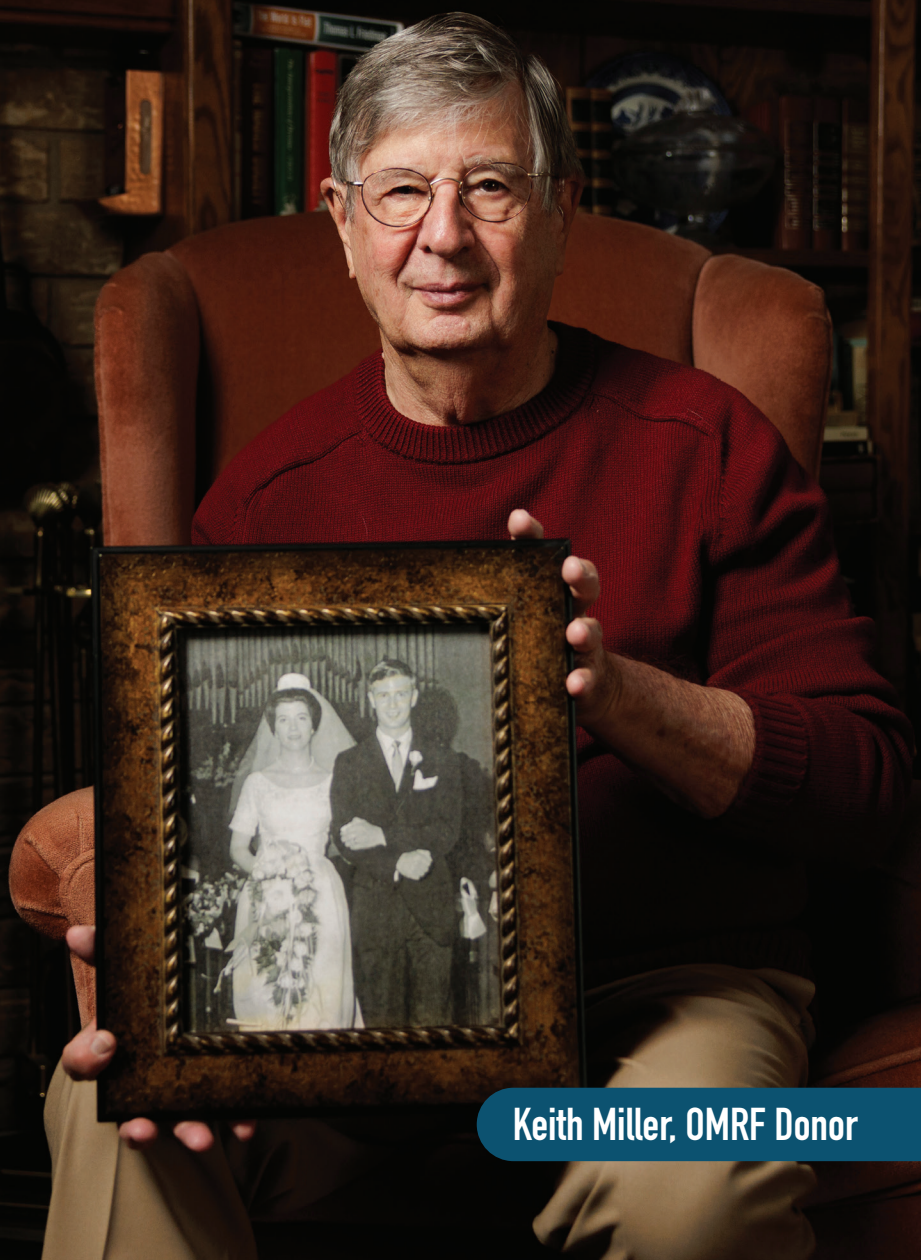


Before my wife lost her memories to Alzheimer's, she was proud to support medical research because she wanted to help others. Today, I donate to OMRF because I don't want anyone else to experience this devastating disease.

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Keith Miller, OMRF Donor

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Chartered in 1946, OMRF is an independent, nonprofit biomedical research institute dedicated to understanding and developing more effective treatments for human disease. Its scientists focus on such critical research areas as cancer, diseases of aging, lupus and cardiovascular disease.

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With a Little Help From Our Friends



It's always fun to catch up with some of your favorite people. So, for our special 35th anniversary issue of Findings, we're doing just that.

Since OMRF started this magazine in 1991, we've been extremely fortunate. During this time, our scientists' and physicians' work has impacted the lives of so many. And over the years, quite a few of them have been kind enough to entrust their narratives to us.

As we told those stories, we got to know the people they belonged to. And in pretty much every case, we grew quite fond of those folks.

I mean, really, how could we not?

They're people like Madison Cain, whom we first met as a bead-collecting second grader: She kept one colorful glass bauble for each medical visit in her long odyssey of living with a rare skeletal disorder. There was Mike Schuster, a brain cancer patient who refused to let long odds dim his hope for recovery. And Liz Haughey Hartley, a social studies teacher who overcame multiple sclerosis to return to her classroom – and her life.

To celebrate 3 ½ decades of Findings, we decided to reconnect with Madison, Mike, Liz and some other special people who've been kind enough to share their lives with us over the years. You can read their stories starting on page 8. Spoiler alert: Their days are not without

challenges, but they're doing great.

In the photo above, I'm holding two issues of Findings: our first, and our most recent. As you can see, the publication has evolved significantly since we first launched it. But two things haven't changed.

The first is our commitment to quality. Since that first black, white and green issue, we have made sure to provide content that is accurate, entertaining and informative. In a world in which trustworthy scientific and medical information is increasingly difficult to find, you can trust us to deliver the facts.

The second thing that has remained steadfast is our focus on people. Yes, medical research is what we do at OMRF. But, as our mission statement proclaims, we do it for a very specific reason: So that more may live longer, healthier lives.

It's those lives that provide the "why" for what we do. And while the research itself is interesting – at least to scientists like me! – what makes it important is the people it serves.

When it comes to ensuring we stay true to our guiding principles, we feel like we're pretty clear-eyed. Still, it's nice when organizations like the Oklahoma Society of Professional Journalists confirm our judgment, awarding Findings two top prizes in the organization's most recent statewide competition – one for feature writing, the other for best public relations publication.

In the coming years, we'll keep bringing you stories like the ones we've been telling for 35 years. Stories of lives touched, lives changed. We hope you enjoy reading them as much as we enjoy telling them.



Dr. Andrew S. Weyrich

Vaccination Education

Dear Dr. James,

The Centers for Disease Control and Prevention has recently changed its recommendations regarding many vaccinations, and these new recommendations often seem in conflict with prevailing scientific guidance. Are there websites or other resources a person can use to help make well-informed decisions about which vaccinations they and their family members should receive?

Hal Ellis
Stillwater, Oklahoma



Dr. James Prescribes

As you point out, the vaccine situation in this country has become confusing. With the changes in policies and recommendations, it can be tough to keep up. In addition, multiple newer vaccines, along with reformulation of prior vaccines to increase effectiveness, make decisions about when and which vaccines to receive more complicated.

In addition to the CDC's Advisory Committee on Immunization Practices, several other resources are now available.

For children, the American Academy of Pediatrics' website offers comprehensive and reliable information and guidance on vaccinations, including a recommended child and adolescent immunization

schedule. The American Academy of Family Physicians also offers vaccine schedules that reflect the scientific consensus among caregivers, and it has schedules both for children (birth to 18 years old) and adults (ages 19 and up). Those schedules can be found on the AAFP's website.

Mayo Clinic also now provides an online resource, its Vaccine Planner. This tool allows you to input brief information about your age, underlying health conditions and previous vaccination history to provide a more individualized look at which vaccines may be most appropriate for you or your family members.

As always, your healthcare providers are the best resources when it comes to this (and other!) topics related to your well-being. Even if you don't have an appointment scheduled soon, I'd encourage you to reach out to them

with questions, and tools like online patient portals have made this easier to do.

Finally, because it is – as of this writing – high season for respiratory viruses, I would be remiss if I didn't call your attention to research published in *The New England Journal of Medicine* just before Halloween. That study, prompted by the recent changes at ACIP and the CDC, conducted a systematic review of vaccinations for influenza, Covid and respiratory syncytial virus vaccines since 2019. It found that all three vaccines were safe and effective.

Dr. Judith James, a rheumatologist and immunologist, is OMRF's executive vice president and chief medical officer. Submit your health questions at omrf.org/AskDrJames.

Mom Genes

How one OMRF researcher balances science and parenthood

Joyce Ocañas has gone to her fair share of scientific conferences. There was the American Aging Association meeting in Madison, Wisconsin. A neurobiology gathering in Niagara Falls. She even attended a neurobiology of aging symposium in Austria.

Not bad for someone celebrating her second birthday in January.

As you might have guessed, Joyce isn't what you'd call an active participant in these scientific meetings. She's accompanying her mother, Dr. Sarah Ocañas, who leads a lab at OMRF that studies Alzheimer's disease and how aging affects men and women differently.

Sarah opened her lab in late 2022, and within six months, she became pregnant. The timing, she admits, was less than perfect. "But as a woman with a career in science, there's no ideal time," she says.

According to a 2019 study in the journal *Nature*, nearly half of all women in full-time science jobs leave the sector or switch to part-time employment after the birth of their first child. Meanwhile, less than a quarter of men showed a similar career shift. That disparity likely stems from a multitude of factors, including unequal childcare burdens for mothers and fathers, as well as the inability of women to "catch back up" in the fast-moving world of scientific discovery when they take leave for childbirth.

Sarah and her husband, Mike, had struggled with infertility in the past, "so we'd come to terms with the fact that it might not happen," she says. "And then we were really blessed that, unexpectedly, it did happen."

Up until that time, says Sarah, "my superpower was my ability to work nonstop." She "could wake up in the morning, make coffee, come to work right away, do experiments in the lab all day, then go home and work some

more." With pregnancy, that quickly changed. "I was super sick" – with frequent bouts of nausea and near-constant fatigue – "so I had to force myself to slow down."

Still, at 34 weeks, she was hospitalized with gestational hypertension. "My blood pressure was something crazy like 180 over 120." Following a tense three weeks, doctors induced labor, and a few days after New

Year's 2024, Sarah gave birth to Joyce, a healthy baby girl.

Sarah had planned to develop a detailed roadmap for how her lab would operate while she was out on maternity leave. But that idea went out the window with her unexpected admission to the hospital and Joyce's early arrival. "So," she says, "I told my staff, 'I guess we're just going to figure this out.'"



Dr. Sarah Ocañas and her husband had struggled with infertility, so pregnancy with her daughter, Joyce, was a welcome surprise.

It took only a few weeks of “full new mom” duty – “Nobody was sleeping: not Joyce, not me, not Mike” – before work began creeping back into Sarah’s life. On Valentine’s Day, she gave a presentation on Alzheimer’s research at the Oklahoma State Capitol. The following week, she was evaluating grant proposals for the National Institutes of Health.

Fortunately, the all-day grant review session was virtual, allowing Sarah to keep Joyce on a pillow beside her, just beyond the view of the camera. “When they’re small, it’s easy,” says Sarah. “You put them in one spot, they don’t move, and they sleep a lot.”

About two months after giving birth – “honestly, it’s all a little fuzzy” – she returned to work. Mike, a former teacher, would stay home with Joyce. Although her husband had plenty of experience with children, Sarah admits to being a bit nervous about the new setup. “This was his first time taking care of a baby.” But, she says, “Once we figured out a routine, it got easier.”

•••

These days, that routine kicks off before sunrise, when Joyce rouses Sarah, or vice versa. After getting her daughter changed and dressed, Sarah prepares breakfast, which tends to be heavy on eggs and yogurt. “She’s a toddler,” she says. “She’s pretty picky.” During warmer months, before the day heats up, a trip to a nearby park often follows. Then Sarah hands Joyce off to Mike and heads to work, where a full day in her OMRF lab awaits.

Unlike pre-Joyce times, though, Sarah’s days at OMRF typically end at 5 o’clock. Once home, she makes dinner, then spends the balance of Joyce’s waking hours singing, dancing and playing with her toddler. After putting Joyce to bed around 8:30, Sarah has an hour or two to answer emails and tend to other work issues before going to sleep herself.

This new world, says Sarah, “feels like working two full-time jobs.”

To Dr. Courtney Griffin, OMRF’s vice president of research, that analogy sounds about right. But, she says, another one is equally apt: “Starting a lab is like having another child.”



Parenting and running a research lab, says Ocañas, mean “always sacrificing on both sides.”

For a researcher like Ocañas, who’s working hard to establish a scientific reputation among her peers, do experiments, write papers and obtain grant funding for her work, “the physical and mental demands of a young lab are never-ending,” says Griffin. And those obligations, she says, “inevitably overlap with the demands of running a young family.”

At that stage of her career and family, Griffin – whose children are now grown – came to a realization: Try as she might, she couldn’t achieve a perfect distribution of time and attention between the two. “It’s never 50/50,” she says. “That is a fallacy.”

There will, Griffin says, “be days when something epic is going on with your child and, understandably, your brain is going to be skewed toward the family.” Conversely, some days will pass at OMRF “when you don’t think about your kid until 5.” If “you become comfortable that it’s all going to even out in the wash, it creates a healthy relationship with both.”

To Ocañas, the key to striking that balance has been taking a purposeful approach to both phases of her life. “I’m figuring out how to be most productive during the hours I’m at work, because I no longer have the freedom of unlimited time at home,”

she says. “And when I’m with Joyce, I want to be fully present as a parent.”

Sarah recognizes that she’s “blessed” with a “super supportive spouse who can take care of a lot of the duties at home.” Similarly, she counts herself fortunate to have a capable and understanding lab staff. The day before the interview for this article, she’d been home, taking care of a sick daughter and husband. “It’s a constant balancing act,” she says. “And I’m always sacrificing on both sides.”

In November, Sarah, Mike and Joyce took their first “official” vacation – one that wasn’t just an extra day tacked onto a scientific conference – spending time at the beach in South Texas. Sarah hopes the future holds plenty of similar family getaways.

In the meantime, she’s excited for all the milestones and moments that will come as Joyce grows. Recently, much of that development has happened in the area of language. In addition to “no,” which is always a toddler favorite, she’s begun invoking terms like dog, ball, bird, bubble and cookies, along with Dada, which she’s been saying for almost a year.

Just before Halloween, Joyce made yet another addition to her vocabulary. “I was like, ‘Finally!’” says Sarah.

The long-awaited word? Mama.



WHERE ARE THEY NOW?

To celebrate 35 years of Findings, we decided to check in with a half dozen special people we've profiled over the years.

By Lindsay Thomas, Kate Miller, Tony Thornton and Adam Cohen
Photos by Rob Ferguson, Kim Craven and Brett Deering



Embracing the Ride

Madison Cain and her family have learned that life with a rare skeletal condition brings plenty of ups with the downs

To experience the soaring loops of the roller coasters at Missouri's Silver Dollar City, you have to be almost four-and-a-half feet tall. Most kids hit that mark by age 10. But Madison Cain isn't most kids – and at 12 years old and 48 inches flat, the thrill-seeker wasn't sure she'd ever get to experience the coasters her younger brother had been riding for several summers.

"Those three or four inches seemed impossible," says Melissa Cain, Madison's mother.

In August, Madison, her brother, mother and father strolled up to the entrance of the theme park's tallest coaster during the Broken Arrow family's annual summer trip to the Ozarks. Madison hung back with her mom, expecting to watch her brother and dad from below.



Madison recently learned she'd grown tall enough to ride the roller coasters at Missouri's Silver Dollar City.

"We said, 'Oh, she's 48 inches,'" says Melissa. The ride attendant studied Madison. "Are you sure?" he asked. "She looks taller."

Madison stepped up to the measuring stick and pressed her back to the ruler. She stood 52 inches tall – exactly the minimum height required. "We were like, 'You've grown, and we didn't realize it!'" says Melissa. Madison's smile could've powered the whole park. She rode the roller coaster five times in a row.

Born full term at 5 pounds, 9 ounces, Madison has always been little. It wasn't until she seemed to stop growing just after her first birthday that her parents became concerned about her petite stature.

They took Madison to specialists who ultimately gave the 1-year-old a clean bill of health. "They finally said she was just small for her age," says Melissa, a pediatric nurse practitioner.

But soon after Madison started walking, she was diagnosed with hip dysplasia, a painful condition where the joint doesn't function properly. Following the surgery to correct her hips, the Cains noticed changes to Madison's eyes. Cataracts. Two more operations followed.

By the time Madison was entering kindergarten, she had endured broken bones, impaired mobility and crippling digestive issues. Despite extensive physical therapy, she couldn't run or jump. She slept up to 15 hours a day, sometimes dozing off at school. At 6, to help her gain weight, she got a feeding tube. Through it all, no one could tell the Cains why.

In 2019, the Cains turned to specialized genetic testing. They learned their daughter had a mutation in a gene known as MBTPS1, and worldwide, there was just one published research study on the variant. They were prepared to take Madison anywhere to get answers, but it turns out they wouldn't even need an overnight bag: The scientists were just 100 miles away, at OMRF.

OMRF's Drs. Lijun Xia and Patrick Gaffney had already spent two years unraveling this genetic mystery. They were





Where once she was “scared all the time” for her daughter, Melissa Cain has found peace since Madison’s diagnosis.

the first to identify the condition, a skeletal disorder now known as spondyloepiphyseal dysplasia, Kondo-Fu type (SEDKF), in a child from Yukon, Oklahoma.

Until Melissa reached out to OMRF, the researchers thought the patient from Yukon was one of a kind. After meeting 6-year-old Madison and confirming she had the same condition, they expanded their search for SEDKF patients to learn more about the rare disease and find therapies to help.

Six years later, Xia and Dr. Wei Jing, a researcher in his lab, have identified 17 people globally with the variant. OMRF also holds a patent on a potential therapy for the condition. But to move forward with a clinical trial, they need more patients.

In the U.S., rare diseases are defined as those that affect fewer than 200,000 people. To secure a pharmaceutical partner for a trial, Xia says they need at least 100 patients in the U.S. “Even for a rare genetic disease, this is on the extremely rare side,” says Xia, who holds the Merrick Foundation Chair in Biomedical Research at OMRF. “Our work right now is to publicize it.”

In addition to broadcasting their study through OMRF’s website and publications, Jing regularly checks scientific literature for new mentions of the variant. The OMRF researchers have also connected with genetic testing companies to inquire about serving as a point of contact for

patients with the mutation and have registered the condition with national and international organizations for rare disorders and skeletal dysplasia.

Xia suspects many others are waiting to be found. With genetic testing becoming more accessible, he believes increasing numbers of patients and doctors will reach out to OMRF. The more patients Xia and his team can study, the better their chances of finding answers for Madison. “When you see a patient, that’s powerful,” says Xia. “I feel a strong responsibility to keep working on this condition.”

When Madison was 9, the Cains began taking regular trips to Nemours Children’s Hospital in Delaware, which specializes in the treatment of skeletal dysplasia. There, Madison has undergone numerous surgeries to correct her knees and ankles, allowing her to walk without pain. She uses a small, purple wheelchair to get around after surgeries and for outings that involve a lot of walking, like a full day at the zoo or a theme park. Her feeding tube is long gone. She’s likely to need joint replacements in the future. Driving will come with its own set of challenges.

Now 13, Madison says she doesn’t feel different from anyone else in middle school. “I’m just shorter,” she says. “If it’s not a height thing, I think I can do anything.”

The seventh grader plays the snare drum and xylophone and dreams of joining the high school marching band. She’s taken over three of her mom’s kitchen cabinets with baking supplies and developed her own chocolate-coffee icing recipe, a step on the way to her career goal of becoming a baker. She collects rocks and stuffed animal mascots from the Major League Baseball stadiums she’s visited (four down, 26 to go). She loves Taylor Swift, her Girl Scout troop, the Atlanta Braves, and, of course, roller coasters. Madison sums it up with a shrug: “I’m normal.”

For Madison’s parents, who once feared their daughter might never live independently, the years since they first connected with OMRF have brought peace. “In the 2015 to 2020 era, we were just scared all the time,” Melissa says. Once the foundation’s scientists confirmed Madison’s diagnosis, the family stepped off a roller coaster. “We now know that when she’s going through a surgery or having lots of pain, that isn’t forever,” says Melissa. “We get through it and move on to the next day.”

Madison seems to agree. She’d be the first to tell you that the dips don’t last. They’re just part of the ride.



“If it’s not a height thing, I think I can do anything,” says Madison, who dreams of becoming a baker.

MIKE SCHUSTER, 2017



Don't Count Him Out

Mike Schuster marks a decade after a daunting diagnosis

In 2016, Mike Schuster decided to try one last Hail Mary.

Less than a year earlier, Mike, then 50, had been diagnosed with glioblastoma, an aggressive and nearly always fatal form of brain cancer. Despite a pair of surgeries, radiation and chemotherapy, the cancer had grown back.

On the heels of the second surgery, his doctor delivered more bad news: He'd been unable to remove enough of the tumor to allow him to qualify for a clinical trial aimed at developing a glioblastoma vaccine. "We were heartbroken," says Mike's wife, Teresa.

However, the physician offered a backup plan: a clinical trial for OKN-007, an experimental drug developed at OMRF. "I remember telling him, 'If you think it's a good idea, I think it's a good idea,'" says Mike. He chuckles at the memory. "Turns out, it was a good idea."

Today, Mike is almost unique among glioblastoma patients. On the day before Thanksgiving, he marked the 10th anniversary of when he first learned he had cancer. That makes him truly exceptional: According to a study in the *Journal of Clinical Neuroscience*, only 0.71% of glioblastoma patients survive a full decade following diagnosis.

"I'm incredibly fortunate," says Mike.

We first featured Mike in *Findings* in 2017, when he was making monthly trips from his home in Norman to the University of Oklahoma's Stephenson Cancer Center to receive intravenous doses of OKN-007. At the conclusion of the 24-month clinical trial, doctors could no longer detect any traces of the cancer. That remains true today.

"We don't often talk about remission in people with brain cancer, because so few of them reach that point," says Dr. James Battiste, the neuro-oncologist who's been treating Mike at Stephenson since he was first diagnosed with glioblastoma. "But with Mike, you can accurately say he's in remission."

Mike has made the most of the years since. He's attended both of his sons' college graduations. He watched one get married, and he's counting down the days until the other one does. He and Teresa have traveled extensively

and welcomed a pair of grandchildren. This past year, they celebrated both their 33rd wedding anniversary and Mike's 60th birthday.

At each of these milestones, says Mike, "It's impossible not to make mental notes. I'm always stepping back and thinking, 'I can't believe I'm here.'"

Life in the wake of glioblastoma, though, has come with more than its fair share of challenges. He still vividly recalls the 31 doses of radiation he received. Specifically, he remembers the odor that came with the treatments. "It was a charred smell," he says. And when it wafted into his nose, he'd think, "Hmm, I think that was my brain."

TODAY





“I’m always stepping back and thinking, ‘I can’t believe I’m here.’”

Since Mike’s cancer diagnosis, he and his wife, Teresa, have celebrated one son’s wedding and are counting down the days until the other’s.

He’s had more than a dozen surgeries – “We’ve lost count,” says Teresa – on his head. That includes not only the initial ones for cancer removal but also follow-up procedures for wound healing, repeated staph infections, insertion of a titanium plate and then, to curb infections, removal of that same plate. The site of those many surgeries, which required incisions up to eight inches long, remains prone to infection and lacks a large chunk of what was once Mike’s skull. “It looks like my head’s bashed in,” he says. As a result, he relies on a substantial hat collection.

He can’t bend over or lift more than 10 pounds. For fear of infection, he’s given up swimming, and to avoid pressure on the surgical site, he sleeps on his left side each night. Although Mike’s short-term recollection is good, his long-term memory, says Teresa, “can get a little dicey.”

Nevertheless, Mike says, “Every morning when I wake up, I’m thankful.”

Mike is not the only glioblastoma patient to look to OKN-007 for hope. After successfully completing the Phase I safety trial in which Mike participated, the investigational drug recently wrapped up its second phase of clinical trials.

At an American Association for Cancer Research conference, Battiste and colleagues reported the results of those trials. In 57 patients, treatment with OKN-007, in combination with a common chemotherapy drug, increased the number of patients who lived for a year or longer by nearly 50%. It also added an average of more than two months to patients’ lives. While that may not seem like a big number, for a disease where the average time of survival from diagnosis is 12 to 15 months, every day can make a meaningful difference.

Even though not all patients who received OKN-007 have fared as well as Mike, “his is not the only great response,” reports Battiste. However, it remains to be seen whether the drug will proceed to Phase III, the final – and most expensive – step of clinical trials.

In the meantime, Mike remains vigilant about his own health. He continues under Battiste’s care, where he receives regular MRI scans to rule out new tumor activity. “I know I’m never cured. The cancer could come back with just one cell,” Mike says.

Still, he sees the world through a decidedly different lens than he did a decade ago. “There was a time when imagining the future seemed pretty bleak,” he says. “OKN-007 made it possible to dream again.”



“Every morning when I wake up, I’m thankful,” says Mike, pictured here with granddaughter Phoebe.

DANIELLE JAMISON, 2021



Taking Back Her Life

An OMRF drug has helped Danielle Jamison focus on what really matters to her

On a sweltering September afternoon in Walterboro, South Carolina, a 15-year-old waits in front of her high school’s football stadium. She’s a water girl, and she’s forgotten her uniform shirt. Her mom pulls up, passes it through the car window, and smiles as her daughter runs off to practice.

For Danielle Jamison, once a regular in hospital beds while suffering from the unrelenting complications of sickle cell disease, this small act – simply being there for her daughter – means everything.

“That’s Danielle,” says her older sister, Tonya. “Cheer mom, dance mom, PTO mom – pain or not, if it’s for Jocelyn, she’ll be there.”

Danielle’s fierce devotion has always battled her body’s limits. Like the more than 100,000 other Americans living with sickle cell disease, Danielle was born with the condition. The life-threatening genetic disorder causes pliable, round red blood cells to change to rigid, crescent-shaped “sickles.” Instead of moving smoothly through the bloodstream, they clump together, choking off the blood supply to tissues and organs and causing long-term damage. The excruciating pain that results from the clustered cells, known as a crisis, can start anywhere in the body and last for weeks. “It’s like being hit over and over,” says Danielle.

The disease disrupted every part of Danielle’s life for more than 30 years. She spent her childhood in the hospital beside her younger sister, who also lives with the condition. Because of the persistent lack of blood flow, bone tissue in Danielle’s hips died; she needed a hip replacement at age 24. It took nine years to earn her college degree, and even then, she couldn’t keep a full-time job due to pain. Then came Jocelyn, and Danielle couldn’t be the mother she wanted to be.

“She’d call me from the hospital when Jocelyn was little, and I’d tell her, ‘You deal with what you’re dealing with, I got her,’” says Tonya. “Even when she was in all that pain, her mind was on her daughter. Always.”

In 2017, when Jocelyn was 7, Danielle volunteered for a clinical trial of what would become Adakveo, a drug designed to prevent sickle cell crises by stopping blood cells from sticking together. It grew



“To go from constantly being in the hospital to this, it’s amazing.”



Dr. Rod McEver’s research at OMRF led to Adakveo, the drug that helped change Danielle’s life.

from discoveries by OMRF’s Dr. Rod McEver, a hematologist and the foundation’s former vice president of research. When the U.S. Food and Drug Administration approved the medication in 2019, it became the first new treatment for sickle cell disease in 25 years.

Danielle had been on Adakveo for three years when her story appeared in Findings in 2021. During that time, she was never hospitalized for a crisis, a record in her adult life. Today, despite having stopped taking the drug in 2023 when she started experiencing pain following infusions, she’s approaching nine years without a hospital stay.

“To go from constantly being in the hospital to this, it’s amazing,” says Danielle. “I never imagined that I could experience this.”

These years without crises and hospitalizations, says Dr. Julie Kanter, a hematologist and sickle cell specialist who treats Danielle, likely saved her patient’s life. The time allowed Kanter to work with Danielle to customize her treatment plan and help her adopt new strategies to control pain at home. “We see that the more times you’re hospitalized, the more likely you are to die relative to your sickle cell disease,” says Kanter. “So, being out of the hospital is one of the many ways to stay very safe.”

Living most days without acute pain allowed Danielle to be the parent she wanted to be. She had more energy to volunteer at Jocelyn’s school and shuttle her to activities. “She was really more active,” says Tonya. “And the more she did, she didn’t complain about pain.”

Free from constant crises, Danielle also devoted time to advocacy and raising awareness of her disease. The pharmaceutical company that manufactures Adakveo featured Danielle in a national advertising campaign, and the hospital that hosted her clinical trial highlighted her on its website. She appeared on TV, in newspapers and on podcasts. “I want my story to help,” says Danielle. “Especially for the generations coming up behind me.”

Though the worst crises remain behind her, most days Danielle rates her baseline pain as at least a 5 on a 10-point scale. Now 41, she feels the lifetime toll of the disease on her body. She needs a second hip replacement. While she realized her dream of becoming an event planner, the physical demands ultimately proved too much.

“I’d come home, and for three, four days, my body was aching,” Danielle says. For now, she opts for flexible work, like rideshare driving and deliveries.

Danielle knows the average life expectancy for Americans with sickle cell disease is about 20 years shorter than that of others, but she doesn’t dwell on statistics. She focuses instead on the older people she sees at the sickle cell clinic: men and women in their 60s and 70s who’ve made it to graduations, weddings and grandparenthood. “That gives me hope,” she says. She knows her health may decline, but, she says, “I want to live as much as possible, for as long as possible, especially for my daughter.”

Now a sophomore and an honors student, Jocelyn is on track to graduate early. She’s looking at colleges and is eyeing a career that lets her help her mom. “My baby is almost out of high school,” Danielle says, half in disbelief. “What am I going to do?”

Jocelyn’s teasing response: “Mom, you’re just going to end up moving wherever I go to school.”

Maybe, Danielle thinks. After all, someone’s got to be there when Jocelyn forgets her shirt.



Without pain crises, Danielle is able to be there for her daughter, Jocelyn, 15.

Boring Is Good

ELEANOR, KATIE AND JACK FRIDDLE, 2018



Katie Friddle doesn't have much to report about living with lupus since we first told her story. And that's just fine with her.

Many Saturdays, you can find Jack Friddle on a soccer field, tapping the seemingly endless well of energy available only to 8-year-olds. And when he looks to the sidelines, he sees his mom, Katie, cheering him on – despite the lupus that threatens to slow her down.

Under the care of OMRF rheumatologist Dr. Eliza Chakravarty, Katie had two successful pregnancies and births: Jack and his big sister, Eleanor, now 13. We first met the Friddles in 2018, when Katie and her husband had just welcomed Jack.

At the time, some physicians discouraged lupus patients from getting pregnant, for fear it would trigger complications from the disease. But not Chakravarty, who'd long before decided her role was not to counsel women with lupus about whether to have children. "If women want babies," she says, "they should be able to have them."

Instead, Chakravarty built a practice around helping lupus patients who wanted to become mothers. "Every time a mother came to me and said, 'I want to get pregnant,' I was in," says the now-retired physician.

In lupus, the immune system turns on itself, launching attacks – known as flares – on tissues, leading to joint aches, fatigue, painful rashes and, sometimes, organ damage. Katie had her most significant flare as she weaned Eleanor from

nursing. The episode sent her to the hospital, where doctors treated her with massive doses of steroids. Soon after, an MRI revealed the bone in one of her hips was collapsing due to lack of blood supply, likely the product of long-term use of prednisone to control her flares. At the age of 31, following months of mounting pain and immobility, she underwent hip replacement surgery.

After recovery, Katie, who works in historic preservation for Oklahoma City, nervously broached the idea of a second child during a visit to OMRF's rheumatology clinic. Chakravarty immediately gave her the thumbs up. "As always, Eliza was supportive and encouraging," says Katie.

Katie's pregnancy with Jack, as well as his birth and the years since, proved happily uneventful. She says that knowing what to look for has been key to managing her lupus. "Every day I understand more about the warnings my body is giving me," she says.

She also attributes her "pretty boring" experience with lupus to a supportive family. If fatigue looms, Katie's parents are quick to step up. "When things are busy, we take the kids for an evening," says Katie's mother, Kathy McLaughlin. "Even just a break from packing lunch and reading stories can make a big difference."

Quarterly blood draws allow OMRF physicians to monitor Katie's progression and to tweak her treatment plan when needed. "Most of the anxiety from when I was really sick has faded, but I still call my mom with an update after every appointment," Katie says.

Those monitoring appointments also pull double duty. The blood samples and information about her condition are stored away as part of the Oklahoma Lupus Cohort, a collection of tens of thousands of samples that researchers at OMRF and beyond use in their quest to better understand, treat and prevent the disease.

"When Katie was diagnosed, there was only one FDA-approved treatment option for lupus," says Dr. Cristina Arriens, the rheumatologist who now cares for Katie at OMRF. "Today there are more, and we're constantly involved in clinical trials to find the next thing that can help our patients."

Katie still struggles with the fatigue, sun sensitivity and annoying rashes that are common with the condition. But they don't hold her back, either in her career or from being a wife and busy mother of two active children.

"We're in the thick of kid life," Katie says. "They're changing so fast and becoming little grown-ups, and we're just happy to be riding along on this adventure with them."



With her lupus under control, Katie says she is "in the thick of kid life," raising Eleanor, 13, and Jack, 8.

SANDY ROARK, 2008



New Chapters

When doctors diagnosed Sandy Roark with a rare blood condition, she thought her life was ending. A drug born at OMRF changed that.

Sandy Roark wasn't supposed to be here. Not for her 85th birthday. Not for her eight great-grandchildren to be born. When she learned she had a rare blood disorder in 2000, the life expectancy for her condition hovered around eight years. The first specialist she saw in Oklahoma City offered an even grimmer outlook: "He basically gave me two years to live," Sandy says.

At the time, Sandy, the wife of an Oklahoma Baptist University professor and mother of three, was 60. "I thought my life was over," she says.

What she didn't know was that a pair of scientists at OMRF had been studying her disease for more than a decade. And, thanks to their efforts, a treatment breakthrough was coming.

Paroxysmal nocturnal hemoglobinuria, or PNH, is a genetic disorder brought on by a random bone marrow mutation. It causes the body to create abnormal red blood cells, which the immune system attacks. Experts estimate that each year, about 500 people in the U.S. are diagnosed with the condition, which leads to severe anemia and a high risk of infections, blood cancers, blood clots, and a condition called bone marrow failure syndrome, which is fatal without a bone marrow or stem cell transplant.

"People with PNH kind of walk on eggshells," says Dr. George Selby, a hematologist who treated Sandy at the University of Oklahoma Health Sciences Center. "They're just waiting for something to happen."

Doctors initially prescribed immunosuppressants and steroids to tamp down Sandy's immune system, along with blood transfusions to increase her hemoglobin levels. This kept her alive, but the steroids alone came with "their own boxcar full of side effects," says Selby: weight gain, insomnia, fluid retention, muscle weakness and mood swings.

"There's no counting the gratefulness we feel for OMRF."

Meanwhile, the transfusions caused iron to build up in Sandy's body, which can be deadly; she had to sleep wearing a pump to remove it. They also dashed her candidacy for a bone marrow transplant, the only cure for PNH. With so much donor blood in her body, the risk of bone marrow rejection was too high.

She was alive, sure, "But I wasn't living," she says. "You think, well, if I go lie down, I'll feel better. But you don't. Nothing could help that horribly depleted, weak feeling that I always had."

When Sandy's doctor referred her to a PNH expert at the National Institutes of Health, she and her husband, Mack,

TODAY





Research that Drs. Therese Wiedmer and Peter Sims began at OMRF in the 1980s led to the treatment that would ultimately transform Sandy's life.

learned that a new drug was in clinical trials. "He said that if it came through, it would be almost a miraculous cure," remembers Mack.

At OMRF, the husband-and-wife research team of Drs. Peter Sims and Therese Wiedmer had been working toward a solution to PNH since the 1980s. Their work led to Soliris, a drug the U.S. Food and Drug Administration approved in 2007. It was the first therapy the agency greenlit for the treatment of PNH.

Within hours of her initial infusion, Sandy knew something was different. "It immediately changed my life," she says. Within months, she was the "old" Sandy.

"It was what we had been hoping and praying for all along," says Mack, "something that would stop all the symptoms and give her a normal life."

The Roarks wondered who was responsible for their miracle, so they began researching. "We found it came right out of the red dirt where we were born," says Mack. "It was serendipity."

After her story was published in this magazine in 2008, Sandy and Mack visited OMRF to meet Sims and Wiedmer. Seeing them, Sandy found herself momentarily speechless. "I gasped," she says. And then? "I said, 'Thank you, thank you, thank you!'"

Today, physicians use Soliris worldwide to treat PNH, as well as a trio of other rare autoimmune disorders that affect the blood, brain and spinal cord. Sandy receives infusions every two months and sees her hematologist about three times a year, though she says those appointments are a

formality. Her disease is stable. It's aging, she says, not PNH, that limits her now.

This past summer, the Roarks celebrated 68 years of marriage at a local restaurant. At the end of the meal, the server brought out a special ice cream dessert decorated with "Happy Anniversary" in caramel sauce. "I hope I get to be as happy as you all are when I get to my 68th," she said as she presented them with the plate.

She couldn't have known that this anniversary hadn't been promised. That so many of Sandy and Mack's years together – and the quality of those years – had been made possible by medical research.

"There's no counting the gratefulness we feel for OMRF," says Sandy. "What it means to me in my life and the lives of so many others, the wonderful work they're doing there, there's no way to say it."



Sandy and her husband, Mack, celebrated their 68th anniversary this past summer.

Not Backing Down

When we met Liz Haughey Hartley in 2017, she was defiant in the face of multiple sclerosis. Nine years later, she's just as steadfast.

There isn't much vacant real estate on the walls of Liz Haughey Hartley's classroom. The AP U.S. History teacher at Tulsa's Booker T. Washington High School has filled the space with famous photographs, art, inspiring quotes, pictures with former students and even a hanging, plastic shoe divider that she calls the "cell phone hotel," where her teenage pupils deposit their phones before class.

One poster draws your eye first. It reads "GROWTH MINDSET" from top to bottom in Booker T.'s signature orange and black, each letter of mindset set off with an affirmation:

*I can learn from my **mistakes**.*

*I can **improve** by working hard.*

*I will **never** give up.*

*I am **determined** to do my best.*

*Self-reflection can help me **succeed**.*

*I can overcome challenges with **effort**.*

*I can **train** my brain.*

If Liz's students ever doubted these words, they wouldn't need to look further than their teacher's life for confirmation. She's been living with multiple sclerosis for 15 years – and she's determined not to let the disease best her.

MS is one of more than 100 known autoimmune diseases. It causes the immune system to attack the body's myelin, the insulating layer that protects nerves in the brain and

spinal cord. This damages the nervous system's ability to transmit signals throughout the body. Although the condition manifests differently in each individual, symptoms often include vision problems, fatigue, muscle weakness, balance and coordination issues, and difficulty with speech, memory, and concentration.

For Liz, it began with her balance. Next, she gradually lost all feeling on the left side of her body, forcing her to take a leave of absence from teaching. And then came that Easter morning in 2011, when she woke up with blurred vision. She tried to get out of bed, but she couldn't stand up. She was 28 years old, and she thought her life was over.

Liz spent more than four months hospitalized in Tulsa, but doctors couldn't pinpoint what was wrong. They referred her to the Mayo Clinic in Rochester, Minnesota, where an MRI revealed an explosion of lesions throughout her central nervous system. That was when she first heard the words multiple sclerosis.

LIZ HAUGHEY HARTLEY, 2017



TODAY



At home in Oklahoma, Liz was referred to OMRF and Dr. Gabriel Pardo, a physician who'd devoted his career to caring for patients with MS and who had launched the foundation's Multiple Sclerosis Center of Excellence. He'd seen countless cases like Liz's and believed she needed aggressive treatment. "The disease was overwhelming her," Pardo says.

After Liz's first infusion of a drug designed to target her attacking immune cells, she began to regain her coordination. She could stand with support. Soon, with the encouragement of her parents and siblings, she began to learn to walk again. First with a walker, then a cane. *I can improve by working hard.*

After her next infusion, she asked Pardo about the possibility of returning to teaching. "He told me, 'If you think you can, you can,'" she says. By late fall, she was back at the whiteboard. *I am determined to do my best.*

This year marks Liz's 21st as a teacher at Booker T. A year after her story appeared in Findings, she married Jim Hartley.

"I always thought MS would be a deal-breaker in a relationship," says Liz. She told her future husband about her diagnosis on their second date. He was not deterred. "I just didn't think it was that big of a deal," says Jim.

Liz still receives a monthly infusion of the same drug she started under Pardo's care 15 years ago. Her disease is stable, and annual MRIs show no new lesions on her brain or spinal cord. The cane she once required to walk is ancient history.

Still, MS is a difficult road: She overheats easily and walks slowly. Her vision was so damaged at the disease's onset that she can't drive on the highway; Jim takes her to all her appointments at OMRF. She carries a magnifying glass and can't read the faint writing of a pencil, so her students can only use pens. She fatigues quickly and sometimes pays a price if she stays up late grading. "I wake up completely exhausted," Liz says. "It's like my body reminding me, 'You can't do that anymore.'" *I can learn from my mistakes.*



Liz believed her MS would be a "deal-breaker" in a relationship. "I just didn't think it was that big of a deal," says Jim, who married Liz in 2018.



Liz, pictured here with some of her former Booker T. Washington students, is a staple at the school's football and basketball games.

For the last two years, Liz lived with a nerve issue that scrambled her bladder's communication with her brain, waking her as many as 40 times a night to go to the bathroom. She recently had a medical device placed in her lower back to override those misfires, cutting her wakings to about eight a night. She's working with a neuro-urologist to find more relief. *I can train my brain.*

None of this, though, stops Liz from enjoying her life. "There's no, 'Why me?' This is the hand I've been dealt," she says. "I'm going to live my life to the fullest, whatever that looks like." *Self-reflection can help me succeed.*

Life may look nothing like the one she imagined before MS. But the one she's built, she says, is wonderful. It's spending time with her family. Going to church. Watching Star Trek with Jim. Cheering on her students at football games and every home basketball game; she didn't miss a single one last year. She lights up talking about going to the homecoming dance, winter formal and prom. "I don't have children," says Liz. "These are my kids."

Last summer, she took a solo trip to Kansas City to serve as a reader for the AP exams that high school students complete for college credit. Liz has been to Europe more than a dozen times, but this was her first fully independent trip in years. Flying by herself and navigating transit to get to the hotel, "that was a really powerful thing for me," she says. *I can overcome challenges with effort.*

For Pardo, seeing patients like Liz experience milestones big and small can be summed up in a word: "awesome." Then he adds two more: "It's fantastic."

Liz, says Pardo, is far from alone. Over the past two decades, research like that performed in OMRF's labs and clinics has given birth to more than a dozen new MS medications and countless new approaches to managing patient care. With this progress, patients are living longer, fuller lives.

At each of her appointments, Liz asks Pardo for updates on the latest in MS research. "I'm just blown away by it. It's so hopeful," she says. "When they find a cure, I'm going to get my first tattoo. It will say 'MS = Mystery Solved.'"

I will never give up. 📍

Rare Bird



An OMRF scientist traveled to the mountains of Costa Rica to unlock the genetic secrets of the resplendent quetzal

By Adam Cohen and Tony Thornton

It's tough to know what kind of life the bird with the brilliant, emerald feathers had lived. But as a resplendent quetzal, it had probably enjoyed a pretty good existence, at least by avian standards.

You see, in Costa Rica, where this particular bird resided, quetzals are a protected species. The Aztecs and Mayans considered them sacred. Today, Costa Rican law prohibits their harm or capture. So, the creatures have little to fear from humans, who are primarily responsible for their now-dwindling numbers.

Naturally shy, quetzals nest high in the trees of Costa Rica's rainforests, sometimes 200 feet above the ground. The greenery disguises the iridescent birds, which occasionally leave their abodes to hover among the branches of aguacatillo trees and pluck their favorite delicacy, a small fruit much like an avocado.

It's nice to imagine the quetzal in question had just finished a pleasant meal of wild avocados when it met its unfortunate demise. That end came swiftly, as the bird tried to fly through a window. And while that window was closed, it did, at least proverbially, open another one.

Costa Rica's protections of quetzals are so complete that not a drop of blood can be removed from their bodies. This means that even if scientists wanted to extract a minuscule biological sample – say, as part of the Earth BioGenome Project, a worldwide effort to create a comprehensive genetic catalogue of all known species – they could not.

However, with this ill-fated quetzal no longer among the living, genetic cataloguing became possible. Costa Rican law still dictated that what remained of the bird, down to its last feather, could not leave the country. But if a scientist came to Costa Rica, it could work.

And that's where Dr. Graham Wiley entered the picture.

Wiley is a tall, stoic sort. If you spend any time with him, you might get the sense he prefers the company of large tables of scientific data over that of most human beings. And you wouldn't be wrong.

The lion's share of that data comes from deoxyribonucleic acid, or DNA, the genetic blueprint for each living creature. Every cell in every being contains copies of those blueprints, and Wiley has made a career of documenting them.



Dr. Graham Wiley

Since 2021, he's run OMRF's Clinical Genomics Center. There, he oversees five scientists and a wealth of carefully calibrated research equipment, all devoted to reducing living beings to long strings of letters: A, T, C and G, the four chemical bases that make up the genetic code in DNA molecules. The letters stand for adenine, thymine, cytosine and guanine, and their specific sequence determines the identity of every organism.

Wiley and his team work closely with OMRF scientists, so they focus on the two organisms at the center of OMRF's research: humans and mice. However, since he began sequencing genomes – the term scientists use to describe an organism's complete genetic blueprint – Wiley has also used his skills to map out the DNA of rats, fish, frogs, viruses that affect grass, a plant with a peppery flavor similar to horseradish and mustard, falcons, and a mole-like rodent called a vole.

So, when Dr. Caio França, director of the Quetzal Education Research Center in Costa Rica, called in early 2025 and asked if Wiley could perform the first-ever genetic sequencing of a resplendent quetzal, the OMRF scientist signed on without hesitation. He did so even though he “had no idea” resplendent quetzals existed – until França “said he had a dead one in his freezer.”

Because Costa Rica bans the export of any portion of a quetzal's remains, Wiley would need to bring all the equipment necessary to sequence the bird's genome to the Center.

In May, he made the 2,000-mile journey from Oklahoma City to Costa Rica's capital city of San José. He did so while toting a \$10,000, football-sized sequencer OMRF loaned him for the occasion.

In Houston, where his flights connected, a customs inspector opened Wiley's backpack and eyed the sequencer. Wiley thought about producing the letters of transit he'd prepared for just such an encounter – but opted to stay mum. “Speak when spoken to,” he says. The inspector closed the pack and let it pass without a word.

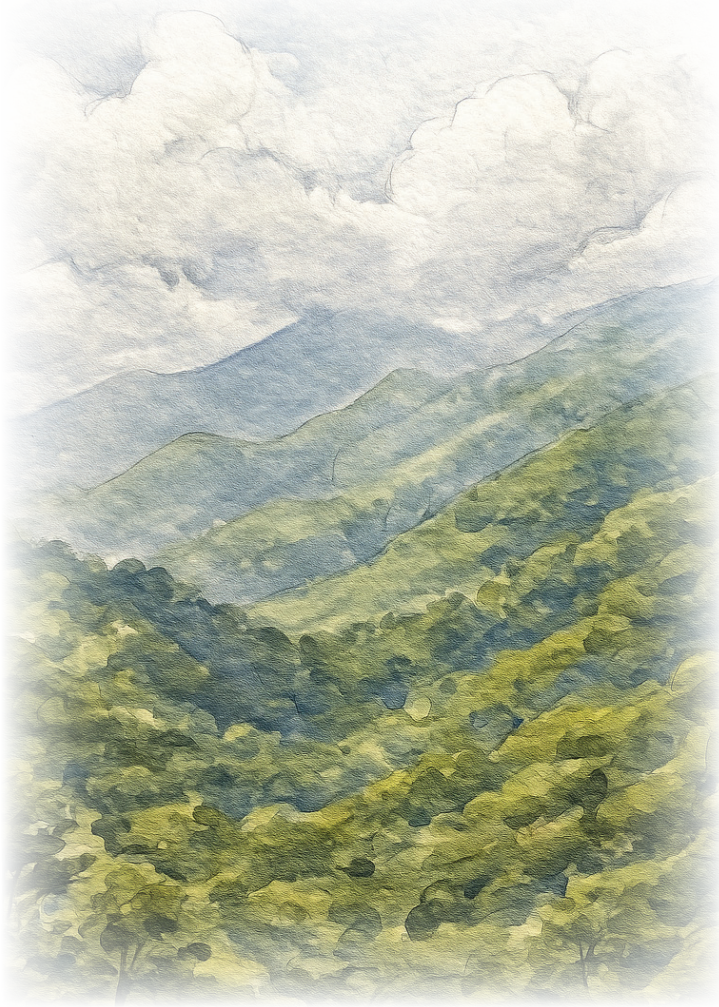
From San José, a car took Wiley another three hours south to the Center. The journey, he says, was perilous.

As night fell, the driver negotiated narrow, twisting mountain roads through cloud forests, high-altitude rainforests wrapped in – you guessed it – clouds. “You couldn't see the trees because of the clouds, fog and darkness,” says Wiley. The few approaching cars they encountered remained invisible until their headlights materialized at the very moment they passed.

Around midnight, they arrived at the Center, which sits more than a mile above sea level in the Talamanca Mountains. Wiley pulled himself from the car and rested on the ground for a few minutes to regain his bearings. “I have never felt worse from motion sickness,” he says.

The Center sits on a small tract of land alongside an ecotourism resort, which together once made up a large cattle ranch. It consists of a pair of cinder block buildings, and França led Wiley to a freezer in one of them, from which he gently extracted the reason for the OMRF scientist's odyssey: the quetzal.





Wiley beheld the bird, whose body was roughly the size of a water bottle. It was female, so it lacked the long tail that males of the species flaunt to attract mates. Other than some red on its underbelly, the bird's coloring matched that of the trees it had once called home. And while the quetzal had spent months in cold storage since its untimely encounter with the window, its feathers still shimmered.

Wiley headed upstairs to his quarters, a room with a pair of triple bunk beds he'd share with five other scientists. The windows were open, and they looked out on the cloud forest.

Even at night, birds continued to sing and chatter, contributing to a rich nocturnal soundscape. But Wiley heard none of it. Before laying his head upon his pillow, he'd popped in a pair of earplugs.

Although he'd unspooled the genomes of thousands of organisms, this would be the first time he'd done so outside the confines of a sequencing laboratory. And for that, he'd need some sleep.

The next morning, following a breakfast heavy on fried plantains, Wiley set to work. In a room that had neither heating nor air conditioning – “I wore a beanie and layers, then shed them as the day went on” – he used a scalpel to extract a small piece of flesh from the bird's body. He placed the sample in a small test tube, then dissolved it in an enzyme solution. With magnetic beads and polyethylene glycol, a compound found in a wide range of products that

include toothpaste and colonoscopy preparation kits, he extracted the quetzal's DNA from the solution. After a few more steps to purify, stabilize and repair any damage that the DNA might have sustained as he prepared the sample, he loaded it into the sequencer for processing.

And then he started over.

Each sample required about three hours of preparation. While the sequencer did its work, he'd prepare another sample. In each instance, he'd extract from a different part of the quetzal: the kidneys, different muscles, the liver.

“The samples weren't from a living bird, and I was working in field conditions,” he says. “So, extracting from multiple tissues ensures we can generate data from the longest strands of DNA we could get.”

Wiley did this process for three straight days, from shortly after the sun rose until it dipped into the evening sky. Another scientist, an ornithologist who'd flown from the United Arab Emirates, did the same. The two are now working with França and other collaborators to finish processing the data they generated in Costa Rica and publish their findings in a scientific journal. The quetzal's genetic sequence will then join the thousands of other species catalogued to date by the Earth BioGenome Project.

For França, who's been pursuing the quetzal's genome for a half-decade, completing the project is “a dream come true.” And while Wiley is newer to the quest, he's likewise excited to share that information with the scientific community. “It's always fun to be the first person to figure something out,” he says.

Still, for him, there's one piece of the quetzal puzzle that remains incomplete.

One morning, after he and the ornithologist had loaded their samples into sequencers and were awaiting results, the pair decided to take a hike. If we're spending all this time unmasking the quetzal's genetic makeup, they figured, we should see a live one while we're here.

For 2 ½ miles, they walked along a road in a valley. On each side of their path stood white oaks more than 100 feet tall, perfect nesting spots for the quetzals.

The two scientists spotted plenty of tourists who, like them, hoped to lay eyes on – and to photograph – the reclusive avian.

But no resplendent, green birds presented themselves. Their walk back yielded the same results.

Now back in Oklahoma City, Wiley knows he won't encounter a quetzal in Scissortail Park. But someday, he says, “I would like to see one in person.”





In 2026, Wiley and his colleagues expect to publish the first genetic sequence of a resplendent quetzal, whose worldwide numbers have shrunk to less than 50,000 and continue to decrease.



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Print Pioneer

Long before the first printing of Findings, OMRF's first president, Ancel Earp (pictured here, center, with Gov. Roy Turner, left, and Horace Falls), helped create the foundation's first newsletter. Launched in 1946, The Research Reporter showcased new hires and scientific progress for supporters of the growing foundation.

