



Oregon

Theodore R. Kulongoski, Governor

Department of Human Services

Office of the Director
500 Summer St. NE, E-15
Salem, OR 97301-1097

503-947-5110

Fax: 503-378-2897

TTY: 503-947-5080

December 14, 2009

The Honorable Peter Courtney, Co-Chair
The Honorable Peter Buckley, Co-Chair
Joint Committee on Ways and Means
900 Court Street NE
H-178 State Capitol
Salem, OR 97301-4048



Re: Retroactive Request to Apply – Competitive – Non-ARRA Funded
Population-based Birth Defects Surveillance and Utilization of Surveillance
Data by Public Health Programs (DHS-PH-49)

Dear Co-Chairpersons:

Nature of the Request

The Department of Human Services (DHS) Public Health Division (PHD) requests retroactive approval to apply for the Population-based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs cooperative agreement for federal funding of up to \$1,100,000 over five years beginning February 1, 2010 and ending January 31, 2015. The Joint Committee on Ways and Means was alerted on November 16, 2009 of the department's intent to seek approval for this grant.

The funding is available through the U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC). The request for applications was received on October 28, 2009, and was due November 30, 2009. This cooperative agreement requires no state matching funds or maintenance of effort beyond the grant period.

Agency Action

A birth defects registry is used to collect information about children with birth defects for monitoring the frequency, trends and causes of birth defects. A registry

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can help initiate assessment, referrals, follow up and self care for children and their families; it can also lead to programs that reduce medical treatment costs. Oregon is one of only four states without a birth defects registry system. States with a birth defects registry are better able to focus public health prevention strategies to decrease further birth defects. We estimate birth defects can be detected in approximately 600 Oregon infants each year at birth; and in approximately 1,800 children within their first three years of life. Up to 24 percent of all infant deaths per year in Oregon are caused by birth defects, compared with 20 percent across the United States. Oregon is currently unable to accurately determine the causes or populations at risk for birth defects, and therefore has limited ability to improve the lives of those at highest risk, provide early intervention care for children, and reduce lifetime costs to families and to health, social, and education services.

During the 2009 Legislative Session, the Legislature, DHS PHD and community partners worked hard to find funding to support a registry. This effort was not successful. This grant opportunity provides Oregon with the much needed resources to get a birth defects registry up and running.

The purpose of this program is to support:

- Development, implementation, expansion, and evaluation of state population-based birth defects surveillance systems;
- Development and implementation of population-based programs to prevent birth defects;
- Development and implementation of activities, including referral to services, to improve the access of children with birth defects to health services and early intervention programs; and
- Evaluation of the effectiveness of the referral activities and the impact on the affected children and families.

This program addresses the “Healthy People 2010” focus area of Maternal, Infant, and Child Health.

Measurable outcomes of the program will be in alignment with the following performance goals for the National Center on Birth Defects and Developmental Disabilities:

- Prevent or reduce birth defects and developmental disabilities.
- Reduce health disparities in the occurrence of folic acid-preventable spina bifida and anencephaly by reducing the birth prevalence of these conditions.

The DHS Office of Family Health will partner with the DHS Office of Environmental Health, DHS Oregon State Public Health Lab, DHS Oregon Vital Statistics, OHSU Child Development and Rehabilitation Center, the March of Dimes and other community partners to design and implement the registry. Proposed staffing for the five years includes a Medical Records Abstractor (.50 FTE) to abstract data from medical records at birthing hospitals and provider clinics, a Research Analyst (.50) to analyze the data and conduct the evaluation of the entire grant program, an Office Specialist 2 (.50 FTE) to provide office support services. The team will be lead with existing staff including an Operations and Policy Analyst (.50 FTE) to develop and implement the population-based programs to prevent birth defects and develop, implement and expand activities and processes related to family referrals to services and access of children with birth defects to health services and early intervention programs; and the MCH Medical Epidemiologist who will provide overall epidemiology leadership and technical consultation for the design of the surveillance and evaluation components of the program and advise the program coordinator in surveillance methodology. He will lead activities related to dissemination of epidemiological results including presentations and articles for publication.

This cooperative agreement does not require any maintenance of effort by the state, or continued funding at the end of the project period. The results of this project intend to build a comprehensive and coordinated system to better understand birth defects in Oregon and use the information to reduce the birth defect prevalence, promote better birth outcomes, and improve the outcomes for those children born with birth defects. Continuation or expansion of the work after the five year period will depend upon federal and local funding available at that time. If no additional funding is available at the end of the grant period, we anticipate that the population-based prevention programs and the referral services would not continue. Costs associated with the continuation of the birth defect registry would be minimal and achievable without additional resources from the stat. Our intent is to use the five years to develop diversified and sustainable funding base with partners.

Action Requested

The Oregon Department of Human Services Public Health Division requests retroactive approval to apply for federal funds available through the U.S.

Department of Health and Human Services, Centers for Disease Control and Prevention for the Population-based Birth Defects Surveillance and Utilization of Surveillance Data by Public Health Programs for federal funding up to \$1,100,000 over five years.

Legislation Affected

For additional information, please call Katherine Bradley at 971-673-0233.

Sincerely,

A handwritten signature in black ink, appearing to read "JRS", with a long horizontal flourish extending to the right.

Jim Scherzinger
Deputy Director of Finance

CC: John Britton, Legislative Fiscal Office
Sheila Baker, Legislative Fiscal Office
Blake Johnson, Department of Administrative Services