



## 2009 Annual Meeting

Wednesday, July 15, 2009 & Thursday, July 16, 2009  
Denver Airport Marriott at Gateway Park  
Denver, CO

### Agenda

#### Tuesday, July 14, 2009

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|-----------------|--|
| 4:00pm – 5:00pm | MSGRCC Laboratory Quality Assurance Project – Review Panel Meeting |
| 5:00pm – 6:30pm | MSGRCC Laboratory Quality Assurance Project – Participant Meeting  |
| 6:00pm – 8:00pm | MSGRCC Advisory Council Meeting                                    |

#### Wednesday, July 15, 2009

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|-------------------|---|
| 8:00am – 9:00am   | Continental Breakfast for Full Group  |
| 9:00am – 9:30am   | Welcome & State of the Region<br><i>Celia Kaye, MD, PhD, MSGRCC PI</i>  |
| 9:30am – 10:45am  | Keynote Session on Ethics with Reaction Panel<br><i>Jeffrey R. Botkin, MD, MPH, Professor of Pediatrics and Medical Ethics, Associate Vice President for Research, University of Utah</i>   |
|                   | Reaction Panel:<br><i>R. Stephen Amato, MD, PhD, Medical Geneticist, Phoenix Genetics Program, St Joseph's Hospital and Medical Center, Phoenix, AZ</i><br><i>Vickie Thomson, PhD, Director, Newborn Screening Programs, Colorado Department of Public Health and Environment</i> |
| 10:45am – 11:00am | Break   |
| 11:00am – 12:00pm | Project Updates   |
| 12:00pm – 1:30pm  | Lunch with Parent Speaker<br><i>Brad Thompson, MA, LPC, Director, The Hali Project</i>  |

- 1:45pm – 3:15pm      National Activities
- Health Resources and Services Administration  
*Michele Puryear, MD, Chief, Genetic Services Branch, Maternal and Child Health Bureau*
  - Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC)  
*R. Rodney Howell, MD, FAAP, FACMG, ACHDNC Committee Chair, Professor of Pediatrics, Miller School of Medicine, University of Miami*
  - National Newborn Screening and Genetics Resource Center  
*Brad Therrell, PhD, Director, NNSGRC*
  - National Coordinating Center for the Genetics and Newborn Screening Regional Collaborative Groups  
*Michael S. Watson, PhD, FACMG, Project Director, National Coordinating Center, Executive Director, American College of Medical Genetics*
  - Centers for Disease Control and Prevention  
*Cynthia F. Hinton, PhD, MS, MPH, Health Scientist, Pediatric Genetics Team*
- 3:30pm – 5:00pm      Project Updates, continued
- 5:00pm – 5:30pm      Informal Networking and Poster Session
- 5:30pm – 7:00pm      Dinner Presentation  
Rick Guidotti, Founder, Positive Exposure
- 7:30pm – 9:30pm      Emergency Preparedness Workgroup Meeting  
Co-Chairs: Donna Williams & Lynette Borgfeld

## Thursday, July 16, 2009

|                  |   |
|------------------|---|
| 7:30am – 8:00am  | Continental Breakfast   |
| 8:00am – 12:00pm | Concurrent Workgroup Meetings<br>Newborn Screening Workgroup<br>Co-Chairs: Jeffrey R. Botkin, MD, MPH & Susan Tanksley, PhD<br>Telemedicine Workgroup<br>Chair: TBD |
| 12:00pm – 1:00pm | Lunch and Workgroup Report  |
| 1:00pm           | Adjourn   |
| 1:00pm – 4:00pm  | Consumer Advocacy Workgroup Meeting<br>Co-Chairs: Joe Martinec and Rod Slaght   |
| 1:00pm           | **Begin MSGF Meeting  |
| 1:15pm – 4:00pm  | Hemoglobinopathies Newborn Screening and Follow-up Meeting<br>Project Lead: Kathryn Hassell, MD<br>Find more information <a href="#">here!</a>                      |

\*\*Immediately following the close of the MSGRCC Annual Meeting, the Mountain States Genetics Foundation will kick-off the annual Education Meeting. For more information on this, please visit [www.mostgene.org](http://www.mostgene.org).