

Deadly delays

The nation's newborn screening programs depend on speed and science to save babies from rare diseases. But thousands of hospitals fall short, deadly delays are ignored and failures are hidden from public view — while babies and their families suffer.



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Sophia Elm's heel is pricked for her newborn screening last month at Wheaton Franciscan Healthcare-St. Joseph in Milwaukee.

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The baby in Arkansas seems healthy at birth. Warm, fuzzy skin. A normal weight. But Aiden Cooper can't keep down formula.

Don't worry, he's fine, doctors assure his mother as they leave the hospital. You're just a first-time mom.

Aiden goes home and sleeps in a bassinet beside his mother's bed. Soon his stomach becomes

swollen, bulging with veins. He breaks out in a rash. He is limp, pale, won't eat.

In North Carolina, a baby is born with chubby cheeks and the same button-nose as his big brother. At 11 days old, Garrett Saine turns gray, stops breathing, then turns blue.

Blood pours from the nose and mouth of a newborn boy in Wisconsin. A baby girl in Indiana has seizures, then quits breathing.



Aiden Cooper, 2, walks down steps as he works with physical therapist assistant Heather Beshiers last month at ArKids Pediatric Day Center in Paragould, Ark. Aiden has galactosemia, a metabolic disorder that caused developmental delays for which he gets speech, occupational and physical therapy.



YALONDA M. JAMES / FOR THE JOURNAL SENTINEL

Aiden's galactosemia should have been caught within the first few days of life, but it took 3½ weeks for his blood sample to be tested.

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In each instance, doctors frantically try to figure out why the baby is so sick. Routine blood samples taken shortly after birth have the answers. But the samples haven't been tested.

They should have been sent to a lab within 24 hours to be screened for disorders that can often be treated if caught early. But they weren't. Instead, samples sit at hospitals for a few days. A week. Some samples are lost.

Nearly every baby born in the United States has blood collected within a day or two of birth to be screened for dozens of genetic disorders. The entire premise of newborn screening is to detect disorders quickly so babies can be treated early, averting death and preventing or limiting brain damage, disability and a lifetime of costly medical care.

Yet one of newborn screening's most important metrics — speed — is ignored for tens of thousands of babies' tests each year, a Milwaukee Journal Sentinel analysis of nearly 3 million screening tests shows.

In Arkansas, it took 3½ weeks for Aiden's blood sample to be tested. Infection raged through his tiny body as he lay in neonatal intensive care in Little Rock. Eventually a doctor got Aiden's test results: abnormal.

The test revealed Aiden has galactosemia, a treatable disorder that prevented his body from digesting sugar in breast milk and formula. So every time he ate, he was being poisoned. Doctors eventually switched him to soy formula and he improved, but damage was done. Now almost 3 years old, Aiden doesn't say more than two or three words at once. He walks unsteadily and has a hard time feeding himself because of developmental delays.

"Every day is like a new battle for us," said his mother, Shauna Cooper.

Last year, at least 160,000 blood samples from newborn babies arrived late at labs across the country, according to the newspaper's analysis of screening tests from 31 states. The Journal Sentinel also compiled information about newborn screening programs in every state and the District of Columbia. Among the findings:

■ Labs in half the country are closed on weekends and holidays, meaning babies born later in the week could have their results delayed two or three days, postponing diagnosis and

increasing harm to affected children. In February, Garrett Saine stopped breathing three times on a Sunday while his positive test results sat inside the closed North Carolina state lab. A baby born on a Friday in Colorado died the day before his newborn screening results alerted doctors to a treatable condition.

■ In nearly three-quarters of the country, hospitals are supposed to send samples using overnight delivery or courier services. Yet it still takes days for hundreds of thousands of samples to arrive at labs for testing. At one hospital in Phoenix, 70% of samples took five or more days to get to the state lab just seven miles away. Some hospitals still send blood samples through the U.S. Postal Service's regular mail. It saves them money.

■ Many hospitals ignore regulations that require them to quickly send babies' blood samples to labs, and suffer no consequences when they're late. Last year in New York, only 60% of samples arrived at the state lab within 48 hours of collection — the time period required by state law.

■ For nearly 15 years, federal regulators and public health officials have discussed the need to standardize newborn screening systems throughout the country, but little action has been taken beyond increasing the number of conditions tested. Most state-run programs do not follow guidelines issued in 2005. As a result, programs vary so widely that a baby born with a disorder in one state can have a worse outlook than if born in the state next door. Some labs don't even track how quickly hospitals send samples.

■ Lab administrators and public health officials in dozens of states have fought to keep the track records of hospitals hidden. Expectant parents have no way of knowing if the hospital where their baby will be born delays sending blood samples for these lifesaving tests.

The Journal Sentinel requested newborn screening data from every U.S. state and the District of Columbia. Twenty-four states and Washington, D.C., would not release information identifying hospital names. Many cited patient privacy, even though children's names and outcomes of tests were not requested. Other states said releasing such information would be adversarial to hospitals or might reveal their business prac-

tices.

Twenty-six states, including those with the highest number of births — California, Texas and New York — released newborn screening data with hospital names. Five others released statewide totals only. The data shows for the first time that there are dangerous and deadly delays in a celebrated public health program designed to save babies' lives.

Edward McCabe, who has been involved with newborn screening since the 1970s, called the delays “ridiculous” for a program that has been refined and developed for decades.

“If we set up a system and undermine its effectiveness, why have we invested so much in the system?” said McCabe, a pediatrician and geneticist who is now chief medical officer for the national March of Dimes. “What the hospitals and people in the nursery are doing is looking at what is convenient for them.

“They think they are saving a few dollars in their budget, but they are putting babies' lives at risk.”

Many hospitals across the country do send most of their newborn blood samples quickly for testing. Those that don't blame delays on a variety of factors: New staffers don't know the protocol; mail or delivery services are delayed; cost-cutting, holidays and vacations reduce the number of workers so samples aren't sent as frequently.

At some hospitals, staff told the Journal Sentinel that they consider it more efficient to “batch” samples, or send them in bunches periodically instead of each day. This can save the hospitals money on shipping charges, but it defies adamant warnings from health officials that babies can die or suffer permanent disability from delays in treatment caused by batching. Often, delivery costs are covered by the states or insurance. The hospitals batch anyway.

Several hospitals with particularly bad records admitted batching their newborn screening samples. When contacted about their hospital's poor performance, officials told the Journal Sentinel they would change their practices — or said they had just recently recognized the problem themselves.

In Wisconsin, the state lab director fought for five months to keep hospital performance hidden, saying it would be antagonistic to identify specific facilities. Last week after information was finally released, leaders of several hospital systems, including the state's largest, said they had been unaware of their track records until contacted by the newspaper and would immediately change how newborn screening samples are handled.

Developed 50 years ago, newborn screening is considered a major public health success, identifying disorders in time to improve or save the lives of more than 12,000 newborns in the United States each year.

About one in every 800 babies is born with a potentially severe or deadly condition that can be treated and managed if the child is properly tested. These babies often appear healthy at birth but can become extremely sick within days.

While the disorders are rare, diagnosing a single child early not only can preserve or dramatically improve the life of that infant and his family, but can also prevent millions of dollars in medical bills, follow-up care and lifelong assistance. Babies are screened for as many as 56 conditions or as few as 28, depending on the state.

Galactosemia is one of the disorders that can very quickly endanger newborns' lives. Those affected cannot process galactose, a sugar in milk, so toxins build up in their cells as they drink breast milk or traditional formula. Undiagnosed, babies can develop serious infections and kidney and liver problems that lead to brain damage, organ failure and even death.

Aiden Cooper was born on Jan. 13, 2011, at Arkansas Methodist Hospital in Paragould. A virus was going around and several nurses had called in sick to the maternity ward, recalled his mother, Shauna Cooper, and grandmother, LaVonda Cooper, who works as an X-ray technician at the hospital.



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Karen Kennedy-Parker, supervisor of the newborn screening lab at the Wisconsin State Laboratory of Hygiene, reviews hemoglobin screening gels for results that would indicate a metabolic disorder.

When an abnormal result is identified, the lab alerts the child's doctor for follow-up treatment.

The baby spent most of his time in Shauna's hospital room instead of the short-staffed nursery. Shauna needed to change his baby bed frequently because Aiden spit up in large amounts after eating, drenching his tiny hospital gowns and bedding. It took nurses a long time to bring fresh linens.

At 2 days old, Aiden's heel was pricked for the newborn screening test. At 4 days old, he went home. Only his mom seemed alarmed that the baby appeared to spit up nearly everything he ate.

Screening is a simple process

Newborn screening is required by law in every state. Parents can refuse tests for religious reasons, but nearly 98% of the nation's newborns are tested.

The protocol is straightforward: A baby's heel is pricked 24 to 48 hours after birth. A few spots of blood are collected in small circles on a filter paper card. The card is to be sent within 24 hours to a lab for testing and should arrive at the lab within three days after the sample is collected, according to 2005 recommendations from a newborn screening committee created by the U.S. Department of Health and Human Services.

Iowa and Delaware were the only states that met that turnaround time for 99% of blood samples last year, the Journal Sentinel analysis found.

Throughout the country, tens of thousands of samples in dozens of states — from Arizona to New York, Missouri to Tex-

as — arrive at testing labs five, six, seven or more days after they're collected. For the 25 programs that refused to release data, there is no way for prospective parents to know how well their hospitals or labs perform at newborn screening.

The Journal Sentinel used five or more days as a metric for lateness in most states, as that period is considered unacceptable by many lab directors. Some labs would only report samples that took six or more days to arrive. Samples often are not tracked on a tighter time frame or labs would not release the information, making it impossible to analyze for many states how many hospitals delivered samples within the recommended three days. As a result, the newspaper's calculation of 160,000 delayed samples is very conservative.

Five days is considered by many experts to be an exceedingly long time for samples to reach labs because an infant could be well over a week old before results are available — too late for babies with certain disorders.

Some hospitals and states have particularly bad records.

At Maryvale Hospital Medical Center in Phoenix last year, 70% of newborn screening samples arrived at the state testing lab five or more days after they were collected. Arizona regulations require that babies' samples be sent within 24 hours of collection, and the state pays for its recommended FedEx delivery. Still, it took at least five days for 646 blood samples to get from Maryvale Hospital to the state lab only seven miles away.

A Maryvale spokesman said in an email that the hospital "found it was more efficient" to send samples to the lab in batches. That despite strongly worded guidelines issued to hospitals by the Arizona health department that say batching "seriously increases the risk of irreversible harm or death" for infants.

Arizona has one of the worst track records in the country, with 17% of all newborn screening samples arriving at the state lab five or more days after collection in 2012.

That's actually an improvement over 2010, when 29% of samples statewide were late. Still, more than 10% of samples arrived late from 33 of the state's 42 hospitals last year.

"As you've pointed out, there are hospitals that need extra attention," said Ward Jacox, chief of Arizona's newborn screening office, when informed of the state's performance. "You did more analysis than we did."

In response to the Journal Sentinel's findings, the Arizona Hospital and Healthcare Association said it will conduct a training event for hospitals throughout the state.

Arizona is hardly alone. The Journal Sentinel analysis revealed hospitals across the country are sending samples late — huge birthing centers in major cities as well as small community hospitals in rural areas.

At the tony Lenox Hill Hospital on Manhattan's upper east side — where singers Beyoncé and Jay-Z had their baby last year — 14% of almost 4,900 newborn screening samples arrived at the state lab in Albany five or more days after they were collected.

Only 35% of samples from Lenox Hill met the New York state regulation requiring newborn screening cards to arrive at the lab within two days of collection, the Journal Sentinel found.

A spokesman said the hospital's track record has improved significantly this year, adding that superstorm Sandy paralyzed the city for weeks in 2012.

Statewide in New York, 13,000 samples took five or more days to arrive at the state lab. In California more than 11,000 samples were delayed, while in Florida nearly 9,000 samples took six days or longer.

While that amounted to 5% or fewer of the total samples in those states, any late test could be catastrophic for a child with one of the disorders caught by screening. Hours can mark the difference between a child who suffers permanent brain damage and a child who lives a healthy life with a modified diet.

Jack Chapman was 6 days old when diagnosed with a rare disorder that can suddenly kill a baby whose blood sugar gets



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Above: Kristin Saine feeds her son Garrett last month at their home in Cleveland, N.C. Garrett has galactosemia, a rare genetic disorder that does not allow his body to metabolize galactose, the sugar in milk.

Garrett stopped breathing three times, while a test showing he had galactosemia was sitting in a closed state lab. Above, Garrett with parents Brian and Kristin Saine and brother Carson.

WHAT NEWBORN TESTS COST

The cost for each newborn screening test varies by state, ranging from \$20 to \$157. The fee, typically paid for by insurance, can cover various things in each state — shipping or courier charges, follow-up care, special formula for affected children, administrative costs. Costs also vary because states test for different numbers of conditions.

too low. Jack's mom got a warning call from his pediatrician in Columbus, Ohio, when Jack was 4 days old. His newborn screening test had come back abnormal.

Jack was retested the next day and within 24 hours doctors confirmed he had MCAD deficiency, a disorder where the body cannot properly convert some fats to energy. When that happens, fatty acids can build up and plunge the child into metabolic crisis. A baby who takes a long nap and goes too long without eating can end up dead or brain damaged. But when it is diagnosed early, parents know to wake and feed the child regularly and continue a low-fat diet throughout life.

Jack benefited from being born at a hospital that quickly sent his test to the state lab. Last year, 98% of the 6,240 blood samples from Riverside Methodist Hospital arrived at Ohio's state lab for testing within three days of being collected, the Journal Sentinel found. Jack is now a healthy and energetic 3½-year-old.

It is impossible to tell how many children have died or been negatively affected by late samples because test results are confidential. Although some children diagnosed early may still face health problems, experts agree that early treatment can dramatically improve the outcome of their conditions.

"Any time you have a condition that you know can produce ill effects, you want it to be diagnosed as soon as possible," said R. Rodney Howell, a professor of pediatrics at the University of Miami's medical school and chairman of the group that established newborn screening guidelines for the U.S. Department of Health and Human Services in 2005.

Babies vary greatly in how quickly they show symptoms. With a condition like galactosemia, a child must be treated before galactose builds up in the body, leading to infection, liver damage and brain damage.

After coming home from the hospital, Aiden Cooper continued spitting up and losing weight. When he was 2 weeks old, his mother gave him a bath and noticed a rash. Then she saw that his little stomach was puffed out, as if a balloon had been blown up inside. She took him to their family doctor who checked him over, left the room then walked back in, his face pale. They were sent to a pediatrician. Aiden's heart was beating too fast and an ultrasound found that his liver and spleen were enlarged. An ambulance rushed him 2½ hours to Arkansas Children's Hospital in Little Rock.

For the next two weeks, teams of doctors tried to sort out why the baby was so sick. He received a spinal tap, feeding tube and IVs. They switched his formula, trying goat's milk, then soy. His condition began to improve, but still no one knew he had galactosemia.

Shauna was at Children's Hospital with Aiden when a nurse from Arkansas Methodist back home called her cellphone. Apologizing profusely, the nurse said something about a test that had been lost but then found. Shauna didn't know what the nurse was talking about. A few days later Aiden was released from Children's Hospital with a tube inserted into a vein near his shoulder so he could continue to receive medication.

A lab report from Arkansas Methodist Hospital shows that Aiden's blood was collected Jan. 15, two days after he was born. The sample was not tested until 24 days later at the Arkansas State Laboratory in Little Rock. It took another week for doctors to tell Shauna the baby had galactosemia.

Lana Williams, chief nursing officer at Arkansas Methodist, would say only that the hospital follows state guidelines in handling samples.

Recommendations not met

Since 1999, groups of medical experts assembled and funded by the U.S. Department of Health and Human Services have recommended that the nation's newborn screening programs be standardized, with policies set so every baby is effectively tested in a timely manner. That hasn't come close to happening, the Journal Sentinel analysis shows. State programs vary

Condition: **Galactosemia (GALT)**

■ **Description:** Inability to metabolize galactose, a type of sugar found in milk. Newborns usually appear normal but begin to vomit and have diarrhea after being fed milk between two days and two weeks after birth. They also become lethargic, jaundiced and can develop liver damage.

■ **Effects:** Untreated, the disorder can result in mental retardation, blood infections, speech and growth delays, cataracts and — in severe cases — death.

■ **Treatment:** If detected early, the disorder can be managed with a special food plan, including not consuming breast milk or formula that contains lactose.

■ **Prevalence:** 1 in 30,000 to 60,000 babies.

widely — from the days labs operate to how and when samples are delivered.

While more than half the country has regulations that require hospitals to send blood samples for testing within 24 hours of collection, the Journal Sentinel could find no instance where a hospital was penalized for ignoring the rules. State labs and public health departments rarely have legal authority to enforce screening regulations.

There also are no newborn screening standards for hospitals under the Joint Commission, an independent medical association that sets patient care standards and accredits the majority of U.S. hospitals.

Although 36 states recommend overnight or courier delivery, only eight require it by law. Even when they do, there is little evidence the laws are working outside of a handful of states.

In New York, for example, samples must be sent to the testing lab within 48 hours of collection. Almost 106,000 samples from babies in New York did not meet that mark last year.

No sanctions or fines were issued. The state health department said it provides periodic performance reports for hospitals and works with them to improve — although there was essentially no improvement statewide from 2011 to 2012, the Journal Sentinel found.

Garrett Saine was born on Jan. 31, a Thursday, at Rowan Regional Medical Center in Salisbury, N.C. A healthy 8 pounds, 3 ounces, he came home from the hospital two days later and appeared fine, although he ate little.

At a checkup the next day, the scale showed Garrett had lost weight. His mother, Kristin Saine, worked hard to feed the baby, but he often slept through meals and didn't seem hungry. At an appointment a few days later, Garrett had dropped more than a pound. His pediatrician ordered a test of the baby's bilirubin levels to make sure his liver was functioning properly.

Kristin was getting her hair colored at a beauty salon two hours later when her husband, Brian, called. He'd been told to immediately take the baby to the hospital. Garrett's bilirubin test had come back: 24 milligrams. Levels around 25 milligrams can cause deafness, cerebral palsy and other brain damage.

The stylist washed out the color and, hair still wet, Kristin ran to her car.

Garrett was 7 days old that Thursday. On the same day that his parents rushed him to the hospital, his newborn screening test arrived at the North Carolina state lab in Raleigh, five

days after it had been collected. The hospital sent it by regular mail.

On Friday, the state lab ran its first screen of Garrett's blood, which showed 13 milligrams of galactose. Anything over 10 milligrams prompts a second test. No one called Garrett's doctor to report the preliminary results. A second run of Garrett's sample was started on Friday afternoon but would take six hours to process; it wasn't finished when the lab closed for the weekend, the lab director later told Kristin.

At the hospital, the weekend became a "horror" for the Saine family, Kristin said.

Garrett was placed under blue lights to treat his jaundice and bring down his bilirubin levels. On Saturday, he mostly slept. Doctors said feeding him would make him better. Kristin had to bend the nipple of his bottle to pour milk into his mouth.

In Raleigh, his second test had run its course, but since the lab is closed on weekends, no one was there to read the results.

Garrett grew more lethargic, his skin turned gray. At one point, he wouldn't even blink. Doctors and nurses ran more tests.

On Sunday, Kristin held her tiny baby, smaller now than when he was born. Suddenly monitors started beeping and Garrett changed from gray to blue. He wasn't breathing. Kristin screamed. Nurses ran in and resuscitated him.

The little boy stopped breathing two more times that day. His organs were shutting down. The doctors talked about doing a liver transplant.

On Sunday evening, a doctor came to Garrett's room having reviewed his tests from the hospital. She thought the baby might have galactosemia, but the hospital wasn't set up to treat metabolic disorders. His 7-pound body was put on an adult stretcher and he was taken by ambulance to Levine Children's Hospital in Charlotte, 25 miles away.

On Monday, a geneticist at the new hospital called the state lab to check the results of Garrett's newborn screening test. Lab staff told her the baby's galactose levels were high.

The formula and breast milk he had been eating for 11 days had been poisoning him.

"If you are doing a newborn screen for a life-threatening situation, why take five days to send the test?" Kristin said. "Especially when milk is the only thing a newborn eats."

Garrett is now 9 months old and has developmental delays. He is in physical therapy for high muscle tone on the right side of his body, which makes his limbs stiff and suggests damage to the left side of his brain. He is showing signs of cerebral palsy, most likely from the lack of oxygen when he quit breathing and the severe jaundice he suffered, said his pediatrician, Hal Levin.

Although children with galactosemia can have some developmental delays and cataracts even if their conditions are caught early, their risk of full-body infection, severe disability and death increases as they keep drinking milk and go without treatment.

Officials from Rowan Regional Medical Center wouldn't comment on Garrett's case but said they send newborn screening samples each day to the state lab using the U.S. mail's regular service. The state lab makes available pre-addressed first-class envelopes, which take about three days to arrive, but hospitals can ship samples any way they choose.

After being interviewed about Garrett's case by the Journal Sentinel, Levin checked additional newborn screening tests from 10 of his own patients and said it took samples as long as eight days to get to the state lab.

"That needs to be fixed," he said. "I certainly don't want another baby suffering."

Levin pointed out another problem: Unlike states where lab officials immediately call doctors when a test indicates a positive result, he said the North Carolina lab tends to send a letter in the mail.

State health department officials said all "abnormal" or

"elevated" newborn screening results are immediately reported by phone to the doctor whose contact information is submitted with the sample.

That did not happen for Garrett Saine.

In North Carolina, the public cannot determine how often there are delays in sending or testing newborn screening samples. The State Laboratory of Public Health said it could not provide information on how quickly hospitals send blood samples.

Tracking samples

Tracking sample transit times by hospital and evaluating a facility's procedures can help identify why samples are late and prevent it from happening in the future. Illinois, Minnesota and California do this to identify problems.

Sutter Solano Medical Center is a 102-bed hospital in Vallejo, Calif., 30 miles northeast of San Francisco.

Last year, the hospital had the worst record of any California hospital, with 58% of babies' blood samples arriving at the lab five or more days after collection. That was 367 samples in 2012.

Even though California's screening program provides a pre-paid courier service for each hospital, Sutter Solano was sending samples by U.S. mail.

A coordinator with the state's screening program is required to visit each hospital every two years, and met with Sutter Solano to give advice and set up the courier service in November 2012. In the third quarter of 2013, zero samples arrived at the lab after five days, compared with 50 in the prior three months.

"That's quite a success story . . . and a simple fix!" hospital spokesman Gary Zavoral wrote in an email to the Journal Sentinel.

Newborn screening programs in California provide hospitals with quarterly evaluation reports to chart their progress.

That's more than many states do to measure performance.

The director of lab administration in Maryland, for example, said his office doesn't track the performance of individual hospitals. Little to no data is collected about samples from babies born in Washington, D.C., according to the district's Department of Health bureau chief. Officials at the Oklahoma State Department of Health said they are in the process of developing a way to track samples from hospitals — but it won't be implemented for two to five years.

Even states that do provide hospitals with feedback need improvement. Texas has sent "report cards" to track newborn screening performance for at least five years, said Susan Tanksley, lab operations unit manager for the state.

Yet last year, more than 54,000 newborn screening samples arrived at the state lab five or more days after they were collected — 15% of all samples statewide.

This summer the lab began sending reports monthly instead of quarterly, so hospitals could receive feedback quickly and make changes. Tanksley said she was not aware of particular hospitals that consistently send samples late. The Journal Sentinel found that 124 facilities in Texas sent at least 20% of their samples late.

"This has raised some awareness," Tanksley said. "Every day is critical for a baby that has one of these conditions. We are doing things constantly to try to improve. We can only do what we can with the staff that we have."

Iowa makes strides

In stark contrast with most of the nation, Iowa has made vast improvements in its newborn screening program over the past seven years.

In 2005, nearly 30% of babies' blood samples in Iowa took five or more days to reach the state lab. Most hospitals sent samples through the U.S. mail, plus the lab was closed on Saturday afternoons and Sundays. Lab director Stanton Berberich didn't like the risk.

Babies are born every day of the year, he said, and each deserves the full benefit of newborn screening.

Berberich wrote up a proposal to use a courier service for newborn screening and keep the lab open 365 days a year. In 2006, the Iowa Department of Public Health approved the plan.

Instead of having more than 10,000 blood samples arriving at the lab after five or more days as in 2005, only 67 samples were that late last year.

The cost per test increased by \$17, to \$77, when Iowa decided to keep the lab open overnight, on weekends and use a courier service. Fees for each newborn screening test vary throughout the country, ranging from \$20 per test to as much as \$157. Those costs are often picked up by insurance and are considered relatively small when compared with the benefits and cost savings of diagnosing a child early.

“Economically, newborn screening must be the biggest bargain in America,” said Howell, the pediatrician from the University of Miami.

Iowa’s state lab aggressively tracks individual hospital performance. Data is reviewed quarterly and a hospital that appears to be batching or consistently sending unsatisfactory samples will get a call from the lab, follow-up letters and — if necessary — a warning to top hospital officials, said Kimberly Noble Piper, Iowa state genetics coordinator.

Lab officials try to figure out what is responsible for delays. Often they’re caused by budget cuts that reduce staff, Piper said. Hospitals are reminded of Iowa’s regulation requiring that a state-financed courier collect samples daily from hospitals and deliver them to the lab, where testing begins that night.

Piper also points out potential consequences much worse than breaking a state regulation.

“I remind them, ‘If you have a baby whose specimen didn’t get to the lab, I wouldn’t want to be in your shoes,’ ” she said.

Ron Hardy heads Central Delivery Service of Iowa, the courier service contracted to collect and deliver newborn screening tests from throughout the state. Hardy has spent most of his life in the trucking business — first as a boy, loading and unloading trucks owned by his father, then managing logistics for trucking fleets that hauled candy, appliances, paper and other products. Now Hardy wakes up each morning and carefully plans out how his 12 drivers are going to blanket Iowa to pick up newborn screening tests from every hospital in the state.

“I explain they will never handle anything more important than these specimens,” Hardy said.

At 7 a.m., seven days a week, hospital staffers start logging into the CDS website when they have samples for pickup. Between October and March, Hardy monitors three websites for bad weather in case he has to direct his drivers to alternative routes.

Drivers living throughout Iowa begin the day by picking up

samples at hospitals on the outskirts of the state, then work their way inward to meet other drivers and transfer samples to them. At the end of the day, a few drivers bring all samples in to the company’s headquarters near Des Moines. Samples are scanned, sorted and transported to the state lab for testing by about 11 p.m. Hardy or his son will call the lab if they are going to be more than 20 minutes late. Testing of the blood samples begins as soon as they arrive and continues through the night. The goal is to have any positive screens reported by midafternoon so affected babies can be seen by their doctors that day.

“Timeliness here is everything,” Hardy said. “A commitment level has to be met every night.”

In 2008, Iowa experienced the worst flooding in state history — most of downtown Cedar Rapids was underwater and roads throughout the state were closed. Hardy’s team of courier drivers tacked an additional 800 miles on to the usual 3,500 miles they drive each day, taking detours to reach every hospital.

Similar dedication to timely delivery took place in New Jersey last year during superstorm Sandy when state police retrieved newborn blood samples from hospitals after UPS closed down because of the storm.

Elsewhere, where evidence shows little commitment to timeliness, parents of children who have died or been disabled by a disorder that could have been caught and treated are left wondering how things could have gone so wrong.

Shauna Cooper hasn’t been able to get answers from anyone at Arkansas Methodist Hospital as to what happened with Aiden’s newborn screening sample.

“No one had the nerve to tell me, ‘We lost his newborn screen.’ ” she said.

“You don’t want to lose your child from something that was just a little mistake. If they would have spoke up about it sooner . . . ”

Aiden now attends day care at a facility for children with special needs that is paid for by Medicaid. He works with several therapists each week to improve his speech and ability to do what 3-year-olds do. One day this fall, he practiced walking up and down a series of four wooden steps while a therapist held his hand. He pointed his toes and stepped unsteadily down to the next wooden step. Later, to strengthen his weak core and hands, Aiden wrapped his legs and arms around a red and blue bulb hanging from the ceiling and swung back and forth.

Therapists won’t predict how he will fare in the future.

“You wonder what he would have been like if he hadn’t had the 3½ weeks of poison,” said Annemie Welman, his physical therapist. “You can’t go back and start over.”

Twitter: twitter.com/egabler

Allan James Vestal, John Fauber and Mark Johnson of the Journal Sentinel staff contributed to this report.

Newborn screening across the U.S.

The Milwaukee Journal Sentinel analyzed nearly 3 million screening tests from 31 states in 2012 to see how long it took newborns' blood samples to arrive at labs.


This list is not meant to be a direct comparison between states. Public health officials collect data differently and provided it in various ways. Some states wouldn't release any information.

The Journal Sentinel used five or more days as a metric for lateness in most states, as that period is considered unacceptable by many lab directors. Guidelines commissioned by the federal government recommend three or fewer days.

To read more, go to jsonline.com/deadlydelays/methods

Total newborn screening samples: 2,966,720

Total samples delayed: 160,732 (5.42%)

 = NO DATA PROVIDED	THRESHOLD FOR LATENESS	SAMPLES TESTED	SAMPLES LATE	PERCENTAGE LATE
Alabama				
Alaska	6+ days	10,966	575	5.24%
Arizona	5+	77,995	12,986	16.65
Arkansas				
California	5+	481,388	11,367	2.36
Colorado				
Connecticut				
Delaware	5+	11,411	31	0.27
District of Columbia				
Florida	6+	252,834	8,689	3.44
Georgia	6+	148,480	7,033	4.74
Hawaii	6+	18,812	99	0.53
Idaho	5+	21,882	2,785	12.73
Illinois	6+	174,409	1,204	0.69
Indiana	6+	82,514	6,200	7.51
Iowa	5+	37,737	67	0.18
Kansas				
Kentucky				
Louisiana				
Maine	5+	12,284	362	2.95
Maryland				
Massachusetts	5+	72,282	1,468	2.03
Michigan	5+	110,550	1,305	1.18
Minnesota	4+	66,986	1,300	1.94
Mississippi	5+	38,397	5,556	14.47
Missouri	5+	65,752	7,586	11.54

Montana				
Nebraska				
Nevada	6+	34,367	1,528	4.45
New Hampshire				
New Jersey				
New Mexico	6+	24,671	850	3.45
New York	5+	262,308	13,126	5.00
North Carolina				
North Dakota	5+	11,127	238	2.14
Ohio	6+	139,418	1,450	1.04
Oklahoma				
Oregon	5+	43,497	2,934	6.75
Pennsylvania	5+	144,557	8,516	5.89
Rhode Island	5+	11,561	67	0.58
South Carolina				
South Dakota	5+	12,498	235	1.88
Tennessee				
Texas	5+	374,019	54,426	14.55
Utah	5+	50,845	4,758	9.36
Vermont	5+	5,481	146	2.66
Virginia				
Washington	5+	107,433	2,076	1.93
West Virginia				
Wisconsin*	5+	60,259	1,769	2.94
Wyoming				

*Wisconsin provided one year of data from March 2012 through February 2013. Lab officials said data from all of 2012 is not available because of a change in computer systems.

Reporting and data analysis: **ELLEN GABLER**/egabler@journal sentinel.com; Journal Sentinel reporting: **ALLAN JAMES VESTAL**/ajvestal@journal sentinel.com

Secrecy clouds efforts to track newborn blood tests

Babies suffer preventable harm due to states' scattershot approach



MARK F. CONRAD / FOR THE JOURNAL SENTINEL

Patrick O'Connor plays with his son Peter, 6½, at home in Darien, Conn. Peter's newborn screening test was lost in 2007, leading to a 99-day delay in doctors diagnosing him with congenital hypothyroidism. Thyroid hormones are crucial for growth and brain development. Peter has significant developmental delays as a result.

By **ELLEN GABLER**
egabler@journalsentinel.com

Darien, Conn. — For the first 99 days of his life, no one knew why little Peter O'Connor was so sick. He wasn't growing. His eyes wouldn't track. His skin was cold.

Doctors should have known within his first week of life that the baby didn't have a functioning thyroid gland, which produces hormones crucial for growth and brain development. Since the 1970s, a routine blood test for newborn babies has alerted doctors to the condition, which is easily treated with a daily dose of thyroid hormone.

It should have been that way for Peter.

"Doctors said you'd have to go to a Third World country to find a child who hadn't been diagnosed for this long."

Patrick O'Connor,
Peter's father

routine procedure it should be to quickly diagnose and treat infants with genetic disorders. Thousands of hospitals send blood samples late to state labs; labs in half the country are closed on weekends; and many hospitals and labs fail to follow guidelines and regulations meant to make newborn screening effective. There is often little oversight of the process and no consequences for hospitals or labs that perform poorly.

As a result, children who should be diagnosed and treated shortly after birth are suffering preventable brain damage, disability and even death — as if they had been born decades before today's screening tests and treatments were available.

The Journal Sentinel's investigation was based on an analysis of nearly 3 million newborn screening samples from 26 states. Connecticut was one of 24 states that refused to release data on how long it took specific hospitals to send samples to state labs. // // //

In December, health officials in Connecticut, Maryland and New Hampshire finally released the information, revealing more hospitals that have failed to quickly send in babies' blood tests. In Connecticut, nearly 8% of blood samples arrived at the lab six or more days after they were collected. At three hospitals, more than 30% of samples were that late. The state only provided data for six or more days, not the three-day delivery time-frame recommended by federal guidelines.

In the remaining 21 states and the District of Columbia, parents have no way of knowing if the hospital where their baby will be born handles newborn screening tests in a timely manner. It was Katrina O'Connor who first thought to ask about her son's newborn screening test 93 days into his ordeal.

Peter spent his first 3½ months in and out of the hospital. For nearly all that time, the baby was tethered to oxygen as doctors and his parents tried to figure out what was wrong.

The newborn screening test would have quickly alerted Peter's doctors that he has congenital hypothyroidism, a condition that affects about 1 in every 3,000 to 4,000 newborns.

Peter is essentially missing the butterfly-shaped organ located at the base of most people's necks. Without the proper amount of thyroid hormone, a child's body and brain don't develop normally.

Decades ago, children with the condition usually suffered significant brain damage before they were diagnosed and treated. But since the 1970s, when states began screening babies for the disorder, those affected go on to lead typical and healthy lives because they start receiving hormone treatments within the first week or two after birth, before brain damage occurs.

Peter's parents remember what the neurologist said after their son was finally diagnosed: "There is a profound likelihood there was neurological damage."

"You hear something like this and you never forget it," said Patrick O'Connor, Peter's father.

Now 6½, Peter O'Connor is an expressive little blond-haired boy who likes blocks, dinosaurs and wrestling with his two big brothers. But the neurological damage he suffered in his first three months of life has left him significantly behind his peers in most everything.

His speech is difficult to understand, and he has a hard time with motor skills, from running and zipping his coat to brushing his teeth and buttoning his pants. His grip is weak; his movements clumsy.

In his kindergarten classroom, Peter requires an aide and receives speech, physical and occupational therapy, as well as social support from a school psychologist.

He is terrified by simple things most children his age understand. A siren from down the street can have him in tears. Earlier this month, a tree branch moving slightly in the wind at a Christmas tree farm sent him into hysterics. It's as if his brain isn't able to process what is going on around him, Patrick said.

Earlier this year his parents settled a medical malpractice case against Stamford Hospital, where Peter was born. Neither the O'Connors nor their lawyer, Ernie Teitell, would comment on the lawsuit, citing a confidentiality agreement.

But the O'Connors are worried the same thing could happen to another child if hospitals, state authorities, doctors and parents don't pay more attention to newborn screening.

Patrick believes newborn screening is not taken as seriously as it should be, treated as nothing more than "a compliance issue" at many hospitals.

"It's just a box to check," he said. "What test do you take at your doctor that you don't hear back from?"

Condition: **Congenital hypothyroidism (CH)**

■ **Description:** Affects babies' thyroid gland, a small organ in the lower neck. Babies are unable to produce enough thyroid hormone, a chemical essential for healthy growth and development.

■ **Effects:** Early signs include jaundice, constipation, weak muscle tone, swelling around the eyes, swollen tongue, hoarse-sounding cry and delayed growth. Delayed treatment can put children at risk for intellectual disabilities, learning disabilities, developmental delays and delayed growth.

■ **Treatment/solutions:** Babies may need to take L-thyroxine pills, a synthetic thyroid hormone, to replace the natural thyroid hormone that their bodies do not make enough of. Babies may also need to restrict the amount of soy and iron in their diet.

■ **Prevalence:** Affects 1 in every 3,000 – 4,000 babies born in the U.S.

STATES RELEASE SCREENING DATA

With the addition of Connecticut, New Hampshire and Maryland, 29 states have now released hospital-by-hospital newborn screening data to the Milwaukee Journal Sentinel. The remaining 21 states and the District of Columbia have refused to release the information:

Alabama
Alaska
Arkansas
Colorado
District of Columbia
Hawaii
Kansas
Kentucky
Louisiana
Montana
Nebraska
Nevada
New Jersey
New Mexico
North Carolina
Oklahoma
South Carolina
South Dakota
Tennessee
Virginia
West Virginia
Wyoming

For a list of lab directors and other officials to contact about newborn screening programs in each of the states, go to jsonline.com/checkyourstate.

Systems vary by state

Stamford Hospital said in a statement it has in place “rigorous procedures to ensure compliance with the newborn screening process,” a response to the “tragic situation involving Peter O’Connor more than six years ago.”

The hospital said it verifies each step related to newborn screening, including timely collection of blood samples, shipping to the state lab and receipt of reports from the lab. The hospital also said it has extensive, ongoing training for all staff who are involved with newborn screening to make sure they understand the entire system.

In 2012, Stamford Hospital had almost 98% of babies’ blood samples arrive at the lab within five days. However, that means that 49 blood samples still took six or more days to reach the lab after being collected.

New Hampshire used the same cutoff in reporting its newborn screening data. In that state, almost 97% of samples arrived at the lab within five days of being collected.

Five days is considered by many experts to be an exceedingly long time for samples to reach labs because an infant could be well over a week old before results are available — too late for babies with certain disorders. The babies often appear healthy at birth but can become extremely sick, or die, within days, so timeliness is critical.

Several states are now making an effort to have hospitals meet standards recommended in 2005 by a newborn screening committee created by the U.S. Department of Health and Human Services. That standard recommends that all blood samples take no more than three days to arrive at a lab for testing after they have been collected.

That will be the new goal in Maryland.

Earlier this year, Maryland health officials said they did not track the timeliness of newborn screening samples so they could not release information to the Journal Sentinel.

In September, in response to the newspaper’s inquiries, the health department began a quality improvement initiative to inform Maryland hospitals about the need to improve the timeliness of sending babies’ blood samples to the state lab for testing.

State officials now have a goal of making sure 90% of babies’ blood samples reach the state lab within three days of collection. In the first six months of this year, 67% of samples met that mark, according to a Journal Sentinel analysis of newly released data from Maryland.

The same measure is being targeted in Arizona. Will Humble, director of the Arizona Department of Health Services, said he wants 95% of all newborn screening samples to reach the state lab within three days of when they were collected. Last year in Arizona, nearly 17% of samples took five or more days to get to the state lab for testing.

The Journal Sentinel found that Iowa and Delaware were the only states that met the three-day turnaround time for 99% of blood samples last year.

Many state lab and health officials don’t notify hospitals unless samples have taken seven, 10 or even more days to arrive after collection.

When contacted by the Journal Sentinel, hospitals said they were unaware of their performance because state labs had not given them feedback.

Health officials in dozens of states have made specific plans to improve their newborn screening programs, from keeping labs open on weekends to identifying problem hospitals and providing them with regular performance reports. National advocacy organizations, trade groups for state labs and U.S. senators from both parties have also promised reforms within the past month.

The Association of Public Health Laboratories is leading an effort to collect information on how each state tracks newborn

screening samples, which can then be used to improve state systems.

In Iowa — which has one of the most comprehensive and effective newborn screening programs in the country — the state lab is updating its tracking system using open-source software so that other states can duplicate the Iowa system for little cost.

“If you don’t have a tracking system, the lab doesn’t know they didn’t receive the specimen. The hospital doesn’t know it wasn’t received,” said Stanton Berberich, program manager at Iowa’s State Hygienic Laboratory.

Hospital staff overseeing newborn screening can generate reports to look up the status of samples received by the lab, check results for individual patients, run quality control reports and review “turnaround statistics” to see how quickly samples get to the lab and results to the hospital.

“It provides a protection for the babies and helps the hospitals’ systems be more efficient as well,” Berberich said.

Difficulties after birth

Katrina held Peter for about 15 minutes shortly after he was born in 2007. The baby had rosy cheeks and resembled his oldest brother, Will, except with his own look: surprisingly blond hair, a cowlick already visible in the yellow fuzz.

Doctors said he was having trouble breathing, maybe just fluid in his lungs from birth. Soon he was in neonatal intensive care. Peter stayed at Stamford Hospital for the next month. Oxygen levels in his blood were low, and he just wasn’t thriving. He was sleepy most of the time and his skin felt rough.

At the end of September, Peter was transferred to Yale-New Haven Hospital. The baby underwent dozens more tests. Doctors thought he might have a condition where the tissue between his lungs wasn’t quite developed. The O’Connors contacted a doctor in Texas who was an expert in these conditions. He agreed to have his team review the case.

In mid-October, Peter was sent home. The plan was to have the baby get a little bigger and stronger before doing more invasive tests.

Patrick and Katrina brought their son home with tanks of oxygen in their car. Medical tubing wound throughout their home, connecting to an oxygen compressor in Peter’s bedroom. The baby needed to breathe oxygen through a tube in his nose at all times, even during his baths. The family dog, a golden retriever named Grady, had to go.

In mid-November, Peter was scheduled for a lung biopsy so doctors could determine why he was having trouble breathing. The night before the surgery, Patrick had been at Mass with the two older boys and called Katrina on his way home.

“Father Frank and Father Chris are coming to baptize Peter,” he said.

The priests arrived with the huge brass baptismal font that usually sat near the altar at church. Peter was baptized that night in the family’s living room.

The lung biopsy was the next day. Peter had trouble waking up from the anesthesia and was put into intensive care. He was discharged two days later, but at home again, he got sicker.

Katrina noticed his head wasn’t growing. He had barely any muscle tone and wouldn’t smile.

The doctors in Texas were studying part of the tissue from Peter’s lung biopsy. A young pathologist called his parents and said she thought Peter might have a metabolic issue. They had seen lung tissue like this once before in a child who didn’t have a thyroid gland.

Katrina thought about the newborn screening test she believed all three of her boys had received. She knew it tested for metabolic disorders. She called the pediatrician’s office on Nov. 29, 2007. Peter was just over three months old. The test wasn’t in his medical file. But Peter had been so sick, trans-

ferred to so many different hospitals and units, she thought it probably had just been separated from his other paperwork.

That was a Thursday. The doctor's office said it would take a new blood sample from Peter but would wait until Monday, since the state lab is closed on weekends and the sample wouldn't be tested on the weekend anyway.

A few days later Peter was back in the hospital. He had a cold, then a respiratory infection. Again, he got sicker.

As Patrick was changing Peter's clothes, the baby stopped breathing. Monitors rapidly beeped and his room was flooded with nurses and doctors. Patrick called Katrina at home. A friend who was delivering a plate of fried chicken had just walked in their door. Katrina left her with the other two boys and drove 40 minutes to the hospital.

Peter was intubated — a tube inserted down his throat — when Katrina got to the hospital. Over the next few days, nurses took blood from the baby several times to run more tests. Katrina asked them to do a thyroid screen. A few hours later she was on her cellphone down the hall when Patrick beeped in on the other line. She needed to come back to Peter's hospital room.

At least 10 doctors and nurses were crammed into the room. They went down the line, introducing themselves. The last three doctors were endocrinologists.

"It's his thyroid, right?" Katrina remembers asking.

"We don't even think he has a thyroid," a doctor replied.

Tests showed that Peter had virtually no thyroid hormone in his body. Infants with his condition are usually quickly given replacement hormones to supplement what their bodies can't naturally produce.

Treatment started immediately, but doctors weren't sure he would survive. Family and friends came to the hospital and gathered by his bed.

Within 10 days, Peter had improved significantly. His cheeks became rosy again, his skin soft and white like when he was first born. He started smiling and making eye contact. His head started growing.

"I remember thinking I was so happy that his brain was growing," Katrina said. "But then it would remind me that it hadn't been growing."

About two weeks after Peter was diagnosed, he was able to go home. Each day, Patrick and Katrina gave him hormone replacements by crushing a pill into his formula and feeding it to him with a dropper.

He was still on oxygen but started physical therapy with an in-home therapist within a few weeks, working on holding his head up and rolling over.

Therapy, doctor's appointments and daily treatments have been Peter's life ever since. His parents and doctors don't know his ultimate prognosis.

"Doctors said you'd have to go to a Third World country to find a child who hadn't been diagnosed for this long," Patrick said.

Database

www.jsonline.com/checkyourstate

JOURNAL SENTINEL



DATA



DEADLY DELAYS | A JOURNAL SENTINEL WATCHDOG REPORT

Newborn screening programs, state by state

Published Nov. 16, 2013 | Newborn babies are tested for genetic disorders before they leave the hospital. Affected babies often appear healthy at birth but can become sick within days. Early detection and treatment can prevent brain damage, physical disabilities and death.

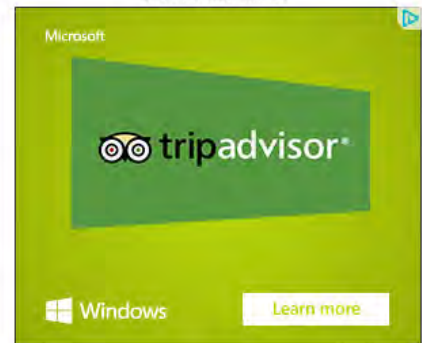
Newborn screening saves lives when it works. But sometimes, there are deadly delays.

Blood samples are lost or not sent from hospitals in a timely manner; labs in some states are closed on the weekends; shipping regulations vary so samples aren't sent by courier or overnight mail.

Newborn screening programs are different throughout the United States. The Milwaukee Journal Sentinel requested data from all states. In 26 states, you can see how specific hospitals performed. Others refused to provide information. [How states measure up »](#)

Related Story: [Delays at hospitals across country undermine newborn screening programs](#)

ADVERTISEMENT

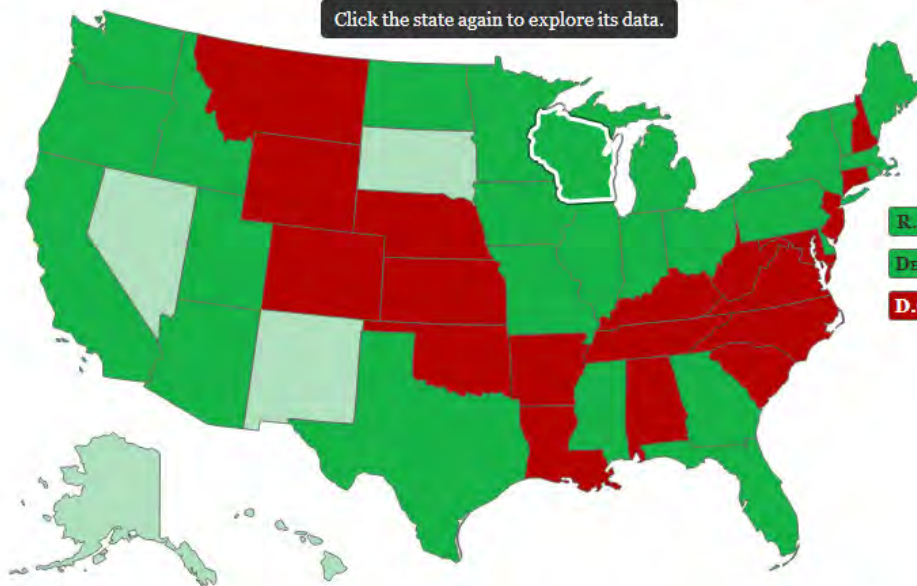


View: [Type of information released](#) / [Delivery guidelines](#) / [When labs are open](#)

UNDER PUBLIC RECORDS LAWS, REPORTERS SOUGHT DATA ABOUT HOW QUICKLY BLOOD SAMPLES ARRIVED AT LABS.

■ Hospital-specific information released ■ Statewide totals released ■ No information released

Click the state again to explore its data.



WISCONSIN ✕

The Wisconsin State Laboratory of Hygiene tests samples.

[BROWSE RECORDS](#)

[SEARCH HOSPITALS >](#)

- Hospitals should send samples via courier or express mail
- Testing lab is open Monday-Saturday
- Hospitals should send samples within 24 hours



Newborn screening in Wisconsin

A blood sample is taken from a baby's heel shortly after birth to screen for rare and serious disorders. The sample is supposed to be sent quickly from the hospital to a testing lab for analysis. Some hospitals perform better than others. Explore facilities in Wisconsin below.

[Back to nationwide view](#) / [How states measure up](#)

60,259
samples tested in 2012*

1,769
(2.94%) of samples took 5+ days to reach labs

44
conditions tested in Wisconsin

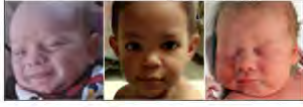
30 FACILITIES
had more than 5 percent of samples reach a lab 5 or more days after they were collected.

[See these facilities »](#)

AN EXAMPLE: From March 2012 to February 2013, **Mile Bluff Medical Center** in Mauston, Wis., had **12.62% of its newborn screening samples** arrive at the lab 5 or more days after they were collected.

That means out of **206 blood samples** sent that year, **26 arrived 5 or more days after** they were collected.

BABIES' STORIES
Read about babies whose lives were saved because of newborn screening and others who experienced serious or deadly delays.



[Read stories »](#) [Share your own »](#)

TAKE ACTION
Do you have questions or concerns about newborn screening in your state?

[Contact Wisconsin officials »](#)

WISCONSIN'S SCREENING PROGRAM
The Wisconsin State Laboratory of Hygiene tests samples.

- Hospitals should send samples by courier, overnight delivery or express mail
- Most samples are sent by courier or UPS, but some hospitals mail them to the lab.
- Testing lab open Monday-Saturday
- Hospitals should send samples within 24 hours of collection

[Wisconsin screening program website »](#)

EXPLORE WISCONSIN'S HOSPITALS

View: [Table](#) / [Map](#)

Published Nov. 16, 2013 | Search the table and map to see how many days it took for samples to arrive at a lab after collection. Initially, facilities have been ranked by the highest percentage of delayed samples.

Search any Wisconsin facility by name or city...

Facility	City	2012 samples*	5+ days	%
Vernon Memorial-La Farge Medical Clinic	La Farge	102	24	23.53%
Berlin Memorial Hospital	Berlin	169	32	18.93%
St. Nicholas Hospital	Sheboygan	285	53	18.60%
Black River Memorial Hospital	Black River Falls	137	25	18.25%
Lakeview Medical Center	Rice Lake	212	36	16.98%
Burnett Medical Center	Grantsburg	42	7	16.67%
Mayo Clinic Health System-Red Cedar Medical Center	Menomonie	249	33	13.25%
Mile Bluff Medical Center	Mauston	206	26	12.62%
Ministry Door County Medical Center	Sturgeon Bay	108	13	12.04%
Mercy Walworth Hospital	Lake Geneva	140	16	11.43%
Theda Clark Medical Center	Neenah	953	107	11.23%
Aurora Medical Center-Kenosha	Kenosha	1,064	119	11.18%
Westfields Hospital	New Richmond	76	8	10.53%
Monroe Clinic Hospital	Monroe	417	41	9.83%
Aurora BayCare Medical Center	Green Bay	1,731	164	9.47%
Hudson Hospital and Clinics	Hudson	612	55	8.99%
Aurora Sinai Medical Center	Milwaukee	2,518	204	8.10%
Aurora Medical Center-Oshkosh	Oshkosh	594	48	8.08%
Aurora Medical Center-Grafton	Grafton	732	53	7.24%
Ministry Howard Young Medical Center	Woodruff	208	14	6.73%

SOURCES: WISCONSIN STATE LABORATORY OF HYGIENE, JOURNAL SENTINEL ANALYSIS

* Wisconsin provided one year of data from March 2012 through February 2013. Lab officials said data from all of 2012 is not available because of a change in computer systems.

The number of conditions screened in each state is based on standardized lists compiled by [BabysFirstTest.org](#) and analyzed by the Journal Sentinel.

WHAT'S INCLUDED

States collect and report information differently, so information may vary between states. This state's data:

- Covers a period from March 2012 to February 2013
- The Journal Sentinel analyzed data for each state. In Wisconsin, lab officials said they could not provide a full year of data from 2012 because they had switched to a new computer system. Instead, they provided one year of data ranging from March 2012 through February 2013.
- Shows facilities with 1 or more births a year
- Includes initial screenings only
- No "unsatisfactory sample" reports

[Our methodology »](#)

30 FACILITIES

had more than 5 percent of samples reach a lab 5 or more days after they were collected.

See these facilities »

Read about babies whose lives were saved because of newborn screening and others who experienced serious or deadly delays.



SCREENING PROGRAM

The Wisconsin State Laboratory of Hygiene tests samples.

Hospitals should send samples by courier, overnight delivery or express mail

Officials to contact

Beyond the release of hospital data, there are many aspects of newborn screening programs where states fall short, including oversight of problem hospitals and lab hours. Here are key state and federal officials involved with newborn screening issues, and how they can be reached.

Charles Brokopp

DIRECTOR, WISCONSIN STATE LABORATORY OF HYGIENE
 (608) 890-1569 | cdb@slh.wisc.edu

Darrell Bazzell

VICE CHANCELLOR, UW-MADISON
 (608) 263-2467 | dbazzell@vc.wisc.edu

Kitty Rhoades

SECRETARY OF HEALTH SERVICES
 (608) 266-9622 | kitty.rhoades@wisconsin.gov

Karen McKeown

ADMINISTRATOR, DIVISION OF PUBLIC HEALTH
 (608) 267-7828 | karen.mckeown@wisconsin.gov

Scott Walker

GOVERNOR
 (608) 266-1212 | govgeneral@wisconsin.gov

Robin Vos

SPEAKER OF THE WISCONSIN STATE ASSEMBLY
 (608) 266-9171 | rep.vos@legis.wisconsin.gov

Scott Fitzgerald

WISCONSIN SENATE MAJORITY LEADER
 (608) 266-5660 | sen.fitzgerald@legis.wisconsin.gov

Peter Barca

WISCONSIN STATE ASSEMBLY MINORITY LEADER
 (608) 266-5504 | rep.barca@legis.wisconsin.gov

Chris Larson

WISCONSIN SENATE MINORITY LEADER
 (608) 266-7505 | sen.larson@legis.wisconsin.gov

Ron Johnson

UNITED STATES SENATOR
 (202) 224-5323 | ron_johnson@ronjohnson.senate.gov

Tammy Baldwin

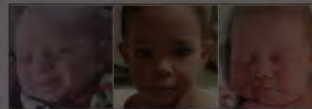
UNITED STATES SENATOR
 (202) 224-5653 | senator_baldwin@baldwin.senate.gov

30 FACILITIES

had more than 5 percent of samples reach a lab 5 or more days after they were collected.

See these facilities »

Read about babies whose lives were saved because of newborn screening and others who experienced serious or deadly delays.



Read stories » Share your own »

SCREENING PROGRAM

The Wisconsin State Laboratory of Hygiene tests samples.

Hospitals should send samples by courier, overnight delivery or express mail

Most samples are sent by courier or UPS, but some hospitals mail them to the lab.

Testing lab open Monday-Saturday

Lakeview Medical Center

1700 W. Stout St.
 Rice Lake, Wis. 54868

Hospitals are supposed to send blood samples to labs within one day after a sample is collected. The analysis below shows how many days it took samples to arrive at a lab.

	2012*	
	THIS HOSPITAL	WIS.
Total samples	212	60,259
5+ days	36	1,769
5+ days %	16.98%	2.94%
0-3 days	118	52,599
0-3 days %	55.66%	87.29%

* Wisconsin provided one year of data from March 2012 through February 2013. Lab officials said data from all of 2012 is not available because of a change in computer systems.

EXPLORE

Published after collection

Search

Facility

Vernon Medical Center

Berlin Memorial Hospital

St. Nicholas Hospital

Black River Memorial Hospital

Lakeview Medical Center

Burnett Medical Center

Black River Falls

Rice Lake

Green Bay

15

25

18,259

36

16.98%

118

55.66%

60,259

1,769

2.94%

52,599

87.29%

212

36

16.98%

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