

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	Networking Sessions (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)

Tuesday, October 2, 2018Potential 6.25 hours CEU's

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

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

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

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

can Inform Health Policy (Kay (Milewski) Kelly)

^{*}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-3:45pm

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)

Potential 6 hours CEU*

Accessing Genetic Services: Policy and Financial Considerations (Sue Ginsburg)

5:30pm-6:30pm

Reception

Wednesday, October 3, 2018 7:00am-5:00pm 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: TBA

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)

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