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# Kansas expands screenings for newborns

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Because of a rare genetic disorder, Melina Kroll, now 6, nearly died days after being born.

- [Genetic screening list for newborns in Kansas, Missouri](#)

Eleven days after Melina Kroll was born, her parents got the nightmare phone call.

*There's a problem with your baby, the doctor said. Go to the hospital now. She might die if you don't.*

Unknown to anyone, Melina had a rare genetic disorder. Her body couldn't hold on to salt, and she was severely dehydrated.

Her doctor discovered it after running tests during a checkup. Parents Tonia and Michael Kroll rushed Melina to the hospital just in time.

"The doctor told us we were within minutes of losing her," said Tonia Kroll, of Lansing. "Most babies with this (disorder) perish within two weeks. We were lucky."

If Melina had been born today, doctors would have caught her condition a day after she was born. Starting this week, Kansas health officials will screen the blood of every Kansas newborn for 29 disorders — including Melina's condition.

Previously, Kansas screened for four disorders, trailing nearly every state in the nation. Missouri now tests for 63 disorders and plans to add another later this year.

New tests probably will be added in both states as geneticists identify new disorders and treatments. Kansas' list now includes only illnesses that can be treated effectively.

Health experts said the expansion was long overdue.

"We've been wanting to do this for a long time," said James Casey, a University of Kansas Medical Center pediatric endocrinologist who advised the state on the expansion. "We can identify so many more of these (disorders) now, it just makes sense that we require it."

The tests identify tiny genetic differences that wouldn't otherwise be obvious until it's too late. With the exception of sickle cell anemia and cystic fibrosis, you've probably never heard of most of them. Almost all are rare — Melina's condition affects only one out of every 30,000 births.

But without prompt treatment, most will kill or disable, sometimes within days of birth.

The screening involves a blood sample taken from an infant's heel 24 hours after birth. A state lab in Topeka tests the sample and immediately reports abnormalities to the baby's doctor.

Topeka mother Michelle Black lobbied lawmakers for the expansion, though it came too late to help her son Connor.

She noticed little differences early — Connor didn't babble as much as other infants and he lacked energy. But doctors couldn't diagnose the problem until one looked for a certain genetic disorder.

Connor's genes make it hard for him to process certain proteins and fats. If untreated, the disorder can lead to developmental problems, kidney and pancreatic disease, even death.

The treatment? Vitamin B-12 and changes in diet.

Connor is 3 now, a happy boy who loves to talk. But because the disorder wasn't discovered soon enough, his life will always be a bit harder.

"He wears leg braces and stutters, and things are more difficult for him," said his mother. "If they had tested him the day after he was born, we would have started him on B-12 right away."

Black said she "assumed the state was doing everything they could."

But in fact, Kansas was falling behind.

The state started screening newborns' blood for phenylketonuria, a protein disorder known as PKU, in 1965. Sickle cell anemia, galactosemia and hyperthyroidism were added later. But other states beefed up their testing.

Kansas lawmakers voted to expand the testing in 2007. It took a year for the state to prepare for the change.

House Speaker Melvin Neufeld, an Ingalls Republican who pushed for more screenings, called it one of the most significant health policies in the last 20 years in Kansas.

“Science has showed us that earlier is always better,” he said. “I’d rather have a healthy child that grows up to be a productive adult than put the families through these terrible conditions.”

The expanded testing for the 40,000 Kansas babies born each year costs the state about \$2.5 million. That’s a bargain compared with the cost of late treatment: A federal study showed that treatment can cost \$1 million over the lifetime of a child if the disorders aren’t caught early.

“If you can step in and make significant changes for the better by identifying these disorders, that’s the definition of public health in my mind,” said Joe Blubaugh, a spokesman for the Kansas Department of Health and Environment.

In Missouri, hospitals or health providers pay a \$50 fee per baby for the screening, a cost that’s typically passed on to parents.

Missouri tests about 80,000 newborns each year and typically finds several dozen with disorders.

Neufeld said he hopes to expand Kansas’ program again as new disorders are identified and treatments are found.

Michelle Leeker has a disease she’d like to add. The Baldwin City woman lost her son Trevor in 2001 to Krabbe’s disease, which almost always proves fatal. Neither Kansas nor Missouri screens for it.

Trevor was born healthy, but at 4 months the disease made its presence known. Krabbe’s disease attacks nerve cells and progresses until the body shuts down. Trevor died before his 2nd birthday.

Today, Leeker said, a child like Trevor could get an experimental treatment if the disorder is caught early.

Melina Kroll, the little Lansing girl who almost died, is now 6 and is doing well. She’ll be on medication for the rest of her life, but it should be a long and healthy life.

“She’s wonderful. She’s very active,” Tonia Kroll said. “She’s just lost her two front teeth.”

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#### **ON THE WEB**

More information on genetic screenings in Missouri and Kansas is available at the state health departments’ Web sites.

•In Missouri: [www.dhss.mo.gov/ NewbornScreening](http://www.dhss.mo.gov/NewbornScreening)

•In Kansas: [www.kdheks.gov/ newborn\\_screening](http://www.kdheks.gov/newborn_screening)

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@ For a complete list of conditions that Missouri and Kansas screen for, go to **KansasCity.com**.

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