Pregnancy/Apps/ArticlePrint.aspx?POSTINGGUID={44A85B87-8AC5-4CDD-8840-E617A15C09C3}&FRAMELESS=true&NRNODEGUID=%7b44A85B87-8AC5-4CDD-8840-E617A15C09C3%7d

This article goes over what a preterm baby may look like and some possible medical complications for preterm babies.

• http://www.wockhardthospitals.net/images/Wockhardt%20guide%20on%20prem aturebaby.pdf

This brochure informs parents of the possibility of having to take care of a preterm baby with special needs, feeding your baby, encouraging good sleep, some tips on preventing infections, bonding with your baby, and encourages parents to take care of themselves.

• http://contemporarypediatrics.modernmedicine.com/contpeds/Features/The-late-preterm-infant-A-little-baby-with-big-nee/ArticleStandard/Article/detail/483620

This article is directed towards what parents should know about their late preterm infant. It is somewhat of an instruction sheet geared towards NICU personnel on how/what parents should know.

• http://pediatrics.aappublications.org/cgi/reprint/118/3/1207

This publication was from a workshop sponsored by the National Institute of Child Health and Human Development and it deals with optimizing the care and outcomes for late preterm infants.

• http://pediatrics.aappublications.org/cgi/reprint/120/6/1390

This article is from "Pediatrics", The Official Journal of the American Academy of Pediatrics. The purpose of this report is to define "late preterm," recommend a change in terminology from "near term" to "late preterm," present the characteristics of late-preterm infants that predispose them to a higher risk of morbidity and mortality than term infants, and propose guidelines for the evaluation and management of these infants after birth.

• http://children.webmd.com/tc/premature-infant-the-first-weeks-at-home

A short explanation of some of the trials parents will face with their baby during the first few weeks at home. There are descriptions of sleeping and wakefulness, fussiness, sleeping positions, feedings, nutrition, exposure to disease/smoke, protection from illness.

• http://www.kangaroomothercare.com/whatis01.htm

Offers a definition of kangaroo care, which is skin to skin contact between a parent and a baby. This kind of care helps to regulate the baby's heart rate and body temperature which are two bodily functions that preemies have a hard time regulating. Kangaroo care also stimulates milk production by the mother.

• http://premature-infant.com/index.html

Created by a mother who experienced the NICU as a nurse and mother, this brochure provides parents with preemie articles, NICU do's and don'ts, links to other resources including shopping for preemies, and stories from nurses and parents.

PARENT'S COPING

• http://www.ehow.com/how_3942_support-new-mother.html

A list of helpful things for a spouse/partner to do for the new mother.

http://www.marchofdimes.com/prematurity/21295 6090.asp

A brief explanation of Kangaroo care.

http://www.marchofdimes.com/prematurity/21295_6085.asp

Recommends taking care of payment for NICU care early.

http://www.marchofdimes.com/prematurity/21292_29534.asp

Understanding your feelings as a NICU parent.

• http://www.marchofdimes.com/prematurity/21292_11191.asp

Some recommendations on coping with the NICU roller coaster.

• http://www.marchofdimes.com/prematurity/21292_11225.asp

Addresses the father's role in the NICU experience. It focuses on the fact that it is ok for fathers to feel strong emotions and that there may be strain on the relationship between partners and other family members. It also encourages the father to take care of himself and recommends things to do for the baby.

http://www.marchofdimes.com/prematurity/21295_6082.asp

Recommends ways to interact and get closer to your new baby.

• http://www.marchofdimes.com/prematurity/21579_5769.asp

Offers recommendations on family support programs for NICU families.

• http://www.parentingyourprematurebaby.com/feelings.html

Encourages parents to allow themselves to experience the pain and grief of having a premature baby. Additionally, offers an explanation of initial coping strategies and recommendations when seeking any professional help.

http://www.parentingyourprematurebaby.com/parenting.html

Offers tips for coping with separation from your baby and leaving the hospital without the baby you expected to leave with. It also addresses the concerns of taking care of a preemie baby and building confidence in your abilities. Lastly, it addresses the emotional journey you have been through.

http://mchb.hrsa.gov/pregnancyandbeyond/depression/morethanblues.htm

Discusses perinatal depression; what causes it, who is at risk, types of depression, and symptoms.

• <u>ftp://ftp.hrsa.gov/mchb/pregnancyandbeyond/depression.pdf</u>

A booklet describing perinatal depression and the signs and symptoms.

NICU

• http://www.thechildrenshospital.org/wellness/info/parents/22608.aspx

Explains what the NICU is, who will be caring for babies within the NICU, what questions to ask, what to expect (in terms of what babies may have stuck in them or placed around them and what all the machines are), what are some good ways to bond with your baby, some other things to know, and how to make the NICU stay manageable.

http://www.marchofdimes.com/prematurity/21295_6084.asp

Recommendations on becoming an informed parent, becoming involved in the care of your baby, and being prepared for uncertain situations.

http://www.marchofdimes.com/prematurity/21295_6080.asp

Talks about building your confidence in terms of caring for your child.

TRAVEL

• http://www.ccmckids.org/safetransport/tipsheets/PrematureInfants.pdf

Recommendations on choosing the proper seat for your baby and how to position the child in the seat. It also addresses adjusting the harness and installation of the seat and car beds.

- http://pediatrics.aappublications.org/cgi/reprint/123/5/1424?maxtoshow=&HITS= 10&hits=10&RESULTFORMAT=&fulltext=Safe+Transportation+of+Preterm+a nd+Low+Birth+Weight+Infants+at+Hospital+Discharge&searchid=1&FIRSTIN DEX=0&sortspec=relevance&resourcetype=HWCIT
- http://children.webmd.com/tc/premature-infant-taking-your-baby-home

Things to do for your baby in preparation for taking him home.

SLEEPING

• http://www.medicalnewstoday.com/articles/37273.php

Focuses on the fact that premature children are at a higher risk for Sudden Infant Death Syndrome (SIDS). The article states that clinicians/physicians should tell parents of premature children of the risk of SIDS earlier in order to prepare them and prevent SIDS.

FEEDING

• http://www.ehow.com/how_4242_breast-feed-premature.html

A set of 10 steps to feeding a premature baby.

• http://medicalcenter.osu.edu/PatientEd/Materials/PDFDocs/women-in/infant/feeding/feeding-premature.pdf

Explains why premature babies can not breast feed right away, and how many of them will be fed through tubes. It explains when a baby can nipple feed and the physical actions a baby must perform to be capable of such feeding.

• http://www.babycenter.com/0_breastfeeding-premature-babies_8480.bc?showAll=true#

Explains why breast milk is so important for premature babies. It also goes through some of the problems a mother might face regarding milk production.

http://www.marchofdimes.com/prematurity/21295_6091.asp

Addresses the subject of feeding your baby. Encourages mothers to talk to the medical team, start pumping ASAP, establish a ritual, keep pumping despite the hardships, and remember that it is for your brand new baby.

http://www.oregon.gov/DHS/ph/wic/docs/preterm.pdf

Addresses a number of subjects surrounding preterm feeding. The type of milk/formula given to premature children is important and not all kinds of milk/formula are recommended. It explains the benefits of breastfeeding, and recommended vitamin intake and type. Describes fluid intake requirements, the discharge of the preterm infant, and is overall the best and most informative material on feeding.

OTHER HELP / EARLY INTERVENTION

• http://www.health.com/health/library/topic/0,,tn5684_tn5684-ConRes,00.html

Offers a list of services. Including American Academy of Pediatrics, March of Dimes, Postpartum Support International, SHARE: infant and pregnancy loss support.

http://www.health.state.nm.us/ddsd/fit/

Family Infant Toddler Program (FIT) offers early intervention services which are available to help families who have concerns about the development of their young child (birth to 3).

http://www.clovis-schools.org/losninos/referral_process.html

Los Niños Early Intervention Center is part of the Clovis Municipal School District and is a special education program designed to help preschool children who have developmental disabilities or delays before they reach school age. This website describes the referral process for parents to have access to Los Niños services and the evaluation process for acceptance into the program.

http://www.swcr.org/

Abrazos Family Support Services provide a variety of specialized educational, health, developmental, and parent support services that help families to meet the special needs of their infants, children, and adult family members with disabilities. They are also a partner in Adaptech4Kids.org, a virtual specialized therapeutic equipment bank developed to enhance services to children with disabilities and their families by making a variety of assistive and adaptive technology products available to families at no cost.

• http://www.altamiranm.org/

Alta Mira Specialized Family Services, Inc. is a 501c3 nonprofit that supports individuals with developmental risks, delays or disabilities and their families, to optimize quality of life. Alta Mira provides developmental early intervention services for children birth to age 3; inclusion training, support and consultation for child development centers; lifespan support services for people with developmental disabilities and their families; and respite services, including a respite home for short-term and family-crisis care.

http://carcinc.org/

The mission of CARC, Inc. is to provide services for people with special needs that enable them to be active citizens feel accepted and find meaning in life. Children age birth to three years who have developmental delays or are at risk of having a delay as determined by the parents/guardians, professionals and other members of the Individual Family Service Plan Team are given needed services.

http://www.nectac.org/topics/bie/growinginbeauty.asp

Hozloogo Jinooseet or Growing in Beauty accurately defines the Navajo Nation's desire for ALL Navajo children to grow into beautiful individuals, within an environment of caring, family, and harmony. Growing in Beauty's goal is to assist Navajo families who have a child with a disability with early intervention services. Early intervention services are designed for children between birth to five years of age to eliminate or minimize long-term developmental delays.

• http://www.lavidafelicidad.org/

La Vida Felicidad provides early intervention services to infants and children through three years old in Valencia County who have a developmental delay or disability or are at risk for a developmental delay or disability.

• http://clas.uiuc.edu/fulltext/cl00201/cl00201.html

The Laguna Interagency Coordinating Council for Young Children (ICC) is responsible for implementing the "System of Care" model which is designed to provide services which are child-centered, family-focused, comprehensive, integrated, coordinated, culturally-appropriate, and community based. The ICC proudly sponsors the annual "Celebrating Our Young Children" conference and other culturally -specific events and activities.

• http://www.lascumbres-nm.org/

Las Cumbres Community Services is a private, 501(c)(3) non-profit agency that promotes the health and well-being of people of all ages in northern New Mexico. Agency direct services—offered primarily in Rio Arriba, Los Alamos and Santa Fe Counties—along with statewide training, education, outreach and referral activities benefit more than 8,000 individuals each year through a wide range of programs.

• http://www.lifequestsd.com/

LifeQuest is a private, nonprofit, community agency that provides services and supports to people with developmental disabilities. Family Support services are available to all families who have children with disabilities. These services include service coordination, information and referral, respite/child care, transportation, in-service training for families, and other individualized supports.

• http://cdd.unm.edu/mfcmp/staff.asp

This website is the staff directory for the Medically Fragile Case Management Program at the Center for Development and Disability at UNM.

HEALTH PROBLEMS

• http://www.thechildrenshospital.org/wellness/info/parents/20574.aspx

Discusses the following diagnoses: anemia, apnea, bradycardia, bronchopulmonary dysplasia, hydrocephalus, intraventricular hemorrhage,

jaundice, necrotizing enterocolitis, patent ductus arteriosus, periventricular leukomalacia, respiratory distress syndrome, retinopathy of prematurity, sepsis, transient tachypnea of the newborn in terms of what causes it, how it is diagnosed, how it is treated, and how long the baby will likely be in the NICU because of it.

• http://www.thechildrenshospital.org/wellness/info/parents/20823.aspx

Discusses apnea in premature babies.

• http://children.webmd.com/tc/cerebral-palsy-topic-overview

Discusses cerebral palsy, the causes, the symptoms, how it is diagnosed, how it is treated, and offers links that answer common questions.

• http://children.webmd.com/tc/chronic-lung-disease-in-infants-topic-overview

Discusses chronic lung disease, the causes, the symptoms, how it is diagnosed, how it is treated, and offers links that answer common questions.

http://www.nhlbi.nih.gov/health/dci/Diseases/pda/pda_what.html

Gives a very brief overview of what "patent ductus arteriosus" is.

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