

## **Role of the State Clinical Lead and Active Participation Inborn Errors of Metabolism – Information System (IBEM-IS) 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. (Champion)
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. (Liaison)
3. Review/provide input on registry materials and planning. (Expert)
4. Actively participate in the Inborn Errors of Metabolism – Information System (IBEM- IS) by routinely collecting data at patient visits. (Partner)
5. Assure entry of the data into the IBEM- IS at periodic intervals. (Steward)
6. Assure that a representative from the state, preferably the state clinical lead, attends face- to- face meetings and communicates information back to state health department and metabolic sites in the state. (Participant)
7. Support and encourage active participation in IBEM- IS related research and publications. (Advocate)