

**Call for Self-Nominations to the Follow-up and Treatment Subcommittee of the
Secretary's Advisory Committee for Heritable Disorders in Newborns and Children (SACHDNC)**

The Follow-up and Treatment Subcommittee of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) announces two vacancies for members who represent such professions as: 1) an official in state public health; and 2) a physician provider in hematology. Each member will be selected for a 4-year term with an optional extension for up to 3 years after the initial term. A member may voluntarily remove themselves from the Subcommittee at any time by submitting a resignation letter to the Chair and Co-Chair of the Subcommittee. **There is a 2-week open self-nomination period, with all requested materials due back to HRSA by Tuesday, August 21, 2012.**

The **Charge** of the Follow-up and Treatment Subcommittee is to:

- Engage in a multi-step process that:
 - Identifies barriers to post screening implementation and short and long-term follow-up, including treatment, relevant to newborn screening results;
 - Develops recommendations for overcoming identified barriers in order to improve implementation and short and long-term follow-up, including treatment, relevant to newborn screening results; and
 - Offers guidance on responsibility for post-screening implementation and short and long-term follow-up, including treatment, relevant to newborn screening results.

The Follow-up and Treatment Subcommittee **Project Priorities** include:

PRIORITY A: Screening program implementation. Project 1 – Assess the challenges of new Point of Care tests, beginning with hearing screening follow-up as a case study. Project 2 - Ongoing evaluation of CCHD implementation.

PRIORITY B: Closing gaps in systems of care. Project – Ensure that the Projects undertaken for Priorities A and C will include a focus on learning what are the current (and variable) roles and responsibilities in Long-Term Follow-Up (LTFU) for children with hearing impairment or sickle cell (disease or carrier) and CCHD; and how these models might apply to other conditions.

PRIORITY C: Real world impacts and outcomes. Project – Case study of Sickle Cell to explore the impact of newborn screening (NBS) and to develop strategies that will be useful in future studies to understand the real world impact of newborn screening (NBS) for other conditions.

Member Representative Openings:

- **State Public Health:** Persons interested in fulfilling this opening must be employed at a state health/agency department. The self-nominee should be familiar and actively involved with the development and implementation of newborn screening and follow-up programs (short and long-term); state health care systems; and state legislation and policies for conditions included on the Recommended Uniform Screening Panel (RUSP) of the SACHDNC (including blood spot, hearing and CCHD).

- **Hematology Physician Provider:** Persons interested in this opening must have clinical experience in a hospital/center or clinic setting; familiarity with sickle cell newborn screening and short and long term follow-up programs; knowledge of utilization of newborn and long-term surveillance data for sickle cell disease; and awareness of sickle cell education activities for individuals and their families (disease and carrier).

Those interested in becoming a member of the Follow-up and Treatment Subcommittee must provide the following information listed below to Jill Shuger, ScM, at HRSA MCHB Genetic Services Branch; e-mail jshuger@hrsa.gov.

1. Self-nominee's Curriculum Vitae.
2. Brief description of the self-nominee's perspective and expertise.
3. Why the nominee's perspective and expertise would benefit the Subcommittee.
4. How the Subcommittee's work may benefit or impact families with or at risk for heritable disorders.

Self-nominees are responsible for attending SACHDNC in-person meetings in Washington, D.C. including travel and lodging. Also, participation in monthly Follow-Up and Treatment Subcommittee conference calls is important. All final decisions regarding membership will be made by the Chair of the SACHDNC and the Designated Federal Officer of the Advisory Committee. Once a membership decision has been made, HRSA staff will send an approval letter to each new member by the end of August 2012. The next SACHDNC meeting is scheduled on September 13-14, 2012 in Washington, DC. Please direct any questions to Jill Shuger at jshuger@hrsa.gov.

Other information:

Link to SACHDNC website: <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/>

Link to RUSP website:

<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/recommendedpanel/index.html>

SACHDNC 2013 meeting dates: January 31-February 1; May 16-17; and September 19-20.