

# Legal Framework for the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC)

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# Presentation Overview

- Background - role of OGC
- Legal Framework for SACHDNC:
  - Background - Federal Advisory Committee Act (FACA)
  - SACHDNC Authorizing Legislation
  - Section 2713, PHS Act (added by Affordable Care Act)

# Office of the General Counsel (OGC)

- Provides legal advice and assistance to HHS
- OGC provides legal advice and assistance to HRSA/MCHB and other HHS organizations and officials
- Advises and provides assistance to the DFO regarding responsibilities relating to SACHDNC-related management processes

# Federal Advisory Committee Act

- Public Law 92-463, as amended (5 U.S.C. App. 2)
- Implemented by 41 C.F.R. Parts 101-6, 102-3

# Federal Advisory Committee Act

The Federal Advisory Committee Act (FACA) applies when Congress or an agency establishes, manages, or controls a group that includes one or more participants who are not federal employees for the purpose of obtaining the group's advice or recommendations on agency issues or policies.

# Federal Advisory Committee Act

- Became law in 1972; establishes how federal advisory committees operate
- Enacted to ensure that advice provided to the federal government by advisory committees formed over the years is objective and accessible to the public
- Emphasizes open meetings, chartering, public involvement, and reporting

# Advisory Committees under FACA

- “Advisory committee”
  - any committee, board,... panel, task force, or other similar group, or any subcommittee or other subgroup thereof, which is –
    - (A) established by statute or reorganization plan, or
    - (B) established or utilized by the President, or
    - (C) established or utilized by one or more agencies,in the interest of obtaining advice or recommendations for the President or ... agencies or officers of the Federal Government.

# Statutory Purpose

- “... the function of advisory committees should be advisory only, and ... all matters under their consideration should be determined, in accordance with law, by the official, agency, or officer involved.”



# HHS Statutory Responsibilities

- Establish uniform administrative guidelines and management controls for advisory committees established by HHS, consistent with General Services Administration (GSA) directives
- Maintain systematic information on the nature, functions, and operations of advisory committees within its jurisdiction.

# Agency Statutory Responsibilities

- Designate an Advisory Committee Management Officer who shall –
  - Exercise control and supervision over the establishment, procedures, and accomplishments of its advisory committees
  - Assemble and maintain the reports, records, and other papers of any such committee
  - Carry out the provisions of 5 U.S.C. 552 with respect to reports, records, and other papers

# Agency Statutory Responsibilities

- HRSA/MCHB performs most such responsibilities relative to SACHDNC on HHS's behalf

# SACHDNC Authorizing Legislation

- Section 1111 of the Public Health Service (PHS) Act (42 U.S.C. § 300b-10)
- Provides advice, information and recommendations to the Secretary regarding:
  - newborn and childhood screening
  - development of policies to enhance the abilities of the State and local health agencies
  - the grant program established under 42 U.S.C. § 300b-8

# Role of SACHDNC

- Provides advice, information and recommendations to the Secretary of HHS within the parameters set by the authorizing legislation

# Roles of SACHDNC

- The authorizing legislation sets the legal standard for what is within its purview and what is not.
- Within the scope: advice, information, and recommendations to the Secretary in certain identified areas
- Outside the scope: actions not described by the legislation, such as recommendations for action by States or individual HHS OPDIVs

# Preventive Care and Screenings

- ACA added section 2713 of the Public Health Service Act (42 U.S.C. § 300gg-13).
- The Recommended Uniform Screening Panel (RUSP) is part of the preventive care and screenings for infants, children, and adolescents provided for in comprehensive guidelines supported by HRSA.
- Such screenings must be covered by non-grandfathered group health plans and health insurance issuers without cost-sharing (i.e., co-pays, deductibles).
- SACHDNC recommends to the Secretary items for addition to or removal from the RUSP. The Secretary makes the final determination.

# Therefore, ...

- SACHDNC may fulfill its statutory purpose more effectively by assisting in the provision of information, advice, and assistance to the Secretary that may help inform states and other actors



# Framing Recommendations

## Program Take-Aways



- Addition of conditions to the RUSP
- Direction/advice to other HHS agencies
- Direction/advice on how to direct NBSSLA grant program

# Framing Recommendations

## Program Take-Aways



- Recommendations to States  
– especially involving funding
- Direct interaction/  
recommendations to other  
entities apart from the  
Secretary (including non-  
HHS agencies)

*Any questions?*

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