

Family action sheet for mucopolysaccharidosis type II (MPS II or Hunter syndrome)

If a newborn blood screening result shows that your baby could have a serious condition called mucopolysaccharidosis type II (MPS II or Hunter syndrome), this 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 MPS II?

Mucopolysaccharidosis type II or MPS II prevents the body from breaking down sugars properly.

This causes a range of symptoms that affect many parts of the body. Symptoms can include bone, muscle, heart, and lung problems, as well as developmental delays.

There are different forms of the disease, some more severe than others. The most severe form can appear in the first year of life. In a milder form, symptoms may not appear until later in childhood.

MPS II almost always affects males. MPS II is an inherited condition. This means it is passed from parents to children.

Is there treatment for MPS II?

Yes, there are treatments for MPS II. Early identification and treatment can help to delay the progression of the condition. Enzyme replacement therapy and sometimes stem cell transplant may be recommended as treatment. There are also new treatments being studied that may be available in the future.

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



Next steps

1. Your baby's medical provider will refer you to specialists with MPS II experience. The specialists will arrange for further evaluation to determine what treatment or monitoring may be needed for your baby.

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

It is important that you keep all appointments and start treatment if instructed.

Where can I get more information?

Your infant's medical provider and specialists are the best people to teach you about MPS II. Find more information at these websites:

- **Baby's First Test** (<https://www.babysfirsttest.org>). Type "MPS II" into the "Find a Condition" Box. Follow the link. For Spanish, click on the top right black box marked "en Español"
- **Health Resources & Services Administration (HRSA)** (<https://newbornscreening.hrsa.gov/conditions/mucopolysaccharidosis-type-II>)

