

## Heartland Genetics and Newborn Screening Collaborative

Annual Conference  
September 16-18, 2009  
The Peabody Little Rock  
Little Rock, Arkansas

### Agenda

#### WEDNESDAY, September 16

Time	Session	Location
1:00 - 4:30 pm	Telegenetics Workshop (pre-registration required)	UAMS Campus
4:00 - 5:00 pm	Evaluator interviews with State Genetics Coordinators: GSA project (Jackson)	Parlor #1
4:00 - 8:00 pm	Registration Open	Conference Center (Level 3)
5:00 - 8:30 pm	Advisory Board meeting	Chicot Room (Level 2)

#### THURSDAY, September 17

7:00 am	Registration Open Vendor and Poster set-up (Arkansas Ballroom)	Conference Center (Level 3)
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#### Plenary Session

Time	Topic	Speakers	Location
8:00	Welcome Remarks	Paul Halverson, DrPH John Mulvihill, MD	Conway Lecture Hall (Level 2)
8:20	The State of Clinical Genetics in Arkansas 2009 Evolution of the UAMS Genetic Counseling Program	Brad Schaefer, MD Bruce Haas, MS, CGC	Conway Lecture Hall (Level 2)
9:00	Heartland Back-up Testing Project and Newborn Screening Harmonization Activities	Patrick Hopkins, BS Stan Berberich, PhD Julie Miller, BS	Conway Lecture Hall (Level 2)
10:00	Newborn Screening: “What Providers Need to Know” and “Parents’ Attitudes and Knowledge About Blood Storage”	Sharmini Rogers, MBBS, MPH	Conway Lecture Hall (Level 2)
10:30	<b>Break</b>		Arkansas Ballroom (Level 3)
10:45	Birth Defect Surveillance Programs: Research and Primary Prevention	Charlotte Hobbs, MD PhD	Conway Lecture Hall (Level 2)
11:15	Newborn Screening: Update on National Priorities and Perspectives	Amy Brower, PhD	Conway Lecture Hall (Level 2)

12:30	<b>Lunch</b>		Riverview Room (Level 1)
<b>Roundtable Discussions (select 2)</b>			
1:30	<ul style="list-style-type: none"> <li>• Genetic counselor Licensure</li> <li>• Birth defects registries</li> <li>• Transition for youth to adult care</li> <li>• Ethical decision-making around genomic discoveries</li> <li>• Usher syndrome and hearing loss</li> </ul>	Williamson & Stein Hobbs Vogel & Coffman Sandra Daack-Hirsch  Burk	Riverview Room (Level 1)
3:00	<b>Break</b>		Arkansas Ballroom (Level 3)
<b>Breakout Sessions</b>			
	Poster Session (authors stand by posters for 30 minutes until 3:30 pm)		Arkansas Ballroom (Level 3)
3:30	Advocate Work Group Meeting		Grampas Room (Level 2)
	Ad Hoc Work Group: Genetics Education for Nurses Project (Coffman)		Ouachita Room (Level 1)
	Other ad hoc work group meetings		Chicot Room (Level 2)
4:45	<b>Adjourn</b>		
5:00	Peabody Ducks		Main Lobby
<b>Social Event and Dinner</b>			
6:30	William J. Clinton Presidential Center (Dinner and Tour)		Clinton Presidential Center (Map included)
<b>FRIDAY, September 18</b>			
<b>Plenary Session</b>			
<b>Time</b>	<b>Topic</b>	<b>Speaker</b>	<b>Location</b>
8:15	RCC Annual Report <ul style="list-style-type: none"> <li>• HRCC Report</li> <li>• GSA update</li> <li>• Heartland Evaluation: Successes and Challenges</li> </ul>	Lori Williamson, MS Ann Chou, PhD, MPH Barbara Jackson, PhD	Conway Lecture Hall (Level 2)
9:15	HRSA Update	Jill Shuger, MS	Conway Lecture Hall (Level 2)
9:45	The Regional Genetics Collaboratives: Looking Back Over Last Year's Outcomes and Activities	Gloria Weissman, MA	Conway Lecture Hall (Level 2)
10:15	<b>Break</b>		Arkansas Ballroom (Level 3)

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		Clinical Services	Chicot Room (Level 2)
		Education	Grampas Room (Level 2)
10:30	Work Group meetings	Newborn Screening	Ouchita Room (Level 1)
		Early Hearing Detection and Intervention	Neosho Room (Level 1)
12:30	<b><i>Lunch</i></b>		Riverview Room (Level 1)
12:30	Advocate Lunch Meeting		Neosho Room (Level 1)
	Wrap up session		
	<ul style="list-style-type: none"> <li>• Pilot Projects RFA</li> <li>• Sarah Lawrence Scholarship</li> <li>• Collaborative Research</li> <li>• Publishing</li> <li>• What have we learned, and where do we go from here?</li> </ul>		
2:00		John Mulvihill, MD	Conway Lecture Hall (Level 2)
3:00	<b><i>Adjourn</i></b>		
3:00-5:00 pm	Tour of UAMS Campus (optional) (pre-registration required)		