

CP 1.3 Special (Expedited) Collection and Handling of Specimens for Newborns who have Siblings with Phenylketonuria (PKU)

Purpose: Because newborns with siblings who have PKU are at increased risk of also being affected, they should be screened as early as possible to alleviate parental anxiety and expedite detection and treatment, if indicated.

Protocol:

Resp. Person	Action
ASC NBS Coordinator or Program Specialist	<ul style="list-style-type: none">• Upon learning of impending birth of baby who has a sibling with PKU, notifies parent and newborn's physician of protocol for special collection and handling of specimens.• Contacts perinatal facility and instructs staff to:<ol style="list-style-type: none">1) collect NBS specimen as soon after 12 hours of age as possible and no later than 24 hours of age, and2) send specimen to NAPS lab by NAPS lab-provided courier or overnight delivery.• Contacts NAPS lab to alert them to courier or overnight delivery.• Calls out results to newborn's physician on the day they are posted in SIS.• Documents all attempts at notification, interactions with physicians and parents using tracking events or case notes in SIS.