

Aloha Everyone,

We are all looking forward to the upcoming holidays, and we want to wish everyone a happy and safe holiday season! Below are news and updates for the month:

### **Newborn Screening Saves Lives Reauthorization Act Passed**

On December 10<sup>th</sup>, the House of Representatives passed the Newborn Screening Saves Lives Reauthorization Act which was originally introduced in the Senate by North Carolina Senator Kay Hagan and Utah Senator Orrin Hatch. The bill is now awaiting President Barrak Obama's signature to be signed into law. To read the bill, go to:

<https://www.govtrack.us/congress/bills/113/hr1281/text>

### **Paper about the Affordable Care Act Website Published in the Journal of Genetic Counseling**

A paper entitled, "Genetic counselors and health literacy: the role of genetic counselors in developing a web-based resource about the Affordable Care Act" was recently published as an electronic publication in the Journal of Genetic Counseling. This paper describes the development and evaluation of the WSGSC's Affordable Care Act website. To read the abstract of the paper, go to: <http://link.springer.com/article/10.1007/s10897-014-9799-z>

### **Family-to-Family Health Information Center Grant Renewals**

We were pleased to be able to provide letters of support to the Family-to-Family Health Information Centers (F2FHIC) in our region for their grant renewals. We wish all of the F2FHICs good luck during the grant renewal process!

### **Family Advocates Partnership Program**

Two family advocates from the WSGSC will participate in the Family Advocates Partnership Program with the National Coordinating Center to attend the annual American College of Medical Genetics (ACMG) meeting in March. Congratulations to Rosslyn Bethmann, from Washington's Parent to Parent Program, and Rachel Vandiver, from Alaska's Stone Soup Group. We hope you both enjoy the ACMG meeting!

### **IRB Approval for the UNITY-GC Survey Received from Seattle Children's Hospital**

As you know, the UNITY-GC survey assesses the needs of young adults and teens living with genetic conditions including their health insurance needs and how they access health care. We have received over 80 responses so far and are still hoping to recruit more participants. We are excited to announce that we recently received IRB approval from Seattle Children's Hospital Institutional Review Board, so we may now begin recruiting through clinics within Seattle Children's Hospital. Please help distribute the survey to any individuals who may be interested! You can find a flyer about the survey as well as the survey, itself, by going to:

[http://www.westernstatesgenetics.org/files/Unity\\_GCsurvey.pdf](http://www.westernstatesgenetics.org/files/Unity_GCsurvey.pdf)

### **The New England Genetics Collaborative's Policy Brief about Genetic Disorders and Health Care Reform**

The New England Genetics Collaborative developed a policy brief for state policymakers entitled, "New England Children with Genetic Conditions and Health Care Reform: Information and Recommendations for State Policymakers". The brief outlines gaps in insurance coverage and benefits experienced by children with genetic disorders and their families, based in part on

the results of an online survey of families of children with genetic disorders living in the six New England states. The WSGSC is planning a similar activity within our region. To read the brief, go to: <http://hdwg.org/sites/default/files/NEGC-Policy-Brief-2014.pdf>

**Short-Term Follow-Up Webinar Series Sponsored by NewSTEPS**

The Newborn Screening Technical assistance and Evaluation Program (NewSTEPS) will continue to sponsor bi-monthly short-term follow-up webinars for the newborn screening community. The next webinar is scheduled for January 12, 2015 at 3:00pm Eastern Time and will focus on severe combined immunodeficiency (SCID). For more information, go to: <https://www.newsteps.org/educational-resources/short-term-follow-webinar-series>

For more information about the WSGSC, go to: [www.westernstatesgenetics.org](http://www.westernstatesgenetics.org). Thank you!