



**Agenda**

Friday, June 13<sup>th</sup> 2008  
11:00 – 12:30pm Central  
12:00 – 1:30pm Eastern

1. Role Call & Introductions - Abby
2. Parent Co-Lead position - Barbara
3. Review of Previous Meetings - Abby
  - a. WG Charge and Year One Plan
  - b. Group Focus: Parent Education Materials
  - c. Rated and Revised List of Materials
  - d. Defined Medical Home & General Educational Objectives
  - e. Revisions to Family Guide to Michigan's Children's Special Health Care Services Program
4. Region 4 Family Guide Draft #1 Overview - Jane
5. Adapting medical home materials to address the needs of children with heritable disorders in Region 4 (See **Education Plan**)
  - a. Resources currently available on the Region 4 Website
    - i. Specialist maps
    - ii. ACT sheets (NBS disorder specific information)
    - iii. Links to NBS programs in Region 4 states
    - iv. State specific parent support resources
  - b. What information specific to genetics do parents want?
  - c. What information specific to Region 4 do parents want?
6. Year 2 Conference call schedule
7. Regional meeting

**Materials**

Region 4 Family Guide Draft #1  
Education Plan



## Medical Home Education Work plan

Goal: Educate primary care providers, specialists, and families about the importance of providing a medical home for children with heritable disorders.



<b>A. Year One Goal: Identify, review and select existing initiatives and materials to educate Region 4 families and providers</b>			
<b>Objective</b>	<b>Who</b>	<b>What</b>	<b>When</b>
<b>1. Identify existing training initiatives and materials</b>	<b>MPHI</b>	<b>Conduct Internet research</b>	<b>December 2007</b>
	<b>Group</b>	<b>Provide input re: state initiatives</b>	
	<b>Group</b>	<b>Provide existing State materials</b>	<b>January 2008</b>
	<b>MPHI</b>	<b>Compile and distribute list of materials/initiatives</b>	
<b>2. Develop criteria for assessing materials (quality, cost, feasibility, adaptability)</b>	<b>Group</b>	<b>Discuss existing materials</b>	<b>February 2008</b>
	<b>Co-chairs/MPHI</b>	<b>Research assessment tools</b>	
	<b>Group</b>	<b>Brainstorm assessment criteria</b>	
	<b>Co-chairs/MPHI</b>	<b>Develop/modify assessment tool</b>	
<b>3. Review training initiatives/materials based on established criteria</b>	<b>Group</b>	<b>Review and finalize assessment tool</b>	<b>March 2008</b>
	<b>Co-chairs/MPHI</b>	<b>Assess materials using assessment tool</b>	
	<b>Group</b>	<b>Compile/summarize reviews</b>	
<b>4. Identify the best methods to disseminate information (on-line course, face-to-face training, individual consultation, etc.)</b>	<b>Group</b>	<b>Refine list of materials and training initiatives</b>	<b>April 2008</b>
	<b>Co-chairs/MPHI</b>	<b>Literature review (training and dissemination)</b>	
	<b>Group</b>	<b>Review literature summary</b>	
	<b>Group</b>	<b>Determine best methods for each target group</b>	
<b>5. Develop Region 4 education plan</b>	<b>Co-chairs/MPHI</b>	<b>Summarize group recommendations</b>	<b>May 2008</b>
	<b>Group</b>	<b>Draft education plan</b>	
	<b>Group/co-chairs</b>	<b>Provide input on education plan</b>	
<b>B. Adapt medical home materials to address the needs of children with heritable disorders in Region 4</b>	<b>Group/co-chairs</b>	<b>Adopt finalized education plan</b>	<b>Year 2</b>
	<b>Group</b>	<b>Provide input on education plan</b>	
	<b>Group/co-chairs</b>	<b>Adopt finalized education plan</b>	
<b>C. Share adapted materials with region 4 partners, other regions, and national audiences</b>			<b>June 2008</b>
<b>D. Provide educational opportunities in Region 4</b>			
<b>B. Adapt medical home materials to address the needs of children with heritable disorders in Region 4</b>			<b>Years 2-5</b>
<b>C. Share adapted materials with region 4 partners, other regions, and national audiences</b>			
<b>D. Provide educational opportunities in Region 4</b>			