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May 13, 2015

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

Re: Request to Apply Letter – Competitive Grant – Surveillance of Congenital Heart Defects Across the Lifespan (OHA-PH-15-09)

Dear Co-Chairpersons:

Nature of the Request

The Oregon Health Authority (OHA), Public Health Division requests permission to apply for the Surveillance of Congenital Heart Defects Across the Lifespan Cooperative Agreement for federal funds up to \$425,000 a year for 4 years, beginning October 1, 2015 and ending September 30, 2019, for a total of up to \$1,700,000.

The intent of the grant is to develop and implement approaches for identifying the prevalence of Oregonians with congenital heart defects using population-based data sources. The funding is available through the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities. The request for proposals was received on March 25, 2015, and the application is due on June 1st, 2015. This grant funding requires no state matching funds. There is no federal requirement for maintenance of effort.

Agency Action

Oregon's Birth Anomalies Registry (BAR) sits in the OHA Public Health Division, Maternal and Child Health Section. The purpose of the BAR is to provide public health tracking to: (1) collect information on birth anomalies and other adverse reproductive outcomes; (2) report the incidence, trends and causes of birth anomalies and other adverse reproductive outcomes; (3) report information for the development of prevention strategies to reduce the incidence of birth anomalies and other adverse reproductive

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outcomes; and (4) develop strategies to improve the access of children with birth anomalies to health and early intervention services.

This Congenital Heart Defects Cooperative Agreement builds on the BAR, allowing us to develop a deeper understanding of the congenital heart defect anomaly, which is seen more often in adolescence and adulthood. While the BAR currently focuses on newborns, this grant looks across the lifespan, with a special focus on women of child-bearing age.

The public health burden of congenital heart defects (CHDs) is significant. Anomalies of the heart and circulation constitute one of the most common forms of congenital defects, with CHDs affecting approximately 1% of all births. Unfortunately, many adults with CHDs that were identified in childhood have become lost to follow up, increasing their risk for later-age heart conditions and avoidable death. The key objective of this project is to identify all Oregonian across the lifespan with a CHD, with a special focus on women of child-bearing age (15-45 years). We will accomplish this through creation and utilization of multiple partnerships and subsequent linkages of multiple existing data sources. These include administrative claims data through Medicaid and All Payers All Claims data systems, Oregon Child Health Information Data Systems (ORCHIDS) - a public health home visiting database, vital records, CHD-specific patient databases, and medical records review. These linkages will provide the program with a greater understanding of the effects of CHDs into adulthood.

This grant will be implemented with existing OHA staff and will require no new positions. We will work with partners to collaborate on meeting grant requirements. The OHA positions will include staff from Public Health and Health Analytics programs. An Interagency Agreement with OHSU will be obtained to seek physician cardiac clinical consultants with expertise in pediatric and adult congenital anomalies.

There is no expectation that the state will continue to fund these activities or positions at the end of the grant period. Knowledge gained in the form of prevalence rates for CHD will be able to be used by the BAR in future work.

The OHA mission is to help people and communities achieve optimum physical, mental and social well-being through partnerships, prevention and access to quality, affordable health care. An essential function of the public health system is to provide data and information about the health of Oregonians. Most of the information about the frequency of risk factors for deaths, illnesses and injuries across the state comes from the public health system's activities to track disease and health behaviors. The funding to conduct this CHD Cooperative Agreement would contribute to the larger public health and health

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care systems' knowledge and inform strategies to improve the health of Oregonians with CHD.

Action Requested

The Oregon Health Authority (OHA), Public Health Division requests authority to accept a Surveillance of Congenital Heart Defects Across the Lifespan Cooperative Agreement from the Centers for Disease Control and Prevention if the state's application is successful.

Legislation Affected

None

For additional information, please contact Cate Wilcox at cate.s.wilcox@state.or.us, or at 971-673-0299.

Sincerely,

Bill Coulombe

Budget Director

Oregon Health Authority

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CC: Ken Rocco, Legislative Fiscal Office George Naughton, Chief Financial Office Linda Ames, Legislative Fiscal Office Kate Nass, Chief Financial Office Art Ayre, Chief Financial Office