

Family action sheet for primary congenital hypothyroidism (PCH)

If a newborn blood screening result shows that your baby could have a serious condition called primary congenital hypothyroidism (PCH), this result does not mean that your baby has this condition, but more tests are needed.

All babies born in California have a routine blood screen shortly after birth. The goal of this newborn screening is to find those at risk for serious medical conditions. Babies can look healthy at birth and still have one of these conditions. Babies with these conditions benefit from early diagnosis and treatment.

What is primary congenital hypothyroidism or PCH?

Primary congenital hypothyroidism or PCH is a condition that affects the body's thyroid gland, a small organ in the lower neck. Babies with hypothyroidism may have thyroid glands that are small, located in the wrong place, or missing altogether.

When the thyroid gland does not produce enough thyroid hormone to meet the body's needs, it is called hypothyroidism. Thyroid hormone is needed for growth, brain development, and changing food into energy.

Is there treatment for PCH?

Yes, there are treatments for PCH. If PCH is found early, the treatment is more successful.

Thyroid hormone may be prescribed to replace the missing hormones the baby's body cannot make. It is important that the baby receive enough hormone every day to help the baby grow.

Newborn screening takes blood from a newborn's heel to screen for medical conditions



Next steps

1. Your baby's medical provider will help arrange more testing as soon as possible

These tests will let you know if your baby has PCH.

2. Work closely with your baby's medical provider and follow recommendations

Your baby's medical provider may refer your baby to a doctor with more experience in PCH. It is important that you keep all appointments and start treatment if instructed.

Where can I get more information?

Your baby's medical provider or PCH doctor is the best person to teach you about PCH. Find more information at these websites:

• Baby's First Test

(<https://www.babysfirsttest.org>). Type "congenital hypothyroidism" into the "Find a Condition" Box. Follow the link. For Spanish, click on the top right black box marked "en Español"

• MedlinePlus

(<https://medlineplus.gov/genetics/condition/congenital-hypothyroidism/>)

