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August 2010

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Greetings!

As the summer winds down and fall begins to look like a reality, MSGRCC is happy to announce the results of our review of proposals submitted in response to our call for innovative projects in telemedicine and telehealth. Funding for these projects was secured through our successful application for supplemental funds from the Genetic Services Branch of the Health Resources and Services Administration (HRSA), MSGRCC's funding agency.

We were able to fund two of the projects submitted in response to this call, and I'll describe them briefly in alphabetical order of the project lead. **Susan Landgren**, Certified Genetic Counselor at the Billings Clinic, will serve as project lead for the Montana Tele-genetics Project: Improving Access, Educating Providers and Consumers. This project, which was submitted in collaboration with the Eastern Montana Telemedicine Network (EMTN), will improve access to genetic counseling and provide genetic education to consumers and health care providers in rural and frontier Montana, Wyoming, North Dakota and South Dakota. This project will extend services of the one genetic counselor located in Billings to a vast region that is presently underserved. Telemedicine is used frequently by medical oncologists at the Billings Clinic and by the Maternal Fetal Medicine department; many third-party payers already reimburse telemedicine CPT codes. The EMTN is used routinely for educational presentations to professional groups. Thus many pieces are in place to extend clinical and educational services in genetics to individuals in this geographic area. Project staff will develop protocols and content materials, advertise the project to providers and patients in the region, provide the educational and counseling services, and evaluate the project using four assessment tools developed for this project.

Vickie Thompson, Ph.D., Director of Newborn Screening Programs at the Colorado Department of Public Health and Environment (CDPHE), will lead a project entitled Genetic Counseling for Early Hearing

Detection and Intervention (EHDI). The goal of the project is to provide a community based comprehensive system of care for families and their children identified with hearing loss using a medical home approach. **Kristia Kocsis, M.S.**, is the only genetic counselor in Colorado with expertise in the genetics of deafness, and she is located in the Denver metropolitan area. Colorado has vast rural areas that are not served by specialists with expertise in deafness, and the Marion Downs Hearing Center has been using telemedicine to provide early intervention support to families who do not have access to an early interventionist with expertise in working with children who are deaf and hard of hearing. This project would provide direct genetic consultation via the existing telemedicine network, giving families the opportunity to learn valuable information about their child's deafness in their own home or community. Additional diagnostic evaluations, if needed, will be scheduled through one of the Regional Genetics Clinics. Through this project, a training manual will be developed, consultations will be provided to families, and families will be surveyed on the use of telehealth and the benefits of genetic counseling. In addition, all direct contacts with families will be entered into the existing CDPHE Genetic CHIRP database and linked to the Infant Hearing CHIRP database. Queries would determine how many children who have been diagnosed with permanent hearing loss are receiving either a genetic consultation and/or testing.

We are very excited about this opportunity to use telemedicine to begin to address some of the problems related to access to genetic services in our large region. As these projects unfold, we will keep you informed about their challenges and successes. We feel sure they will act as models for service provision in our region and throughout the U.S. In the next few months, we will also let you know about the accomplishments of the other projects currently funded by MSGRCC.

Once fall arrives, we at MSGRCC will be attending the next meeting of the Secretary's Advisory Committee on Hereditary Disorders in Newborns and Children (SACHDNC) in September, and the Maternal and Child Health Bureau/Health Resources and Services Administration celebration of the 75th Anniversary of Title V in October. We'll be sure and report the highlights of these important meetings to you.

As these monthly messages become familiar to you, some of you have taken the opportunity to email me with your thoughts and suggestions for MSGRCC. These are very, very helpful to me and the other MSGRCC staff, and I hope you will continue to do this - or send your first message! We appreciate the suggestions that have already been made to connect us to people we should know or point us toward activities that will help families and providers in the region.

Warm regards,

A handwritten signature in cursive script that reads "Allie V. Kaye".

Celia I. Kaye, M.D., Ph.D.
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