



# *Virtual Winter Meeting State Team Update*

January 28<sup>th</sup>, 2020

New Mexico



# Overview of State Team Membership

- Co-Chairs: Drs. Sandy Whisler (Pediatrician) and Dale Alverson (Neonatologist and Telehealth Consultant)
- New and established members:
  - Dr. Mike Marble, Geneticist and Division Chief, UNM Pediatric Genetics Division
  - Cathy Salazar, Patient Advocate, PRO
  - Mallery Quetawski, Zuni Tribe and Artist
  - Maggie Andrews, Parent Advocate, Prader-Willie Association
  - Pam Hanson, Patient Advocate
  - Winton Wood, Patient Advocate
  - Jennifer Bartz, Patient Advocate
  - Josey Foo, Navajo Representative, Program Administrator, Navajo Family Voices
  - Susan Chacon, NM DOH, Public Health Practitioner, NM Title V Children's Medical Services
  - Brenda Romero, NM DoH, Pediatric Genetics Nurse, State Genetic Coordinator RNBSN
  - Dr. Susan Scott, MD and JD, UNM Professor Emeritus, Neonatology and Endocrinology, Newborn Screening Advocate
  - Carla Ortiz, Newborn Screening Genetic Nurse Consultant
  - Kirsten Bennett, Pediatric dietitian and QI specialist
  - Kathryn Coakley, UNM Assistant Professor, Nutrition Program
  - Kori Marmon, Consumer Advocate, Laguna Pueblo



# State Team Activity To Date

- Working with New Mexico Department of Health and Children's Medical Services to develop a network of Tele-genetic Clinics using the state-wide public health clinics as originating sites.
- Use this network approach in providing virtual services to compliment the University of New Mexico Department of Pediatrics, Genetics Division that currently does 36 on-site outreach clinics across the state
- Identified first T4G Clinic, Taos, NM
- Honoring past member, Trish Thomas of Laguna Pueblo, Consumer Advocate, Leader for Family Voices and Tribal Representation



# Experiences as a State Team

- Being sensitive to cultural perspectives regarding genetic conditions; “Living with a Condition as opposed to “Having a Condition” so as to appropriately engage patients, families and representatives of the tribes.
- Need to address protocols for emergency/disaster response as applied to patients with disabilities, such as genetic conditions, regarding critical public health issues, such as COVID-19 pandemic
- Need to develop mechanisms for patients/families to access genetic services when “local” access is significantly delayed and utilize a regional network such as MSRGN



# Time 4 Genetics: Clinic & Location



- Taos Clinic for Children and Youth, Director, Dr. Sylvia Villarreal, Taos, NM (<https://www.taospeds.org>)

