WISCONSIN STATE JOURNAL

Regents boost salary ranges

Move aims to give UW System more negotiating power as high-profile searches for new leaders get underway

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EYING PRIZE

Packers appear to have easiest schedule among NFC bye contenders

SPORTS. B1

Hostages managed to flee

Missionaries held in Haiti found freedom last week by making a daring overnight escape

NATION&WORLD. A10

Biggest stories of 2021

This full-page photo gallery takes a look at some of the top headlines from a busy year

NATION. A11

COVID-19 | THE HEALTH CARE SYSTEM

Close to breaking point

Officials urge small holiday gatherings as surge continues

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As a COVID-19 surge leads some Wisconsin hospitals to cancel procedures and turn away patients, health officials on Monday urged residents to get vaccinated, wear masks indoors and keep holiday gatherings small to prevent cases of the new omicron variant from overwhelming already strained facilities.

Dane County extended its mask mandate until February, with the county's weekly COVID-19 case rate nearly three times that from early November and coronavirus-related hospitalizations at the highest level this year.

"Our health care organizations have been pushed to the breaking point, and it is quite possible that omicron will push us beyond the breaking point," said Dr. William Melms, chief medical officer of the Marshfield Clinic Health System, which has discontinued elective surgeries requiring inpatient beds and is turning away 100 referrals a week. "Something's got to give."

With 96% of intensive care beds and 98% of intermediate care beds already in use, and hospitals and nursing homes struggling to find nurses and other staff to care for patients, state Department of Health Services Secretary Karen Timberlake pleaded for unvaccinated people to get shots and for

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■ **Inside:** *Justices to rule on challenge to Dane County's mask mandate.* **A3**

■ **Nation:** *Omicron now the dominant strain across the United States.* **A9**

NO TIME TO LOSE | FINDING RARE DISEASES IN INFANTS

AMBER ARNOLD PHOTOS, STATE JOURNAL

Theo Gutzdorf, with parents Rikki and Josh Gutzdorf at their home in Watertown, was born with numerous medical problems for which routine tests couldn't identify a cause. Through genome sequencing, he was diagnosed with the rare disorder Stuve-Wiedemann syndrome, which helped doctors know how to treat him. Josh custom-made Theo a walker before the 3-year-old started walking on his own.

Next step, sequencing

Mapping genome can help when screening doesn't have answer

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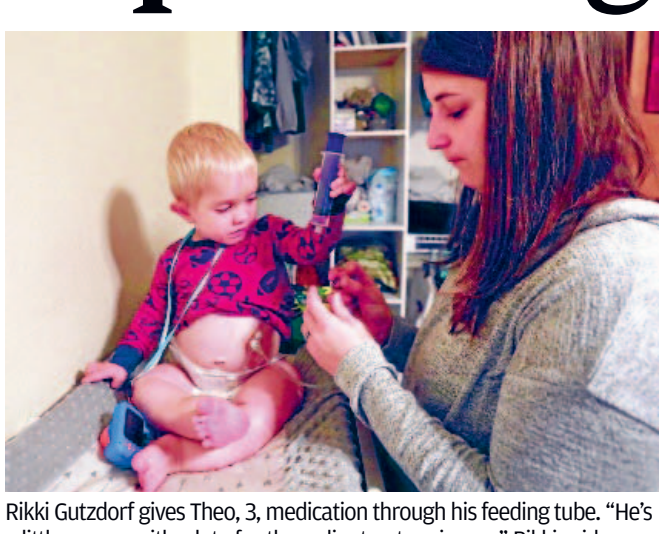
Rikki and Josh Gutzdorf knew from prenatal testing that their child would have abnormally shaped bones.

After son Theo was born, other problems emerged: He could barely breathe and had a dangerously high fever. Tests, including a spinal tap, couldn't identify a cause.

Doctors at Children's Wisconsin hospital near Milwaukee turned to genome sequencing, mapping the protein-making parts of the baby's DNA. The analysis showed Theo had Stuve-Wiedemann syndrome, a rare genetic disorder marked by curved leg bones, respiratory distress, poor regulation of body temperature, swallowing problems and, often, death within a year.

The finding helped doctors decide to adjust the boy's oxygen level, start him on a

Please see DNA, Page A6



Rikki Gutzdorf gives Theo, 3, medication through his feeding tube. "He's a little person with a lot of orthopedic structure issues," Rikki said.

FAR EAST SIDE

Jail calls support homicide charge

Decomposed body found in September

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A Madison man has been charged with first-degree reckless homicide after police in September found the decomposed body of his former girlfriend at the Far East Side home where they had lived, then listened to jail calls between him and his current girlfriend as the two settled on a story to tell police, according to a criminal complaint.

Gregg G. Raether, 56, told police he had nothing to do with the death of a 55-year-old woman identified in the complaint only by her initials but by the Dane County Medical Examiner's office on Monday as Patricia A. McCollough, of Madison.

Raether

The complaint, filed late Friday, says police believe McCollough died on or about July 22. Police went to her home on Sept. 16 after a caller who identified herself as McCollough's daughter asked police to check on her mother's welfare since she had been unable to reach her by phone.

After looking through windows and seeing that the house was in disarray and getting no answer at the door, police entered the home and found McCollough's body in a bedroom, buried under a pile of dresser drawers, shelving, televisions and bedding material.

Please see HOMICIDE, Page A5

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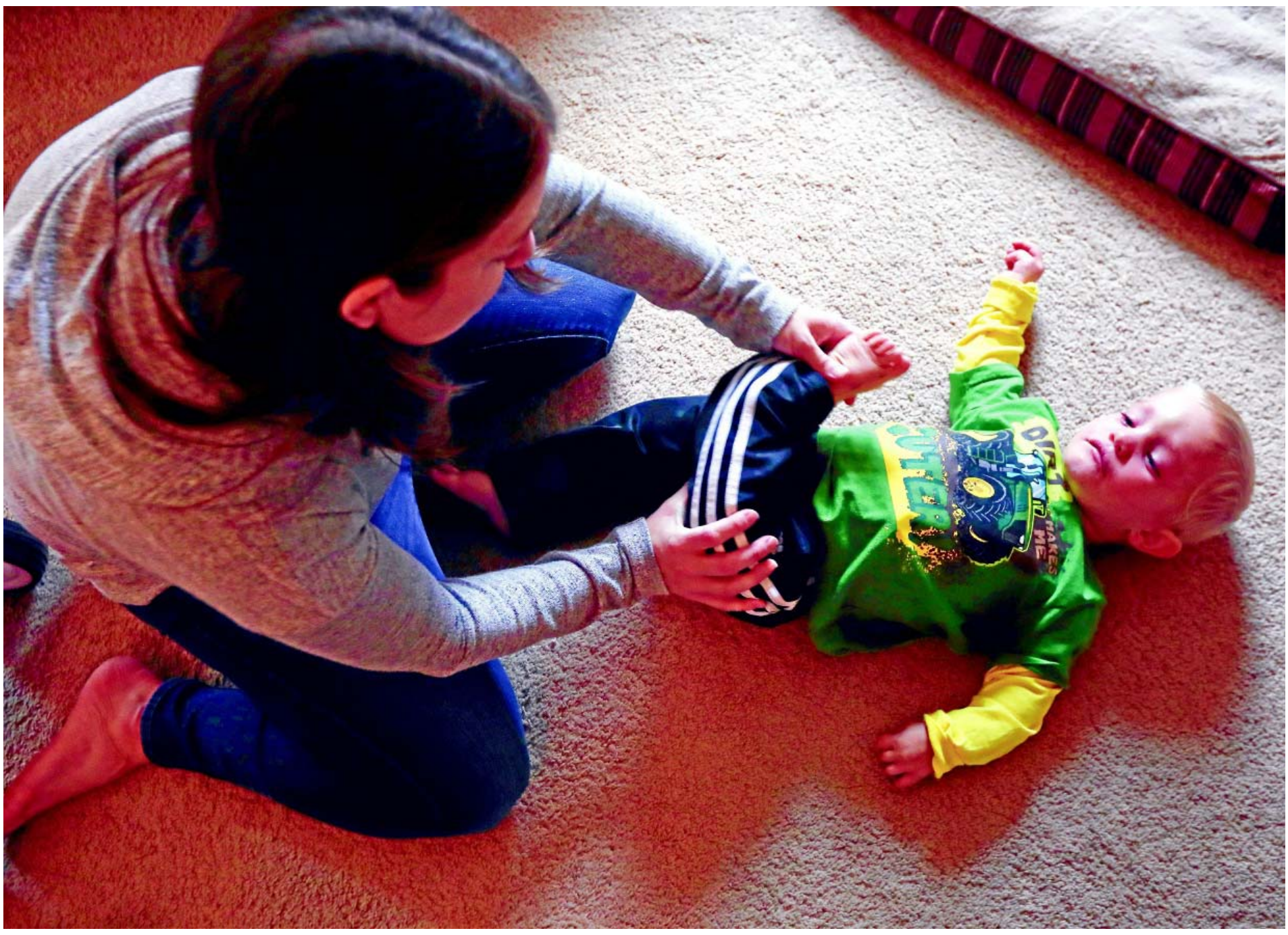


AMBER ARNOLD PHOTOS, STATE JOURNAL

Rikki Gutzdorf regularly takes Theo, who has Stuve-Wiedemann syndrome, to therapy appointments and does stretches at home. The rare disorder can be fatal by age 1, but with an early diagnosis and regular care, Rikki said her son can thrive. "We want to make sure we're giving Theo the best possible life," she said.

DNA

From A1

medication to lower his temperature and give him a feeding tube. Since the disorder also involves a lack of the reflex to blink, they initiated eye drops. Theo spent his first 100 days in the neonatal intensive care unit, but he hasn't been in the hospital since and turned 3 in September.

"It was very much life or death," said Rikki Gutzdorf, of Watertown. "We firmly believe that without the genetic testing, we wouldn't have had a diagnosis and known how to treat it, and possibly would not have our son with us today."

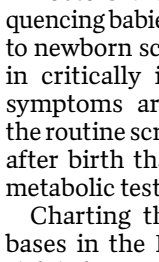
Doctors are increasingly sequencing babies' genes in addition to newborn screening, especially in critically ill children whose symptoms aren't explained by the routine screening a day or two after birth that mostly involves metabolic tests.

Charting the A, C, G and T bases in the DNA molecules of sick infants can yield answers — sometimes in three days or less, according to a California study — that can improve treatment and save lives. The technology, which often involves enzymes made in Madison by the company Illumina, offers the potential to sequence all babies — not just for childhood disorders but, as a Boston study showed, for risk of adult-onset diseases such as some types of cancer.

The prospect of universal newborn sequencing, and looking for adult-onset conditions, raises questions about personal autonomy, according to a federally funded ethics group. In 2018, the group said the evidence "does not support genome-wide sequencing of all babies at birth."

Still, "at some point, that's going to be a reality," said Dr. Donald Basel, medical director of genetics at Children's Wisconsin. "We're all going to have knowledge of our genomic data."

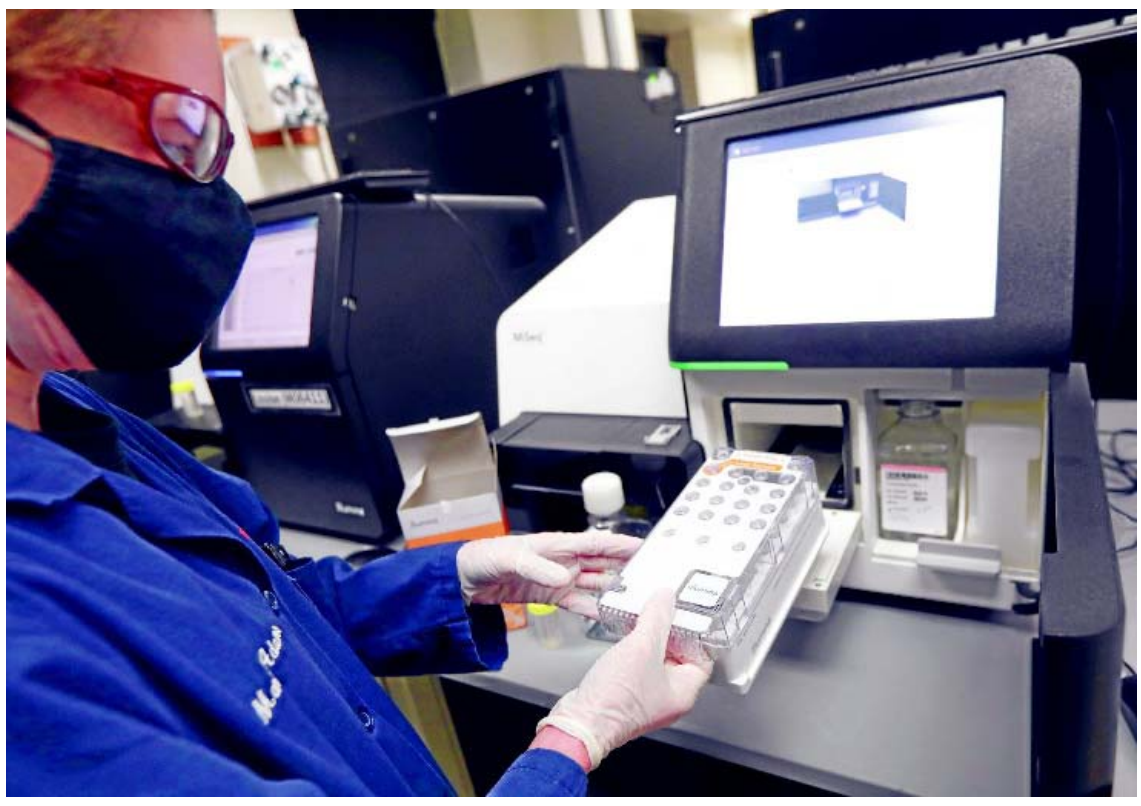
For now, Basel said, genome sequencing at Children's Wisconsin is done on about 200 patients a year, primarily children in the neonatal or pediatric intensive care units. The testing leads to a diagnosis about 43% of the time and often leads to better care, he said.



Basel

"We've definitely made some significant changes in treatment based on the genomic data we've gotten back," Basel said.

At UW Health, doctors in April started sending blood samples from perplexing NICU patients to Rady Children's Hospital in San Diego, which leads an effort to do rapid whole genome sequencing on sick infants. In July, UW opened an Undiagnosed Genetic Disease Clinic to identify rare diseases in children and adults, with the somewhat slower sequencing involved taking place on campus.



Amanda Maegli, research specialist at the DNA sequencing lab at the UW-Madison Biotechnology Center, loads a cartridge with DNA samples into a DNA sequencer.

LEFT: Rikki Gutzdorf was a preschool teacher specializing in special education before Theo was born with Stuve-Wiedemann syndrome. Her background, she said, "was the universe's way of preparing us for Theo."
RIGHT: Josh Gutzdorf said he's grateful for every day with Theo, who spent his first 100 days in the neonatal intensive care unit. "We didn't know if he was going to make it past one year of age," Josh said.

Each of more than 7,000 known rare genetic diseases affect relatively few people, but collectively the conditions are believed to be present in about 8% of the population, or roughly 450,000 Wisconsin residents, said Dr. Stephen Meyn, director of the UW Center for Human Genomics and Precision Medicine, which includes the new clinic.

Until recently, it took three to five years to diagnose one of the conditions, and doctors were successful less than 10% of the time, Meyn said. Now, with genome sequencing, the speed is quicker and the success rate is closer to 40%, he said.

Meyn

"We are, as geneticists, thrilled with those numbers," Meyn said. "But that means most patients walk out of the clinic without a diagnosis. We have a lot of work to do still."

Rapid sequencing

A federal program that explored newborn genome sequencing in recent years included projects by researchers in San Diego and Boston.

Dr. Stephen Kingsmore, CEO of the Rady Children's Institute for Genomic Medicine, led Project Baby Bear, which used rapid whole genome sequencing to analyze the genetic code of 184 infants at five NICUs in California covered by the state's Medicaid program.

The sequencing produced a diagnosis for 74 babies, or 40%, in a median time of three days, the researchers reported in June in the American Journal of Human Genetics. The testing, which cost $1.7 million, led to about $2.5 million in savings in treatment, the researchers said. California has approved $3 million annually to expand the program statewide.

In one case, a scan showed problems in the brain of an inconsolable 5-week-old boy, whose older sister died at 11 months after seizures. Genome sequencing on the boy, completed in a record 13 hours in October 2020, identified a severe vitamin B disorder called THMD2. Soon the boy was started on a vitamin treatment and recovering from the condition that likely killed his sister, Kingsmore and colleagues reported in June in the New England Journal of Medicine.

"This case illustrates the potential for decreased suffering and improved outcomes through the implementation of rapid genome sequencing," they wrote.

The BabySeq Project, at Boston Children's Hospital, involved sequencing of nearly 1,000 genes on 127 healthy babies and 32 NICU patients. Some 8% of healthy babies and 9.4% overall had mutations for childhood genetic disorders, which were not predicted by clinical or family history, researchers reported in 2019 in the American Journal of Human Genetics.

Parents of more than half of the sequenced babies agreed to look for actionable adult-onset conditions. Three babies had such genetic risk factors, two for breast cancer and one for colon and endometrial cancer.

The information gleaned from the sequencing didn't cause undue distress for the parents, including the 15 families whose babies had an unexpected risk gene for childhood disease, according to survey results reported in August in JAMA Pediatrics. Now, BabySeq2 aims to expand the research to more diverse families in Boston, New York City and Birmingham, Alabama.

Wisconsin doctors seek answers

In Michigan, Dr. Caleb Bupp heads up Project Baby Deer — which, like its California precursor, is named after the state animal. Eight hospitals in the state have sent samples from more than 80 children to Rady in San Diego for rapid genome sequencing, with analysis of the first 30 cases showing 40% led to diagnoses and 45% resulted in changes in treatment, said Bupp, chief of medical genetics at Spectrum Health Helen DeVos Children's Hospital in Grand Rapids.

Michigan's Medicaid program in September started covering genome sequencing for children up to a year old. Michigan's project also involves private insurers, including the state's largest carrier, Blue Cross and Blue Shield, for whom children with unexplained symptoms up to age 18 can be sequenced.

The testing helps parents by providing answers and doctors by providing direction, Bupp said. "It's also good for hospitals and payers, because if we know why we're treating folks, we give them better care and the cost of that care is lower," he said.

UW's American Family Children's Hospital is among 10 hospitals in the Sanford Children's Genomic Medicine Consortium — led by Sanford Health, based in Sioux Falls, South Dakota — that are sending samples to Rady for rapid genome sequencing, Meyn said.

Since April, sequencing has been performed on four NICU patients from UW, with three leading to diagnoses within five days, Meyn said. He said "the results led to major changes in medical management for all three of the diagnosed patients."

UW doesn't have enough cases to justify running costly sequencing equipment around the clock on site for the rapid results needed to help deteriorating newborns, Meyn said.

Please see DNA, Page A7

About this series

Sunday: 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.

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

Series online

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

AMBER ARNOLD, STATE JOURNAL

Theo Gutzdorf, who has a type of Stuve-Wiedemann syndrome that involves dwarfism, or short stature, uses a stool to navigate his play kitchen.

DNA

From A6

With older children or adults who have spent years trying to pinpoint the cause of their conditions, speed is not as vital, he said. That's why genome sequencing for patients at the new Undiagnosed Genetic Disease Clinic is done at UW-Madison's Biotechnology Center, which can run so-called "long-read" sequencing that can provide even more answers.

Bupp

UW plans to study up to 500 patients at the clinic over five years, with the goal of diagnosing rare disorders and discovering new disease genes.

Children's Wisconsin has been doing genome sequencing on some patients for more than a decade, Basel said. In 2009, the hospital received national attention for reading the genetic script of 4-year-old Nic Volker of Monona to diagnose his rare condition and treat him with a cord blood transplant.

Most sequencing at the hospital yields results in two or three weeks, but the timing can be sped up to about five days for urgent cases, Basel said. In those situations, scientists using the sequencing equipment for research are asked to temporarily give it up.

"They basically have to put everything they're doing on hold so we can run our sample," he said. "We flood the plate with just our sample for a quick turnaround."

Adapting to a rare disease

At the Gutzdorfs' house in Watertown, Theo climbed a step to arrange pots and pans in his play kitchen on a recent afternoon before scuttling across the floor to pet Phil, the family's Lab mix.

Theo started walking on his own a year ago, a few months after he turned 2. Earlier, he used a walker Josh Gutzdorf fashioned out of PVC pipe. Medical walkers, even pediatric ones, were too big.

Theo is a little person, or dwarf, one aspect of his Stuve-Wiedemann syndrome. With his leg bones not only short but curved, doctors plan to operate on his hip to help him walk better. After surgery, he will need to be in a partial body cast for six weeks. His parents scheduled the procedure for January, when it's cold.

Theo's body temperature can still be hard to regulate, even with the medication he takes.

"It's a lot easier to warm him up than it is to cool him down," Josh said. When it's hot, "we can only be outside for 15 minutes, maybe, before he starts showing a lot of distress."

Theo is largely nonverbal but recently learned to say a few words, including "bye." His parents are trying out communication devices and teaching him some American Sign Language. Signing is a challenge, though, because his condition makes it difficult for him to open his fingers. At rest, his hands form fists.

He goes to speech therapy, physical therapy and occupational therapy. Though he eats mostly by mouth, he still has a feeding tube, used for medication, hydration and, when he's ill, nutrition, Rikki Gutzdorf said. His parents give him eye drops several times a day to prevent scarring of his cornea and hope he'll learn to blink when he gets older.

Stuve-Wiedemann is exceedingly rare, especially in the United States, so Theo's parents aren't sure what to expect for his future. They credit genome sequencing for helping him so far.

Without it, "we wouldn't be in the place we are today," Rikki said. "I ache for the families that don't have a diagnosis or a (disease) name."

Illumina makes reagents, tools for DNA sequencing

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At the west end of University Research Park on Madison's West Side, workers brew a potion with a powerful purpose.

Their flasks and tanks resemble those at breweries, but these workers aren't fermenting yeast to make beer. They're using harmless strains of E.coli bacteria to grow enzymes for genome sequencing.

San Diego-based Illumina has a major share of the global DNA sequencing market, and the company's manufacturing center in Madison makes enzymes — proteins that speed up chemical reactions — to run its sequencing machines. With 180 employees, the hub also produces what is called "library prep," or kits to prepare blood or saliva samples for sequencing.

"We're producing all the reagents and tools for everything the company does," said Bill Checovich, general manager at Illumina's Madison campus.

In 2011, Illumina bought Epicentre Biotechnologies, a Madison company founded in 1987. Epicentre developed a technology, called Nextera, to simplify and speed up preparation of samples for DNA sequencing, which is now part of Illumina's products.

In a building that opened in 2019 on Genomic Drive, workers make about 40 different enzymes. They induce E.coli cells to produce the desired proteins and purify the mixtures by passing them through centrifuges, filters and columns.

In the fermentation room, equipped with a 1,000-liter tank, a caramel-colored liquid containing glucose and other ingredients feeds the E.coli cells. "The more cells you have that are expressing enzyme, the more enzyme you have when you go to break the cells open and purify them," said Carolyn Pettersson, associate director for manufacturing operations.

Genome sequencing conducted through efforts such as Project Baby Bear in California and BabySeq in Boston has used Illumina sequencers, said Julia Ortega, the company's director of scientific research. The DNA sequencing lab at UW-Madison's Biotechnology Center also has Illumina machines.

A study led by Illumina involved 354 infants with suspected genetic conditions at five neonatal intensive care units in five states. Half of the patients had whole genome sequencing within 15 days of admission and the other half got it within 60 days.

In both groups, the sequencing doubled the portion of babies who received precise diagnoses that altered their care, the researchers reported in September in JAMA Pediatrics.

"It really shows the power of the genome to provide a single test that can replace multiple tests that might be done and hopefully diagnose children earlier," Ortega said.

AMBER ARNOLD, STATE JOURNAL

Will Wayland, a manufacturing specialist at Illumina, checks valves on a fermentation tank. The company's facility in Madison makes enzymes for use globally in its DNA sequencing machines.

ECONOMY

Inflation puts squeeze on holiday budgets

ANNE D'INNOCENZIO
Associated Press

NEW YORK — Emarilis Velazquez is paying higher prices on everything from food to clothing.

Her monthly grocery bill has ballooned from $650 to almost $850 in recent months. To save money, she looks for less expensive cuts of meat and has switched to a cheaper detergent. She also clips coupons and shops for her kids' clothing at thrift stores instead of Children's Place.

For the holidays, she's scaling back on gifts. She plans to spend $600 on her three young children instead of $1,000, and she won't be buying any gifts for relatives.

"It's stressful," said the 33-year-old stay-at-home mother from Boardman, Ohio, whose husband earns $30,000 a year making pallets for stores. "You want to give it all to your kids, even though (Christmas) is about family. They still expect things. It is hard that you can't give them what they ask for."

Retailers may be forecasting record-breaking sales for the holiday shopping season, but low-income customers are struggling as they bear the brunt of the highest inflation in 39 years.

The government's report last week that consumer prices jumped 6.8% over the past year showed that some of the largest cost spikes have been for such necessities as food, energy, housing, autos and clothing.

Overall, rising prices are changing shopping habits for many Americans. For some, they're a mere inconvenience, pushing them to delay building a deck on their house amid higher lumber prices. But for lower-income households with little or no cash cushions, they're making harder choices such as whether they can put food on the table or if they'll have to drastically scale back on holiday presents for their children — or forgo them completely.

DARRON CUMMINGS, ASSOCIATED PRESS

Customers wait in line to check out during a Black Friday sale Nov. 26 at Macy's in Indianapolis. Retailers overall are expecting record-breaking sales for the holiday shopping season, but low-income customers are struggling as they bear the brunt of the highest inflation in 39 years.

"Inflation is devastating the pocketbooks of low-income households," said C. Britt Beemer, chairman of the America's Research Group, estimating that low-income households are cutting back their holiday buying by 20% from a year ago. "They are going to have to decide what they are going to buy and what they're going to eat."

Even some retailers that built their businesses around the allure of ultra-low prices have begun boosting them. Dollar Tree — the last true dollar store — is increasing its prices to $1.25 for a majority of its products because of higher costs of goods and freight. Velazquez says that 25 cents extra per item adds up, and the increase will force her to scale back on impulse buying there.

Growth forecast

Despite the inflation pressures — as well as supply chain disruptions and the new COVID-19 omicron variant — the National Retail Federation says this year's holiday shopping season appears to be on track to exceed its sales growth forecast of between 8.5% and 10.5%.

According to a poll by The Associated Press-NORC Center for Public Affairs Research, about three-quarters of Americans say they will be giving gifts to friends and family to celebrate the winter holidays this year. But the rising costs have not gone unnoticed. About 6 in 10 Americans say holiday gift prices are higher than usual, while only 2 in 10 say they are not. Roughly 2 in 10 say they did not purchase gifts recently.

Overall, 4 in 10 Americans say it has been harder to afford the things they want to give as gifts this year. Roughly half say it's neither easier nor harder, while few say it has been easier.

But people in lower-income groups are feeling the cost pressures most acutely.

Forty-five percent of Americans in households earning less than $50,000 annually and 40% in households earning between $50,000 and $100,000 say it has been harder to afford gifts this year, compared with 30% in higher-income households.

"It was hard enough a year ago, five years ago, for lower-income families to find extra money to buy gifts. But it is that much harder now," said Ted Rossman, senior industry analyst at CreditCards.com, whose survey in October found a significant number of low-income people were completely opting out of holiday gifting this year amid higher prices on essentials.

Financial stress

Such financial stress is being felt at the food pantries such as the one at Shiloh Church in Oakland, California. In the past three months, Shiloh has seen a spike in the number of people, particularly those with jobs, coming in to pick up a weekly box of essentials or shop at its market for free produce and other food, according to Jason Bautista, who runs the food pantry.

That prompted Bautista to bring in more holiday toys for the annual giveaway set for this Saturday. It will have about 2,000 toys to donate to families this weekend compared with about 1,500 a year ago.

"Families that would normally go to Safeway can't afford to with their fixed incomes," Bautista said. "Their dollar is not stretching."

Miriam Canales, 34, of Oakland, has been going weekly to Shiloh for free food since the beginning of the pandemic. Her husband lost his job as a chef at a restaurant that permanently closed in the spring of 2020. He got another job at a different restaurant a few months ago, but he's only working on average six hours a week.

She said higher food prices have added financial stress, and she will not be buying gifts for her children, ages, 13 and 6. Instead, she plans to pick up toys on Saturday at Shiloh Church.

But Canales says she feels grateful this holiday season because of her husband's job as well as her daughter's recovery from brain radiation that landed her in the hospital with epilepsy a year ago. Now she's healthy again.

"I feel blessed," Canales said.