

Aloha Everyone,

We hope all of you are enjoying the spring! Below are news and updates for the month:

NCC Listening Sessions

As part of the new needs assessment priority for the National Coordinating Center (NCC) grant renewal, the NCC is asking each region to organize a series of Listening Sessions. During these sessions, the NCC is hoping to assess gaps in policies, services, education, and family support across the regions. HRSA wants this information very soon, so we are planning to help the NCC schedule a series of WSGSC webinars throughout the month of May. We will be sending out a doodle poll within the next week to determine the best dates and times to hold these Listening Sessions. To help us with this process, please respond to the doodle poll as soon as you receive it! Thank you!

Secretary's Advisory Committee on Heritable Disorders in Newborns and Children

The next meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) will be held on Monday, May 11, 2015 from 10:00am to 4:30pm Eastern time, and Tuesday, May 12, 2015 from 10:00am to 2:30pm Eastern time. The meeting will be held via webinar. The meeting will be open to the public, and you can provide public comment. All participants must register in advance at <https://www.blsm meetings.net/ACHDNCMay2015/>.

Genetic Services Outcomes Work Group Conference Call

The first conference call for the Genetic Services Outcomes Work Group is scheduled for May 18th at 1:00pm Pacific time. This work group will build upon our previous work in the area that lead to our [2009 AJMG article](#). If you are interested in joining the work group or would like to participate in the conference call, please contact Jennifer Boomsma at jennifer@hawaiiogenetics.org.

Family Advocate Reports on the ACMG Meeting

Family Advocates Rachel VanDiver, from Alaska's Stone Soup Group, and Roz Bethmann, from Washington State's PAVE, attended the recent 2015 American College of Medical Genetics annual meeting and reported on their experience in the NCC Advocates Partnership Program. Their reports are available at: http://www.westernstatesgenetics.org/Family_Advocate_Reports.htm

Future SACHDNC Meeting Dates

Future meeting dates for the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children have been scheduled. The two remaining meetings for 2015 are:

- August 27-28, 2015 (available in-person and via webinar)
- November 2-3, 2015

2016 meeting dates are scheduled for:

- February 11-12, 2016
- May 9-10, 2016
- August 25-26, 2016
- November 3-4, 2016

For more information, go to:

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

Newborn Screening Pilot Studies

The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), National Institutes of Health (NIH), Intellectual and Developmental Disabilities (IDD) is planning to issue a RFP for multiple Indefinite/Delivery, Indefinite/Quantity (IDIQ) task order contracts for a period of five (5) years for Newborn Screening Pilot Studies.

The purpose is to create a pool of high throughput newborn screening laboratories with the capacity to screen a large number of newborns in relatively short periods of time that are representative of various regions of the United States. The selected Contractors will operate under an IDIQ Task Order contract to rapidly develop protocols and initiate testing shortly after the addition of a new condition to the Recommended Uniform Screening Panel (RUSP).

A request for proposals will likely be issued on May 18, 2015 with an anticipated due date for submission of proposals on July 2, 2015.

For more information, go to:

https://www.fbo.gov/?s=opportunity&mode=form&id=65e27248a4af7c1bc105b39fa3021fdb&tab=core&_cview=0

Working Together Survey

The National Coordinating Center has created an online survey for all seven of the Regional Genetics Collaboratives to assess how they are functioning. Thanks to everyone from our region who completed this survey! We will send out any results as soon as we receive them.

UNITY-GC Surveys

Understanding the needs of teens and young adults with genetic conditions is important to delivering family-centered genetic services. Please help us with this goal by disseminating the UNITY-GC survey (<http://www.surveymonkey.com/s/UNITYGC>) to all families who have a teen or young adult with a genetic condition. This public health needs assessment is approved by both HI DOH and Seattle Children's Hospital IRBs. We are planning to close the survey on August 31st, and would really like to get several more surveys completed before then. Thanks for your support!

For more information about the WSGSC, go to: www.westernstatesgenetics.org. Thank you!