



Region 4 Genetics Collaborative

REGIONAL MEETING 2008 SEPTEMBER 15 - 17

James B. Henry Center

Lansing, Michigan

Agenda

Monday, September 15, 2008

4:00 – 8:00pm Parent & Family Member Meeting - B108/110

Invited Guest: Renee M. Turchi, MD, MPH, Director, PA Medical Home Program (EPIC IC), Center for Children with Special Health Care Needs- St. Christopher's Hospital for Children, Assistant Professor, Drexel University School of Public Health

Supported by the American Academy of Pediatrics Visiting Professorship Award

6:00 – 8:00pm Welcome Dinner & Registration - Shubui Greenhouse
Dinner and Cash Bar



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Tuesday, September 16, 2008

8:00 – 9:00am **Registration & Breakfast** – Lobby & Atrium

9:00 – 9:45am **Opening Remarks** - Amphitheater A169

[State of the Region](#) - *Cynthia Cameron, Ph.D., Director, Region 4 Genetics Collaborative*

[Regional Genetics and Newborn Screening Collaborative: An Overview](#) – *Jill F. Shuger, MS, Project Officer for Regional Collaboratives*

[Activities of the National Coordinating Center for the Genetics and Newborn Screening Regional Collaborative Groups](#) – *Judith Benkendorf, MS, CGC, Project Manager for the Regional Collaboratives, ACMG*

[NCC Fact Sheet](#)

9:45 – 12:00pm **Exploring Regional Opportunities to Support State and National Initiatives** – Amphitheater A169
Break 10:30 – 10:50

[The Illinois Emergency Department Pain Management Collaborative: Improving Emergency Department Pain Management for Adults with Sickle Cell Disease](#)

Paula Tanabe, Research Assistant Professor, Feinberg School of Medicine

[Chronic Disease and Family Functioning: Fatty Acid Oxidation Disorders](#)

Darin J. Erickson, Ph.D., Assistant Professor, University of Minnesota

[Assessing Access to Genetic Services in Michigan](#)

Joan Ehrhardt, MS, CGC, Birth Defects Program Coordinator, MDCH

[Michigan Endocrine Screening Evaluations: State, Regional and National Opportunities for Continued Research](#)

Steven J. Korzeniewski, MA, MSc, Section Manager

William I. Young, Ph.D., Program Manager

[Two Collaborative Clinical Trials for IEMs: The UCD Rare Disease Consortium and CoQ-10 for Mitochondrial Disease](#)

Shawn McCandless, MD, Assistant Professor of Genetics and Pediatrics

Director for Genetic Residency Program

Acting Director Center for Human Genetics

- (Continued)
- [Initiatives and Research Update on the congenital Adrenal Hyperplasia and Disorders of Sex Development Endocrine Workgroup](#)
Kyriakie Sarafoglou, MD, Director, Leo Fung Center for CAH and Disorders of Sex Development
- [Midwest Emergency Medical Services for Children Information System \(MEMSCIS\): An integrated approach to emergency care planning for patients with heritable conditions](#)
Kristi Bentler, MS, RN, PHN, CPNP
- 12:00 – 1:00pm **Lunch** - Atrium
- 1:00 – 2:00pm **Regional Opportunities to Support State and National Initiatives Discussion Breakout Groups**
 Presenters will be leading discussion groups on the morning presentations. Participants are welcome to select which group they would like to attend.
- Pain Management for Sickle Cell Disease - Board Room A155
- Chronic Disease and Family Functioning - B106
- Assessing Access to Genetic Services – A122/124
- Michigan Endocrine Screening Evaluations - A135/136
- Two Collaborative Clinical Trials for IEMs - B108/110
- Initiatives and Research on CAH and DSDs – B113/121
- MEMSCIS: Emergency Care Planning – B120
- 2:00 – 2:20pm **Break**
- 2:20 – 5:00pm **Priority 1 Workgroup Meeting** – Amphitheater A170
- 2:20 – 5:00pm **Communication Among Primary Care Physicians, Specialists and Families** – Amphitheater A169
Renee M. Turchi, MD, MPH, Director, PA Medical Home Program (EPIC IC), Center for Children with Special Health Care Needs-St. Christopher's Hospital for Children, Assistant Professor, Drexel University School of Public Health
- Supported by the American Academy of Pediatrics Visiting Professorship Award
- 3:15 – 4:30pm **Region 4 State Leads Meeting** – B183
- 5:30pm **Region 4 Advisory Board Dinner** – Fireplace Room
 Dinner and Cash Bar



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Wednesday, September 17, 2008

.8:00 – 9:00am **Breakfast** – Atrium

.8:00 – 8:45am **IBEM-IS Training** – Amphitheater A170
.Optional session for anyone interested

.9:00 – 12:00pm **Region 4 Activities Reports** – Amphitheater A169
.Break 10:30 – 10:50

[Region 4 Endocrine Project: Final Summary](#)

*Charles Mundt, MA, Outreach Specialist,
MSU Institute for Healthcare Studies*

[Family is the Center of the Medical Home](#)

(Medical Home Education Workgroup)

*Nancy Deising, BS Care Coordination Specialist, Michigan Department of
Community Health*

*Jane Turner, MD Professor, Department of Pediatrics and Human
Development, College of Human Medicine, Michigan State University*

[Early Hearing Detection & Intervention \(EHDI\) Follow-up Workgroup](#)

Gary Hoffman, Manager, Wisconsin Newborn Screening Lab

[Long-term follow-up after NBS: the Inborn Errors of Metabolism
Information System \(IBEM-IS\)](#)

*Susan A. Berry, MD, Professor and Director,
Division of Genetics and Metabolism*

[Care Coordination Workgroup Update](#)

Jennifer Arveson, Parent Advisor

Kathleen Wood, RN, BSN Nurse Coordinator

[Progress report of Priority 1 project: laboratory quality improvement of
newborn screening by MS/MS](#)

Piero Rinaldo MD, PhD, Professor, Mayo Clinic College of Medicine

.12:00 – 1:00pm Lunch – Atrium

.1:00 – 3:00pm

Workgroup Breakout Meetings

.Endocrine Workgroup – B113/121

.Priority 2 Workgroup – Amphitheater A169

.EHDI Workgroup – B108/110

.Medical Home Education Workgroup – B122/124

.Care Coordination Workgroup – A135

.Genetic Expertise Workgroup – Board Room A155

.Priority 1 Workgroup – Amphitheater A170

.3:00pm

Adjourn