Oregon WIC Local Agency WIC Nutritionists (LAWN) Quarterly Meeting

Birth Anomalies Surveillance System (BASS)
and
Early Hearing Detection and Intervention (EHDI)

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Three types of newborn screening

1. Bloodspot **2. Pulse oximetry** **3. Hearing**

2. Pulse Oximetry Screening and Birth Anomalies Surveillance System (BASS)

What is Pulse Oximetry/ Critical Congenital Heart Defects Screening

- Essential test that measure the blood oxygen saturation level and heart rate
- Key indicator for Critical Congenital Heart Defects (CCHD)
- A sensor is place on the baby’s right hand and one foot. The procedure is quick, non-invasive, and painless
- Conducted at least 24 hours of age and before discharge. If baby is to be discharged from the hospital before 24 hours, screening should be done as late as possible before discharge
- Mandate for CCHD screening added in the US Recommended Uniform Screening Panel (RUSP) in 2011

Why Pulse Oximetry Screening

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

- 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.

Oregon’s Birth Anomalies Surveillance System (BASS)

What is Birth Anomalies Surveillance System (BASS)?

- Recognize gaps in knowledge and lack of information about birth anomalies
- No legislative mandate
- Established passive surveillance using administrative data
- One of the last four US jurisdiction to track birth anomalies

History of Birth Anomalies Surveillance System (BASS)

- 2000 onwards- conversations begin related to fetal alcohol syndrome and developing a tracking system
- 2008- Supplemental funds from Environmental Public Health Tracking (EPHT)
- 2013- Participated in data submission to National Birth Defects Prevention Network collaborative work
- 2016 – funded first time by CDC
- 2021- CDC funding ended

What do Birth Anomalies Surveillance System (BASS) do?

- Surveillance
  - Establish baseline information
  - Monitor patterns

- Education/Prevention
  - Disseminate information
  - Educate public to promote healthy pregnancy

- Building capacity
  - Linking families to resources

Prevalence estimate

Target prevention and outreach

Educational materials

Identify disparities

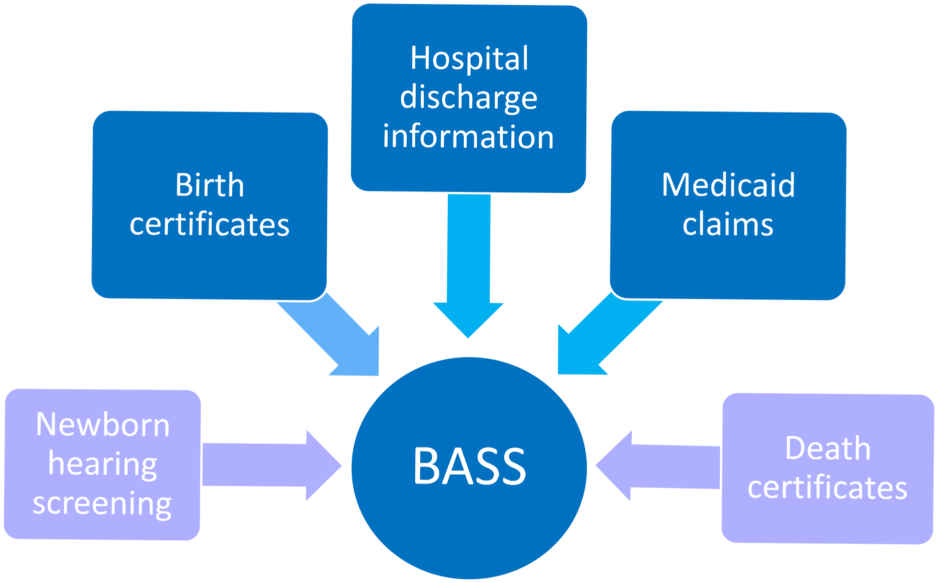
Strengthen Collaborations

Trends

Understand birth anomalies and impacts

How our system works?

- Passive surveillance
- Using administrative data
- Combine data sources via linkage processes
- Tracking births 0-5 years old


Hospital discharge information

Birth certificates

Medicaid claims

Newborn hearing screening

BASS

Death certificates

We grew quickly

- Participate in National Birth Defects Prevention Network
- Anomalies tracked: 12→ 50
- Added data source for triangulations

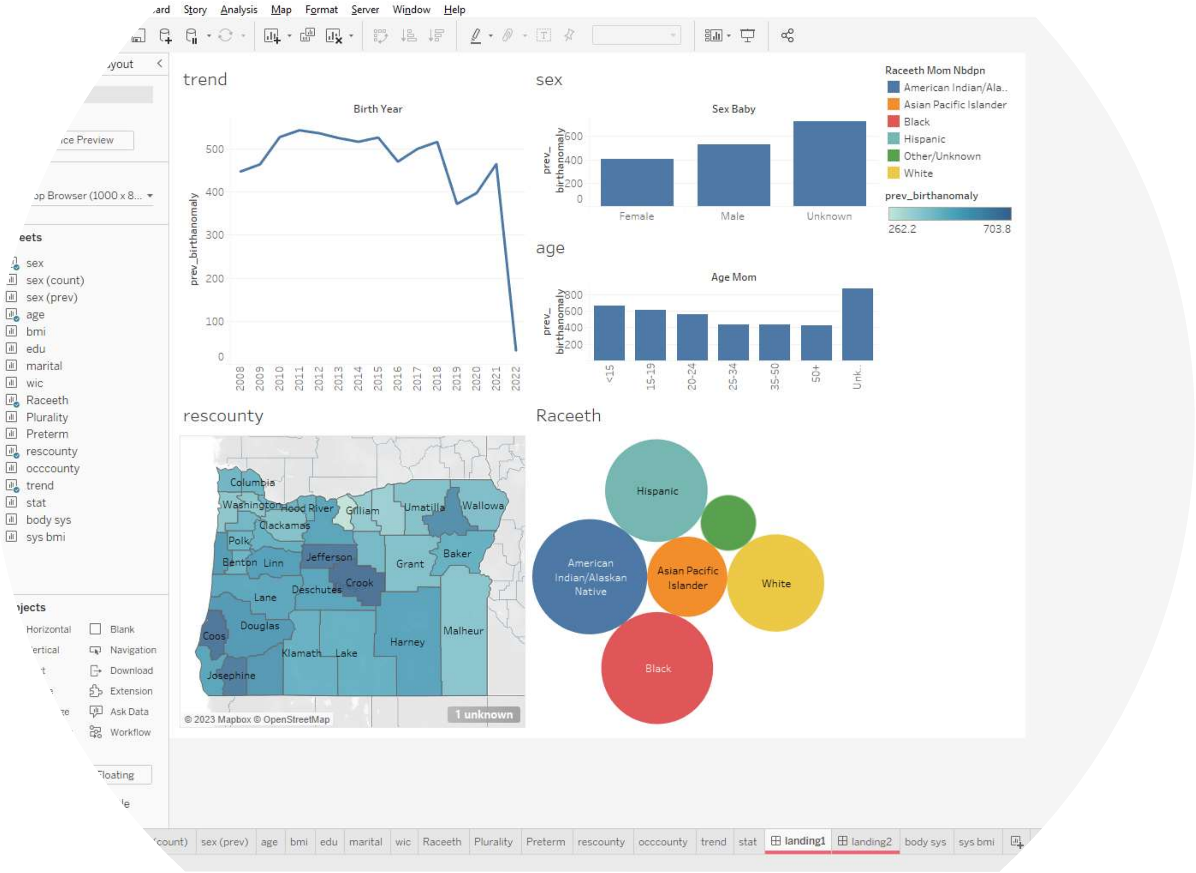
Major Birth Anomalies Groups

- Central nervous system
- Eye
- Ear
- Cardiovascular
- Orofacial
- Gastrointestinal
- Genitourinary
- Musculoskeletal
- Chromosomal

What we learned from BASS

- ~40,000 Oregon babies born each year
- ~ 2,000 infants have a birth anomalies annually
- Families prefer to use the term birth anomalies rather than birth defects

Data Dissemination



Realignment of program goals to Title V work

Limitations of BASS

- No stable funding
- Can't report identification info to partners for follow up
- No mandatory referral requirements
- No registry = no follow up
- Can't conduct active surveillance

Partnership: Family-to-Family Health Information Center

- Connect families to the resources and support they need
- A team of parents, all have children or youth with special needs (physical, developmental, behavioral, emotional) or disabilities
- Experience navigating Oregon's complex health care, community, and education systems
- Each state has an F2F HIC, funded by the federal government.

Oregon Family-to-Family Health Information Center

One-to-one Support

Table Talks

Toolkits

Tip Sheets

Free Trainings

Website

855-323-6744 (English) 503-931-8930 (Spanish)

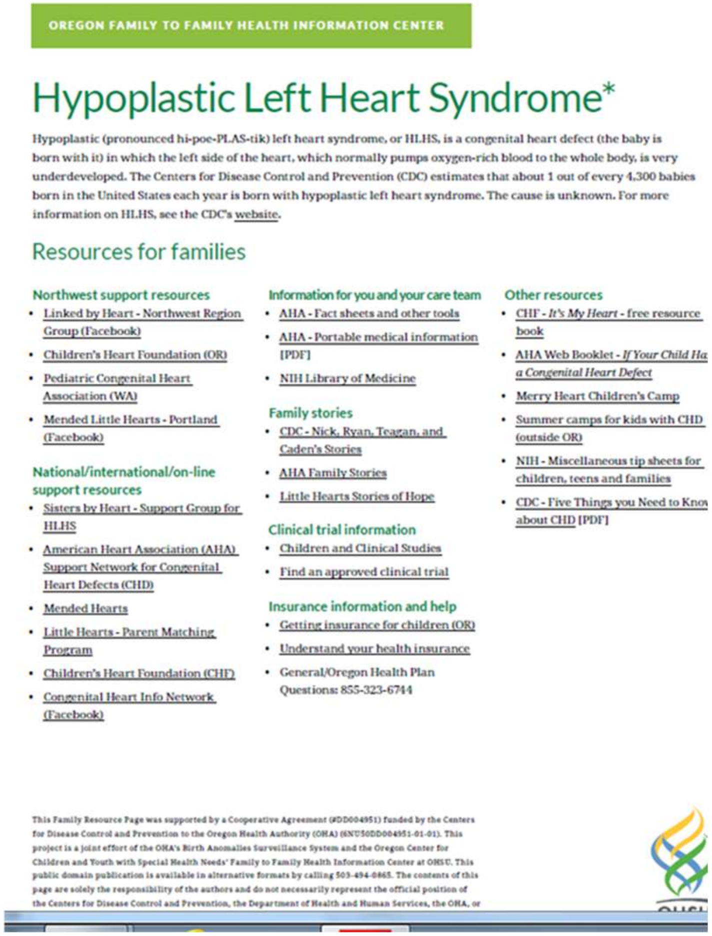
www.oregonfamilytofamly.org

Oregon Family-to-Family Health Information Center: More than Resources

- Health Care Advocacy
- Transition to Adult Health Care
- One Page Profiles for the Medical Setting

Resource Sheet for Families - Example

- Categories Include:
    - Northwest Support Groups
    - National/International/Online 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*

Hypoplastic (pronounced hi-poe-PLAS-tik) left heart syndrome, or HLHS, is a congenital heart defect (the baby is born with it) in which the left side of the heart, which normally pumps oxygen-rich blood to the whole body, is very underdeveloped. The Centers for Disease Control and Prevention (CDC) estimates that about 1 out of every 4,300 babies born in the United States each year is born with hypoplastic left heart syndrome. The cause is unknown. For more information on HLHS, see the CDC's website.

Resources for families

Northwest support resources

- Linked by Heart - Northwest Region Group (Facebook)
- Children's Heart Foundation (OR)
- Pediatric Congenital Heart Association (WA)
- Mended Little Hearts - Portland (Facebook)

National/international/on-line support resources

- Sisters by Heart - Support Group for HLHS
- American Heart Association (AHA) Support Network for Congenital Heart Defects (CHD)
- Mended Hearts
- Little Hearts - Parent Matching Program
- Children's Heart Foundation (CHF)
- Congenital Heart Info Network (Facebook)

Information for you and your care team

- AHA - Fact sheets and other tools
- AHA - Portable medical information [PDF]
- NIH Library of Medicine

Family stories

- CDC - Nick, Ryan, Teagan, and Caden's Stories
- AHA Family Stories
- Little Hearts Stories of Hope

Clinical trial information

- Children and Clinical Studies
- Find an approved clinical trial

Insurance information and help

- Getting insurance for children (OR)
- Understand your health insurance
- General/Oregon Health Plan Questions: 855-323-6744

Other resources

- CHF - *It's My Heart* - free resource book
- AHA Web Booklet - *If Your Child Ha a Congenital Heart Defect*
- Merry Heart Children's Camp
- Summer camps for kids with CHD (outside OR)
- NIH - Miscellaneous tip sheets for children, teens and families
- CDC - Five Things you Need to Kno about CHD [PDF]

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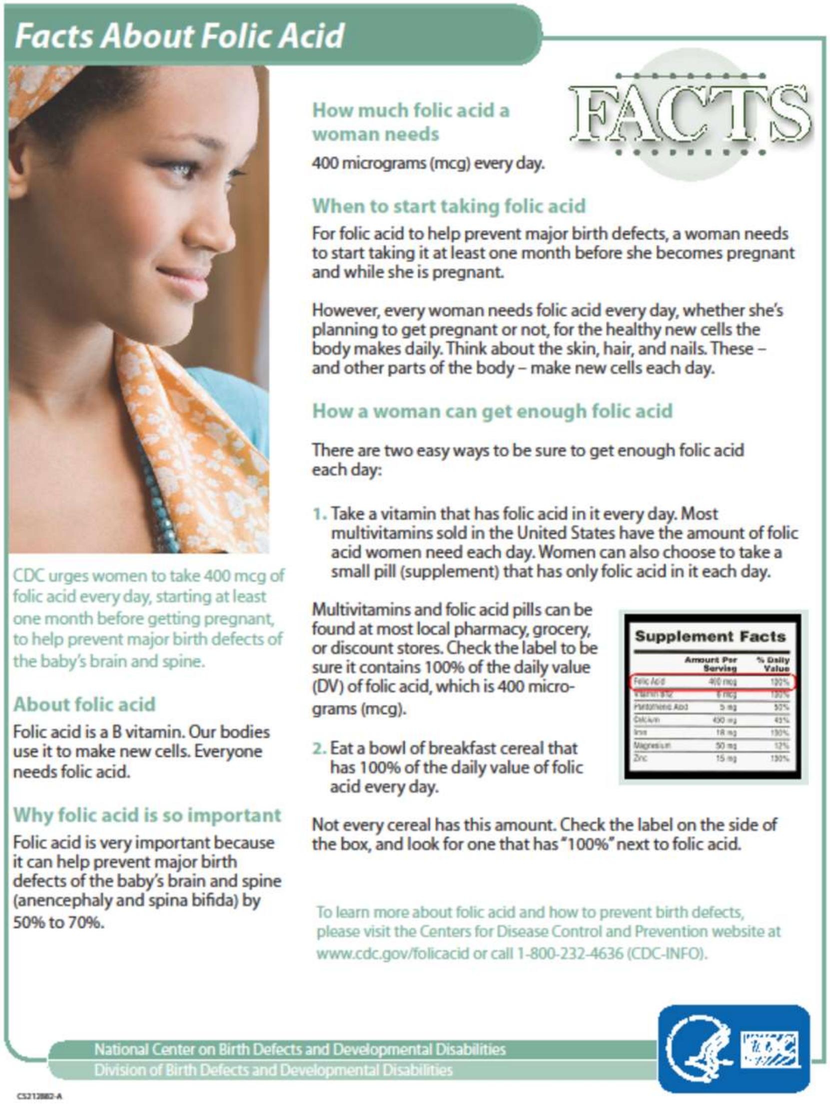
That’s Where You Come In…

Folic Acid and Neural Tube Defects

- 400 micrograms (mcg) every day reduce the incidence of neural tube defects such as anencephaly and spina bifida
- Fortification of grain products (cereal, flour, rice, pasta etc) became mandatory since 1998
- Disparity in Folic Acid intake highly associated with social economic status
- In 2016, FDA allowed voluntary fortification of corn masa flour



Facts About Folic Acid

FACTS

CDC urges women to take 400 mcg of folic acid every day, starting at least one month before getting pregnant, to help prevent major birth defects of the baby's brain and spine.

About folic acid

Folic acid is a B vitamin. Our bodies use it to make new cells. Everyone needs folic acid.

Why folic acid is so important

Folic acid is very important because it can help prevent major birth defects of the baby's brain and spine (anencephaly and spina bifida) by 50% to 70%.

How much folic acid a woman needs

400 micrograms (mcg) every day.

When to start taking folic acid

For folic acid to help prevent major birth defects, a woman needs to start taking it at least one month before she becomes pregnant and while she is pregnant.

However, every woman needs folic acid every day, whether she's planning to get pregnant or not, for the healthy new cells the body makes daily. Think about the skin, hair, and nails. These – and other parts of the body – make new cells each day.

How a woman can get enough folic acid

There are two easy ways to be sure to get enough folic acid each day:

1. Take a vitamin that has folic acid in it every day. Most multivitamins sold in the United States have the amount of folic acid women need each day. Women can also choose to take a small pill (supplement) that has only folic acid in it each day.

Multivitamins and folic acid pills can be found at most local pharmacy, grocery, or discount stores. Check the label to be sure it contains 100% of the daily value (DV) of folic acid, which is 400 micrograms (mcg).

Supplement Facts

	Amount Per Serving	% Daily Value
Folic Acid	400 mcg	100%
Vitamin B12	6 mcg	100%
Pantothenic Acid	5 mg	50%
Calcium	450 mg	45%
Iron	18 mg	100%
Magnesium	50 mg	12%
Zinc	15 mg	100%

2. Eat a bowl of breakfast cereal that has 100% of the daily value of folic acid every day.

Not every cereal has this amount. Check the label on the side of the box, and look for one that has "100%" next to folic acid.

To learn more about folic acid and how to prevent birth defects, please visit the Centers for Disease Control and Prevention website at www.cdc.gov/folicacid or call 1-800-232-4636 (CDC-INFO).

National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities

CS212882-A

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*

How can you help?

- Help pregnant people understand different newborn screening so they know what to expect when baby is born

- Promote folic acid supplement for people who are pregnant or planning to be pregnant to prevent neural tube defects

- Help families know about our public health programs

3. Newborn Hearing Screening and Early Hearing Detection and Intervention (EHDI)

Why newborn hearing screening

- Congenital hearing loss is very common
  - 3/1000 births (0.3%)
  - Only <u>half</u> 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**

Importance of Screening, Diagnostic, and Early Intervention

- Babies begin learning as soon as they are born to help develop skills such as:
  - *communication* (talking, listening, signing, understanding);
  - *cognition* (thinking, learning, solving problems);
  - *physical* (reaching, rolling, crawling, and walking);
  - *social/emotional* (playing, feeling secure and happy); and
  - *self-help* (eating, dressing).

Communication Spectrum

Auditory communication

Auditory and visual communication

Visual communication

All can lead to successful language and communication for children and families

Legislative History of EHDI

1999 – Requires hearing screenings for babies born in hospitals with at least 200 births per year, those with less must provide information. Screening and diagnostic facilities must report hearing testing results within 10 days.

2003 – Allowed for additional information sharing among partners to reduce delays in supporting language development among infants

2009 – Language updates for development of OHA

2017 – Facilities must provide educational information about congenital cytomegalovirus (cCMV) transmission to families

2025 – New cCMV screening requirements for hospitals and birthing centers and expansion of information shared with identified partners. Screening begins no later than April 1, 2026.

What is EHDI

- **E**arly **H**earing **D**etection and **I**ntervention
- National and state-based program
- Housed in the state health department, Oregon Health Authority
- Small team of dedicated staff

What does EHDI do?

- **Goal:** To identify children who are deaf and hard of hearing (D/HH) and refer to supportive services for their ongoing growth and development

- Monitor all
  - hearing screening results,
  - diagnostic audiology evaluations, and
  - enrollment in early intervention services

- Collaborate with partners including community-based organizations, state programs, other state EHDI programs

Who does EHDI monitor

- 0-36 months of age
- All babies born in Oregon
- Babies born out of state to Oregon residents (along the borders) who have an identified risk factor

EHDI 1-3-6 Goals

1 month

Screening

- All babies receive hearing screening

3 months

Audiology

- All babies who don’t pass screening get full hearing test

6 months

Early Intervention

- All babies who are deaf or hard of hearing are enrolled in EI

Why 1-3-6

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

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

Lessons From Our Work

- Over **98%** of Oregon babies are screened for hearing every year!
  - Nearly *all* of the <u>unscreened</u> babies are born at home or in small hospitals/birth centers where screening isn't readily available.

- **~1200** babies each year **do not pass** screening:
  - Of these, ~1,000 get their follow-up diagnostics
    - Over **80** babies with hearing loss found in Oregon each year.
  - But >*200* babies each year **do not** receive further testing!

Half of these babies are in WIC

- 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.

Support we provide

- Follow-up with providers and families for documentations
- Partner with other programs such as State Public Health Lab, home visiting program, WIC, DMV, Medicaid etc, to enhance follow-up capacity
- Facilitate Early Intervention enrollment
  - Special instruction and other services, including speech, physical, and occupational therapy
  - Home visiting to help families support their child's development in everyday activities
  - Itinerant services in community childcare
  - Connections to community services and programs.
- Referral to parent support
  - Hands and Voices - Guide By Your Side program

We cannot do our work alone

Rely on partners to help support children and families throughout the state

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How can you help?

- Help pregnant people understand different newborn screening, so they know what to expect when baby is born
- Help families know about our public health programs as necessary
- Flagging local community needs to the EHDI team so we can provide more support/guidance
- Continuing to offer high-quality and timely services to babies and families
- Identifying families and other providers to be leaders in the EHDI system, driving improvements from all levels