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Maine CDC Newborn Bloodspot Screening Program

My Baby had a Positive SCID Screening Test, Now What?

** The most important thing to remember is a positive screen does not always Mean your baby has SCID, it means your baby needs more tests**

What is SCID?

- SCID stands for Severe Combined Immunodeficiency
- A baby with SCID has little or no immune system
- If a baby has SCID he or she can get infections easily

What does a positive SCID newborn screening mean for my baby?

- A positive screen result may not mean your baby has SCID
- Your baby needs another test to find out if he or she has SCID
- If found early SCID **can** be treated and often cured

How do I find out if my baby does have SCID?

- A blood test called flow cytometry is needed to find out if your baby has SCID
- Your baby's doctor will help you get this blood test for your baby
- It takes about 2 days to get test results. Your doctor will then tell you if your baby
 - o is no longer at risk for SCID
 - needs to have more tests
 - o needs to see a special doctor

How can I keep my baby safe?

- Get the flow cytometry blood test done
- Keep your baby away from people you know are sick
- Have people wash their hands before holding or touching your baby
- Try to keep your baby out of crowded places like the grocery store

Where can I get more information?

- Talk with your baby's doctor
- Call the Maine CDC Newborn Bloodspot Screening Program at (207)-287-5351
- For general information visit: <u>http://www.genome.gov/13014325</u>

If you choose to look at this website, remember your baby does not yet, and may never have SCID, so this information may not apply to your baby.