

Fact #4: Newborn Screening is a dynamic program as it is always evolving and improving

Missouri's newborn screening system has been protecting infants for 50 years, since 1965, with the development of the first screening test for PKU and the dried blood spot collection system that is still in use today.

Through the years additional tests have been added to the newborn screening panel: primary congenital hypothyroidism in 1979; galactosemia in 1985; hemoglobinopathies in 1989; congenital adrenal hyperplasia and hearing screening in 2002; amino acid, fatty acid and organic acid disorders in 2005; cystic fibrosis in 2007; biotinidase deficiency in 2008; Krabbe disease in 2012; Fabry disease, Gaucher disease, Hurler disease, and Pompe disease in 2013; and critical congenital heart disease in 2014.

Missouri currently screens for over 70 disorders and screens for 30 of 31 universal screening disorders as recommended by the Advisory Committee on Heritable Disorders in Newborns and Children endorsed by the Secretary of Health and Human Services. As advancing technologies allow for detection of markers for more conditions, and treatments are available, additional tests for disorders will be added to the newborn screening panel.

Parent stories...

I thought my baby could hear my every word. I sang to her, played peek-a-boo, and made every funny noise in an attempt to make her laugh and respond. I had no idea she was born with progressive hearing loss. My words became lost in her muffled, and mostly silent, world. She went undiagnosed for nearly three and a half years.

Your baby did not pass the newborn hearing screening. Since the initial screening results are not always certain, your baby needs a follow-up rescreening to see if further diagnostic testing for hearing loss is needed. This follow-up should be done as soon as possible.

Babies who are diagnosed with hearing loss by 6 months of age have the best chance to learn to communicate successfully. Please go for the follow-up hearing screening. Your baby is counting on you.

Mom to a wonderful daughter with hearing loss/deafness

