



Perinatal Care Matters

A Publication of the Regional Perinatal Programs of California (RPPC) Summer, 2005

PREVENTING SEVERE HYPERBILIRUBINEMIA

REGION 1

North Coast Perinatal
Access System
415/ 478-3868

REGION 2

Northern California
Perinatal Outreach Prog.
916/ 733-1750

REGION 3

East Bay Regional
Perinatal Program
510/ 204-3937

REGION 4

Mid-Coastal California
Perinatal Outreach Prog.
650/ 723-5763

REGION 5

San Joaquin/ Sierra
Regional Perinatal Program
559/ 221-6315

REGION 6.1

Perinatal Outreach
Education Program
562/ 595-6459

REGION 6.2

South Bay Perinatal
Access Project
310/ 222-3651

REGION 6.3-6.6

PAC/LAC
818/ 788-6850

REGION 6.7

Community Perinatal
Network
562/ 464-0042

REGION 7

Inland Counties
Regional Perinatal Program
909/ 558-3970

REGION 8

Orange County
Regional Perinatal Program
714/ 456-6706

REGION 9

San Diego/ Imperial
Counties Regional
Perinatal System
858/ 536-5090

REGION 10

Northern Kaiser Regional
Perinatal Program
510/ 987-3430

REGION 11

Southern Kaiser Regional
Perinatal Program
626/ 405-605

www.perinatal.org

Jaundice is a common complication occurring in 50-60% of newborns. An increase in serum bilirubin concentration, hyperbilirubinemia causes the skin to appear yellow. Most cases are benign, however high bilirubin levels can become toxic. Newborns should be screened to identify those at risk of severe hyperbilirubinemia, acute bilirubin encephalopathy and chronic, permanent brain injury (kernicterus).

In 2001 the Centers for Disease Control (CDC) reported an increase in kernicterus cases in the United States, with more than 120 cases reported in the last 20 years. Kernicterus is largely preventable. To reduce or prevent kernicterus, the CDC encourages: systematic risk assessment of bilirubin levels before discharge from the birth hospital; prompt, effective treatment; lactation support, follow-up care as well as and written oral parent education. The American Academy of Pediatrics (AAP) published revised guidelines for identifying and managing jaundice in newborns of at least 35 weeks gestation. The revised guidelines promote greater uniformity and consistency of care.

Cause

Bilirubin is a by-product of the normal breakdown of red blood cells (RBCs). As RBCs breakdown, the bilirubin pigment is deposited into the skin giving it a jaundiced or yellow appearance. At birth, infants have immature livers that do not efficiently conjugate bilirubin so that it can be excreted as waste. Newborn babies will begin to appear jaundiced when they have \geq 5-7 mg/dL of bilirubin in their blood. Physiologic jaundice is the most common form and usually causes no problems.

Risk factors placing infants at increased risk of serious jaundice include;

- High bilirubin levels before leaving the hospital;
- Signs of jaundice in the first 24 hours of life;
- Born prior to 37 weeks of pregnancy;
- East Asian descent;
- Being breastfed, those who are not nursing well;
- Congenital disorders, history of G6PD deficiency;
- Urinary tract or congenital viral infections;
- Cephalohematoma;
- Maternal-fetal blood type incompatibility; and
- Polycythemia.

AAP 2004 Guidelines

The focus of the guideline is to reduce the incidence of severe hyperbilirubinemia while minimizing unnecessary costs or treatment. AAP advises:

- Assessment of jaundice is unreliable;

- Promote and support breastfeeding at least 8-12 times a day the first days of an infant's life;
- Establish nursery protocols for the identification and evaluation of hyperbilirubinemia;
- Obtain transcutaneous bilirubin (TcB) or total serum bilirubin (TSB) if jaundiced at \leq 24 hours;
- Interpret all bilirubin levels according to the infant's age in hours;
- Infants \leq 38 weeks' gestation, particularly those, who are breastfed, are at higher risk of developing hyperbilirubinemia and require close surveillance;
- Perform a systematic assessment before discharge by measuring the TSB or TcB, assessing risk factors, or both;
- Provide follow-up based on the time of discharge and risk assessment. Follow-up visits should be scheduled within 3-5 days of birth;
- Provide prompt, effective treatment when indicated with phototherapy or exchange transfusion to prevent the development of bilirubin encephalopathy or kernicterus.

Joint Commission of Accreditation of Hospital Organization (JCAHO) recommends that all hospitals and health care professionals caring for newborn infants both in the hospital and after discharge observe the recommendations cited in the updated AAP clinical practice guidelines.

Summary

The goal is to prevent severe hyperbilirubinemia, which can lead to bilirubin encephalopathy. Additional resources and tool kits are available from your RPPC program kernicterus exacts significant emotional cost for infants, and families afflicted, as well as major financial cost to families and society..

Additional Information

- Revised AAP guidelines: www.aap.org
- JCAHO's Sentinel Alerts:
<http://www.jacho.org/sentinel+event+alert>
- <http://www.cdc.gov/ncbddd/dd/kernicterus.htm>
- Jaundice in Newborns: Information for Parents
<http://www.aap.org/family/jaundicefaq.htm>

References

- AAP. Management of hyperbilirubinemia in the newborn infant 35 or more weeks of gestation. *Pediatrics*. 2004;114:297-316
- JCAHO Sentinel Event Alerts • Issue 18/31. 4/2001 and 7/2004
- March of Dimes <http://www.marchofdimes.com>

Submitted by: Fran Snavelly, RN, CMN: Region 7

EXCLUSIVE BREASTFEEDING AMONG LATINA WOMEN

California has met the 2010 Healthy People Objective of 75% breastfeeding initiation according to the CDC, 2003 National Immunization Survey. The study reports that California has an 83.7% breastfeeding initiation rate for all babies discharged from the hospital. At 6 months of age the rate dropped to 45.6% with a further drop to 25.1% at 12 months. These rates are also near the Healthy People 2010 Goals of 50% and 25% respectively.

The benefits of breastfeeding are numerous. According to the *Blueprint for Action on Breastfeeding* released by the Department of Health and Human Services (HHS) in 2000: "breastfeeding not only improves resistance to infectious and chronic diseases among infants, it promotes infants' physical and cognitive development, maternal health, and offers socioeconomic benefits to families and communities". Despite these benefits, the US has one of the lowest rates of breastfeeding among developed countries. While most new mothers initiate breastfeeding, by six months more than half wean and only 13% exclusively breastfeed (defined as feeding only breast milk and water with no solids or other liquids).

Exclusive breastfeeding provides immunological protection against many childhood diseases and increases the likelihood of continued breastfeeding throughout the first year. The AAP, American College of Obstetricians and Gynecologists, American Academy of Family Physicians, Academy of Breastfeeding Medicine, World Health Organization and United Nations Children's Fund (WHO/UNICEF) all recommend exclusive breastfeeding for the first six months of life. Breastfeeding initiation rates have increased steadily since 1990, but, the proportion of infants who are exclusively breastfed six months after birth has increased at a much slower rate.

Although California is doing well in breastfeeding initiation rates it lags behind fifteen other states in exclusive breastfeeding. The Ross Labs Mother's Survey Report (2002) indicated that the biggest drop occurs between two and three months of age, when mothers begin returning to work. The California Department of Health Services; Maternal, Child and Adolescent Health Branch, Epidemiology Section, reports exclusive breastfeeding rates at time of hospital discharge were 41.2% in 2002 and have remained unchanged since 1993. Rates vary greatly by maternal ethnicity: White-62.7%, Native American Indian-48.7%, Asian-39.2%, Pacific Islander-29.6%, African American-30.2% and Hispanic-29.1%. Although many ethnic groups have increased their exclusive breastfeeding rate by 2-9% in the last 10 years, the Hispanic rate has declined from 31.4% in 1993 to 29.1% in 2003. Since the Hispanic birth rate represents 50% of all births in California, this decline significantly impacts the exclusive breastfeeding rate for the entire state.

To enable mothers to establish and sustain exclusive breastfeeding for 6 months, WHO and UNICEF recommend:

- Initiation of breastfeeding within the first hour of life;
- Exclusive breastfeeding;
- Breastfeeding on demand; and
- No use of bottles or pacifiers.

In addition the AAP recommends:

- Healthy infants remain in direct skin-to-skin contact with their mothers immediately after delivery until the first feeding is accomplished.

One way to impact exclusive breastfeeding rates is to follow the WHO/UNICEF and AAP recommendations that encourage exclusive breastfeeding during the initial postpartum period. While California is making progress in breastfeeding initiation we must continue to eliminate the obstacles that prevent mothers from exclusive breastfeeding for at least six months to one year.

References:

- AAP Work Group on Breastfeeding. Breastfeeding and the use of human milk. *Peds.* 1997;100: 1035-1038.
- Curtis, M. (2004) Breastfeeding Initiation Among Race/Ethnic Groups: 1993-2003, presentation of the Ca. Statewide Breastfeeding Advisory Committee.
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- HHS "Blueprint for Action" 2000
- Kramer M (2001) Promotion of Breastfeeding Intervention Trial (PROBIT): a randomized trial in the Republic of Belarus. *JAMA*, 285 (4): 413-420.
- Mothers Survey, Ross Products Abbott Division. Breastfeeding Trends, 2003
- *Pediatrics*, Vol. 115 No.2 February 2005, pp 496-506
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- UNICEF (1992) "The Global Criteria for the WHO/UNICEF Baby-Friendly Hospital Initiative." New York.
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Submitted by: Barbara Boehler, RN, CMN: Regions 2 and 3

BIRTH CERTIFICATES MATTER

The California Office of Vital Records (OVR) is conducting a second series of informational workshops for birth clerks, medical records and perinatal professionals to improve the quality, timeliness and efficiency in collecting, recording and reporting birth and fetal death certificate data. These workshops are interactive opportunities to clarify definitions and regulations, define best practice models and identify barriers to optimal vital records registration.

Workshops are scheduled regionally

- September 14th – Stockton;
- September 22nd – Oxnard (Ventura County);
- October 4th – Orange County;
- October 19th – Santa Rosa;
- November 8th – Long Beach; and
- December 8th – San Bernardino.

Additional workshops will be scheduled in Santa Barbara, Monterey, Eureka, Redding, Pasadena and San Diego. For more information, contact your OVR consultant.

New legislation is progressing through the California Assembly. Bill 1278 would revise the medical and social information to be included on a certificate of live birth relating to prenatal activities, procedures and principal sources of payment for prenatal care and delivery. This bill would require the State Registrar to instruct the local registrars to collect additional information relating to, the mother's mailing address, height, weight, and smoking habits among other things. Existing law requires the certificate of fetal death to contain all those items necessary to establish the fact of fetal death and a section containing those items relating to medical and health data. This bill would provide that the latter, as well as the electronic file of certain birth information remains confidential.

MAJOR EXPANSION OF THE NEWBORN SCREENING PROGRAM

Beginning summer 2005, the California Newborn Screening (NBS) Program will expand substantially, bringing the number of disorders identified by the Program to over 70. The additions to the screen are congenital adrenal hyperplasia (CAH) and a multitude of metabolic disorders. (Please visit the RPPC web site for a complete listing of additional diseases screened www.perinatal.org) It is anticipated that 35 to 50 newborns with CAH, and 80 to 100 newborns with a metabolic disorder other than PKU and galactosemia will be detected. As with the currently screened-for disorders, early detection and treatment can result in significant improvements in health outcomes and can prevent developmental disabilities, other disabling conditions, and sometimes death. Implementing an expansion of this magnitude necessitates other NBS Program changes, of which perinatal care providers/practitioners need to be aware.

Additions to Screening

The Program will screen for two forms of CAH due to 21-hydroxylase deficiency, i.e., salt-wasting and simple virilizing. It will additionally detect several metabolic disorders of amino acid, organic acid, and fatty acid oxidation utilizing tandem mass spectrometry (MS/MS). This technology makes possible screening for multiple disorders utilizing a single blood spot. For this reason, no additional blood will be required.

Change in Screening Forms

The state is implementing a new web-based computer system (Screening Information System) that requires changes to the specimen collection form. The current form, which consists of a data intake form attached to the specimen collection filter paper, is being replaced by two forms, i.e., the test request form (TRF) on which demographic information is captured and the specimen collection card. The two forms will be linked using barcode stickers, and sent together to the assigned Newborn and Prenatal Screening (NAPS) lab. Hospitals and other newborn screening providers should be receiving the new forms, along with a poster and handouts on how to collect NBS specimens using the new forms. Instructions should be followed meticulously in order to avoid errors or misidentification of specimens

Informing Parents

Since the inception of the Program, state regulations have mandated that mothers be given an informational booklet (*Important Information for Parents About the Newborn Screening Test*) by their prenatal care providers during pregnancy and then by the perinatal facility during the mothers' delivery hospitalization. The booklet has been revised to include the additional disorders and will be sent to providers prior to the start of the expansion. Both prenatal care providers and birth facilities will need to make sure that they distribute the new booklets upon implementation of the expanded program and that they discard the older versions.

Information and Resources Available to Care Providers and Perinatal Facility Staff

Perinatal professionals need to be prepared to discuss newborn screening with parents. In the past few years there has been a great deal of national publicity in the press and on television about newborn screening, and particularly about the importance of screening for the many metabolic disorders detectable by MS/MS. As a result, parents are more informed about newborn

screening and are asking more questions of their care providers. Information for providers and parents about the Program, and about the screened-for disorders, is available on the Genetic Disease Branch website: www.dhs.ca.gov/gdb

The seven Newborn Screening Program Area Service Centers (ASCs) in the state are an invaluable resource to all individuals/institutions with newborn screening responsibilities. ASC staff perform the following services in their assigned regions:

- follow up on all non-negative tests and assure all babies who were inadvertently not screened get tested
- provides consultation technical assistance and on-site training on newborn screening to perinatal facilities, health care providers, public health departments, and others with screening responsibilities
- assist primary care providers in referring babies who might have one of the screened-for disorders to California Childrens Services (CCS) paneled specialists or CCS-approved special care centers (i.e., endocrine, metabolic, and hematology/sickle cell centers).
- inform NBS providers of California's screening regulations and procedures; monitors providers for compliance
- refer primary care provider to specialist consultants upon request.

Please contact the ASC that is assigned to your region or call 510-412-1486 with questions about screening or requests for technical assistance or training.

Newborn Screening Program Area Service Centers:

- Kaiser Permanente - No. Cal.: (510) 752-6192;
- Kaiser Permanente - So. Cal.: (626) 564-3322;
- Stanford Medical Center: (650) 812-0353;
- Children's Hospital Central California: (559) 353-6416;
- UCLA: (310) 826-4458;
- Harbor/UCLA: (310) 222-3751; and
- UC San Diego: (858) 300-1081.

Screening Caveat

Because of the Newborn Screening Program expansion, more children's lives will be saved or improved immeasurably. However, it must be remembered that a screening program, even when operating as designed, will never identify all newborns with a given disorder detectable by the screening technology. Additionally, a negative screening result does not rule out the possibility of a disorder. Health care providers should remain watchful for any signs or symptoms of these disorders in newborns and seek appropriate consultation if a disorder is suspected.

Submitted by: Heidi Lerner, MPH, MS, RN, Genetic Disease Branch, California Department of Health Services (DHS)

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Public Policy Update

California State Budget Fiscal Year 2005-2006

The Governor's May Revision of the State Budget projects about \$4.2 billion in added revenues (including prior-year increases) from improved economic activity. The revised plan proposes to use these increased resources almost exclusively for one-time purposes. The plan retains most of the program savings proposed in January in education, social services, and state employee compensation. Although the financial picture is improved, the administration remains cautious as there is still a budget shortfall of \$4.6 billion during the 2005-2006 fiscal year.

Budget Changes

The budget plan continues to provide new state funding for a series of health policy initiatives:

- Approximately \$6 million from the General Fund (GF) would be provided for efforts to reduce the incidence of obesity;
- The Governor will redirect existing funds from the obesity initiative to add fasting blood sugar and cholesterol screening assessments to CHDP;
- Almost \$4 million is budgeted for the "California Rx" program by which an estimated 5 million low- and moderate-income Californians could receive discounts on prescription drugs at pharmacies;
- \$15 million would be expended for a fee-supported program to expand screening of newborns for various genetic diseases;
- A 3% increase for managed care plans for Healthy Families and AIM programs; and
- Increase Perinatal Drug Treatment funding in MediCal by \$1.2 million.

MediCal Redesign

The May Revision retains, with some minor changes, the MediCal redesign plan presented in January. This includes:

- expand managed care-county organized health system model;
- include aged, blind and disabled into mandatory managed care;
- new premiums (\$4-\$10 per month per person) for beneficiaries with incomes above the federal poverty level (FPL);
- expedite children's applications for health coverage;
- restructure hospital financing; and
- restore "single point of entry" and application assistance program for enrollment in MediCal and Healthy Families.

DHS continues negotiations for a favorable California Medi-Cal Waiver Package. For further information analysis of the May Budget Revision and FY 05-06 Budget Proposal released is available at www.lao.ca.gov

Legislation 2005-2006

AB 291, Koretz. Postpartum mood and anxiety disorders: screening. Referred to Committee on Health.

This bill would include as a component of the department's program of maternal and child health a requirement that pregnant women and new mothers be screened for postpartum mood and anxiety disorders, at designated intervals. The bill would require a physician or other health care practitioner to review and discuss the screening tool with the patient, present the patient with an information sheet on postpartum mood and anxiety disorders, developed or obtained by DHS for distribution in accordance with the bill.

AB 1427, Mountjoy. Abortion: saving tissue for evidence.

Physicians and surgeons performing an abortion on a minor must retain sufficient tissue of the aborted fetus to permit DNA testing for the purpose of determining paternity and establishing the guilt or innocence of the accused in any criminal action regarding sexual crimes relating to the aborted pregnancy.

AB1671, Richman. CAL-Health Act: Single Point of Entry. Scheduled hearing for May 18, 2005.

This bill would enact the Cal-Health Act and require the department to establish an electronic enrollment and retention program to serve as a single point of entry, but not the exclusive method of enrollment and retention, for all health care programs offered by the state and local government agencies.

SB 18, Ortiz. Reproductive health and research.

Scheduled hearing date is May 16, 2005.

The California Stem Cell Research and Cures Act, establishes the California Institute for Regenerative Medicine, the purpose of which is, among other things, to make grants and loans for stem cell research, for research facilities, and for other vital research opportunities to realize therapies, protocols, and medical procedures that will result in, the cure for, or substantial mitigation of, diseases and injuries.

SB116, Dutton. Child Abandonment: newborns.

Under current law, the "Safe Surrender" bill will sunset in 2006. As written, SB116 would delete this date making "Safe Surrender" a permanent program in the State of California.

SB 147, Runner. Fetal pain prevention.

This bill would enact the Unborn Child Pain Awareness Act of 2005, requiring with an exemption for medical emergency, the physician performing the abortion to offer to the pregnant woman information and counseling on fetal pain.

SB 456, Runner. Access for Infants/Mothers (AIM): funding.

This bill would provide that federal moneys allocated to the state under State Children's Health Insurance Program (SCHIP) shall also be expended by the board to support the AIM Program and to support prenatal services provided through Medi-Cal. The bill would require that the moneys received for this purpose be deposited in the Perinatal Insurance Fund. The bill would provide that this provision shall be implemented only to the extent that federal financial participation is available.

SB 869, Bowen. Refer to Sen Approp on suspense file.

This bill would appropriate \$3,500,000 from the General Fund to establish and implement a program to make grants to eligible participating counties for the provision of voluntary visiting nursing services to first-time low-income mothers.

AJR 3, Cohn: Reproductive rights: Roe v. Wade. Scheduled for hearing Senate Rules 6/7/05.

This measure would memorialize the Congress and the President of the United States to protect and uphold the intent and substance of the United States Supreme Court decision in Roe v. Wade, relating to reproductive rights.

ADDENDUM

DISORDERS DETECTABLE BY TANDEM MASS SPECTROMETRY (MS/MS) USING NEWBORN SCREENING DRIED BLOOD SPOTS*

Amino Acid Disorders

- maple syrup urine disease (MSUD)
- phenylketonuria (PKU)
- citrullinemia/argininosuccinic acid synthetase deficiency (ASAS deficiency)
- homocystinuria/cystathionine beta-synthase deficiency (CBS deficiency)
- argininosuccinyl-CoA lyase deficiency (ASAL deficiency)
- argininemia/arginase deficiency
- tyrosinemia

Organic Acid Disorders

- 3-hydroxy-3-methylglutaryl-CoA lyase deficiency (HMGCoA lyase deficiency)
- glutaric acidemia type-1 (GA-1)
- isobutyryl-CoA dehydrogenase deficiency
- isovaleric acidemia (IVA)
- 2-methylbutyryl-CoA dehydrogenase deficiency
- 3-methylcrotonyl-CoA carboxylase deficiency (3MCC deficiency)
- propionic acidemia (PA)
- methylmalonic acidemia (MMA)
- beta-ketothiolase deficiency (BKD)

Fatty Acid Oxidation Disorders

- carnitine transporter deficiency
- carnitine-acylcarnitine translocase deficiency (CAT deficiency)
- multiple acyl-CoA dehydrogenase deficiency (MAD deficiency)/glutaric acidemia type-2 (GA-2)
- 3-hydroxy long chain acyl-CoA dehydrogenase deficiency (LCHAD deficiency)/ trifunctional protein deficiency (TFP deficiency)
- medium chain acyl-CoA dehydrogenase deficiency (MCAD deficiency)
- carnitine palmitoyl transferase deficiency-type 1 (CPT-1 deficiency)
- carnitine palmitoyl transferase deficiency-type 2 (CPT-2 deficiency)
- short chain acyl-CoA dehydrogenase deficiency (SCAD deficiency)
- very long chain acyl-CoA dehydrogenase deficiency (VLCAD deficiency)

*Note: Some of these listed disorders may not be included in the California Department of Health Services, Tandem Mass Spectrometry (MS/MS) Research Project but should be reported by any health care provider making a diagnosis on or after 1/7/02.