

<b>Goal: To improve health outcomes of children with metabolic disorders</b>						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
<b>Objective 1: Refine research and intellectual questions that can be explored employing the data in the disease registry</b>						
Implement a process to collaborate on research issues	<b>PI, state leads</b>	<b>Establish continued consistent participation and support in planning from Region 4 state leads and WG in registry project</b>	Y1-5	List of members, meeting notes <b>Y1 &amp; Qtrs 1-3 of Y2</b>	Increase research opportunities for IBEM	Number of research questions defined
	<b>PI, state leads, metabolic centers</b>	<b>Obtain IRB approval from participating centers to enter cases in to the registry</b>	Y1-2	List of center with IRB approval – <b>9 IRB approvals received; 4 centers with IRB reviews in progress</b>	Increase knowledge about the natural history and outcomes for rare disorders	Number of proposals reviewed
	<b>MPHI</b>	<b>Schedule monthly telemeetings &amp; bi-annual meetings</b>	Y1-5	Schedule published on Region 4 website – <b>Y1&amp;Y2 telemeetings scheduled and posted</b>	Improve treatment for children with MCADD	Number of proposals supported
	<b>Workgroup</b>	<b>Set meeting agendas</b>	Monthly Y1-5	Agendas & materials posted on web-site <b>Y1&amp; Qtrs 1-3 of Y2</b>	Improve health outcomes for children with MCADD	Number of metabolic specialists indicating they change practice because of research findings
	<b>Workgroup, MPHI</b>	<b>Prepare meeting materials</b>	Monthly Y 1-5			
	<b>Workgroup</b>	<b>Discuss and resolve any operational issues</b>	As Needed Y1-5	<b>List of operational issues discussed – process guidelines documented</b>		
		<b>Define initial research questions to be studied with MCADD enrollment data</b>	Y1	<b>List of research questions- process for review and type of proposals determined</b>		
		<b>Develop process for requesting, obtaining, reviewing and approving research proposals/requests for IN data</b>	Y1-2	Written process – <b>process development in progress</b>		
		<b>Review proposals for merit – process set up, review initiated.</b>	Y1-5	List of proposals reviewed		
		<b>Provide supporting documentation for researchers seeking funding – process developed and implemented</b>	Y2-5	List of proposals supported –		

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	<b>Who</b>	<b>What</b>	<b>When</b>						
			<b>for review and support of new research proposals</b>						
	Researchers		Complete research studies	Y6-?			Written reports		
		Publish findings	Y6-?	Published reports					
<b>Objective 2: Expand the scope of Inborn Errors of Metabolism Registry</b>									
Add additional metabolic conditions to the registry	<b>Workgroup</b>	<b>Select specific disorders to include in the registry</b>	Y1, qtr 1	<b>List of disorders – 24 disorders selected so far</b> <b>Y1- Q1-3, Y2</b>	Increase capacity of registry to include additional disorders	Number of disorders included  90% of confirmed cases are added to registry			
	<b>Workgroup</b>	<b>Identify potential data elements to be added</b>	Y1, qtr 1	<b>Summary of data elements identified (24 disorders)</b> <b>Y1- Q1-3, Y2</b>					
		<b>Reach consensus on data elements to be included</b>	Y1-2	<b>Final list of data elements to be included (24 disorders)</b> <b>Y1- Q1-3, Y2</b>					
	<b>DocSite</b>	<b>Add data elements to the Registry</b>	Y1-5 ,	<b>Data elements added – 12 disorders to date</b> <b>Y1-Q1-3, Y2</b>					
	<b>Region 4 Metabolic Center</b>	<b>Add cases to the registry - for MCAD</b>	Y1-5,	<b>List of centers adding cases – MN, IL, MI1, MI2, WI, IN, OH1, OH2</b> <b>Y1-Q1-3, Y2</b>					
	<b>Workgroup</b>	<b>Repeat above process to add other disorders to the Registry</b>	7/09 to 6/12	List of disorders added to the Registry					
Add additional cases to the registry	<b>Workgroup</b>	<b>Invite other Regions to participate in project activities – Heartland invited</b>	Y1-5, <b>Y1- Q1-3, Y2</b>	List of Regions entering cases into the Registry	Increase number of cases in the registry	90% of confirmed cases in other participating states are added			
		<b>Provide orientation to new participants</b>	Y1-5 <b>Y1- Q1-3, Y2</b>	Dates of orientation – initial - <b>Orientation complete with 7 sites,</b>					

Priority 2 Follow-up Activity: IBEM-IS Workplan (2007-2011)

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	Workgroup, Region 4	Establish the National IBEM-IS Advisory Group	Y3	List of National IBEM-IS AG Members		
	Region 4	Plan and facilitate National IBEM-IS AG face-to-face meeting	Y3	Meeting materials		
	Heartland Metabolic Centers, others	Enter Cases	Y2-5	List of centers entering data		
<b>Objective 3. Integrate the IBEM Registry with other electronic systems, creating an IBEM Information System</b>						
Integrate registry with other electronic data systems	Workgroup, DocSite	Create link with electronic emergency care plans (See Base Funding proposal description of MEMSCIS)	Y3	Date systems are linked	Increase usefulness of IBEM Registry	Number of electronic systems linked  Percent of partners who indicate usefulness is increased
	Workgroup	Develop collaborative relationships with other electronic data systems (e.g. state NBS systems)	Y3-5	List of collaborative partners		
	Workgroup; collaborative partners	Address issues of access, privacy & integrity of data	Y3-5	List of issues and resolutions – issues discussed in meetings		
	DocSite, Workgroup, intended recipients of linkages	Create web-based interoperability with other systems	Y4-5	Date additional systems are linked		
<b>Objective 4. Evaluate project progress</b>						
Implement project evaluation	Project Leads, Regional Partners, Workgroup	Collect data on process and outcome indicators	Y2-5	Evaluation of progress towards objective goals	Improve effectiveness of IBEM-IS	Percent of partners who indicate effectiveness is improved
	Region 4 Evaluator	Summarize data annually	Y2-5	Written reports		
	Region 4 Evaluator	Share results with Workgroup, Region 4 Advisory Group, other partners	Y2-5	Report posted to Region 4 website		
	Evaluator, Workgroup, Advisory Group, partners	Develop recommendations to improve process and products	Y2-5	List of recommendations		
	Workgroup, DocSite	Modify process and products as needed	Y2-5	List of modifications made		

**Bold = Accomplished through 3/20/2009**