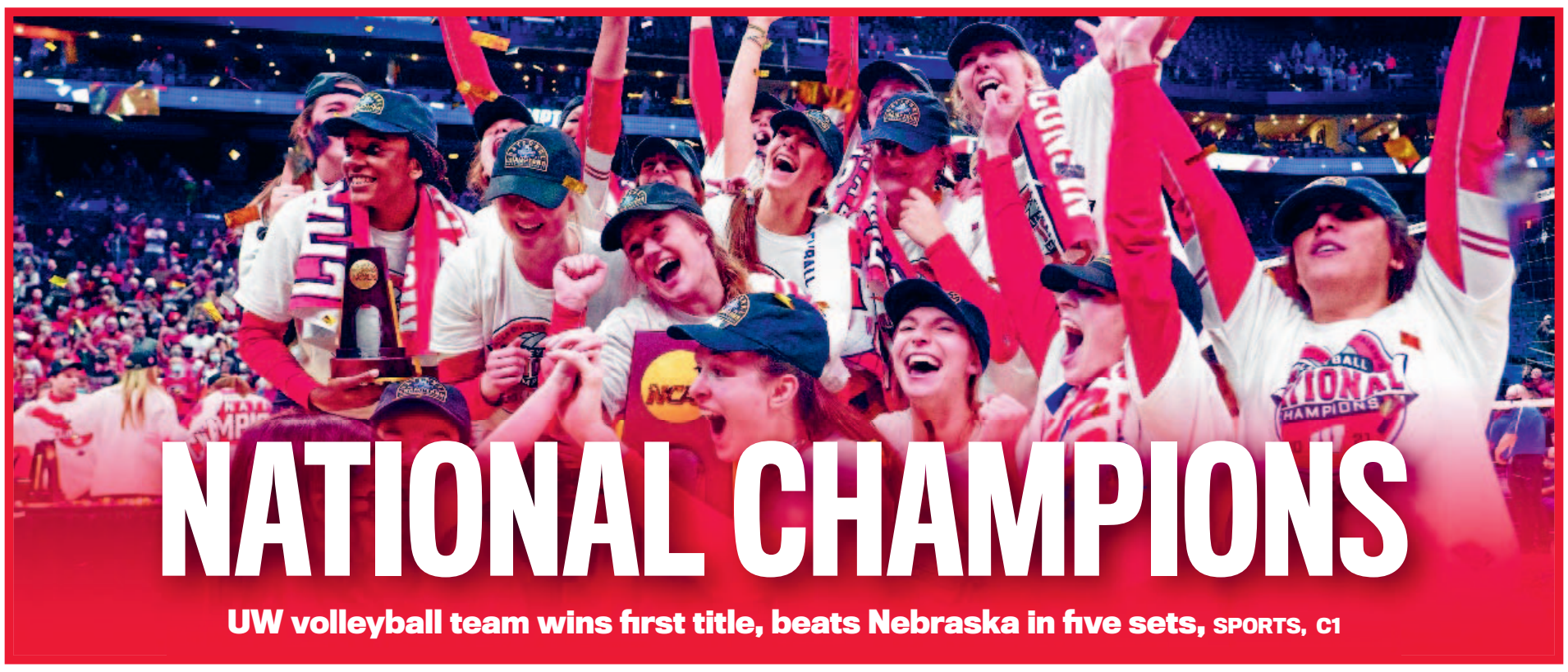
SUNDAY
STATE JOURNAL



NATIONAL CHAMPIONS

UW volleyball team wins first title, beats Nebraska in five sets, SPORTS, C1

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NO TIME TO LOSE | FINDING RARE DISEASES IN INFANTS

AMBER ARNOLD, STATE JOURNAL

Kyle and Jenna Heckendorf, of Spring Green, with children Carter, 6, and Ava, 2, look at photos of Bryce, the couple's first child, who died at 18 months old from a rare disorder called Krabbe disease. Ten states test newborns for Krabbe, allowing parents to seek early treatment. Wisconsin has twice rejected screening for Krabbe. "I wouldn't want any other family to have to go through that, because it was devastating," Jenna Heckendorf said.

Screening for newborns not equal among states

Wisconsin parents have lost children who went untreated

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With blue eyes and a tuft of blond hair, Jenna and Kyle Heckendorf's first child, Bryce, seemed healthy, smiling and giggling during a family vacation at a lake resort.

But shortly after he turned 5 months old, he started eating less. His arms and legs became rigid. When placed on his stomach, he would wail.

He was diagnosed with Krabbe disease, an inherited disorder that causes muscle weakness and other problems, typically becoming fatal by age 2.

"They handed us tissues and said, 'We'll help you keep him comfortable as he passes away,'" said Jenna Heckendorf, a teacher from Spring Green, whose son died at 18 months old seven years ago after being on a feeding tube

Please see **SCREENING**, Page A6

About this series

Today: Wisconsin doesn't screen newborns for some disorders, which can lead to disability and death.

Monday: Testing and treatment have greatly improved the outlook for people with a rare muscle disease.

Tuesday: Doctors are increasingly turning to DNA sequencing to explain conditions missed by screening.

Many hospitals send screening samples late

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Colton Hidde can put his pants on, but he hasn't figured out shirts. When eating, he uses an adaptive high chair. The 9-year-old speaks only a few words, including "ish" for "fish."

A delayed newborn screening test in 2012 left the boy brain-damaged before doctors could diagnose and treat him for argininosuccinic aciduria, or ASA, a rare genetic disorder in which ammonia builds up in the body, according to a lawsuit filed by his parents.

Colton's younger brother, 4-year-old Christian, was also born with ASA

Please see **SAMPLES**, Page A8

2020 ELECTION
AN AP ANALYSIS

Fraud too rare to affect outcome

Disputed votes 0.15% of battleground edge

CHRISTINA A. CASSIDY
Associated Press

An Associated Press review of every potential case of voter fraud in the six battleground states disputed by former President Donald Trump has found fewer than 475 — a number that would have made no difference in the 2020 presidential election.

Biden

Trump

Democrat Joe Biden won Arizona, Georgia, Michigan, Nevada, Pennsylvania and Wisconsin and their 79 Electoral College votes by a combined 311,257 votes out of 25.5 million ballots cast for president. The disputed ballots represent just 0.15% of his victory margin in those states.

The cases could not throw the outcome into question even if all the potentially fraudulent votes were for Biden, which they were not, and even if those ballots were actually counted, which in most cases they were not.

The review also showed no collusion intended to rig the voting. Virtually every case was based on an individual acting alone to cast additional ballots.

The findings build on a mountain of other evidence that the election wasn't rigged, including verification of the results by Republican governors.

The AP review, a process that took months and encompassed more than 300 local election offices, is one the most comprehensive examinations of

Please see **2020 VOTE**, Page A12

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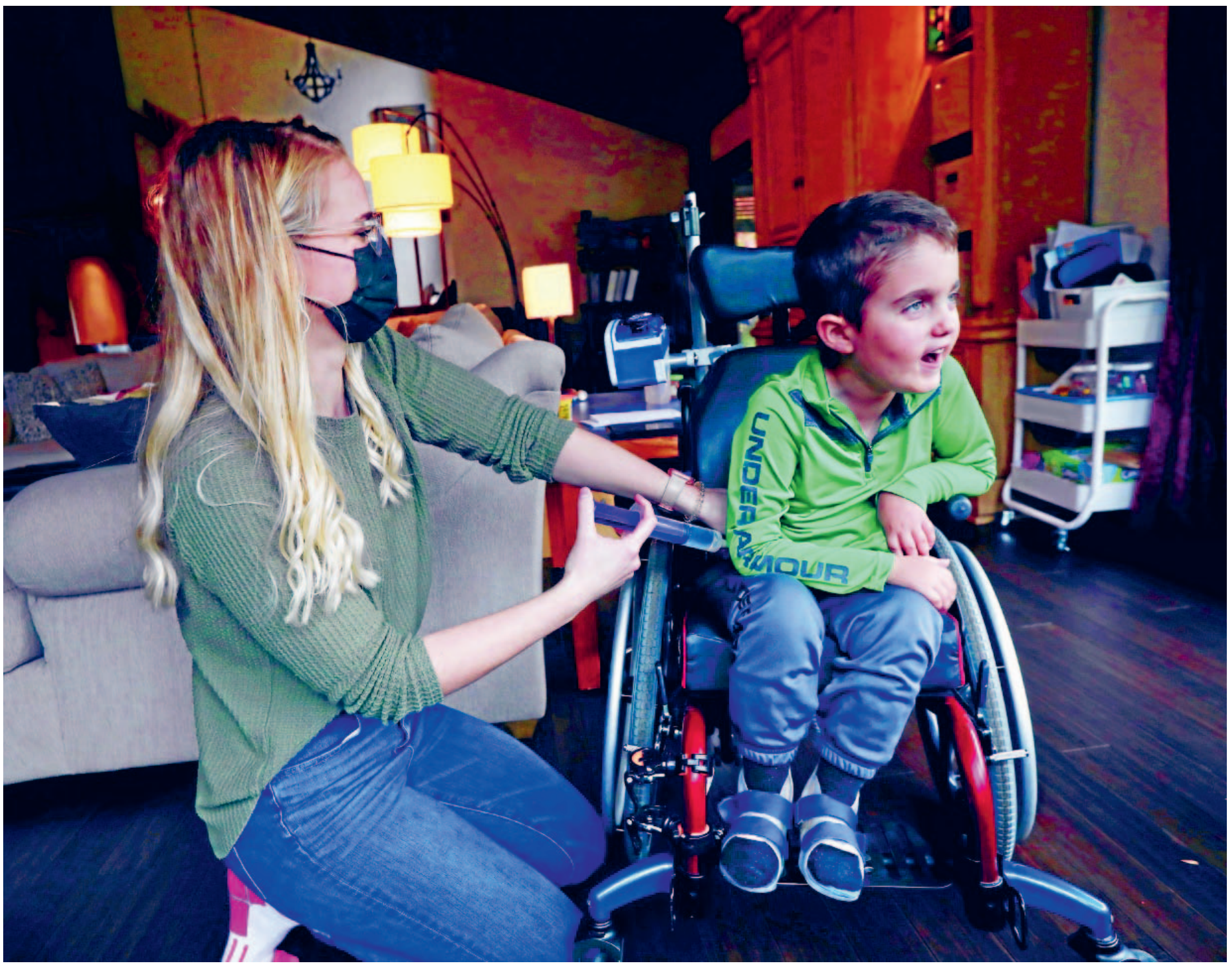


AMBER ARNOLD, STATE JOURNAL

Atlas Faucher, 5, of Oshkosh, with nurse Cassidy Pethke, was born with a rare condition called Pompe disease. Wisconsin doesn't test newborns for Pompe as 27 states do, and Atlas wasn't diagnosed until he was nearly 4 months old, preventing early treatment that could have prevented many disabilities. The state in May 2020 approved screening for Pompe, which is scheduled to begin Jan. 10.

Screening

From A1

and an oxygen machine.

Ten states test infants for Krabbe (pronounced crab-AY), using a few drops of blood collected from their heels a day or two after birth for routine newborn screening. Families whose babies have the condition can try stem cell transplants, which studies show can lead to longer and more normal lives if done within 30 days, before symptoms appear.

Wisconsin has twice rejected adding Krabbe to its newborn screening program. State officials say it's not clear how babies would be sent out of state to the few centers that do the risky transplants for infants with the condition. A bill before the state Legislature would circumvent Wisconsin's scientific committee process for evaluating conditions and require the state to test babies for Krabbe.

"We wish we would have had that option," Heckendorf said of a transplant. "It gives you hope … versus being told there's nothing you can do."

Nationwide, newborn screening has tested babies for rare diseases that are unnoticeable at birth but treatable since the mid-1960s, with some states checking for only a few disorders in the initial decades and others detecting many. Despite a federal effort to make testing more consistent in 2010, states still choose which conditions to add, and considerable variation remains.

Connecticut screens for 73 diseases, while Hawaii looks for 28, according to the federal Health Resources and Services Administration, or HRSA. California and Tennessee test for 67 disorders, while Louisiana does 30 and Alabama, Arizona and Arkansas do 31, the agency says. Wisconsin's panel includes 47 disorders.

Debates over cost, the prevalence and severity of an illness, the effectiveness of treatments and false positive results account for much of the disparity, said Natasha Bonhomme, director of Baby's First Test, a newborn screening education center in Washington, D.C. Some states require legislative approval to add conditions, and others rely on doctors, with varying levels of public input.

Bonhomme

States name and count some conditions differently, so the magnitude of differences is hard to pin down, Bonhomme said.

"If you see one state is screening for 30-some conditions and another state is screening for 60-some conditions, the variation may not actually be a difference of 30 but there is going to be a difference," Bonhomme said.

Federal recommendations

In 2010, the federal government adopted a Recommended Uniform Screening Panel, or RUSP. It currently lists 35 conditions states should screen for and 26 other disorders that can be picked up when testing for the core group.

"We continue to push for states to definitely provide all 35 of the core screenings," said Stacey Brayboy, a senior vice president at the March of Dimes, which has long promoted newborn screening.

Some disorders on the list are relatively well known, such as cystic fibrosis and sickle cell disease, but most are unfamiliar and have complicated names. With most, each parent is an unaffected carrier — usually, unknowingly — and each of their children has a 25% chance of getting the disease.

The prevalence of the conditions ranges from roughly 1 in 3,000 babies to 1 in 300,000. Combined, when hearing loss is included, about 1 in 300 newborns, or nearly 13,000 U.S. babies a year, has one of the disorders.

The diseases typically can be treated with special diets, therapies such as enzyme infusions or procedures such as stem cell transplants. In most cases, doctors say early treatment is essential to prevent death or disability.

In a storage chest in their bedroom, Kyle and Jenna Heckendorf of Spring Green keep belongings of their late son Bryce, including his favorite book, "Commotion in the Ocean." They have donated copies of the book to UW Health's American Family Children's Hospital, where Bryce received much of his care. With them is daughter Ava, 2.

Jenna and Kyle Heckendorf have nearly a dozen photo albums and scrapbooks showing their son Bryce's life before he died at 18 months old from Krabbe disease. "I put every photo I have of Bryce in an album," Jenna said.

Born with Pompe disease, an inherited disorder that impacts muscles and organs, especially the heart, Atlas Faucher of Oshkosh gets physical therapy, occupational therapy, speech therapy and breathing treatments, which are mostly covered by Medicaid.

Missing early treatment

Wisconsin screens for 32 of the 35 core conditions. The state doesn't test for Pompe disease, which disables the heart and skeletal muscles, and was added to the RUSP in 2015. It doesn't screen for mucopolysaccharidosis type 1, or MPS 1, a disease that affects many parts of the body, or X-linked adrenoleukodystrophy, also called X-ALD, which gained attention in the 1992 film "Lorenzo's Oil." Both were added to the RUSP in 2016.

Twenty-seven states screen for Pompe, 26 test for MPS 1 and 22 look for X-ALD, according to NewSTEPs, a resource center run by the Association of Public Health Laboratories.

The Wisconsin Department of Health Services approved adding Pompe (pom-PAY) in May 2020, and the testing is scheduled to begin Jan. 10. Committees are looking at adding X-ALD and have discussed MPS 1, but for now aren't pursuing it.

In a pilot project, Wisconsin screened babies for Pompe from July 2017 to March 2019. No cases of the severe infantile form of the disease were found, but 13 babies were identified as having a less-serious, later-onset form. The state has more than 60,000 births a year.

Faucher

In June 2016, Genevieve and Austin Faucher of Oshkosh welcomed their first child, Atlas. He seemed fragile and floppy, which doctors attributed to being born five weeks early. When the boy developed a persistent cough, his mother demanded a chest X-ray.

The scan found a significantly enlarged heart. Atlas, by then nearly 4 months old, was taken by helicopter to Children's Wisconsin hospital near Milwaukee, where six days later tests revealed he had infantile Pompe. He started on an enzyme therapy that can slow the worsening of symptoms, but it doesn't reverse deterioration that already occurred.

Please see SCREENING, Page A7

Screening

From A6

"That's months of (disease) progression, of damage that he can't get back," Genevieve Faucher said.

Atlas, 5, is fed through a tube and uses a wheelchair. He speaks in muffled words that can be hard to understand. Seven nurses rotate caring for him on weekdays, and his working parents handle weeknights and weekends.

Since he is susceptible to complications from infections, Atlas attends kindergarten online. He receives physical therapy, occupational therapy, speech therapy and breathing treatments, which are mostly covered by Medicaid. A fan of the Disney movies "Aladdin" and "Cinderella," he likes to spin his wheelchair on the family's hardwood floors to the soundtrack of the 2020 film "Zombies 2."

With a 3-year-old sister and an 18-month-old brother who don't have Pompe, comparisons are hard to accept. When his brother took his first steps, "Atlas got so mad, he started yelling at him and said, 'You're not allowed to walk,'" their mother said.

Atlas' future, and longevity, are "a big old question mark," Faucher said.

If Pompe had been part of newborn screening when Atlas was born, he could have started treatment earlier and almost certainly would have fewer disabilities, she said. For babies born with the condition today, "it could literally save people like Atlas' lives," she said.

In Wisconsin, experts appointed by the state health department vote on adding conditions to newborn screening before consideration by a larger committee that meets twice a year.

Another panel, the Secretary's Advisory Committee on Newborn Screening, considers nine criteria, including how accurate tests are and whether treatment is readily available, before making its recommendation to the health department. The department's rulemaking process to add a condition can take 30 months, spokesperson Jennifer Miller said.

Baker

Newborn screening is considered mandatory in all states, though in Wisconsin and many states parents can opt out for religious beliefs or personal convictions. About 99% of babies in the state are screened, said Dr. Mei Baker, co-director of newborn screening at the Wisconsin State Laboratory of Hygiene.

Positive results typically require follow-up testing to confirm a diagnosis, Baker said. False positives can alarm parents, and treatments need to be effective enough to justify early identification of the disease, she said.

"If you list a condition, you also attach an obligation," Baker said.

Krabbe screening

New York was the first state to start screening for Krabbe, in 2006, after former Buffalo Bills quarterback Jim Kelly's son, Hunter, died from the condition the previous year. Missouri added Krabbe to newborn screening in 2012, followed by Kentucky and Ohio in 2016, Tennessee and Illinois in 2017, New Jersey in 2019, Indiana in 2020 and Pennsylvania and Georgia this year, according to the nonprofit Hunter's Hope, started by Kelly.

When Wisconsin first refused to add Krabbe in 2016, state experts said there were too many false positives, and stem cell transplants weren't clearly effective. The federal committee overseeing the RUSP voted against adding Krabbe seven years earlier for similar reasons.

During Wisconsin's second review of Krabbe last year, the secretary's advisory committee said testing had improved, with the false positive rate "near zero." A stem cell transplant still "does not fully treat or cure the disease," according to the committee, which said only a few centers do transplants for babies with Krabbe, notably Duke University in North Carolina.

This February, health department Secretary Karen Timberlake ruled against adding Krabbe, saying follow-up procedures and referral centers need to be identified. In July, Hunter's Hope re-nominated Krabbe at the federal level. The review process could take at least a year.

Kurtzberg

Dr. Joanne Kurtzberg, who has done 57 stem cell transplants for Krabbe at Duke since 1996, published a paper on the earliest patients in 2018. The report said 79% were alive 10 years after the procedures and those transplanted before 30 days moved, spoke and fed better than those transplanted later.

In an interview, Kurtzberg said about a third of the patients end up needing a wheelchair, another third walk with difficulty and another third are minimally impaired, including a 17-year-old who takes dance classes. "If you met her on the street, you would never know," she said.

Early this year, Dr. Kristin Page, who trained under Kurtzberg, moved to the Medical College of Wisconsin near Milwaukee. Page has had "preliminary conversations" about starting stem cell transplants for Krabbe, said Evan Solocheck, a spokesperson for the affiliated Children's Wisconsin hospital.

A difficult life

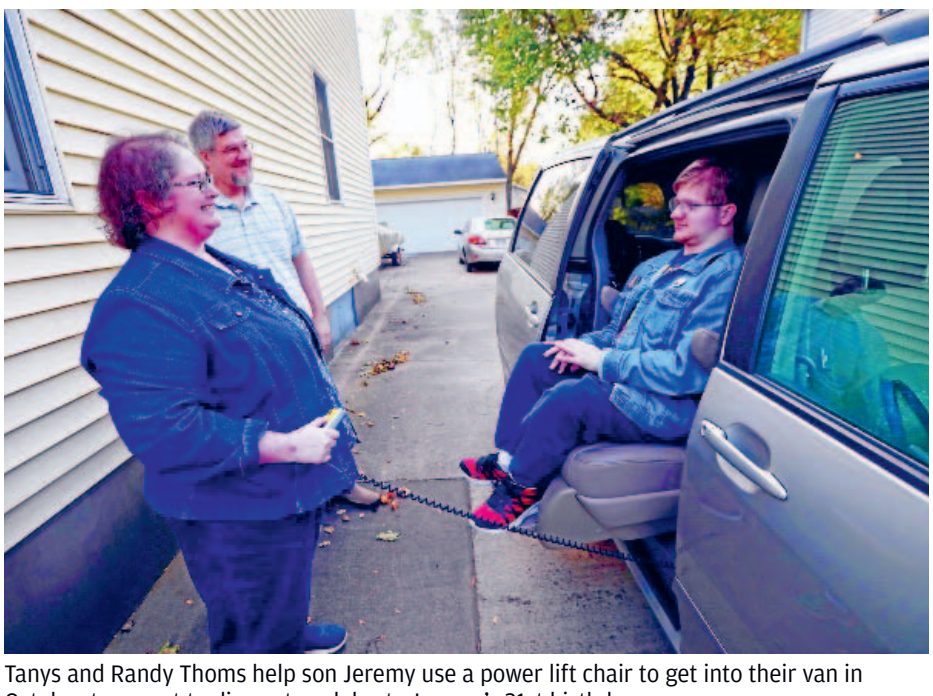
Toys, blankets and pillows, including one stuffed with their son's hair, are strewn across a hospital bed in Judy and Kevin Cushman's living room in Wisconsin Rapids.

AMBER ARNOLD PHOTOS, STATE JOURNAL

Kevin and Judy Cushman, of Wisconsin Rapids, lost their son Collin in January 2019 at age 8 to a rare disorder called Krabbe disease. The Cushmans met with state Sen. Patrick Testin, R-Stevens Point, who introduced a bill to require Wisconsin to screen babies for Krabbe. The state has twice rejected such testing. Babies with the condition can receive stem cell transplants. "It gives parents a choice," Kevin Cushman said.

Jeremy Thoms, 21, likes to joke with his parents, Tanys and Randy Thoms, and play-fight with his plastic swords. He was born with Krabbe disease, a rare inherited condition that is typically fatal by age 2 if untreated. Jeremy, who has disabilities, got a stem cell transplant for the condition as a baby.

Randy Thoms helps his son, Jeremy, up a wheelchair ramp to their house in Eau Claire after getting him off the school bus. Jeremy was tested for Krabbe disease shortly after birth, unlike most babies in Wisconsin, because his older brother died from the disease. "He's alive today because he got treated," Randy said.



Tanys and Randy Thoms help son Jeremy use a power lift chair to get into their van in October to go out to dinner to celebrate Jeremy's 21st birthday.

It has been nearly two years since Collin Cushman died from Krabbe at age 8, but the couple can't bring themselves to get rid of the bed or his breathing machines stored beneath it. For most of his life, Collin couldn't walk, talk, see or eat. He lived on the bed.

"It was months and months before I would spend much time in this room," Kevin Cushman said, his voice quivering.

Judy studied a photo of Collin waving as she held him on a slide when he was 9 months old. "This was one of his last waves," she said.

Soon after, Collin became irritable, had trouble sitting up and clenched his fists. Four months of testing led to the diagnosis of Krabbe.

"You go into shock, denial, anger, all those stages of grief," Kevin said.

The couple persisted as parents, including with a healthy daughter born four years after Collin. They traded shifts watching over their son and worked with his phalanx of nurses. All the while, they wondered how life might have been different if Collin had been tested for Krabbe at birth, in time for a transplant.

"To have a child who could have sleepovers, who could go to sleepovers, who could live somewhat of a normal life, would be huge," Kevin said.

They approached state Sen. Patrick Testin, R-Stevens Point, who in March introduced the bill to require Wisconsin to screen for Krabbe. Testin amended the bill to make the state start Krabbe testing when it begins screening for Pompe, which involves a similar test. That way, it would bring little or no additional cost, state officials said.

Dr. Robert Steiner, newborn screening consultant for the state health department, expressed concern about deviating from the state's reliance on scientific committees. The process aims to "be sure that there will be an overall benefit to families and society, and to avoid negative or unintended impacts," he said.

Living with Krabbe

On a recent afternoon, Jeremy Thoms shifted his body from his wheelchair to an easy chair between his parents' recliners at their home in Eau Claire. He began to sing, joining in a Josh Groban recording on YouTube.

"You raise me up, so I can stand on mountains," Jeremy bellowed off-key, while imparting the inspiration of the song. "You raise me up, to walk on stormy seas."

Lego sets, with Harry Potter, Batman and dinosaur themes, covered much of the floor. At night, Jeremy lines up the dinosaurs so they stare at his father, a running joke.

Jeremy, 21, is in his sixth year of high school by choice. He is slow to speak but can converse. Why Batman over Superman? "Batman doesn't have super powers," he said. "He's a hero no matter what."

Jeremy was diagnosed with Krabbe when he was 8 days old. Kurtzberg gave him a transplant at 28 days. Tanys and Randy Thoms had Jeremy tested because their first son, Alex, died from Krabbe at 13 months. Their middle son, Adam, 33, is not affected.

Jeremy walked on his own until he was 5, when he started using a walker. He has relied on a wheelchair since he was 10. A few years ago, doctors put metal rods in his back to address a related spine condition that can cause fatal breathing problems.

Randy works as Jeremy's caregiver, helping him shower, get on the toilet and change clothes. Tanys works from home as an administrative assistant for Mayo Clinic Health System.

"I wouldn't trade my time with Jeremy for anything," Randy said. "He means so much to us."

Wanting a choice

In Spring Green, the Heckendorfs keep a plastic tote with photo albums and scrapbooks of their son Bryce's 18 months of life. Photos show him lying beside a stuffed toy firefly, propped up on a tractor at the farm where Jenna grew up and strapped into a standing device to help his bones grow.

One shows the book, "Commotion in the Ocean," Bryce's favorite before he became ill.

"We'd get to the shark page, and he'd just light up," said Kyle Heckendorf, who teaches math at River Valley Middle School, where Jenna leads student support sessions in math and reading.

The photos don't show the days when Bryce was in so much pain from his disease that he was inconsolable. "We'd take turns, around the clock, holding him 24 hours a day," Jenna said. "It was horrible."

Like many babies with untreated Krabbe, Bryce lost his sight and hearing. His parents will never know how much of life he absorbed. "To the day he died, we talked to him and read to him," Jenna said.

The couple have two healthy children, Carter, 6, and Ava, 2. They wish they also still had Bryce, who would be 8 today.

"After witnessing what Bryce went through, we would give anything to have been given a somewhat normal life," Jenna said. "We didn't have a choice."

Samples

From A1

but treated right away. He is also developmentally delayed but uses a fork and spoon, unlike Colton, and already speaks many more words.

"There's no way of knowing what Colton would be like if (the newborn screening test) would have been on time, but there's no doubting he wouldn't have been as sick as he was because he would have had normal treatment from the beginning," said his mother, Karen Hidde, of New London.

Hospitals are supposed to collect blood samples from babies 24 hours to 48 hours after birth and send them to the Wisconsin State Laboratory of Hygiene in Madison within 24 hours after collection, according to the lab. But some samples don't make it to the lab on time, which can prevent early treatment that could save or dramatically improve newborns' lives.

"Recently we've noticed a trend towards submitters collecting and submitting samples outside of this recommended time window," said an Oct. 15 letter to providers from the lab and the state Department of Health Services. "As a reminder, delayed submissions can have negative consequences."

The lab, allowing for some flexibility, reports how many samples are received within three days of collection. In April to June, Mayo Clinic Health System-Northland in Barron, SSM Health St. Agnes Hospital in Fond du Lac, Ascension Columbia St. Mary's Hospital Ozaukee in Mequon, Richland Hospital in Richland Center and Tomah Health sent more than 5% of samples more than three days late, according to the lab. Many other hospitals in the state sent some specimens late.

The Mequon and Richland Center hospitals continued to send more than 5% of samples more than three days late in July to September, when Westfields Hospital in New Richmond joined the list. At Aspirus Medford Hospital, more than 5% of samples were more than three days late the first and third quarters of the year.

The Mequon hospital, part of Ascension Wisconsin, sent 26 samples, or more than 12%, more than three days late during the second and third quarters, the worst level at any hospital in the state this year.

"Ascension Wisconsin monitors the monthly reports from the state lab, then reviews with our statewide lab quality team to identify trends and outliers to the established practice," Vanessa Freitag, Ascension's vice president of pharmacy and lab, said in a statement. "When necessary, workgroups are developed with practice/nursing leaders to evaluate and resolve any non-conforming events."

Courier problems

The state lab allows for even more flexibility by not counting against hospitals samples delayed for reasons beyond their control, said Dr. Patrice Held, co-director of newborn screening at the lab. Such delays typically involve holdups by the courier used, which for most hospitals is UPS.

When courier and related problems are included, the vast majority of Wisconsin hospitals had some delayed samples in January to September. Ascension Columbia St. Mary's Women's Medical Center in Milwaukee topped the list with 119 delayed samples, including 17 the lab considered to be the hospital's fault. Ascension St. Elizabeth Hospital in Appleton had 110, including 22 that were its fault, and Froedtert Menomonee Falls Hospital had 88, including nine that were its fault.

In Madison, SSM Health St. Mary's Hospital had one delayed sample and UnityPoint Health-Meriter had six, none considered their fault.

The state lab and the Wisconsin Hospital Association started making the data publicly available in 2014 after a Milwaukee Journal Sentinel investigation, triggered by Colton Hidde's story, uncovered flaws in the nation's newborn screening practices. Colton's sample, taken at what is now ThedaCare Medical Center of New London, didn't arrive at the state lab until five days after it was collected, the Journal Sentinel reported. By then, he had already been taken by helicopter to Children's Wisconsin hospital near Milwaukee, arriving in a coma.

Lawsuit settled

Karen and Michael Hidde in 2018 settled their lawsuit against the New London hospital, which was filed three years earlier. They have a third son, Caleb, 6, who doesn't have ASA.

Colton has a feeding tube, through which he gets medications, but he mostly eats by mouth unless he's ill. He is learning to use a communication device to say his name and some words. He is not expected to become verbal, his mother said.

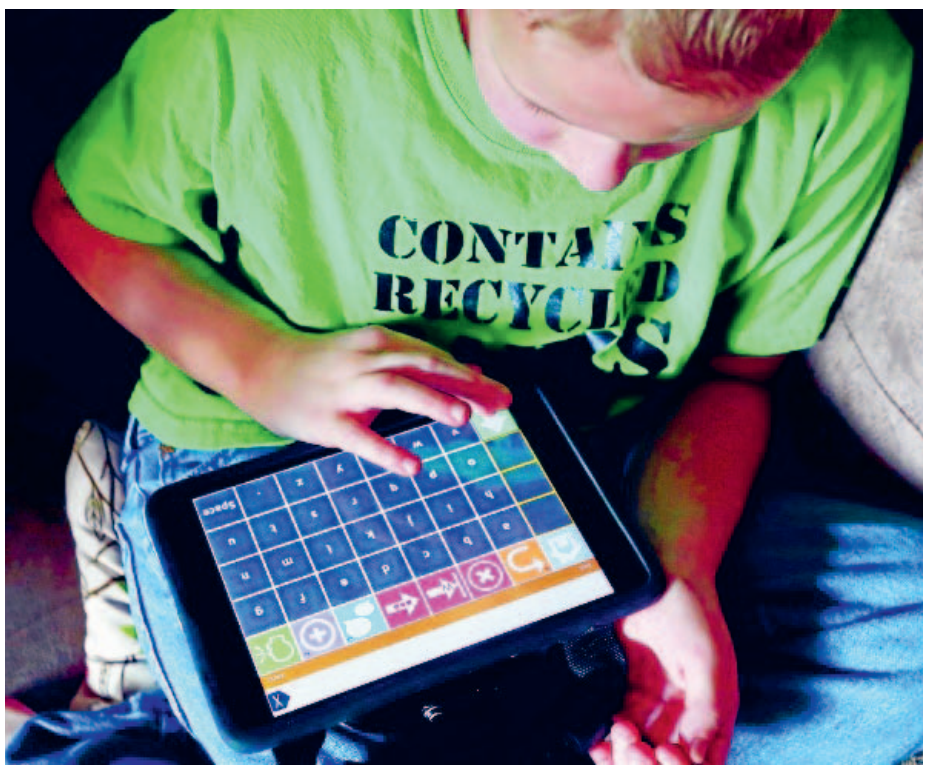
Colton and Christian have received liver transplants, which helps prevent ammonia buildup but requires them to take anti-rejection drugs that weaken their immune systems.

Karen Hidde said she wishes Colton's screening had been processed more quickly so he could have been treated right away, but she is glad the family's ordeal helped spur public reporting of test transfer times.

"Now that they have to post it and let people know, I think it holds hospitals more accountable," she said.

AMBER ARNOLD PHOTOS, STATE JOURNAL

Colton Hidde, 9, left, and brother Christian, 4, right, were born with a rare disease called argininosuccinic aciduria, or ASA. Brother Caleb, 6, middle, doesn't have the condition. Treatment for Colton was delayed after birth because of a late newborn screening test, Karen and Michael Hidde alleged in a lawsuit that was settled. Christian was treated sooner. "Colton will never be verbal, where Christian has the potential to be verbal," Karen Hidde said.



Colton Hidde, 9, who has a rare genetic disorder that causes ammonia to build up in the body, speaks only a few partial words. He is learning to use a device to communicate.

WISCONSIN | BABIES' BLOODSPOTS

State wants to store samples for 10 years

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Minnesota had to destroy more than 1 million newborn screening blood samples after families sued, saying the state was keeping the dried bloodspots for research without their permission.

After a similar lawsuit in Texas, that state got rid of more than 5 million bloodspot cards. In Michigan, a judge ruled in July that the state's retention of specimens before 2010, when the state started seeking consent for storing them, violated the constitutional rights of parents of two children born in 2008.

Wisconsin has long stored babies' blood samples for a year before destroying them, while keeping samples with positive results indefinitely. Now, scientists who lead the state's newborn screening program are looking at holding onto samples for 10 years. That could improve infant testing, enable biomedical research and assist doctors and families in identifying causes of diseases children can develop later in life, they say.

"Retaining for a period of time is really justifiable," said Dr. Mei Baker, co-director of newborn screening at the Wisconsin State Laboratory of Hygiene.

Baker and others who sit on the state's umbrella committee for newborn screening voted Dec. 3 to keep samples for 10 years, a move that still needs to be approved by the state Department of Health Services. The committee also voted to develop a policy on how to handle research proposals and inform the public, including about how people could opt out of storing samples for research.

Newborn screening is mandatory in all states, though in Wisconsin and many states parents can opt out for religious reasons or personal convictions. Five or six drops of blood are collected from the pricked heels of babies and placed on filter paper cards. After screening tests are completed, some states store residual samples for a few months, others keep them for decades and several store them indefinitely, typically without explicit parental permission, according to a University of Utah study published in 2019 in the journal Genetics in Medicine.

Programs use some of the samples to improve infant testing, but scientists also use de-identified specimens to study genetic disorders and other childhood diseases, the Utah researchers found. Some bloodspot cards are used for forensic purposes, such as to identify human remains.

A push to make states obtain consent specifically for retaining samples has been met with concerns that too many parents will say no, making the remaining bloodspots less representative of overall populations. However, consent "may improve trust in newborn screening programs," the Utah researchers said.

Destroying samples

Minnesota in 2014 destroyed 1.1 million bloodspot cards after settling a lawsuit filed in 2009 by 21 families. Under updated laws, samples since August 2014 have been stored indefinitely unless parents opt out.

Texas in 2009 agreed to destroy 5.3 million bloodspot cards stored since 2002 following a lawsuit by the Texas Civil Rights Project. The state had given 800 de-identified samples to a U.S. Armed Forces lab to help build a DNA database to identify missing people and solve cold cases, the Texas Tribune reported in 2010.

Today, Texas keeps bloodspot cards for two years for use by the state health department unless parents agree to store them for up to 25 years, which can include research outside of the department.

In Michigan, bloodspot cards since 2010 are stored for 100 years, but aren't used for research unless parents consent, according to the state. A trial is scheduled for April on how widely samples should be stored and used for research, and whether proper consent is being obtained.

"Do they really need to keep everybody's sample to do that?" asked Philip Ellison, an attorney from Hemlock, Michigan, who sued in 2018 on behalf of four parents of nine children.

What's allowable

Wisconsin doesn't seek consent for keeping bloodspot cards, but parents can ask the state lab not to retain them, Baker said. Positive samples are kept indefinitely or until they're used up, and de-identified for use by the lab to improve testing, she said.

Doctors and parents can request samples for clinical care purposes, and researchers can ask to use samples if their proposals are approved by their institutional oversight boards, Baker said.

Some proposals can be contentious. At the Dec. 3 meeting, Dr. Norm Fost, a UW-Madison bioethicist, said a proposal by a North Carolina researcher a few years ago to test stored Wisconsin samples for Fragile X syndrome, which causes intellectual disability, and contact affected families was "incredibly controversial."

The Fragile X proposal was initially approved in Wisconsin but later rejected. Fost said several committees should sign off on future proposals to ensure thorough vetting.

Baker said that if bloodspot cards were kept longer, they could help families of children who develop symptoms of certain diseases long after birth. Hearing loss can stem from cytomegalovirus, or CMV, which can be acquired in the womb or after birth; a stored sample can help discern the origin.

A small minority of children with cystic fibrosis aren't caught by newborn screening, Baker said. If children later develop symptoms of the lung and digestive disorder, a stored sample could determine if their test was a known type of false negative or an error.

Drops of blood from a baby are put on a filter paper card at UnityPoint Health-Meriter in Madison as part of routine newborn screening in this photo from 2013.

State's screening list is shorter than many others

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Connecticut tests babies for 73 disorders shortly after birth, the most of any state, while Wisconsin screens for 47, fewer than surrounding states, according to the federal Health Resources and Services Administration, or HRSA.

But the numbers can be deceiving, said Dr. Mei Baker, co-director of newborn screening at the Wisconsin State Laboratory of Hygiene. She is also a member of HRSA's Advisory Committee on Heritable Disorders in Newborns and Children.

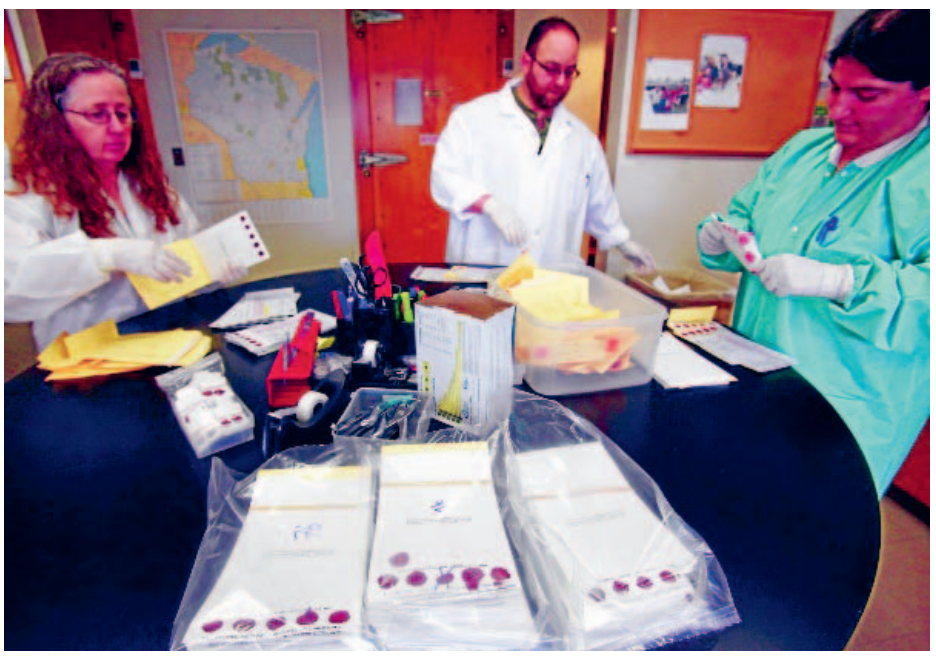
"We never get into a counting game," Baker said. "You really cannot judge a program by how many conditions they list."

Connecticut says it screens for five hemoglobin traits that make people carriers for sickle cell disease from birth, though carriers don't have the blood disease. Wisconsin also detects and reports the carriers but doesn't list them on its newborn screening panel, Baker said.

Connecticut also lists two conditions related to phenylketonuria, or PKU, a protein disorder that can cause intellectually disability. Wisconsin, which lists PKU, can also pick up the related conditions but doesn't list them, Baker said.

Similarly, Connecticut, Michigan and Minnesota list T cell conditions related to severe combined immune deficiency, or SCID. Wisconsin lists SCID and also detects the T cell conditions but doesn't list them.

Additional examples involve disorders Wisconsin picks up incidentally when screening for targeted conditions, Baker said. While some states list those, Wisconsin doesn't unless they meet the state's newborn screening criteria, she said.



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Chemists Mary Carlstedt, Michael Cogley and Marcy Rowe open packages containing newborn screening blood sample cards for testing at UW-Madison's Wisconsin State Laboratory of Hygiene in this photo from 2013.

Series online

Point your smartphone's camera here to view this series online, including additional photos and video.

In 2011, Wisconsin removed three enzyme conditions from its panel because they were found to be benign. One had been found primarily in the state's Hmong community. Connecticut, Michigan, Minnesota and Illinois list some or all of them.

Wisconsin screens for two hemoglobin disorders not listed by many states: beta thalassemia major and hemoglobin e-beta thalassemia. They are more prominent among southeast Asians, Baker said.