

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



Expanded Newborn Screening in Washington State Updates for Your Practice

Newborn screening detects health problems in newborn babies that would not otherwise be known without screening. 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. Currently, 27 disorders are on the Washington State panel of newborn screening tests. Each year, approximately 175 infants in Washington State are diagnosed with one of these disorders (approximately 1 in 500 children). Beginning January 2014, another group of disorders, severe combined immunodeficiency (SCID - also known as Bubble Boy disease) will be added to the mandatory panel.

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.

**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.

Which Disorders Are Screened In Washington State?

Disorder:

Possible Outcomes if Treatment Delayed

Metabolic Disorders

- Amino acid disorders
 - Phenylketonuria (PKU) & 5 others
- Biotinidase deficiency
- Fatty acid oxidation disorders
 - Medium chain acyl-CoA dehydrogenase (MCAD) deficiency & 4 others
- Galactosemia
- Organic acid disorders
 - Glutaric acidemia type 1 (GA-1) & 7 others

- intellectual disabilities, coma, seizures, & death
- metabolic crisis, coma & death
- serious damage affecting the brain, liver, heart, eyes, muscle, & death
- liver failure, sepsis & death
- severe nerve & physical damage & death

Disorders of Endocrine System:

- Congenital hypothyroidism (CH)
- Congenital adrenal hyperplasia (CAH)
- Cystic fibrosis (CF)

- severe neurological & developmental damage
- life-threatening salt loss leading to death
- chronic lung & digestive system disease

Other Disorders:

- Sickle cell disease (3 forms) & other hemoglobinopathies

- splenic enlargement, severe anemia, susceptibility to bacterial infections

Things to Consider For Your Practice:

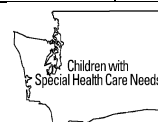
- Be familiar with the disorders screened in Washington State
- Know where to find information about the disorders (See Information and Resources below)
- Assure that all infants in your practice have a second screening test and document the screening status of every child
- Talk with families about 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?

All specimens that are determined to be presumptive positive through the Newborn Screening Program are followed up immediately through direct telephone contact with the child's primary health care provider. This is to ensure that diagnostic testing and treatment, if indicated, is initiated as quickly as possible. Following a definitive diagnosis, a long-term, disease-specific medical management program is implemented.

INFORMATION AND RESOURCES:

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| INFORMATION AND RESOURCES: | | |
| Referral Centers | Diagnostic and follow-up services for disorders identified by the WA State Newborn Screening Program: | |
| | Metabolic Disorders: | |
| | University of WA - PKU/Biochemical Genetics Clinic – CHDD 1-877-685-3015 or 206-598-1800 | |
| | Seattle Children's – Biochemical Genetics Clinic (206) 987-3012 | |
| | Endocrine Disorders: Congenital Adrenal Hyperplasia and Congenital Hypothyroidism | |
| Endocrine Clinic – Seattle Children's (206) 987-2640 | | |
| Endocrine Clinic - Mary Bridge Children's Hospital, Tacoma.....(253) 792-6630 | | |
| Congenital Hypothyroidism Clinic – Univ.of WA – CHDD(206) 598-1800 | | |
| Madigan Army Medical Center (military).....(253) 968-0109 | | |
| Cystic Fibrosis: CF Clinics at- | | |
| Seattle Children's Hospital, Seattle (206) 987-2024 | | |
| Mary Bridge Children's Hospital, Tacoma..... (253) 403-4141 | | |
| Providence Physician's Group at Sacred Heart, Spokane..... (509) 474-6960 | | |
| Oregon Health Sciences Center, Portland, OR (503) 494-8023 | | |
| Madigan Army Medical Center (military).....(253) 968-1980 | | |
| Hemoglobin Disorders (i.e. Sickle Cell Disease): | | |
| Odessa Brown Children's Clinic, Seattle (206) 987-7232 | | |
| Mary Bridge Children's Hospital & Health Center, Tacoma (253) 594-1415 | | |
| Sacred Heart Children's Hospital, Spokane.....(509) 474-2777 | | |
| 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; 1-866-660-9050 www.doh.wa.gov/nbs E-mail: nbs.prog@doh.wa.gov |
| National: | NewSTEPS (Newborn Screening Technical assistance and Evaluation Program) Provides information about NBS laboratory practice, quality improvement, education and training, program evaluation and policy. | https://newsteps.org |
| | Save Babies Through Screening Foundation Provides general information about newborn screening disorders, family stories, resources, and frequently asked questions. | http://www.savebabies.org |



Children with Special Health Care Needs Program
401 5th Ave, Suite 1000
Seattle, WA 98104-2333
206-296-4610
www.kingcounty.gov/health/cshcn

Public Health
Seattle & King County

