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## Maine Newborn Bloodspot Screening Program

## The process for responding to a positive CF screen identified through NBS:

- The result is reported to the PCP's office by an RN from the Maine State Newborn Bloodspot Screening Program, including the likelihood of a positive CF diagnosis, and recommended action.
- A two-part packet is then faxed which includes results and recommendations, "fact sheets" for the PCP, "fact sheets" to be handed to parents, and a referral/order form for the sweat test.
- The PCP's office will be asked to then 1) Fax signed referral form to the lab (fax number indicated on referral form and fax cover) 2) Call Genetic Counselor (phone number indicated on referral form and fax cover) with date of next office visit at which time the family will be told results (Counselor will call you back with the time and date of the sweat test and free counseling which you will relay to the parents at this office visit so that all the appointments are set up), 3) We ask that the PCP discuss the results in person with the family after 2 weeks of age (unable to perform reliable sweat test prior to 2 weeks/age), and give family 3-page handout provided.
- Our program notifies the Pediatric Pulmonologist, Ana Cairns (in the event that clinical follow-up or consultation is required), and alerts the Genetic Counselor to await your call to schedule appointments. The Genetic Counselor schedules the sweat test so that she can meet with the family at the time of the test.
- Our program is responsible to follow all abnormal or positive newborn screening results until a condition is confirmed and the child is receiving necessary care. We follow all cases until the suspected condition has been ruled out by diagnostic testing.

www.mainepublichealth.gov\bloodspot