Oregon WIC

Local Agency WIC Nutritionists Quarterly meeting

Oregon's statewide newborn screenings and the Birth Anomalies Surveillance System

A place where teamwork makes a difference

Suzanne Zane DVM, MPH
Senior MCH Epidemiologist

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February 27, 2018

Three types of newborn screening

1. Hearing
2. Bloodspot
3. Pulse oximetry

2. 3. 1.

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1. Early Hearing Detection and Intervention (EHDI)

(with thanks to Shelby Atwill, AuD)

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Why EHDI?

- Congenital hearing loss is very common
  - 3/1000 births (0.3%)
  - Only half of the babies with hearing loss have any known risk factors
- Hearing loss is invisible, hard to find without specific testing
- Hearing loss can be addressed **best** when caught **early**

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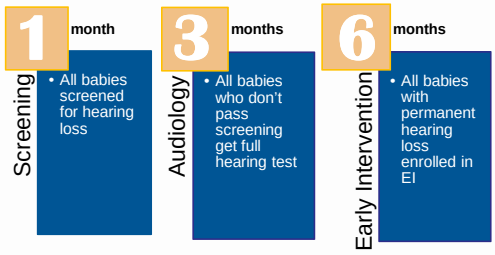
EHDI 1-3-6 Goals



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Why 1-3-6?

If children receive intervention by *6 months*, they are **significantly** more likely to be ready for kindergarten by age 5.

We need to find the kids who need help as quickly as possible!

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EHDI Celebrations and Challenges

- Over **98%** of Oregon babies are screened for hearing every year!
  - Nearly *all* of the unscreened babies are born at home or in small hospitals/birth centers where screening isn't readily available.
- **~1300** babies each year **do not pass** screening: Half of these babies are in WIC
  - Of these, ~1,000 get their follow-up diagnostics
    - Over **110** babies with hearing loss found in Oregon each year.
  - But *>200* babies each year **do not** receive further testing!
- About **75%** of babies with hearing loss are enrolled in Early Intervention each year.
  - Only about *half* of the families enroll by the crucial 6 month benchmark.

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Children with Multiple Disabilities

- 30-40% of children with permanent hearing loss will present with at least 1 other disability:
  - Developmental delay
  - Cleft palate or craniofacial anomalies
  - Vision loss
  - Cerebral palsy
  - Seizure disorders
  - Heart, kidney, or bone/joint needs
  - Autism Spectrum Disorder
  - Attention challenges

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Parent Support

Don't know baby's newborn hearing screening results?
Request records OR get (another) test

Concerns about speech, language, development?
Rule out hearing loss with a test (not a questionnaire)

Other medical/educational concerns in addition to hearing?
Take care of the ears, too – gateway for environmental awareness, spoken language

EHDI Partners:

- Hands and Voices - Guide By Your Side program
- CaCoon home visiting program

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2. Newborn Blood Spot Screening

With thanks to Sara Denniston
Newborn Screening Follow-Up Coordinator
State Public Health Laboratory

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Blood Spot

- Cystic Fibrosis
- Endocrine disorders
- Congenital hypothyroidism
- Fatty Acid disorders
- PKU
- Amino Acid disorders
- Organic Acid disorders
- Immune disorders
- Galactosemia
- Hemoglobin disorders

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FACTS

- ~45,000 Oregon babies born each year
- Oregon is a 2 screen state
  - Collection times:
    - 24 hours old
    - 2 week visit
- Incidence: 1 in 500 babies has something picked up by newborn screening

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Disorders detected in 2016

- Cystic Fibrosis: 18
- Hypothyroidism: 27
- Other endocrine: 11
- PKU: 5
- MCAD: 4
- Metabolic disorders: 21
- Hemoglobin disorders: 5
- Immune deficiencies: 4

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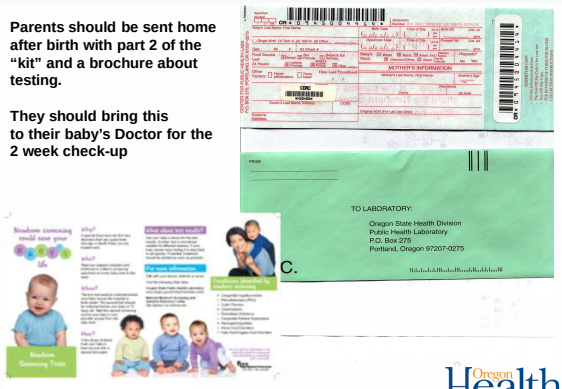
Parents should be sent home after birth with part 2 of the "kit" and a brochure about testing.

They should bring this to their baby's Doctor for the 2 week check-up



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So what should you tell people about newborn screening?

Why it's important:

- Prevents death and/or disability
- Babies may look and act healthy at birth
- The disorders are not very common
- The disorders we screen for have treatments
- Ask your doctor about your baby's results

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Education

Our OHA State Public Health Laboratory site
http://www.oregon.gov/oha/PH/LaboratoryServices/NewbornScreening/Pages/index.aspx

Baby's First Test
http://babysfirsttest.org/

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3. Pulse Oximetry Screening

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Pulse Oximetry Screening
Who, What, When, Where, and Why

Why?

- Pulse oximetry newborn screening can identify some infants with a critical congenital heart defect (CCHD) before they show any signs.

Did You Know?

- Congenital heart defects (CHDs) account for 30% of infant deaths due to birth defects.
- ~17-31% of all CHDs are CCHDs.
- CCHDs require some type of intervention—often involving surgery—soon after birth.

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How? When?

- Pulse oximetry is a simple bedside test, and determines the amount of oxygen in a baby's blood. Low levels of oxygen in the blood can be a sign of a CCHD.
- A pulse oximeter sensor is placed on the baby's skin. The test is painless and takes only a few minutes.
- Screening is done when a baby is 24 to 48 hours old. If the baby is to be discharged from the hospital before 24 hours, screening should be done as late as possible before discharge.

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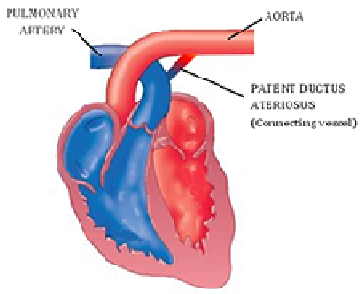
Closure of the ductus arteriosus

~24-48 hours after birth



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Oregon's Birth Anomalies Surveillance System

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What are “birth anomalies”?

What can cause them?

How common are they?

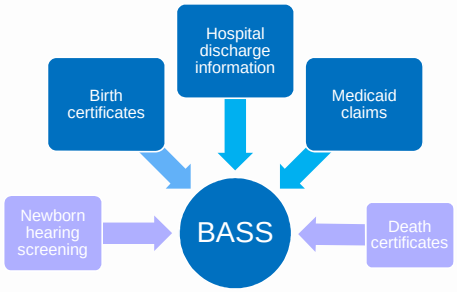
Why would they be tracked by public health?

Major groups

1. Central nervous system
2. Eye
3. Ear
4. Cardiovascular

5. Orofacial
6. Gastrointestinal
7. Genitourinary
8. Musculoskeletal
9. Chromosomal

How our system works



BASS findings for children born 2010-2014

- ~45,000 Oregon babies born each year
- Over a 5 year period (births 2010-2014):

225,611 Oregon births, and among these

16,591 birth anomalies found among 11,611 children

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2010-2014 selected birth anomaly numbers and prevalence

Birth Anomaly	Number	Prevalence*
Spina bifida (without anencephaly)	197	8.7
Congenital cataract	115	5.1
Anotia or microtia	70	3.1
Atrioventricular septal defect	261	11.6
Renal agenesis or hypoplasia	254	11.3
Clubfoot	530	23.5

Number represents an individual anomaly *type*, i.e. it is not the number of *children* with that birth anomaly).
*** Prevalence is number of that BA per 10,000 live births in Oregon**

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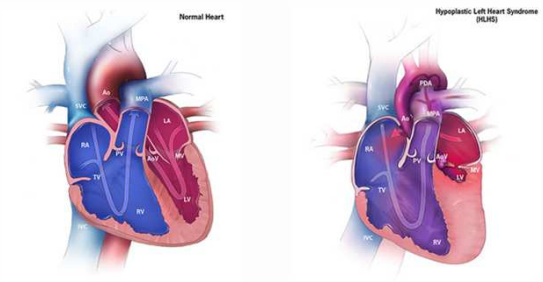
Hypoplastic Left Heart Syndrome



Pulse oximetry can help detect this and other critical congenital heart defects

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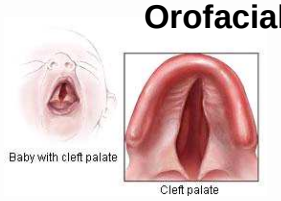
Orofacial Clefts



Cleft palate


Baby with cleft lip

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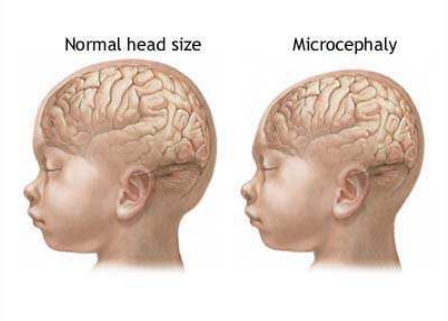
Microcephaly



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Microcephaly

- **Prenatal**
  - Intrauterine TORCH infections, plus Zika
  - Fetal alcohol syndrome
  - Maternal phenylketonuria
- **Postnatal**
  - Perinatal asphyxia
  - Perinatally acquired herpes simplex encephalitis/ meningitis
  - Head injury
  - Endocrine anomalies

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Limitations of the BASS

The BASS cannot use the surveillance information to directly contact families.

The Good: People's privacy is respected

The Bad: It's harder to reach families

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That's where Family 2 Family Health Information Center comes in…

The BASS has contracted with Family to Family HIC to link families to the resources and support they need.

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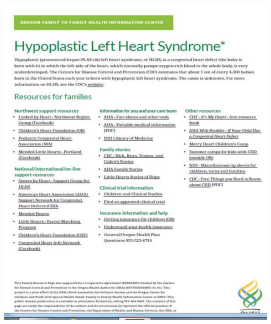
Sample of assistance given

- Parent wants child to have an MRI paid by **insurance,** advocacy coaching
- **Diaper** assistance for 2 month old
- Multiple issues related to **losing OHP, not qualifying for DD.** Needs respite and a medical home.
- Coaching on applying for OHP for 5 year old with **genetic condition requiring vent.**
- Requested advice on sending 2 year old to **early intervention** program
- **Parent support group** for parent of 12 year old with Down syndrome
- Seeking financial help for paying for **braces** for child with disability
- Seeking information about general resources for child with **genetic condition.**
- Needs coaching about how to get **sleep study** approved.

Resources Sheets for Families – Heart Conditions Completed

Categories Include:

- **Northwest Support Groups**
- **National/International/On Line Support Organizations**
- **Information for Care Team**
- **Strengths-Based Family Stories**
- **Clinical Trial Information**
- **Insurance Information**
- **Misc. Resources/Toolkits**


OREGON FAMILY TO FAMILY HEALTH INFORMATION CENTER

Hypoplastic Left Heart Syndrome*

Resources for families

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Overview of Washington State's Anencephaly Investigation

What, Why, When, Where?

- **What is anencephaly?**
  - Rare birth defect in which the baby's brain, skull, and scalp do not fully form.
  - Babies die during pregnancy or soon after birth.
  - A type of neural tube defect. Neural tube defects are birth defects of the brain, spine, or spinal cord. Happen early in pregnancy, often before a woman knows she is pregnant.
- **Why are babies anencephalic?**
  - We do not know the specific causes.
  - However, women who are capable of becoming pregnant can reduce their risk by getting enough folic acid (vitamin B9).
    - Do: take a daily multivitamin with 400 µg folic acid.
    - Also found in
      - Green, leafy vegetables
      - Wheat flour products (fortified with folic acid)

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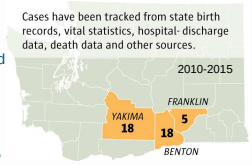
What, Why, When, Where?

- **When and where?**
  - From January 2010 - September 2016
  - Yakima, Benton, Franklin counties
  - Washington Department of Health found higher rates than average, and did an extensive investigation to understand why.
- **How many babies were are affected?**
  - 45 babies confirmed with anencephaly
  - Anencephaly affects ~2 out of every 10,000 babies, but—
  - More than 8 out of every 10,000 babies in these counties had anencephaly.



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Cluster investigations

- Typically for potential groups of cancer or birth anomalies cases
- Very resource intensive
- Historically haven't identified causes

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Washington's Investigation

- Central WA health care provider reported unusual number of infants with anencephaly. Observation verified through hospital records. State partnered with local public health authorities and Centers for Disease Control and Prevention (CDC) for neural tube defects (spina bifida and anencephaly) investigation.
- Convened an Advisory Committee
- Review of prenatal and hospital records for healthy pregnancies and for pregnancies with neural tube defects
- Documented folic acid use and compared use for affected counties with the rest of the state.
- Interviewed mothers with neural tube affected pregnancies
- Looked at drinking water sources based on address for high levels of nitrates
- Responded to concerns of pesticide exposure, mapping residential proximity to fields where pesticides were used

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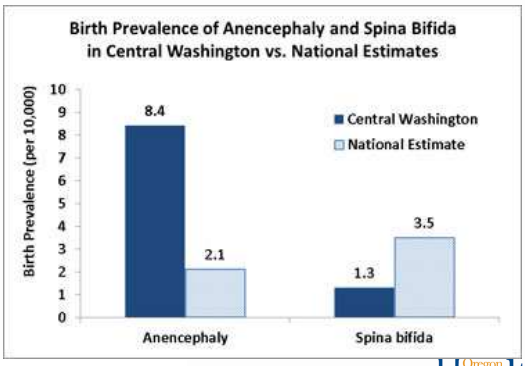
Findings

- Women in 3-county area whose pregnancies were affected by neural tube defects showed low folic acid intake compared with women in the rest of Washington
- Hispanic women accounted for about two-thirds of anencephaly cases in the cluster, but only about 56 percent of total births for that time frame
- Investigators determined that even on private water systems, nitrate levels "continued to be well below 5 mg/L," the level at which nitrates in the water have been potentially linked with NTDs
- Found no history of pesticide drift involving the chemicals most likely to influence anencephaly
- Potential radiation from Hanford or the Fukushima nuclear disaster was considered not a likely source contributing to the cluster



Current Status

- Maintaining and publically posting data each year
- Continuing to try to identify a cause of the higher rates
- Working with health care professionals and providers regarding the importance of prenatal care and folic acid intake
- Continuing to monitor and track new cases, contacted doctors and birth facilities about new cases they may see
- Developed a Community Outreach Plan to focus on increasing awareness about folic acid use and prenatal vitamins
- Collaborating with the 3 local county health departments and the Commission on Hispanic Affairs to increase folic acid use

Menu The Seattle Times

FDA to allow folic acid in corn masa to stop birth defects

Originally published April 14, 2016 at 5:55 am | *Updated April 14, 2016 at 5:21 pm*

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