



## **Medical Home Education Workgroup**

To participate, please call:  
**1/866-489-0573** (toll free)  
At the prompt, enter  
**\*4545164\***

### **Agenda**

Friday, February 8<sup>th</sup> 2008

11:00 – 12:30pm Central

12:00 – 1:30pm Eastern

1. Roll Call/Introductions

Website intro – Region 4 website is currently under construction but Medical Home Education Group section can be viewed at:

[http://dev.mihealth.org/r4genetics/region4/medical\\_home\\_education.aspx](http://dev.mihealth.org/r4genetics/region4/medical_home_education.aspx)

2. Review of Previous Meetings

- a. Region 4 Overview
- b. WG Charge and Year One Plan
- c. State Medical Home Activities
- d. Group Focus: Parent Education Materials

3. Parent Education Materials (Handout 1) - What did you like/what didn't you like?

4. Review Criteria (Handout 2)

- a. Quality – Is the information accurate, and trustworthy?
- b. Usability – Is the information accessible and easy to understand?
- c. Content – Are the right topics covered? Is the information helpful and important to parents?
  - i. What do parents want to know?
  - ii. What information do parents need?
  - iii. What information do parents find helpful?

5. Visiting Professorship

6. Next Steps

**Materials:**

**Agenda and Work plan**

**Updated Parent Materials Index (Handout 1)**

**Parent Education Materials Rating Tool (Handout 2)**





## 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>Group</b>	<b>Discuss existing materials</b>	
<b>2. Develop criteria for assessing materials (quality, cost, feasibility, adaptability)</b>	<b>Co-chairs/MPHI</b>	<b>Research assessment tools</b>	<b>February 2008</b>
	<b>Group</b>	<b>Brainstorm assessment criteria</b>	
	<b>Co-chairs/MPHI</b>	<b>Develop/modify assessment tool</b>	<b>March 2008</b>
	<b>Group</b>	<b>Review and finalize assessment tool</b>	
<b>3. Review training initiatives/materials based on established criteria</b>	<b>Group</b>	<b>Assess materials using assessment tool</b>	<b>April 2008</b>
	<b>Co-chairs/MPHI</b>	<b>Compile/summarize reviews</b>	
	<b>Group</b>	<b>Refine list of materials and training initiatives</b>	
<b>4. Identify the best methods to disseminate information (on-line course, face-to-face training, individual consultation, etc.)</b>	<b>Co-chairs/MPHI</b>	<b>Literature review (training and dissemination)</b>	<b>May 2008</b>
	<b>Group</b>	<b>Review literature summary</b>	
	<b>Group</b>	<b>Determine best methods for each target group</b>	
	<b>Co-chairs/MPHI</b>	<b>Summarize group recommendations</b>	
<b>5. Develop Region 4 education plan</b>	<b>Co-chairs/MPHI</b>	<b>Draft education plan including materials/methods</b>	<b>June 2008</b>
	<b>Group</b>	<b>Provide input on education plan</b>	
	<b>Group/co-chairs</b>	<b>Adopt finalized education plan</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>			

## Handout 1: Medical Home Education (Target Group: Families)

Title	Format	Developer(s)
A Family-Professional Partnership Choosing a Pediatrician Helping Children with Special Healthcare Needs What Should Medical Facilities Look Like?	 Medical Home Series in Exceptional Parent	Exceptional Parent magazine 2000 Exceptional Parent magazine 2000 Exceptional Parent magazine 2000 Exceptional Parent magazine 2000
Medical Home Series 2007 (Articles 1-4)	<a href="#">Medical Home Series</a> * scroll down to find 1-3.	Exceptional Parent magazine 2007
A Guide for Parent and Practice "Partners" Working to Build Medical Homes for CSHCN.	<a href="#">Booklet</a>	Center for Medical Home Improvement.
A NEW WAY...A BETTER WAY. The Medical Home Partnership: Building a Home Base for Your Child with Special Health Care Needs	<a href="#">Brochure</a>	New England SERVE for families in Massachusetts
Family Brochure: Every Child Deserves a Medical Home	<a href="#">Brochure</a>	The Illinois Title V CSHCN program, the Division of Specialized Care for Children
Medical Home: Families and Providers Working Together	<a href="#">Brochure</a>	Washington State
What is a Medical Home: How Can it Help Your Child with Special Needs	<a href="#">Brochure</a>	South Carolina Medical Home Team
A Medical Home: Consistent, Knowledgeable, and Comforting Health Care	<a href="#">Fact Sheet</a>	Family Voices
I want my Medical Home: A parent perspective on what a Medical Home means to families.	<a href="#">Presentation</a>	Center for Medical Home Improvement
Making Health Care Work For You: Medical Home 101	<a href="#">Presentation</a>	AAP
Family Survey of Medical Home Outcomes	<a href="#">Survey</a>	Center for Medical Home Improvement
Texas Medical Home Toolkit for Families	<a href="#">Toolkit</a>  <a href="#">PDF or Word</a>	Texas Parent to Parent, the Texas Medical Home WG and Texas Dept. of State Health Services – CSHCN
AAP Pediatrician Referral Service	<a href="#">Web-based</a>	AAP
Primer on the Illinois Medical Home Model for Families	<a href="#">Website</a>	The Illinois Title V CSHCN
<b>Medical Home Local Capacity Grants Summary of Grants Funded for 2008</b>	 Medical Home Local Capacity Grants.doc	Wisconsin Region Centers Children and Youth with Special Health Care Needs
<b>Medical Home: A Guide for Minnesota Parents</b>	 Brochure-MH4.pdf  Brochure	Minnesota Dept. of Health
<b>Working with Doctors: A Parent's guide to navigating the health system.</b>	Hard Copy Book	Minnesota Dept. of Health /PACER Center.
<b>Special Connections Newsletter</b>	 mdhmspec05f1.pdf  Newsletter	Minnesota Medical Home Coll/Dept of Health

## Parent Education Materials Rating Tool (Handout 2)

Title:

Date of Publication:

Type of Resource: Brochure

Developed by:

Source: Parent Advocacy Group

Criteria	Questions	Score				
		Low	Mid		Hi	
<b>Quality</b>	<b>Is the information accurate, and trustworthy?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Expertise	Does the author or group have experience and/or expertise?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accuracy/Consistency	Does the info correspond with what other materials you have read? Is it correct?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sponsor/ funder	Is there an obvious bias or financial interest?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Source	Are citations or sources listed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Date	Are materials more than a few years old?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Usability</b>	<b>Is the information accessible and easy to understand and?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Reading Level	Is the reading level around 5 <sup>th</sup> grade?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Format	Is information easy to find? (Question and answer is an example of a good format)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Key Ideas	Are there too many key ideas covered? (More than a few is generally too many)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language	Are common words used? Too much jargon?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Length of sentences and paragraphs	Are sentences too long? Do paragraphs cover too many points?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Practical examples	Are relevant examples used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organization	Is the information presented logically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use of graphics	Are graphics helpful and/or attractive?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use of white space	Is the design too cluttered?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Print size/readability	Is text size, color, font easy to read?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emphasis	Are the key points clear? Do they jump out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parent involvement	Did parents review materials?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Translations	Is the material available in other languages?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Usability (Websites)</b>	<b>Additional questions for websites</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
Easy to find	Were you able to find the website or webpage?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clean and uncluttered	Was the overall design cluttered or confusing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easy to use	Was the page easy to navigate?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Site is up to date	Links work and info is updated regularly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Content</b>	<b>Are the right topics covered? Are the topics important to parents?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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## Reviewing Materials - Research

### QUALITY PRESENTATION TOOLBOX [http://geneticalliance.org/ws\\_display.asp?filter=index](http://geneticalliance.org/ws_display.asp?filter=index)

Three tools have been developed as part of the Access To Credible Genetics (ATCG) Resource Network to help families and health professionals assess the quality of currently available educational materials about rare, single-gene disorders. These tools will also help individuals and groups to create quality materials for their own purposes. The tools are listed below with the overarching questions they are designed to address. Click on each of the tools to view them and learn more about how to use them.

1. **Content Scale**: Is the information complete or are there topics not covered?
  2. **Quality Scale**: Is the information right?
  3. **Usability Scale**: Is the information presented in a way that is understandable and accessible?
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### **Usability - Written Materials (*Fact Sheet: Strategies to Improve Patient Education Materials (Center for Health Care Strategies, Inc.)*)**

#### **Tips and Suggestions for Improving Materials:**

- Pictures, diagrams, and videotapes help communicate information to patients, especially those with low literacy skills.
  - Most people, even those who read well, rely on visual clues to reinforce learning.
  - Oral and visual tools help patients absorb new information, which increases learning.
  - Videotaped patient education materials increase knowledge, encourage positive attitudes, and change behavior
  - Most written health care materials are too difficult to read for nearly half the population (should be about fifth grade level)
  - Use clear captions, ample “white space,” and pictures or diagrams to attract the reader’s attention and reinforce the message.
  - Use common words. For example, they replace “chemotherapeutic agent” with “a drug that fights cancer.”
  - Materials should be prepared in cooperation with the intended audience.
  - Materials should be limited to one or two educational objectives. What the reader will learn and do after reading the information.
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### **Website Usability (*Five Guidelines for Developing Customer Friendly Websites (Prepared by Covering Kids & Families November 2006)*)**

#### **A good website will have these features:**

- Clients can find all program information easily and in one place.
- New information is easy to insert and highly visible
- Forms can be completed on-line
- Provider directories and other moving targets are always current
- Visitor finds out about other services they may qualify for and find links

#### **Five guidelines for developing customer-friendly websites:**

1. Make your site easy to find
2. Create a clean and uncluttered design
3. Write for your clients
4. Provide clear pathways for user tasks
5. Conduct usability testing throughout development