

January 6, 2020

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Executive Director Nora Wells Massachusetts Dear Drs. Thomas and Hassell,

We are pleased to write this letter of support for your application for the Health Resources and Service Administration (HRSA) funding opportunity for Regional Genetics Networks (HRSA-20-046). As the current regional genetics network for the mountain states region (Mountain States Regional Genetics Network, MSRGN) you have done valuable work to increase access to genetic services and provide education about genetic disorders. MSRGN has been successful in developing and sustaining collaboration to improve access to genetic services within the region and has supported innovative activities to strengthen the newborn screening and genetic services delivery systems, especially to the regions underserved populations.

In addition, MSRGN has facilitated long-term relationships between public health practitioners, clinical providers, and families in the region. Your efforts to strengthen long-term follow-up of children identified through newborn screening, introduce telemedicine and transitioning, educate professionals and consumers on genetic topics, and incorporate the consumer perspective into all aspects of decision-making have been valuable for the population of individuals with (or at risk for) genetic disorders and their families in your region.

Family Voices supports a network of 59 Family-to-Family Health Information Centers (F2Fs), family-run organizations promoting partnerships between families of children and youth with special healthcare needs, including those who have, or at risk of having, a genetic condition, and the professionals who serve them. In addition, Family Voices does outstanding work to train, mentor, and support family leaders. As you are aware, Family Voices plans to submit an application to become the National Genetics Education and Family Support Program. If the proposal is successful, we look forward to partnering with MSRGN to accomplish the goals and objectives of our respective projects. We look forward to helping link MSRGN members to genetics services, resources, and other supports and will also help disseminate resources and opportunities you share with us regarding family engagement in genetics services.

We are very supportive of MSRGN in its efforts to work with Family Voices and with other partners to ensure that individuals have access to quality genetic services. Collaboration between our programs and activities will improve and maximize access to and education about genetic service to those who need it most.

We are pleased to collaborate with you in this important endeavor.

Sincerely,

Executive Director, Family Voices

Mora Wells