Exploring Birth Defects Surveillance Programs and Opportunities to Align with MCH Title V Activities

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Oregon Birth Anomalies Surveillance System
Overview

• BASS Program
• Oregon MCH Title V
• Program Alignment

*Although birth anomalies are sometimes referred to as birth defects, Oregon uses the term anomalies as a response to community input.
Oregon Birth Anomalies Surveillance System
Oregon BASS Program

Our Team

• Vivian Siu – Research Analyst (.5 FTE)
• Stephanie Glickman – Public Health Educator (.5 FTE)
• Yesenia Gonzalez – Administrative Specialist (less than .5 FTE)
• Suzanne Zane – CDC MCH Epidemiologist Assignee to Oregon (advisory role)
1999
Oregon Legislative hearing regarding Fetal Alcohol Syndrome. Public Health Division, Office of Family Health is directed to address FAS.

2000 – 2002
Early conversations begin about Oregon’s need for conducting birth defects surveillance

2001
First Fetal Alcohol Syndrome prevention grant application submitted – accepted but not funded

2002
Oregon begins participating as a funded state Environmental Public Health site.
Oregon funded as an EPH site
FAS Surveillance Conducted 2004-2009

Oregon funded as an EPH site

FAS Surveillance grant accepted
Oregon funded as an EPH site

FAS Surv. grant accepted

FAS Surv. Conducted 2004-2009

2003 → 2005 → 2007 → 2009 → 2011 → 2013 → 2015

CDC grant approved, not funded
Oregon funded as an EPH site

2003

FAS Surv. grant accepted

2005

FAS Surv. Conducted 2004-2009

2007

CDC grant approved, not funded

2009

2011

EPHT & Title V fund BASS

2013

2015
FAS Surv. Conducted 2004-2009

- 2003: Oregon funded as an EPH site
- 2005: FAS Surv. grant accepted
- 2007: CDC grant approved, not funded
- 2009: EPHT & Title V fund BASS
- 2011
- 2013
- 2015: First data submitted to CDC
Oregon funded as an EPH site

2003
FAS Surv. grant accepted

2005
FAS Surv. Conducted 2004-2009

2007
CDC grant approved, not funded

2009
EPHT & Title V fund BASS

2011
First data submitted to CDC

2013
CDC approved CCHD, not funded

2015
2016 – 2021: BASS funded by CDC!

Program focus areas:
• Surveillance
• Partnerships
• Family resources
• Data dissemination
• Program structure quality improvement
## Surveillance

<table>
<thead>
<tr>
<th>2016 – 2021 program funded</th>
<th>2021 planned activities</th>
<th>Current - program not CDC funded</th>
</tr>
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<tbody>
<tr>
<td>• Improve methodology</td>
<td>• Strengthen capacity</td>
<td>• Maintain passive surveillance methodology</td>
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<tr>
<td>• Increase knowledge about BD prevention</td>
<td>• Develop/improve data system</td>
<td>• Working towards migration to Filemaker database</td>
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<tr>
<td>• Expand conditions tracked</td>
<td>• Passive case finding with case verification</td>
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<tr>
<td>• Explore newborn screening of CCHDs</td>
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<tr>
<td>• Validity and reliability</td>
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<tr>
<td>• Active surveillance of CCHD</td>
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**2021 planned activities**

- Strengthen capacity
- Develop/improve data system
- Passive case finding with case verification

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**Current - program not CDC funded**

- Maintain passive surveillance methodology
- Working towards migration to Filemaker database
### Partnerships

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<th>2016 – 2021 program funded</th>
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<tr>
<td>• Expand collaboration</td>
<td>• Hospital systems to assess accessibility of medical records</td>
<td>• Continued collaboration with Oregon F2F HIC</td>
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<tr>
<td>• Maintain advisory committee</td>
<td>• Work with CDC to improve surveillance methodology</td>
<td>• Close collaboration with NBDPN Health Promotion Committee</td>
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<td>• Collaborate with Oregon F2F HIC (Family to Family Health Information Center)</td>
<td>• F2F HIC for outreach</td>
<td>• Innovations in Newborn Screening Interoperability</td>
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<td>• Title V program to collaborate and reach external Title V partners</td>
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## Family Resources

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<th>2016 – 2021 program funded</th>
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<tbody>
<tr>
<td>• Early identification</td>
<td>• Develop data driven primary and secondary prevention strategies</td>
<td>• Social media</td>
</tr>
<tr>
<td>• Understand referrals systems</td>
<td>• Referral pathways to family resources through home visiting, WIC, 211info, geneticists, and specialists</td>
<td>• Develop data driven primary and secondary prevention strategies (e.g. folic acid outreach)</td>
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<tr>
<td>• Utilization of services for affected individuals and families</td>
<td>• Social media</td>
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<td>• Develop family resource bank including fact sheets</td>
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<tr>
<td>• Improve website</td>
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## Data Dissemination

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<tbody>
<tr>
<td>• Accurate and timely information to organizations, agencies, and individuals</td>
<td>• Contribute to multi-state data</td>
<td>• Data dashboard</td>
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<tr>
<td>• Use data to inform policy and resource allocation</td>
<td>• Develop dissemination plan</td>
<td>• Continuous quality improvement of data visualization</td>
</tr>
<tr>
<td>• Publications</td>
<td>• Identify disparities</td>
<td>• Identify disparities</td>
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<tr>
<td>• Presentations</td>
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<td>• Presentations</td>
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# Program Structure

### 2016 – 2021 program funded
- Program coordinator, research analyst, public health educator, CDC epidemiology assignee, administrative support
- Advisory Committee
- Funded by combination of MCH and CDC grant

### 2021 planned activities
- Staff turnover
- MMRC abstractor to work with BASS
- BASS team excited to get started on new workplan

### Current - program not CDC funded
- No program coordinator
- No abstraction
- Reprioritized workplan
- MCH leadership encouraged BASS team to continue program efforts
- Title V pays for BASS staff FTE
Organizational Structure

- Oregon Health Authority (State Health Department)
  - Public Health Division
    - Maternal & Child Health
    - Public Health Lab
    - Newborn Screening
    - BASS
    - EPHT
  - Enviro. Public Health
  - Center for Health Statistics
  - Birth Certificates
  - Health Systems Division
    - Oregon Health Plan

Agency
Division
Section
Program

BASS - Oregon Birth Anomalies Surveillance System
EPHT - Oregon Environmental Public Health Tracking
OCCYSHN - Oregon Center for Children & Youth with Special Health Needs
OR F2F HIC - Oregon Family to Family Health Information Center
BASS - Oregon Birth Anomalies Surveillance System
EPHT - Oregon Environmental Public Health Tracking
Title V Block Grant
Federal Title V Structure

Federal funding to state MCH programs to support activities that improve the health of pregnant women, children, adolescents, and children and youth with special health needs.

“Title V today gives states flexibility with accountability for systemic approaches to improve health access and outcomes for ALL women, children, youth and families. Title V has been dubbed the framework, the infrastructure and even the “glue” for states’ and territories’ overall strategies, policies and programs. Over the years, many strengths have evolved from Title V: flexibility, adaptability, broad mission focused on national health objectives, responsiveness to states’ and territories’ needs, and accountability for performance. While the dollars for Title V may be a relatively small proportion of a state’s total budget for family health programs, used effectively they can have a big impact.” - AMCHP

https://amchp.org/title-v/
Title V Framework - Domains

- Women/Maternal Health
- Perinatal/Infant Health
- Child Health
- Adolescent Health
- Children and Youth with Special Health Care Needs (CYSHN)
- Cross-Cutting/Systems Building
Oregon MCH Title V Structure

In Oregon, Title V funds are shared between:

- State public health
- Oregon Center for Children and Youth with Special Health Needs (OCCYSHN at OHSU)
- Local public health
- Tribes
Oregon’s Title V Framework

State-level Priorities: Foundations of MCAH
- Social determinants of health and equity
- Trauma, ACEs, and resilience
- Culturally and linguistically responsive services

National Priorities:
- Well woman care
- Breastfeeding
- Child injury prevention
- Bullying prevention

Work focused on:
- Policies and systems
- Workforce capacity and effectiveness
- Assessment and evaluation
- Community, individual and family capacity

To support/enhance:
- Thriving and equitable communities
- Resilient and connected families and communities
- Safe and responsive environments
- Nutrition and healthy development
- Healthy individuals and families
Women/Maternal Health Domain

National Performance Measure
- Percent of women with a past year preventative visit

Evidence-informed Strategy Measures (summary of relevant highlights)
- Focus on women’s behavioral health needs
- Cultural responsiveness
- Community based perinatal, women’s and infant health advisory groups to share best practices, strategize and impact policy change. Engage affected communities including people of color in leadership.
Perinatal/Infant Health Domain

National Performance Measure
- Percent of infants who are ever breastfed
- Percent of infants breastfed exclusively through 6 months

Evidence-informed Strategy Measures (summary of relevant highlights)
- Workplace laws around chest/breastfeeding with a focus on populations with additional barriers.
- Workforce training, especially around cultural responsiveness
- Community based perinatal, women’s and infant health advisory groups to share best practices, strategize and impact policy change. Engage affected communities including people of color in leadership.
Children and Youth with Special Health Care Needs (CYSHN) Domain

National Performance Measure

- Percent of children with and without special health care needs, ages 0 through 17, who have a medical home
- Percent of adolescents with and without special health care needs, ages 12 through 17, who received services to prepare for the transition to adult health care

Evidence-informed Strategy Measures (summary of relevant highlights)

- Primary care involvement in shared care planning
- Young adult with medical complexity/family participation in transition preparation appointments
Cross-Cutting/Systems Building Domain

Title V’s priorities and strategies in this domain are focused on improving the foundations of maternal, child and adolescent health. OCCYSHN (Oregon Center for Children and Youth with Special Health Care Needs) and MCAH (Maternal Child and Adolescent Health) have included strategies that are centered in:

- Trauma-informed care
- Equity and anti-racism
- Workforce diversity
- Addressing systems-level disparities
- Access to care
- Partnerships
- Community capacity
- Economic supports and housing
- Food sovereignty/security
- Emergency preparedness
Title V – Other Programmatic Efforts

Title V funding also supports work beyond the identified priority areas including the BASS program. Additional Title V funded work includes the following:

- Oregon Mothers Care
- Home Visiting
- PRAMS
- Safe Sleep
- Assessment and Evaluation and Informatics

These efforts include partnerships that BASS can tap into to help with our outreach efforts and deeper understanding of data trends.
What are your state Title V priorities/strategies?

https://mchb.tvisdata.hrsa.gov/Home/StateApplicationOrAnnualReport
Program Alignment
Aha! Moment

Surveillance and health education components of BASS have substantial areas of overlap with Oregon’s Title V Women’s and Infant Health.
Why align with Title V?

• MCH leadership sees importance of BASS and decided to support with Title V funds
• National effort to strengthen partnership between Title V and birth defects prevention efforts
• Shared goals and outcomes
• Existing Title V Women and Infants Team includes priority specific work and other related work (e.g. Oregon Mothers Care) – opportunities to collaborate
• Strengthen collaboration between programs to ensure communications and opportunities for partnerships are optimized
• Leverage existing efforts and reduce duplication of work
• Outcomes and interventions/goals are mostly the same on BASS and Title V Women’s and Infants teams
Program Symbiosis

BASS benefits from Title V policy-level expertise, local-level partnerships, flexible workplan, and equity approach.

Title V benefits from BASS surveillance data, health education efforts for outreach, in-house expertise of impacts of birth anomalies, and partnerships.
Shared Program Outcomes

- Healthy pregnancies
- Healthy childbirth
- Healthy infants
- Families impacted by birth anomalies to have the resources they need to thrive
- Individuals with birth anomalies to live happy, healthy lives
Aligned Strategies

- Oregon MothersCare is increasing access to health insurance, prenatal care, and other resources for pregnant individuals.
- Well-woman care increases access to preconception and inter-conception care.
- Breastfeeding promotion and connection with WIC.
- OCCYSHN provides support and resources for families.
- Surveillance of birth anomalies and neonatal abstinence syndrome.
- Education and outreach promoting healthy habits
- Partnership with Family to Family Health Information Center – family informed program decisions, data informed resources for families
BASS – Title V Proposal to MCH Leadership

• BASS team to join monthly meetings with Title V Women and Infants team
• Add state-level strategy to the Title V Well Woman Care Plan in 2023
  – Strategy to strengthen partnership, identify opportunities for collaboration, revised BASS workplan to reflect those activities
• Anchor the existing BASS work plan to reflect the Title V funded BASS scope of work
Benefits of Collaboration

- Broad view of work
- Reduces duplication
- Bridges information gaps
- Leverages connections and existing efforts
- Reduces MCH siloes
Current BASS – Title V Activities

• Data to action
  – Analysis of folic acid consumption rates from PRAMS data and planning improvements for outreach to include engagement with Title V partners

• Health promotion
  – Updating pregnancy outreach for Title V funded sites to include birth anomaly prevention tips

• Cross program collaborations and shared work plans
  – Joint BASS/Title V team
Future BASS – Title V Activities

- Map out existing and potential partnerships
- Incorporate gender inclusive language
- Improve understanding of internal/external workflows
- Facilitate data exchange with partners
Challenges

- Limited capacity without CDC funding
- BASS is still relatively young - lack of infrastructure
- BASS staff are stretched between competing priorities
- No state mandate or funding
- CYSHN is part of a different organization
Contact our team!

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