



ACHDNC

*Secretary's Advisory Committee
on Heritable Disorders in
Newborns and Children*

DACHDNC DRAFT RECOMMENDATIONS FOR TIMELY NEWBORN SCREENING

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APHL Newborn Screening and Genetic Testing Symposium

October 30, 2014

Anaheim, CA

TIMELINESS - BACKGROUND

- In order to effectively reduce mortality and morbidity, NBS must occur in a timely manner.
- NBS is a system – The parts must work together to achieve the best outcomes.
- DACHDNC Laboratory Standards and Procedures Subcommittee tasked with investigating timeliness of newborn screening in the United States
 - September 2013 – public comment at DACHDNC meeting
 - States surveyed on current practices
 - Guidelines/literature were reviewed
- November 2013 – Media attention raises the issue of timely NBS nationally.

TIMELINESS - BACKGROUND

January 2014: 4 recommendations made by DACHDNC & Subcommittee tasked to:

1. Outline the NBS system
2. Investigate existing gaps and barriers in NBS systems
3. Identify best practices to achieving these goals
4. Develop a list of critical conditions that require urgent follow-up
5. Review the recommendations in light of new technologies
6. Suggest revisions, if needed.

APHL fielded survey & developed: Newborn Screening Timeliness – Survey Report

- Current status, gaps, barriers & best practices



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REVISED RECOMMENDATIONS – SEPTEMBER 2014

In order to achieve the best outcomes for babies:

1. Presumptive positive results for time-critical conditions should be immediately reported to the child's healthcare provider but no later than the 5th day of life.
2. All presumptive positive results for time sensitive conditions should be reported to the healthcare provider within 7 days of life.
3. All NBS results should be reported within 7 days of life.

In order to achieve these goals (and reduce delays in newborn screening):

4. Initial NBS specimens should be collected in the appropriate time frame for the baby's condition but no later than 48 hours after birth.
5. NBS specimens should be received at the Laboratory within 24 hours of collection.



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GAPS/BARRIERS THAT IMPACT ABILITY TO MEET GOALS

- Lack of awareness of urgency of NBS
- Lack of training/High turnover of staff performing DBS collection
- Batching by birthing facilities
- Geographic distance from birthing facility to NBS lab
- Lack of availability of courier/overnight delivery services
- Operating hours of the courier
- Operating hours of the NBS Program
- Lengthy testing algorithms to avoid high false positive rate
- Lack of ability to collect complete data
- Inefficiencies in the system
 - Specimens collected in proper timeframe may not be dry & ready for courier pick up
 - Lab results ready but demographic information is not yet entered into LIMS

BEST PRACTICES

- Provide educational activities to birthing facility staff, laboratory staff & parents
- Utilize courier or overnight delivery services
- Expansion of NBS program operating hours (laboratory & follow-up)
- Improve reporting and communications mechanisms (e.g. ELO/ELR)
- Focus on continuous quality improvement activities
 - Batching by birthing facilities/submitters
 - Decrease time from receipt in the lab to reporting
- Improve data collection to allow for evaluation
- Performance monitoring and feedback
- Consider policy, rules, or legislation



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MOVING FORWARD

- Information to be compiled into a report for S/DACHDNC.
- February 2015 S/DACHDNC Meeting – vote on recommendations
- Recommendations are GOALS for NBS systems to achieve the best outcomes for affected babies.
- To achieve goals:
 - Must remove gaps & mitigate barriers
 - Can follow examples of other states
 - Must have buy-in throughout the system
 - Must have funding
- Critical that as we work to improve timeliness that we achieve a balance and not negatively impact the NBS system.
 - False negatives
 - False positives

ACKNOWLEDGEMENTS

- DACHDNC Timeliness Workgroup:

Stan Berberich

Dieter Matern

Michele Caggana

Mei Baker

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