

A JOURNAL SENTINEL WATCHDOG REPORT

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.



Kristyna Wentz-Graff (mailto:kwentz@jrn.com)/Journal Sentinel

Delays at hospitals across the country undermine newborn screening programs, putting babies at risk of disability and death

By Ellen Gabler (mailto:egabler@jrn.com) of the Journal Sentinel staff

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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.

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.



YALONDA M. JAMES FOR THE JOURNAL SENTINEL

Aiden Cooper, now almost 3.

“Every day is like a new battle for us.”

Shauna Cooper,
Aiden Cooper's mother

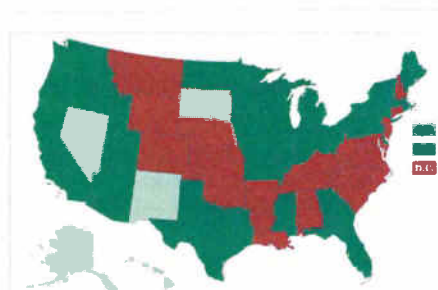
- For nearly 15 years, federal regulators and public health officials have discussed the need to standardize newborn screening systems throughout the country, but little action has been taken beyond increasing the number of conditions tested. Most state-run programs do not follow guidelines issued in 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 practices.


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.

CHECK YOUR STATE



(/watchdog/deadly-delays-newborn-screening-programs-state-by-state-228834411.html)

 **Database:** Newborn screening programs, state by state
(/watchdog/deadly-delays-newborn-screening-programs-state-by-state-228834411.html)

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

Edward McCabe,
chief medical officer, national March
of Dimes

"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, (</watchdog/watchdogreports/Deadly-Delays-Wisconsin-hospitals-sent-newborn-blood-samples-late-state-fought-to-keep-their-performance-hidden-228832311.html>) 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, (</watchdog/watchdogreports/Deadly-Delays-Watchdog-Report-Sons-disability-spurred-researchers-quest-to-create-newborn-screening-test-228832961.html>) 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.

GALACTOSEMIA (GALT)

Inability to metabolize galactose, a type of sugar found in milk.

SIGNS Babies begin to vomit, become lethargic and jaundiced between two days and two weeks after birth.

EFFECTS Untreated, the disorder can lead to liver damage, blood infection, brain damage, developmental delays and death.

TREATMENT/SOLUTIONS 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.

📖 **Database:** Learn about the disorders included in newborn screening (</watchdog/deadly-delays-look-disorders-included-newborn-screening-program-228833391.html>)

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.

STEP ONE

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Throughout the country, tens of thousands of samples in dozens of states — from Arizona to New York, Missouri to Texas — 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 were six or more days late. 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.

ARIZONA

Total samples tested in 2012:
77,995

"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 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.

Samples received after five or more days: **12,986 (16.65%)**

 **Database:** Newborn screening in Arizona (/watchdog/deadly-delays-newborn-screening-programs-state-by-state-228834411.html#!/arizona/)

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.



FAMILY PHOTO

Jack Chapman

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.

MCAD DEFICIENCY

Inability to convert some fats they eat to energy. Unused fatty acids build up.

SIGNS Babies have poor appetite, fever, vomiting, sleep longer than normal.

EFFECTS If untreated a baby's blood sugar can drop, plunging them into metabolic crisis that causes brain damage or death.

TREATMENT/SOLUTIONS Restricted diet, L-carnitine supplements.

PREVALENCE Affects 1 out of every 10,000 - 15,000 babies born in the U.S.

Database: Learn about the disorders included in newborn screening (</watchdog/deadly-delays-look-disorders-included-newborn-screening-program-228833391.html>)

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 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.

NEW YORK

Total samples tested in 2012:

262,308

Samples received after five or more days: **13,126 (5%)**

 **Database:** Newborn screening in New York (/watchdog/deadly-delays-newborn-screening-programs-state-by-state-228834411.html#!/new-york/)

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



FAMILY PHOTO

Garrett Saine is placed under blue lights in intensive care to treat his jaundice.

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.



NANINE HARTZENBUSCH FOR THE JOURNAL SENTINEL

Kristin Saine cuddles Garrett in front of their home.

 **Photo Gallery:** Garrett Saine's story (/multimedia/photos/deadly-delays-newborn-screening-programs-garrett-saines-story-b99136932z1-231497011.html)

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.

The North Carolina State Laboratory of Public Health said it was unable to extract data that measures sample transit time.

 **Database:** Contact North Carolina officials and view newborn screening programs, state by state. (</watchdog/deadly-delays-newborn-screening-programs-state-by-state-228834411.html#!/north-carolina/>)

Even though California's screening program provides a prepaid 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.

CALIFORNIA DATA

Facility	City	Year samples	5+ days	%
Sutter Solano Medical Center	Vallejo	1,200	0	0.0%
Maricopa Hospital	Phoenix	50	0	0.0%
Sutter Lakeside Hospital	Lakeport	1,100	0	0.0%
Northern Davis Hospital	Yuba City	1,000	0	0.0%
Kaiser Permanente Regional Hospital	Redwood City	1,000	0	0.0%
Loma Linda University Medical Center	Upland	1,000	0	0.0%
Palmdale Medical Center	Palmdale	1,000	0	0.0%

(/watchdog/deadly-delays-newborn-screening-programs-state-by-state-228834411.html#!/california/)


Database: Newborn screening in California (/watchdog/deadly-delays-newborn-screening-programs-state-by-state-228834411.html#!/california/)

TEXAS

Total samples tested in 2012:
374,019

Samples received after five or more days: **54,426 (14.55%)**

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.

 **Database:** Newborn screening in Texas (/watchdog/deadly-delays-newborn-screening-programs-state-by-state-228834411.html#!/texas/)

"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.

WHAT THE TEST COSTS

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.

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 ..."



YALONDA M. JAMES FOR THE JOURNAL SENTINEL

Aiden walks down a few steps as he works with physical therapist assistant Heather Beshiers. Now nearly 3, he has weak hands and

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."

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

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core muscles, difficulty speaking and other developmental delays.

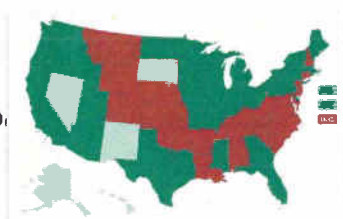
🖼️ **Photo Gallery:** Aiden Cooper's story (</multimedia/photos/deadly-delays-aiden-coopers-story-b99131825z1-231495451.html>) |

🎥 **Video:** Aiden at physical therapy (</multimedia/video/?bctid=2838506180001>)

DEADLY DELAYS

- Lack of weekend lab hours adds to delay, putting babies at risk (</watchdog/watchdogreports/Deadly-Delays-Watchdog-Report-More-than-half-of-state-labs-do-not-process-newborn-samples-on-weekends-creating-critical-delays-in-the-process-228832381.html>)
- Wisconsin hospitals sent samples late; state fought

CHECK YOUR STATE



See how states compare, search hospitals (</watchdog/deadly-delays-newborn-screening-programs-state-by-state-228834411.html>)

BABIES' STORIES



Read more stories, share your own (</watchdog/deadly-delays-lives-saved-tragic-delays-babies-stories-from-around-country-228833661.html>)

to keep
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- Colton Hidde: A late test, a
 life in jeopardy
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- How we reported this story
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