



**Agenda**

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

1. Roll Call/Introductions
2. Review of Previous Meetings
  - a. WG Charge and Year One Plan
  - b. Group Focus: Parent Education Materials
  - c. Revised List of Materials (Handout 1)
    - i. Brochures (Handout 2)
    - ii. Comprehensive resources
  - d. Educational Objectives

**Objective 1: Medical Home**

*What is a medical home?  
What are the benefits of a medical home?  
What can I expect from a medical home?*

**Objective 2: Working with physicians**

*What is a parent/professional partnership?  
What is my role as a parent?  
How do I communicate effectively with my physician?*

**Objective 3: Care coordination**

*What is care coordination?  
What is a care coordination plan?*

**Objective 4: Parent support resources**

**Objective 5: Reproducible forms, tools, checklists (record keeping, etc.)**

3. Comprehensive Resources and Educational Objectives (Handout 3)

*How well does each resource meet our educational objectives?*

4. Parent Meeting May 19<sup>th</sup> and 20<sup>th</sup>
  - a. Update and Reminder
  - b. Questions
5. Regional Meeting September 16<sup>th</sup> and 17<sup>th</sup>
  - a. Update and Reminder
  - b. Questions

6. Next Steps

**Materials:**

**Agenda and Work plan**  
**Revised List of Parent Materials (Handout 1)**  
**State Specific Brochures (Handout 2)**  
**Comprehensive Resources (Handout 3)**

## 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.



### A. Year One Goal: Identify, review and select existing initiatives and materials to educate Region 4 families and providers

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