

Aloha Everyone,

We hope that the first part of 2017 has been excellent for all of you! Below are news and updates for the month:

Family Advocates Meeting on May 22-23, 2017

The WSGSC is hosting a Family Advocates meeting in Honolulu, HI to bring together representatives from Family to Family Health Information Centers and Family Voices (F2F/FV) organizations from each state/territory of the WSGSC, as well as genetics specialists. We will be focusing on the resources (including web and app-based) that are needed by the F2F/FV organizations, and develop a plan to expand these resources amongst the other regional genetics collaboratives.

Save the Date: Regional Summit on October 1-3, 2017

This year's Regional Summit will be held in Seattle, WA on October 2-3 with a Family Advocates Work Group meeting scheduled for October 1. Save the date on your calendars! We will begin contacting participants with details and travel coordination later this summer.

WSGSC and Heartlands Telegenetics Training Session

The WSGSC and Heartland Genetics held a training session in Tuscon, AZ this April, which was a great success. The purpose of the training, which also includes webinars and completion of a series of online modules prior to the in-person meeting, is to introduce genetics providers to telemedicine equipment and how to incorporate telegenetics into clinical practice.

Please contact michelle@hawaiigenetics.org if you or a genetics provider you know is interested in future training dates.

Next ACHDNC Meeting on May 11-12, 2017

The next meeting of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) is scheduled for May 11-12, 2017. This meeting will be available in-person in Rockville, MD and via webinar. For more information, go to:

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

NCC Telegenetics and Evaluation Workgroups

The WSGSC is working with the NCC Telegenetics and Evaluation Workgroups to plan and implement a series of meetings where genetic providers will identify health outcomes of genetics services that can be used to demonstrate the benefits and advantages of services provided, whether in-person or via interactive video-conferencing. Genetics providers from several regional collaboratives, including genetic counselors from the WSGSC will participate. The project is scheduled to conclude May 31, 2017, with the end of the current grant cycle.

NCC Collaborator Newsletter

Check out the latest NCC Collaborator Newsletter, for the *final* monthly newsletter of the 2012-2017 award period.

<http://mailchi.mp/nccrcg/wnyvf84gfk>

NCC Common Measures Submitted

As part of our participation in the NCC Evaluation Work Group, the WSGSC along with other regional collaboratives reports annually on a set of common measures that track work completed by the Collaborative. We recently submitted for the June 2016 – February 2017 period. If you are interested in the contents, please email Jacquie at Jacquie.Stock@seattlechildrens.org for more details.

Family and Baby Expos in Seattle and Sacramento

To continue to better understand parents' attitudes towards newborn screening for later onset disorders, education needs, and preferred contact methods, the Hawaii Genomics Section designed and distributed a short survey at the Seattle Family Expo on March 18 and 19, and the Sacramento Kids Expo on April 9 and 10. New and expectant parents coming to our booth were very interested in newborn screening, and we collected hundreds of completed surveys.

Huge and sincere thanks to the Washington and California State Departments of Health for all their time and invaluable help!

Video: Where to Find MCH Resources

The National Center for Education in Maternal and Child Health (NCEMCH) has released a video, 'Where to Find MCH Resources: An Introduction', by John Richards and Keisha Watson. This 20 minute overview introduces sources of public health information for the MCH workforce, as well as proposes the need for further sources.

<https://www.mchnavigator.org/trainings/1767-resources.php>

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