



**Department
of Health**

**Wadsworth
Center**

Newborn Screening Webinar Series: Referrals to Specialty Care Centers

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October 11, 2019

New Regulation: SACHDNC Recommendations

- Recommendations from the Department of Health and Human Services' (DHHS) Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC)
 - “Initial NBS specimens should be collected in the appropriate time frame for the newborn’s condition but no later than 48 hours after birth, and
 - NBS specimens should be received at the laboratory as soon as possible; ideally within 24 hours of collection.”
- New York State Department of Health (NYSDOH) endorses these recommendations, although the new regulation is actually more stringent (collection at < 36 hours).



New Regulation: It's Here!

- “Newborn Screening for Phenylketonuria and Other Diseases,” Subpart 69-1 of Title 10 (Health) of the Official Compilation of Codes, Rules and Regulations went into effect on **February 13, 2019**



New Regulation: Where to Find It



Services News Government Local

New York Codes, Rules and Regulations

Home Title 10 Title 18 Laws & Regulations

Home / VOLUME A-1a (Title 10) / SubChapter H - Maternal and Child Health
/ Part 69 - Testing for Phenylketonuria and Other Diseases and Conditions/Early Intervention Program/Newborn Hearing Screening
/ Title: SubPart 69-1 - Newborn Screening for Phenylketonuria and Other Diseases

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Outline Up

Effective Date

02/13/2019

SubPart 69-1 - Newborn Screening for Phenylketonuria and Other Diseases

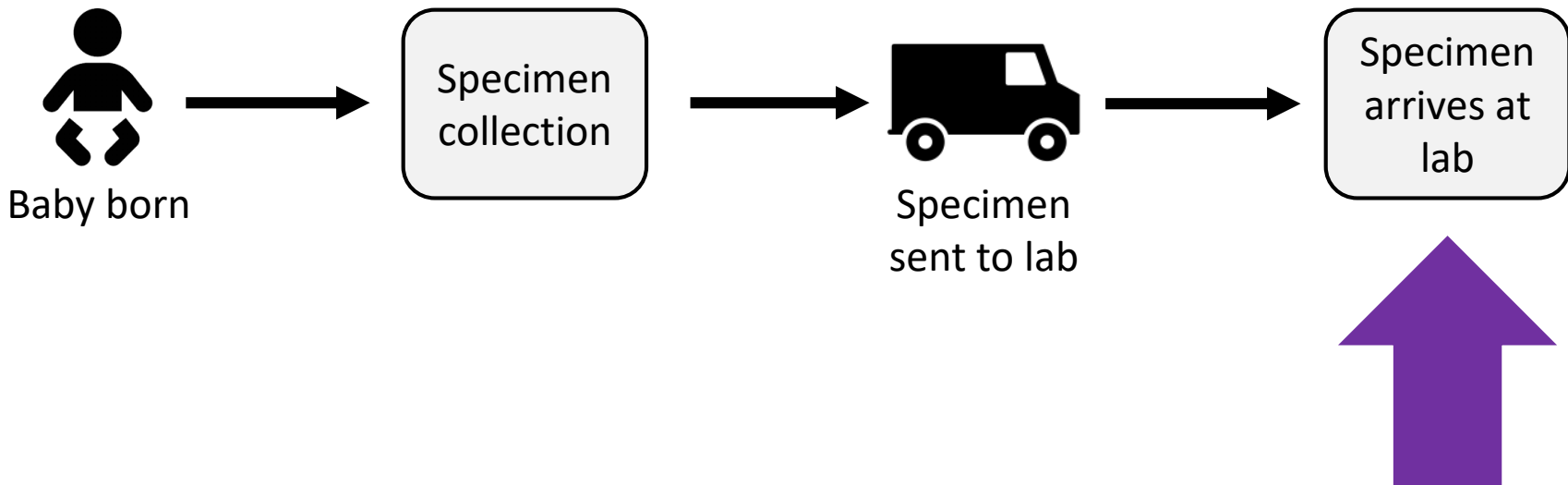
- Section 69-1.1 - Definitions
- Section 69-1.2 - Diseases screened
- Section 69-1.3 - Responsibilities of the CEO of a Hospital
- Section 69-1.4 - Responsibilities of the birth attendant
- Section 69-1.5 - Duties of the responsible provider
- Section 69-1.6 - Responsibilities of the public health officer
- Section 69-1.7 - Responsibilities of the specialty care center director
- Section 69-1.8 - Follow-up review, tracking and educational activities
- Section 69-1.9 - Inapplicability of this Subpart

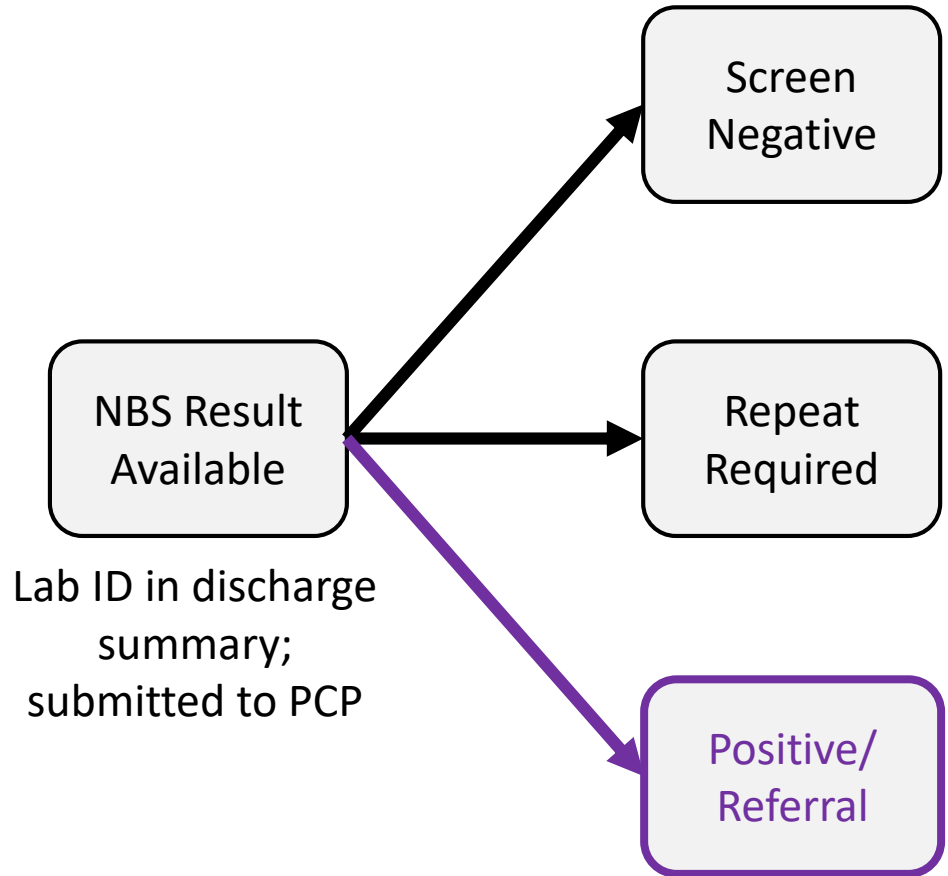
<https://regs.health.ny.gov/volume-1a-title-10/1384929965/subpart-69-1-newborn-screening-phenylketonuria-and-other-diseases>

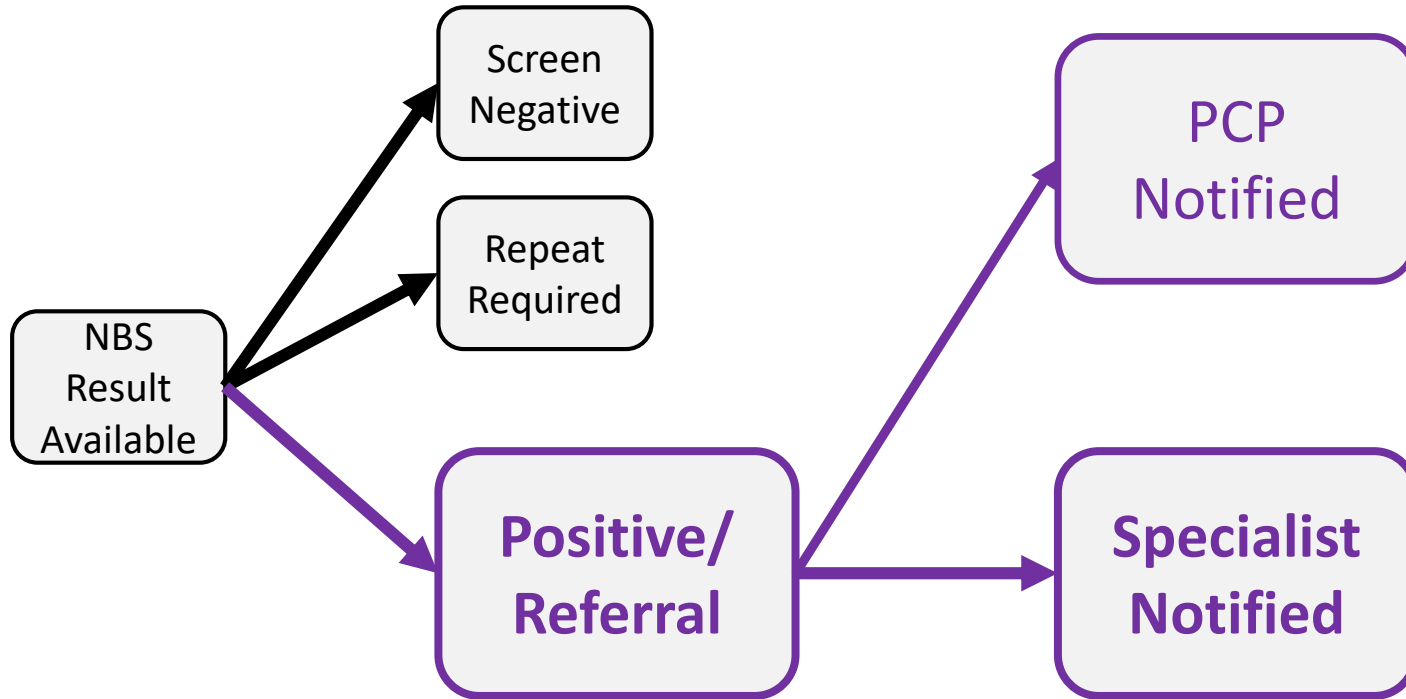


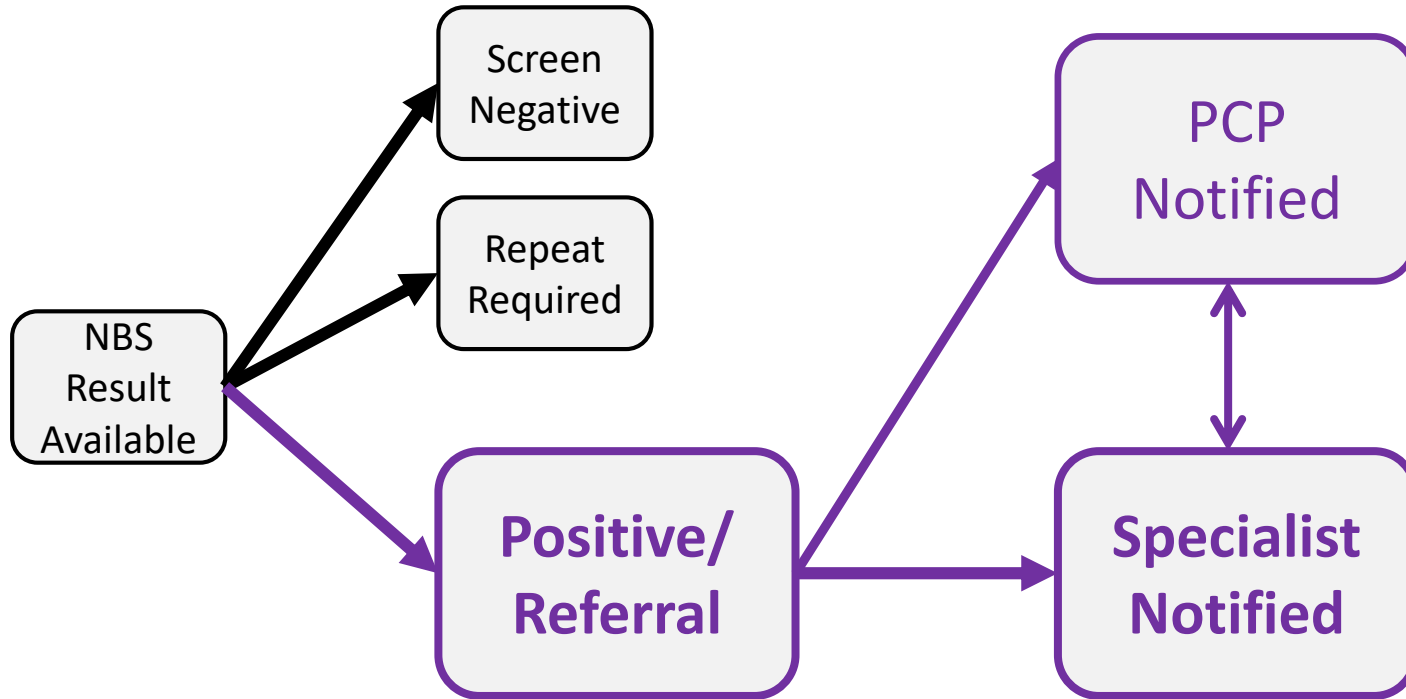
Department of Health

Wadsworth Center









Specialty Care Centers (SCC)



Health care facility established under Article 28 of New York State Public Health Law which is approved by the Department of Health and certified by the Wadsworth Center for Laboratories and Research to provide evaluation, treatment and/or services to children identified by the NBS Program.



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Specialty Care Center Certification Process

- Review criteria for approval as a SCC
- Application
- Application review and interim approval
- Site visit
- Approval



Responsibilities of the SCC Director



- Submitting to the NBS Program, within the time frame for each condition as directed by NBS Program, the diagnostic evaluation, test results and treatment plan for each newborn referred to the SCC.

SCC Responsibilities: Family Education

- The SCC shall provide education, identify resources and any additional assistance to the newborn's parent(s).



SCC Responsibilities: Medical Consultation



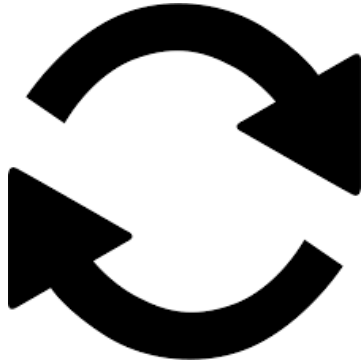
- The SCC shall provide consultation and assistance to hospitals, responsible providers, the testing laboratory and other health providers upon request.

SCC Responsibilities: Case Information

- The SCC shall provide initial and subsequent case information, case management, treatment plan, specimens and other information for tracking and follow-up reviews to the testing laboratory, when requested.



SCC Responsibilities: SCC Changes



- The SCC shall submit written and/or electronic notification to the testing laboratory within thirty (30) days prior to the effective date of appointment of a new Director or change in the location of the SCC.

SCC Responsibilities: Contact Information

- The SCC shall provide the NBS Program with the names and contact information for all personnel, annually, and within ninety (90) days of any request from the NBS Program for such information.



Coming Soon: Certification Maintenance

- The NYS NBS Program is implementing an assessment and follow-up process for maintenance of SCC certification
- Goals of this initiative:
 - Improve time from referral to diagnosis
 - Reduce number of cases lost to follow-up
- Benchmarks are being established and reports will be issued for each SCC to see how they are performing
- Each SCC will be asked to:
 - Submit their protocol for handling NBS referrals
 - Submit an updated contact list



Questions?

- Please email questions to nbsinfo@health.ny.gov
- We will do our best to respond individually, and will also compile all the questions in a 'Frequently Asked Questions' document which will be posted on the NBS website.



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Upcoming Webinars



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New Regulation: Webinar Series

- Birth attendants: September 12, 2019 @ noon





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