



**Region 4 Priority 2 Workgroup**  
**Inborn Errors of Metabolism – Information System (IBEM-IS)**

**Role of the State Follow-Up Lead Representative and**  
**Expectations for Active Participation**

**Each State Follow-Up Lead Representative to the Priority 2 Workgroup will:**

1. Participate in the Region 4 Priority 2 Project activities as the follow-up representative from your state.
2. Review and provide input on workgroup materials, activities, projects and planning.
3. Contribute as a member of the Priority 2 Work group in scheduled monthly conference calls and the Region 4 face-to-face meetings held approximately every 18 months.
4. Support and partner with metabolic centers/metabolic specialists caring for families in your State.
5. Actively participate in the Inborn Errors of Metabolism – Information System (IBEM-IS) by assisting in the development of this system and communicating with others in your State about the purpose and significance of the Project.
6. Support the workgroup consensus document related to research and publication; i.e., “Rules for Research and Use of Materials”.
7. Participate in data entry in your state, if appropriate.