

**Care Coordination Workgroup Meeting ~ Notes**  
**April 26, 2011 ~ 11:00am CT / 12:00 pm ET**

**Co-Leads:** Kathy Wood (IN)

**Facilitators:** Sally Hiner and Liz Ritchie, Region 4 Genetics Collaborative

**Participating:** Cheresse Pullum (IN), Sandy LaPrad (MI), Mary Navara (MN)

**Meeting Goal:** Begin finalizing content for Guide to Care Notebook.

Item	Discussion/Notes	Recommendation/ Action	Follow up (who/when)
I. Welcome and Introductions – Wood			
II. Workgroup Product A: Guide to Care Notebooks – Wood/Group			
General Comments	Although not participating today, David Hoffman (OH) provided feedback prior to the meeting. 'David asked if language in the guide should be broadened to be more inclusive of all special healthcare needs rather than only heritable disorders? Kathy noted developing a care notebook for elder care also could be helpful. The Guide could be useful in developing care notebooks for a broader population.	Consensus - Add language in the introduction regarding the potential expansion of the guide.	Liz, Sally – 5/10/11
Introduction	Kathy Wood (IN) drew the group's attention to information still needed at the bottom of page 1.	Group members are to forward suggestions to Sally and Liz. Liz/Sally revise	WG – 5/10/11 Liz, Sally – 5/16/11
Care Plan Cover Page	No information added or amended.	NA	NA
Emergency Info	Sandy LaPrad (MI) suggested adding the word "secure" when referencing MyEIF.org. Under "Tips for Parents", first bullet, "If your child has <u>no</u> known allergies...". Under the sixth bullet: "If your child is on a special formula (or a difficult to obtain med <u>or</u> equipment)..."	Consensus - Incorporate Sandy's recommendations.	Liz – 5/10/11
Insurance Info	The group discussed how to get guide readers to the proper website locations. Perhaps adding direct URLs? Add all the documents to the Region 4 Genetics website? Add search terms? Under "Tips from Parents", Kathy Wood (IN) suggested combining bullets 2 and 3.	Consensus – Add direct URLs. Under "Tips", combine bullets 2 and 3.	Liz – 5/10/11
Health History	Group members could not open the author's attachment for this section.	Revisit this section at the next meeting.	Sandy – forward to Sally for distribution 5/6/11
Care Team List	No information added or amended.	NA	NA

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Health Tracking	This section is not available yet.	R4 staff obtain and forward to workgroup for review and comment	Sally 05/06/11
Education Info	Parents might be most helpful to edit/review this section. Testing summary information and Individualized Education Plan IEP are great to have included here. Group members wondered if information regarding riding the bus should be included.	Consensus - Add information regarding riding the bus.	Liz 05/10/2011
Transitions & Goals	The group discussed putting direct URLs in this section, especially to Children's Special Health Care Services information. The group discussed including information regarding school planning for youth transition. This section does not address youth who work. There are many resources available. Kathy Wood (IN) also stated that guardianship and legal issues should be addressed here.	Consensus - include URLs, school planning for youth transition, guardianship, and legal issues.  Send resources for working with CYSHCN to Sally and Liz for inclusion in the guide.	Liz, Sally  Mary/All
Expense Tracking	No information added or amended.	NA	NA
III. Next Steps – Wood			
Guide to Care Notebook	Continue gathering comments from group members, particularly on sections not yet received (Health Tracking) or unable to open (Health History).	Members submit comments to Liz and Sally for possible inclusion in the guide.	All
IV. Next Meeting: May 24, 2011 – 12:00pm EST			
V. Adjourn			