



Region4
Genetics Collaborative

**Role of the State Clinical Lead and Active Participation
In the Inborn Errors of Metabolism – Information System (IBEM-IS)
Priority 2 Workgroup**

Each State Clinical Lead in the IBEM-IS Workgroup will:

1. Support and encourage active participation of all metabolic centers/metabolic specialists in the state and the state department of health.
2. Assure metabolic center participation and encourage state department of health participation in scheduled monthly telemeetings; and communicate information back to metabolic sites in the state.
3. Review/provide input on registry materials and planning.
4. Actively participate in the Inborn Errors of Metabolism – Information System (IBEM-IS) by routinely collecting data at patient visits.
5. Assure entry of data into the IBEM-IS at periodic intervals.
6. Assure that a representative from each participating center in the state, preferably the center clinical lead, attends face-to-face meetings and communicates information back to state health department and metabolic sites in your state.
7. Support and encourage active participation in IBEM-IS related research and publications.