PUBLIC HEALTH – SEATTLE & KING COUNTY SUMMER 2007

Child Health Notes

Promoting early identification and partnerships between families, primary health care providers & the community.

Distributed by Public Health-Seattle & King County–Children with Special Health Care Needs Program. This newsletter provides physicians, nurse practitioners, primary health care providers, public health centers and community partners with current information regarding identification and management of special health issues for children. Contributing agencies and programs include: Washington State Department of Health and UW – Center on Human Development & Disability

Saving lives with a simple blood spot

Who Is Screened?

- Washington State law requires that every newborn be tested prior to discharge from the hospital or within five days of age.
- In addition to the required first specimen, it is strongly recommended that every baby born in Washington have a second screening specimen collected between 7 and 14 days of age.
- A third screen is recommended for sick and premature infants.

Expanded Newborn Screening in Washington State Updates for Your Practice

Newborn screening detects health problems in newborn babies. If left untreated, these conditions can lead to brain damage, life-long disability, and in some cases, even death. New laboratory techniques and enhanced technology make it possible to screen for more congenital disorders in newborns. In March 2006 screening for cystic fibrosis was added to the Washington State panel of newborn screening tests, bringing the total to ten disorders. Each year, approximately one hundred infants in Washington State are diagnosed with one of these ten disorders.

Successful newborn screening requires collaboration between the Department of Health State Newborn Screening Program, health care facilities (hospitals, local health departments, clinics), health care providers (pediatricians, family practice physicians, nurse practitioners, midwives), and families of newborns. Early detection prevents chronic disability and helps affected children and their families' access support and services to assure the best health possible.

Which Disorders Are Screened In Washington State?

Disorder:	Possible Outcome Treatment Delayed
Metabolic Disorders:	
Phenylketonuria (PKU)	Severe mental retardation
Medium chain acyl-coA dehydrogenase deficiency (MCAD)	Profound hypoglycemia, death
Maple syrup urine disease (MSUD)	Mental retardation, death
Homocystinuria	Mental retardation, death
Biotinidase deficiency	Mental retardation, seizures
Galactosemia	Mental retardation, death
Disorders of Endocrine System:	
Congenital hypothyroidism (CH)	Mental retardation
Congenital adrenal hyperplasia (CAH)	Mental retardation, death
Cystic fibrosis (CF)	Chronic pulmonary disease, gastrointestinal abnormalities
Other Disorders:	
Sickle cell disease & other hemoglobinopathies	Splenic enlargement, severe anemia, susceptibility to bacterial infections

Things to Consider For Your Practice:

- Be familiar with the disorders screened in Washington State
- Know where to find information about the disorders (See Information and Resources below)
- Assure that all infants in your practice have a second screening test and document the screening status of each patient
- Talk with families about the newborn screening and assure referral to speciality care clinics as necessary
- Respond quickly to information and specimen requests from the Newborn Screening Program

What Happens If Screening Results Are Positive?

Results from screening are either negative or indicated as 'at risk for'. Diagnostic testing is needed to confirm the diagnosis of a 'presumptive positive' result. The Washington State Newborn Screening Coordinator communicates 'presumptive positive' results to the health provider identified on the Newborn Screening card. Information on the specific disorder is faxed to the provider and a 'next step' plan is discussed. The provider shares information with the family and coordinates any additional laboratory work. If the diagnosis of a spedific disorder is confirmed, the Newborn Screening Coordinator notifies the specialty care clinic with the infant's name and family contact information.

Information and Resources:

Referral Centers	**Diagnostic and follow-up services for disorders identified by the WA State Newborn Screening Program:** **Metabolic Disorders:** PKU/Biochemical Genetics Clinic – Center on Human Development and Disability, Univ.of WA ..... 1-877-685-3015 or 206-598-1800	
	Endocrine Disorders: Congenital Adrenal Hyperplasia and Congenital Hypothyroidism Endocrine Clinic – Children's Hospital & Regional Medical Cntr. ..... (206) 987-2640 Congenital Hypothyroidism Clinic – Center on Human Development and Disability, Univ.of WA ..... (206) 598-1800	
	Cystic Fibrosis: CF Clinics at- Children's Hospital & Regional Medical Center, Seattle ..... (206) 987-2024 Mary Bridge Children's Hospital & Health Center, Tacoma ..... (253) 403-4141 Deaconess Hospital, Spokane..... (509) 473-7300 Oregon Health Sciences Center, Portland, OR ..... (503) 494-8023	
	Hematologic Disorders (i.e. Sickle Cell Anemia): Sickle Cell clinics at- Odessa Brown Children's Clinic, Seattle ..... (206) 987-7232 Mary Bridge Children's Hospital & Health Center, Tacoma ..... (253) 594-1415	
State:	**Washington State Newborn Screening Program** Washington State Department of Health Newborn Screening website. Provides separate pages for health professionals and parents.	(206) 418-5410 Fax: (206) 418-5415 nbs.prog@doh.wa.gov www.doh.wa.gov/EHSPHL/PHL/Newborn
National:	**National Newborn Screening and Genetics Resource Center.** Provides information about specific disorders and information for health professionals and parents **Star-G: Screening, Technology and research in Genetics** Provides general information about newborn screening and profiles for specific disorders.	http://genes-r-us.uthscsa.edu www.newbornscreening.info

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Electronic version and copies are available by calling the CSHCN Program at 206-296-4610. Suggestions and comments are welcome.