



Children's National
Medical Center

April 18, 2011

Children's National
HeartInstitute

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The Honorable Kathleen Sebelius
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, D.C. 20201

RE: Secretary's Advisory Committee on Heritable Disorders in
Newborns and Children Recommendation for Universal Newborn
Screening for Critical Congenital Heart Disease

Dear Secretary Sebelius:

On behalf of Children's National Medical Center in Washington, DC and Children's National Heart Institute, we write to express our strong support for the recommendation of the Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) concerning universal screening of newborns for critical congenital heart disease (CHD). We understand you may have some concerns about moving forward with the SACHDNC's recommendation.

Children's National Medical Center, a 303 bed, freestanding children's hospital, is a proven leader in the development and application of innovative new treatments for childhood illness and injury. Children's National Heart Institute is an international leader in pediatric cardiac care. In addition to serving the metro DC region, families travel to Children's National from across the country and from around the world. The Institute brings together a multidisciplinary team to provide specialized expertise and world-class care for children with cardiac defects. Our world class team cares for patients - from fetus to adults - with a wide range of congenital heart disease.

Children's National has been a strong and active supporter of pulse oximetry screening for critical CHD since 2007. Following publication of the AHA/AAP Guidelines in 2008, we began research to evaluate implementation of pulse oximetry screening for critical CHD at Holy Cross Hospital, a large community hospital in Silver Spring, Maryland. The Holy Cross research showed that implementation is possible, fills the diagnostic gap from physical examination and does not require additional staff. In 2010, we testified in support of screening on two occasions at SACHDNC meetings. In addition, we participated in a two day HRSA workshop to discuss and develop recommendations for implementation.

At the state level, we were involved with successful efforts in Maryland to enact House Bill 714 and its companion, Senate Bill 786. These bills direct the State's Department of Health and Mental Hygiene (DHMH) to make recommendations regarding the State's implementation of pulse oximetry screening for critical CHD by December 31, 2011. We were happy to support this bill and were invited to participate in DHMH's consideration of this issue through its State Advisory Council on Hereditary and Congenital Disorders.



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Lastly, we have developed an evidence-based toolkit that contains recommendations for implementation of screening and education materials for health care providers and families. The toolkit has been used to successfully guide implementation of screening in seven hospitals locally, nationally and internationally. In addition, organizations in twenty states and Canada have requested the toolkit and are considering using it in their nurseries. Organizations that have successfully implemented screening have reported no significant barriers and providers have been supportive.

In 2011, the Health Authority of Abu Dhabi (HAAD) requested our team's assistance in implementation of pulse oximetry screening in their 23 associated birthing organizations. We worked with HAAD to create an inclusive training program and traveled to Abu Dhabi in January 2011 for lectures and site visits.

CHD is the most common birth defect, but tragically diagnosis is often missed. We are confident that screening with pulse oximetry will narrow the diagnostic gap. We continue to make progress in our region, implementing pulse oximetry screening one hospital and one state at a time. This piecemeal approach, however, leaves too many newborns and their parents vulnerable. Federal leadership is needed to ensure *all* newborns, regardless of which state or hospital they're born in, are screened for congenital heart disease. We respectfully urge you to continue the federal government's involvement in this issue so that all children born with congenital heart disease benefit from the life saving treatments that have been developed over the past 4 decades. Thank you for your attention to this critical matter.

Sincerely,

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cc: Congressman Chris Van Hollen