

CH Workgroup Survey ~ Summary

What laws and/or pending legislation does your state have concerning follow-up?

IN: IN law maintains that it is the physician's responsibility to obtain the appropriate follow-up for abnormal test results. If the physician is unsuccessful or unknown, the responsibility falls to the local health officer. Once diagnosed, the state is required to maintain a confidential registry of every infant diagnosed. These records are to be used for service delivery and program administration.

NBS Law – IC 16- 41- 17- 10 - <http://www.ai.org/legislative/ic/code/title16/ar41/ch17.html>

IL: Title 77 Ill. Adm. Code 661.50 - Newborn Metabolic Treatment Code recognizes the need for annual follow-up of children diagnosed with newborn screening disorders, authorizes collection of this data.

KY: Not aware of pending legislation adjusting current practice

KRS 214, 155;

KRS 205, 560, 902

KAR 4:030

MI: mandatory with designated fee

MN: Data may be kept for research purposes and follow-up

No specific legislation - the group that took legal action against the state newborn screening is appealing the decision which was in- favor of the state

OH: None

WI: None for CH

State	Follow-up for test positive	Follow-up for CH Diagnosed
IL	After informing the physician and birth hospital of the abnormal results, we follow newborns with "presumptive positive" (high level TSH or borderline TSH with low T4) newborn screens until diagnosis or rule/out of a disorder. For borderline abnormal cases we send a letter to the physician and birth hospital requesting a repeat NBS, and check back within 6 weeks to make certain the baby was retested. If not, we send a second letter to the physician as a reminder of the need for additional testing.	Once the infant is diagnosed, we provide long- term follow-up. Each year a request for information about growth and development and treatment status is sent to the child's pediatric endocrinologist or primary care provider. Collected data in entered into confidential disease registry.
IN	All infants with abnormal screen results for CH are immediately reported to the birth hospital, primary physician and the Pediatrics Endocrinology group for the State. These notifications include phone call, fax and letter requesting serum confirmation testing. Follow- up phone calls are made daily until results are obtained. The help of the local health officer is requested if lab, hospital or physician is unable to obtain f/u. Dr Eugster, State Endocrinologist has a follow up plan for each child.	They are followed in the endocrine clinics. Once the diagnosis of CH is made, the Peds Endo group contacts the infant's physician to coordinate tx. This can include scheduling a clinic visit or just consulting on dosage or other questions. The ISDH, lab and Endocrinologist meet quarterly to make sure all cases have been accounted for and that those infant's are being followed and treated. State Endocrinologist works with PCPs and other Pediatric Endocrinologists across the state to ensure proper follow- up is completed.
KY	State divided with 2 University endocrine divisions managing follow- up. NBS follow- up notifies university specialist and clinician to ensure timely diagnostic testing. NBS follow- up only tracks up to confirmed diagnosis	Initial contact for equivocal values lead to retesting, positive results lead to endocrine management and referral; Follow until diagnosis ruled out or confirmed and treatment started; NBS follow- up case is then closed (at confirmation of diagnosis).
MI	Follow up until diagnosed and treatment initiated (State NBS)	3- year follow up (State NBS)
MN	The public health lab provides the short term follow up to confirm the diagnosis with the PCP. MDH contacts identified endocrinologist for confirmatory data	After the diagnosis is confirmed State NBS follow- up contacts the family for a first assessment and link with resources/services. A letter is sent to the PCP regarding the contact with the family and asking for their assistance in staying connected. Toward the end of the first year the family is contacted a second time for an assessment.
OH	Immediate recheck and start on medication. Pediatrician calls endocrinologist who sees child by 1 month after medication start. Infants are followed until diagnosis is received by lab	Lab does not follow past the diagnostic period. Endocrinologist follows- up by 2m after 1st visit, and every 3 months in 1st 2 yr, then every 4 mo in 3rd yr.
WI	Borderline TSH results - Monitor repeat specimens; letter contact if repeat not received in two weeks; Urgent TSH results - contact PCP for plasma T4, TSH, Diagnosis, treatment date if hypothyroid	None from the state NBS program

State	Date on Screen Positive	Data on Diagnosed
IL	Record of specimen is stored in confidential NBS database along with diagnostic information provided by the pediatric endocrinologist, or if CH is ruled out, the dates of any repeat normal newborn screens and/or diagnostic tests reported to us by the PE or PCP	Long- term annual follow- up data includes: treatment, height, weight, BMI, number of hospitalizations, developmental progress as reported by the child's PE or PCP
IN	Timing of screen and follow- up sample collection, serum results and parties contacted. Currently, state NBS is keeping the NBS results, a hard copy of the follow- up form and a spreadsheet of closed cases	Timing and dosage for treatment (Endocrinologist). Currently State NBS keeps the NBS results, a hard copy of the follow- up form and a spreadsheet of closed cases
KY	Data management prior to 2006 was inadequate for sophisticated analysis. Now, demographic, physician, lab results data are all maintained in electronic database. NBS follow- up tracks NBS results from lab; case reports from universities with serum/scan results, confirmed diagnosis, and treatment/regimen; internal NBS log tracking T4, fT4 & TSH NBS values on positives cases to monitor trends for revision of cut- offs as needed	See previous column. Also, patients ultimately diagnosed with transient CH are supposed to be reported to the state but this is inconsistently done. NBS follow- up collects serum blood levels, T4, fT4, TSH and final case report
MI	Data on all positives until diagnosed or retest negative	Data on all diagnosed until 3 years of age
MN	PCP are asked to confirm diagnosis and indicate if it is a primary, secondary, or transient. They are asked to indicate treatment medication, date treatment started and specialists name, Data includes physician/Endocrinologist involved, confirmatory lab data, date treatment started.	We have data elements from the first and second family assessments, which include linkage to medical home and numerous public programs as well as status with well child check- up, immunizations, developmental status, etc. Confirmatory lab data, date treatment started, date last seen, still on treatment (Y/N)
OH	Screen and results of recheck/confirmatory test results and date treatment initiated	Confirmatory test results and date treatment initiated/start on medication
WI	# screened # of borderline TSH # of urgent TSh % followed up # of confirmed cases Treatment start date, # lost to follow- up	Date Treatment started

Best/Model Practices

- Various protocols have been reviewed and published.
- The Oregon (“Northwest Regional”) program has an extensive follow- up program. They may have models. Colorado as well has an interest.
- I have heard a little about some other practices but I am not well versed in what they are doing and would like to hear more.
- I am very interested in the 3 year endocrine follow- up study initiated by the MI NBS program.

Other topics for workgroup consideration

- Data on associated diagnosis of congenital hearing loss and/or Down Syndrome
- NICU protocols
- Maintenance of certification discussion - if we could get this approved for MOC for physicians it would facilitate a registry greatly