

EXAMPLE of STATE ASSESSMENT



STATE of MINNESOTA

1) Pediatric Endocrine Centers

- a. University of Minnesota (UMN)
 - i. Multidisciplinary CAH/DSD Center
 1. Kyriakie Sarafoglou
 2. Dianne Berg
 3. Walter Bockting
 4. Jane Lewis
 5. Cindy Lorentz
 6. Theodore Nagel
 7. Aseem Shukla
 8. Carrie Ann Terrell
 9. Nancy Vanderberg
- b. Mayo College of Medicine
 - i. Endocrinologists
 1. Siobhan Pittock
 2. Salman Kirmani (endo/genetics)
 - ii. R4GC, R4S, 2nd Tier Testing and Genetic Testing
 1. Piero Rinaldo
 2. Dietrich Matern
 3. Ravindar Singh
 4. Stefan Grebe
- c. Children's Hospitals of Minneapolis/St. Paul (CHM) – hospital based
 - i. Joe Sockalofsky
 - ii. Jennifer Kylo
 - iii. Jennifer Abuzzahab
 - iv. Houa Vue (research nurse)
- d. Park Nicollet Health Services (PNHS) – clinic based
 - i. Amy Criego
 - ii. Betsey Schwarz

Listed above are the four largest pediatric endocrine providers in the state. UMN, CHM and PNHS are located within the greater Minneapolis and St. Paul area and are within 30 minutes of each other. Mayo is located two hours south of Minneapolis.

All four centers are willing to participate. UMN, Mayo and CHM have already done a CAH data collection study (268 patients going back to 1965). Amy Criego at PNHS sent an email agreeing to join but indicated that amount of time would be limited, even with funding.

- 2) Interaction with State Department of Health and Public Health Lab.**
 - a. Weekly teleconference with MDH and Mayo (2nd tier testing)
 - b. Multidisciplinary CAH/DSD Center at UMN – Public health nurse from MDH!
 - c. CAH NBS Projects with MDH and Mayo

- 3) CAH community and academic service**
 - i. Scientific advisor to MN Dept of Health NBS CAH program
 - ii. Newborn Screening Translational Research Network
 - iii. Mn Dept of Health created CAH parents’ support group
 - iv. CARES Foundation – national CAH support group

- 4) Interaction with Urology and Psychology**
 - a. Weekly Multidisciplinary CAH/DSD Center at UMN
 - i. Aseem Shukla – urologic surgeon
 - ii. Jane Lewis – urologic surgeon
 - iii. Dianne Berg – psychologist
 - iv. Walter Bockting – psychologist

- 5) CAH, DSD and Adrenal Insufficiency patients**
 - a. Through 2008, 268 CAH patients (not including PHNS) from retrospective study in Minnesota
 - i. CAH at UMN - 60 active
 - b. DSD at UMN – with new adult CAH/DSD multidisciplinary center about 40 additional active (many Turner’s).
 - c. AI patients – need to contact coding office to check records.
 - d. Electronic records since 2006 – overall records back to 1965

- 6) Support needed for data extraction**
 - a. Retrospective data extraction – centralized could extract data from UMN and the other participating Minnesota centers (some expense from lodging, food, travel at Mayo).