

# DACHDNC: Public Health Impact Assessment



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# DACHDNC: Key Responsibilities

- Make systematic evidence-based and peer-reviewed recommendations for the most appropriate application of universal newborn screening tests
  - Technologies, policies, guidelines, standards
- Develop a model decision-matrix for newborn screening expansion, including an evaluation of the public health impact of expansion
- Consider ways to ensure that all states attain the capacity for screening, short-term and long-term follow-up

# Excerpt from Secretary Sebelius' response to Dr. Howell, Chair of SACHDNC, Sept 21, 2011

As you know, congenital heart disease causes up to 3% of all infant deaths in the first year of life. Heart defects affect about 7 to 9 of every 1000 live births, one quarter of which could be detected and potentially treated by measuring blood oxygen saturation. Given this reality and the available information on the effectiveness of screening, I have decided to adopt the SACHDNC's first recommendation to add CCHD to the RUSP. In addition, I am requesting that the SACHDNC collaborate with the Health Resources and Services Administration (HRSA) to complete a thorough evaluation of the potential public health impact of universal screening for CCHD, as required by the authorizing statute, section 1111 of the Public Health Service Act (42 U.S.C. § 300b-10(b)(4)).

**Approval of SACHDNC recommendation to include CCHD in RUSP**

Net benefit		Feasibility	Readiness		
			Ready	Developmental	Unprepared
Significant benefit	High certainty	High or moderate feasibility	<b>A1</b>	<b>A2</b>	<b>A3</b>
		Low feasibility	<b>A4</b>		
	Moderate certainty		<b>B</b>		
Zero to small benefit	High or moderate certainty		<b>C</b>		
Negative benefit			<b>D</b>		
	Low certainty		<b>L</b>		

# **DACHDNC: Pompe decision**

- **Public health impact assessment included**
  - **Assessment of population-level benefits using Decision Analysis (CWG)**
  - **Survey of Newborn Screening Program Directors followed by interviews with representatives of the NBS programs to assess feasibility and readiness (APHL)**
- **Secretary has referred to Interagency Coordinating Committee (ICC)**
  - **Response expected July 31<sup>st</sup>**

# Pompe decision followup

- **Feedback from within the Committee and from some stakeholders that public health impact analysis needed to be strengthened**
- **Response**
  - **Focus on strengthening public health analysis**
  - **Delayed MPS1 and ALD deliberations**

# Expert Advisory Panel Meeting

- **Purpose:** Strengthen public health impact assessment by development of a systematic approach for evaluation of all necessary information
- **Steering Committee:** Joe Bocchini, Ned Calonge, Alex Kemper, Jelili Ojodu
- **Participants:** Committee members, stakeholders and other experts
- **Held:** April 10-11 at APHL headquarters

# Participants

- Committee members
- Laboratory specialists
- Heritable disorders specialists
- Primary care providers
- Genetic Counselors
- State Public Health Departments
- Ethicist
- Public Health Impact Assessment Experts
- Health Economist
- NCC/Regional Collaboratives
- Payors
- Consumers
- Federal Agencies
- Evidence Review Experts



# Public Health Impact Assessment: Status

- Current matrix does not need refinement
- Key elements of public health impact identified
- **Today:** Presentation to Committee for discussion and input
- **Next step:** Draft of to be circulated to Committee, participants, Regional Collaboratives for input and feedback