

State-to-State Assessment

Name: _____ **State:** _____

1. Please list the 3 to 7 largest pediatric endocrine specialty centers in your state. Include type of center (university based, hospital based, private practice), location and location in relation to state lead's center. Indicate if you know anyone from the specific center, center's willingness to participate and to what degree of participation.
2. Describe your current relationship and interaction with state Department of Health Newborn Screening Program and associated programs (public health labs, 2nd tier labs, children with special needs program, etc).
3. Describe community and academic service: Involvement with CAH parent support groups and committees that involved CAH.
4. Describe your (State Lead's) and/or participating partner's interaction with child psychology and urology sections at their center. If possible, a list of potential individuals to be contacted. Indicate urologist's and psychologist's willingness to enter data elements.
5. Provide an approximate number of CAH, DSD and adrenal insufficiency patients at each participating partner's center. Indicate how many years retrospectively data extraction can be done at each Center (i.e., in Minnesota we went back to 1965). Describe the degree to which medical records are electronic, approximately when electronic records were/will be instituted (this will give us an idea of the time needed to do a retrospective data extraction), and which electronic record product is being utilized.
6. Describe the support needed to perform retrospective data extraction at each participating partner's center and the support needed to perform prospective data entry.