

# **Genetics Summit Draft Agenda**

Monday, October 1, 2018	
11:30am-5:00pm	Registration and Information Desk
12:00pm-1:00pm	State Team Meeting Working Lunch
1:15pm-2:45pm	State Team Updates and Report Out
3:00pm-5:00pm	<b>Networking Sessions</b> (time to discuss specific topics of interest including: American Indian Population, Telegenetics, etc.)
3:00pm-5:00pm	Healthcare Provider Meeting (open to all clinical providers)
5:00pm—7:00pm	Steering Committee Working Dinner (all others dinner on own)

Potential 6.25 hours CEU\* Tuesday, October 2, 2018

7:00am-5:00pm **Registration and Information Desk** 8:00am-9:00am **Breakfast and Networking** 

**Learning Session One – Big Genetics** 9:00am-12:15pm

9:00 am-10:00am:

Changes and Opportunities: The Role of Medical Genetics in the Era of Genomic Testing (Austin Larson, MD, Assistant Professor, Dept of Pediatrics, University of Colorado, Section of Clinical Genetics and Metabolism)

10:00am-10:15am-Morning Break

#### 10:15am-12:15pm:

- Rapid Genome Wide Sequencing in the NICU Uncovers a High Burden of Genetic Disease (David Dimmock, MD, Medical Director, Rady Children's Institute for Genomic Medicine)
- "Do You Want Fries With That?"- The Pros and Cons of Direct to Consumer Genetic Testing (Matthew Taylor MD, PhD, Director, Adult Clinical Genetics, Dept of Medicine, University of Colorado)
- 'Our' Biobank, 'Your' Results: The Why, What, When and How of Returning Results to Biobank Participants (Matthew Taylor MD, PhD, Director, Adult Clinical Genetics, Dept of Medicine, University of Colorado)

12:15pm-1:15pm **Lunch and Networking** 

From Bedside to Representative's Office, How Patient Stories and Parental Experiences 1:15pm-2:00pm

can Inform Health Policy (Kay Kelly)

<sup>\*</sup>Texas Children's Hospital is an approved provider with commendation of continuing nursing education by the Texas Nurses Association - Approver, an accredited approver with distinction, by the American Nurses Credentialing Center's Commission on Accreditation. Texas Children's Hospital provides up to 12.25 contact hours for successful completion of this educational activity

2:00pm-3:15pm

## **Learning Session Two – Consumer Advocacy:**

## Tales from the Trenches: Consumer Advocacy on the Journey

- Joel Lopez, Engagement and Outreach Manager, Genetic Alliance, The National Genetics Education and Family Support Center
- Allysa Seymour, Member, MSRGN New Mexico State Team, Pueblo of Laguna
- Susan Owens, Lead, Autism Oxalate Project, Autism Research Institute
- Heidi Wallis, Vice President, Association for Creatine Deficiencies
- Kristi Wees, MSRGN Consumer Engagement Director and Social Media Coordinator, moderator

3:15pm-3:30pm

#### **Afternoon Break**

3:30pm-5:30pm

#### **Learning Session Three-Access to Genetic Services**

- The UPP Project (Janet Thomas, MD, Professor, Dept of Pediatrics, University of Colorado, Section of Clinical Genetics and Metabolism)
- Cultural Competency and Access to Genetic Services for Special Populations (Mary Ann Coffman, Anita Lena)
- Accessing Genetic Services: Policy and Financial Considerations (Susanna Ginsburg)

5:30pm-6:30pm

# Reception

# Wednesday, October 3, 2018

Potential 6 hours CEU\*

7:00am-5:00pm **F** 

# **Registration and Information Desk**

7:00am-8:00am

## **Breakfast and Networking**

8:00am-12:15pm

#### **Learning Session Four- Clinical Topics**

- 8:00am-9:00am: Spinal Muscular Atrophy Newborn Screening. (Melissa Gibbons, MS,CGC; Erica Wright, MS, CGC, Dept of Pediatrics, University of Colorado, Section of Clinical Genetics and Metabolism)
- 9:00am-10:00am: Update on Hereditary Cancer Syndromes and Red Flags for Referrals (Michelle Springer, MS, CGC, Instructor, Certified Genetic Counselor, University of Colorado Cancer Center)
- 10:00am-10:15am Morning Break
- 10:15am-11:15am: Genetic Evaluation of Developmental Delay, Autism, and other Common Pediatric Complaints (Scott McLean, MD, Clinical Genetics, The Children's Hospital of San Antonio)
- 11:15am-12:15pm: Genetic Disorders in Native American/Alaska Native Children (Diana Hu, MD, Maternal Child Health Consultant, Navajo Area Indian Health Service)

12:30pm-3:30pm

#### **Working Lunch and Training Sessions**

- 1) Consumer Training Session: Serving on Groups
  - Kristi Wees, MSRGN Consumer Engagement Director and Social Media Coordinator
- 2) Telegenetics Training Session: How to put the "Tele" in Telegenetics (Janet Major, BS; Sylvia Mann)

<sup>\*</sup>Texas Children's Hospital is an approved provider with commendation of continuing nursing education by the Texas Nurses Association - Approver, an accredited approver with distinction, by the American Nurses Credentialing Center's Commission on Accreditation. Texas Children's Hospital provides up to 12.25 contact hours for successful completion of this educational activity