



Region 4 Priority 2 Workgroup
Telemeeting Notes - Friday, April 17th, 2009

Participating: Carolyn Anderson, Co-Lead; Kristi Bentler, MN; Barbara Burton, Barb DeLuka, IL; Stephanie Gurnon, Kathy Wood, IN; Jan Askren, Troi Cunningham, KY; Jerry Feldman, MI; Nancy, Leslie, OH; Sally Hiner, Region 4 Genetics Collaborative Coordinator.

I. IBEM-IS Participation Updates:

- Anyone desiring IRB assistance should contact Sally (shiner@mphi.org)

State/Lead	Center	Status
IL/Burton	Children's Memorial Hospital	50 consented
	University of IL	Barbara contacted George Hoganson. He has new staff starting this July and plans on getting on board.
	Rush University Medical Center	No change
IN/Hainline	Riley Hospital for Children	No change – consented 30,
KY/Gowans	University of KY	No Report
	University of Louisville (Askren)	Getting closer to completing application. No change
MI/Feldman	Wayne State	Consenting and enrolling; getting ready to renew IRB
	University of MI	No change
MN/Berry	University of MN	Enrolled 3-4 since last call
	Mayo	No change
OH/ Leslie	Cincinnati Children's Hospital	Consenting
	Case Western Reserve	No change
	Nationwide Children's, Columbus	No change
	Akron	No change
	Dayton	No change
WI/Rhead	Waisman Center – WI center #2	No Report
	Medical Center of WI – WI center #1	No Report
NE/Skrabel	Nebraska	Working on application
IA/Copeland	University of Iowa	No report

Item	Discussion	Next steps	Responsible person(s)
II National and Cross-Regional Collaboration			
A NIH Challenge Grant – FAOD TRN	Region 4 is partnering with 3 sites outside of Region 4 in application for an NIH Challenge grant. If funded, the grant will expand the use of the IBEM-IS for FAODs by involving sites beyond Region 4 in enrollment and data access for research. Jodi Griffin, MPHI, is communicating with our clinical state leads on proposal development and forms submission.	Forms must be submitted to Jodi Griffin by 4/17/09 Direct questions and issues to Jodi Griffin, jgriffin@mphi.org ; 517/381-8247	Participating clinicians
III IBEM-IS Update			
A New surveys available	New enrollment surveys for the following disorders have been added to the IBEM-IS: 2M3HBA Biotinidase Deficiency 3-MCC Glutaric Acidemia, Type 1 3-MGA HCS Deficiency BKT Deficiency HMG CoA Lyase	Provide PDF documents for posting to website Post surveys to website	Kristi Sally
B Status of Survey Entry	Cases entered through the month of March include MCAD - 65 MSUD - 9 TFP - 2 SCAD - 3 LCHAD - 1 IBD - 1 VLCAD - 6	Continue reporting	Participating clinicians
C Adding Disorders			
1 Next disorder for group review (May)	Tyrosinemia	Provide data elements prior to May meeting	Kristi/ Carolyn
2 Disorders under consideration for addition	Kristi and Carolyn are working on the surveys for the following disorders: Interval surveys for : Enrollment and Interval surveys for: 2M3HBA Transcobalamin II BKT Cobalamin C, F SCOT Methylmalonic Acidemia Cobalamin A,B,C 3-ketothiolase deficiency, Propionic acidemia	Prepare update for May meeting	Kristi/ Carolyn

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III Research questions			
A Family Functioning Discussion Groups	Discussion groups are scheduled to occur at all 7 Region 4 State Stakeholder meetings. A mindmapping process is being implemented that asks participants to respond to the issue: "The impact of having a child with a genetic condition on family functioning". Data will be analyzed and provided to Darin Erickson to assist him in developing his next steps.	Prepare update for May meeting	Sally
IV Next Meeting			
A Conflict with MN Stakeholder Mtg	Attempts made to get input on rescheduling the May meeting have met with low response rate. Sally will inquire one last time, then set the date.	Re- Poll group on availability	Sally
		Advise of availability	Workgroup members
		Set date	Sally
		Notify group	Sally

Notes by Hiner