

HOPE FOR KATHERINE BELLE

How one family's journey through the realm of rare disease led them to the newest frontier of precision genetic medicine.

BY TREY POPP

David Faughn W'90 entered parenthood the way many fathers do: suddenly, hopefully, and at a bit of a loss about what to do. Katherine lay on her mother's belly having spent 40 weeks within it. Her father was a foreigner to her. Or that's how it seemed to Dave. The "ten months of uselessness" he had felt during Glenda's pregnancy had not ended in the delivery room, he thought, just taken on a new form. He was as helpless as any new father. Helpless to feed her, helplessly unfamiliar to her, helplessly in love with her, already.

The family's swift release from the hospital, bearing as it did the shock of responsibility, intensified the sensation.

"At first, we were strangers looking at each other," he later recalled in a blog post: "me trying to figure out what to do, and she trying to figure out where mommy went." But a bond was forming. Its profundity hit him one day on diaper duty. Katherine lay on the changing table while Dave made goofy faces, fishing for a smile. She unleashed a raucous belly laugh, a laugh as full-throated as Glenda's. Dave "literally jumped in the air" and called Glenda in a rush of excitement. Her bemused response didn't dent his elation. "At that moment, I became 'daddy,'" he wrote, "and to the most wonderful girl who has ever been or ever will be."

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The first year of Katherine's life suggested the sort of alumni-note announcement that her father wasn't actually the sort of person to write: "Katherine Belle Faughn was born on July 9, 2011, and is already well on her way to joining the Quaker Class of 2033." Dave was an attorney for a Lexington, Kentucky, firm specializing in civil litigation and equine law. Glenda (who kept her birth name, McCoy) worked in the governor's office as a project manager for the Kentucky Commission on Women. Katherine seemed hell-bent on beating her daycare classmates to developmental milestones. The nurs-

ery school staff nicknamed her "Flash" for how quickly she got to crawling—six months—and how speedy she was once she'd mastered it. Glenda began to fret that she'd have a nine-month-old walker on her hands, as though life weren't hectic enough already.

But as her peers began catching up, Katherine seemed to stall. Dave and Glenda weren't inclined to make a big deal out of it. They weren't tiger parents. Dave's aunt hadn't walked until she was nearly two. She'd turned out fine. But the longer the delay persisted, the more it ate at Glenda.

"I would see so-and-so's kid stand up at my feet and start walking across the room," she recalls, "and Katherine would still crawl at everyone's feet. And at 13 months she was still doing it. Everybody in her classroom was up and running around and I sat there thinking, why, *why* is my child not up and walking with them?"

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By 18 months, Katherine was in physical therapy. She seemed to possess the strength to walk, but whenever she tried her limbs would jerk, or her knees would lock, or she would take exaggerated strides, and she would tumble to the floor. She fell a lot—even when crawling, or simply sitting still. The physical therapist was stumped. An occupational therapist wondered if she suffered from a sensory-processing disorder. But then some of those issues seemed to improve. Meanwhile, Katherine kept being Katherine. She was a blond-haired, blue-eyed pixie with energy that wouldn't quit. She liked hide-and-seek and dancing with her daddy. She commanded a vocabulary that was advanced for her age—yet her speech had begun to sound "thick" to Dave and Glenda. The confusion persisted.

Still unable to walk at her two-year pediatric check-up, Katherine was referred to the Cincinnati Children's Hospital's neurology department, which is reputed to be one of the best in the country.

PHOTO BY JONATHAN ROBERT WILLIS



On August 30, 2013, Katherine underwent a brain MRI. A doctor phoned Dave late in the day to discuss the results. Through a thicket of difficult terminology—lactate peaks, T2/FLAIR hyperintensities—one finding landed like a sucker punch: Katherine’s cerebellum was abnormally small.

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The cerebellum is a critical structure in the brain. Every creature with a backbone has a cerebellum. In humans, as in other animals, it is most strongly associated with motor control and coordination. So that solved the mystery of why Katherine had such a hard time keeping her balance. The underlying cause remained unknown, but the test results and the timing of Katherine’s symptoms strongly suggested a metabolic disorder. A team of CCH neurologists, metabolic specialists, and radiologists were confident they knew what it was: infantile neuroaxonal dystrophy, or INAD.

Dave had never heard of it before. INAD is caused by a rare genetic mutation inherited from both parents. Its frequency is unknown, but the disease is estimated to afflict fewer than 1 out of 200,000 newborns. An American is roughly 15 times likelier to be struck by lightning than by INAD. Anyone forced to choose would opt for lightning. By the time the doctor had finished talking, Dave understood two things. Katherine was going to die young. But first she would likely lose her ability to move, speak, swallow, see, and hear.

INAD progressively entraps children inside failing bodies. In time, Katherine’s skin might even lose the capacity to register the sensation of her parents’ touch.

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There was no cure—not even any experimental treatments in the pipeline.

Dave asked the most abject question a parent can utter: “Doctor, is there any hope?”

There was pained and awkward pause. “You have a beautiful daughter,” the doctor replied. “You need to spend as much time with her as you can.”

The phrase “before she dies” was left unsaid, but that’s what the advice added up to. The clock was ticking.

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Dave told Glenda. Her knees buckled. She crumpled to the floor, screaming. A period of time elapsed; pain voided her memory of it. Her eyes fell upon Katherine. Who was smiling but hungry. Who needed a fresh diaper. Who wanted a story before bedtime.

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“We took turns being strong for her,” says Dave. “We didn’t want her to miss out on anything, so we’d laugh and play with her. It’s like you’re putting on a face while the other person went out of the room and just curled up into a ball and died, or felt like they were dying. And then we’d just switch ... put everything aside and just live in the moment with her.”

So life became a series of weighty moments and heartbroken retreats.

“You really do start to appreciate every single moment,” Dave says. “You’re not looking toward tomorrow, because tomorrow’s a nightmare.”

Glenda felt like they were hurtling through the stages of grief. “The sadness and the bargaining and the anger were all happening at once,” she recalls. “It just knocked us both down where we were pretty much in a fetal position,” wondering when they would reach the serenity of acceptance.

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Dave resisted. He typed “INAD” into his web browser and followed every link. He read blogs by families who’d gone through it, watched videos of afflicted children. What he found was not for the

fainthearted. “Most of the things you stumble across on that disease are *In Memoriam* websites about children who died at about seven years old,” he says. “So it’s terrifying.”

Using Google Scholar, he combed the medical literature for INAD references. He researched every finding from Katherine’s MRI report, and began a list of anything besides INAD that might explain it. He investigated things that *hadn’t* turned up on the MRI, and became fixated on iron accumulation in the basal ganglia. It is a hallmark of INAD, but hadn’t been apparent in Katherine’s scan.

By his reckoning, there were four alternative explanations for Katherine’s condition. Each one was even rarer than INAD, but he became convinced that it had to be one of them.

“We were aware of what was happening to us psychologically,” Glenda remembers. “At that point you’re just grasping ... so you wonder, ‘Are we just in the denial part of grief?’”

The medical team at Cincinnati Children’s Hospital listened politely to Dave’s thoughts. And remained confident in their diagnosis. Iron accumulation takes time. The disease may simply not yet have progressed that far in Katherine. She had INAD; they were over 90 percent sure of it.

Dave requested a genetic test, to know definitively. The family’s insurance carrier issued a denial of payment.

It was a \$2,500 test to assess a single gene. If it yielded the desired result—negative for a mutation of the PLA2G6 gene—it could open the door to tests costing an order of magnitude more. Glenda had already left her job to care for Katherine full time. They opened their wallets, and started the process of selling their house.

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But for the fact she was still on all fours, Katherine was in many ways a typical two-year-old. She roamed the patio with



“When you’re undiagnosed, you feel like a refugee.”

a plastic watering can, pulling herself up on flowerpot edges to get at the dirt. She threw tea parties for a congregation of stuffed bunnies, all named Bibi—Bibi, New Bibi, Itty Bibi, Other Itty Bibi, and so on. She liked ordering her daddy to “sit” so she could fasten bows to his hair.

And when the test for the dreaded PLA2G6 gene mutation came back, she didn’t have it.

Yet the doctors still thought she had INAD—just an atypical case of it.

So far, Glenda hadn’t had the stomach to look at Dave’s web research. But now she wanted to see pictures and videos of children with INAD. And when she did, she couldn’t shake the same feeling Dave had: they didn’t look like Katherine. Even apart from the feeding tubes, “they had more weight on them, the look in their eyes was different,” she recalls.

But how do you ask a doctor to pay less attention to an MRI and more to the look in a little girl’s eyes?

Dave had come to believe Katherine suffered from a mitochondrial disease and decided to find a new doctor who

specialized in them. The one they chose, at the Cleveland Clinic, was upfront about his opinion: Katherine did not present like a patient with mitochondrial disease. For one thing, she buzzed with energy. Mitochondria organelles are the cell’s energy centers; mito disease patients tend to lack strength and tire easily. And it just looked an awful lot like INAD.

“But is there hope?” Dave asked, again.

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Hope springs eternal in modern medicine. But some kinds of medical knowledge can extinguish it with brutal finality.

What is known about many rare genetic diseases is especially cruel. The protein mutation that causes Familial Family Insomnia has been found in only a few dozen families worldwide, but it invariably afflicts its sufferers with sleepless delirium that ends in death. Children with Progeria syndrome, caused by a mutated LMNA gene, age prematurely and almost always die be-

fore 20. There are perhaps only 800 people in the world who carry a particular mutation in their ACVR1 gene, but they all suffer the same fate: an errant cellular-repair mechanism that converts their muscles and other soft tissues into bone, until their bodies essentially turn into statues.

There is no known way to reverse any of those diseases. And an INAD diagnosis is just as dire. Dave and Glenda wanted hope for Katherine. But what they really wanted from a doctor was a capacity for doubt.

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Sumit Parikh, who directs the Cleveland Clinic’s Neurogenetics, Metabolic & Mitochondrial Disease program, had an appreciation for the limits of diagnostic certainty. Even if Katherine had INAD, he told Dave and Glenda, the fact that it hadn’t been caused by the typical mutation raised the possibility that it might progress differently as well.

Parikh ordered new tests. As, one by one, each test failed to confirm INAD, the family journeyed deeper into a realm of more profound doubt. It held a feeling of deliverance—even if only provisional deliverance—for virtually any diagnosis carried a better prognosis than the one hanging over them. But chipping away at one hypothesis was bringing them no closer to an alternative.

“When you’re undiagnosed, you feel like a refugee,” Dave told me in October, using the same word Glenda had used at the time in a blog entry. “We all want

a home, even if that home is the worst one imaginable,” she had written. “Any home is better than nothing.”

With all the specific tests and assays exhausted, one option remained: whole-exome sequencing. The exome consists of the one or two percent of the genome that codes for proteins. Sequencing it is therefore cheaper than sequencing the entire genome. But it is not cheap.

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As lawyers go, Dave is conflict-averse. “My job is to push up against things,” he says, “but it goes against my grain. I’m normally not a fighter.”

But when Humana Incorporated denied payment for Katherine’s first genetic test, he threw all his energy into overturning the decision. In a scathing 19-page appeal, he charged the company with misrepresenting the policy contract’s language in a bad-faith “decision to remain intentionally ignorant at the known cost of Katherine’s life.”

Humana coughed up a reimbursement.

Now, after obtaining a pre-approval for whole-exome sequencing, Dave and Glenda sent Katherine’s blood to be tested, along with their own. It was October of 2014. It would take around four months to get results.

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Almost immediately, Katherine pitched into a steep decline. She became clumsy. Her energy vanished. “I can’t climb anymore,” she would tell her parents. “Pick me up.” She had what looked like a seizure, with jerky movements, dry-heave vomiting, and a frightening lapse into non-responsiveness.

Emergency room physicians placed her on Keppra, a seizure medication, and eventually released her. Then the whole thing happened again.

In the run-up to Halloween, Katherine had been scrambling up hay bales and frolicking in piles of fallen leaves. Two

weeks after Thanksgiving she seemed like a different child.

“For the first time, I believed, truly believed, that Katherine had INAD,” Dave wrote. “I had just been in denial. My daughter was dying in front of me. By Christmas, I was convinced that it would be her last.”

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Dave’s emotional strain spilled into public view. He devoted a blog entry to the suicide of Robin Williams, whose autopsy had revealed Lewy Body Dementia, another progressive neurological disorder with symptoms similar to INAD. His mother asked him if he was okay. He blogged about that. “No, I am not ok. I do not know that I will ever be ok again,” he wrote. “None of you want to read that. I am sorry to write it. Yet, that’s the truth.”

He confessed to having panic attacks, haunted by the thought that Katherine would lose her ability to speak while he was at work, and that he would get home too late to hear her say the word *daddy* again.

He also described a happiness of almost excruciating intensity.

“Laughter and joy are Katherine’s currency. She spends them freely. I am more alive than I have ever been. I feel more deeply than I’ve ever felt,” he wrote. “I see genuine goodness in people around me, in friends, family and complete strangers. People who reach out to lift our spirits and to help us practically and emotionally. I see my daughter in all children and love them for it.”

He remembers those three months as the worst period of his life.

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In January, Dave and Glenda took Katherine to Disney World, hoping she would be able to enjoy it. She was “wish-eligible” for assistance from the Make-A-Wish Foundation, but the family feared the

application process would take more time than Katherine had, and weren’t sure her energy would be equal to the Magic Kingdom anyway. Upon arriving in Florida they were dealt two insults in quick succession. The first was a notice from Humana denying payment for the pre-approved whole-exome sequencing, which cost \$27,000. The second was a notice from the hospital informing them that Katherine actually had no insurance at all and owed \$55,000 in bills.

But it was a happy new year. Dave successfully appealed Humana’s denial and traced the hospital charges to a bureaucratic error that was resolved. More importantly, Katherine bounced back. She made it through the Disney marathon with energy to spare—holding her dad’s hands to jump up and down in delight under the nightly fireworks show—and soon was again her gleeful, scrambling self.

February brought the whole-exome results. They were definitive, and wiped the diagnostic slate entirely clean: Katherine had a mutation to a recessive nuclear gene called NUBPL.

Little was known about it. But in 2010 a mutation to that gene had been implicated in a rare mitochondrial Complex I disorder. Very rare: it had since been reported in just five families worldwide.

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Dave and Glenda wasted no time trying to figure out what that meant and what to do about it.

Before pulling the trigger on whole-exome sequencing, they had read a *New Yorker* article about Matt and Cristina Might, who in 2007 had a son with an affliction that stubbornly eluded diagnosis until whole-exome sequencing revealed a mutated gene called NGLY1. The only way to know if it explained the condition was to identify another patient with the same mutation and the same symptoms—but none was known. Matt, a computer scientist, posted an essay on

Identifying a community— even a vanishingly small one— catalyzed the Faughn family’s search for treatment.

the web that went viral. It was titled “Hunting Down My Son’s Killer” and contained detailed information about his son’s symptoms, lab results, and NGLY1. He envisioned it as a “reverse drag net”; if other families were experiencing the same thing and Googled their way to his post, together they might solve the mystery. Then they could band together and seek possible treatments.

“I didn’t sleep for three days after I read it,” Glenda says. They had initially started their blog, “Hope for Katherine Belle,” as a way to provide friends and family members with updates that were too painful to talk about in person. Suddenly it was clear that it could be more.

“I realized for the first time that we had a really big role to play in this,” Glenda says. Dave and Glenda published the genetic codes of Katherine’s mutation and those of other reported cases. (They are reproduced in the section breaks of this article.) They presented Katherine’s clinical progression in depth. And Glenda scoured the web and social media, reasoning that other families might have done some of the same things.

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In March 2015, they posted the first results of their search. “We want to introduce you to the Spooner Family and their daughters Cali and Ryann, both of whom have mutated NUBPL genes like Katherine,” they wrote. “We were undiagnosed for only two years ... their oldest daughter was undiagnosed for thirteen years.”

The girls were six and 15 years old. Glenda had stumbled across a Facebook link to a documentary film about them. Watching it was a transformative experience for a mother consumed by fears that each birthday would be the last, and questions about what clothing her daughter would be buried in.

“That first glimpse at Cali Spooner’s face added years to my child’s life,” Glenda later recalled. “In her photograph I saw Katherine smiling back at the cam-

era. For the first time, I saw Katherine as a *teenager*.” Meanwhile, six-year-old Ryann could walk independently.

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Identifying a community—even a vanishingly small one—catalyzed the Faughn family’s search for treatment options. They enrolled Katherine in a clinical trial of EPI-743, a potent antioxidant that targets a particular enzyme involved in cellular energy metabolism. They got her onto what is commonly called the “mito cocktail,” a blend of vitamins and supplements and antioxidants thought to reduce the excessive levels of free radicals resulting from mitochondrial dysfunction.

Predictably, Humana refused to cover the mito cocktail. (Vitamins and supplements are not considered medicines, nor is their manufacture subject to FDA oversight, so insurers commonly exclude them.) After a second insurer also declined to cover it, Dave took his crusade to the Kentucky legislature.

An attorney he had clerked for in law school, Sannie Overly, had become an influential state representative and a follower of Katherine’s blog. Dave wrote model legislation that would require Kentucky health insurers to cover mito cocktail formulations, and she sponsored it as an amendment to an existing bill. When it passed the Democratic-controlled House only to be voted down in the Republican-controlled Senate, Dave and Glenda targeted the Senate Majority Leader’s open Facebook page.

“We started posting videos of Katherine on there, saying, ‘How are you killing this bill that’s helping my daughter?’” Dave recalls. “And to his credit, he

contacted us personally ... We educated him on what the bill was for, and he came over to our side.”

The revived bill “came out of the committee at 15 till midnight on the last day of the session,” Dave recalls. “It was put in front of the House to vote on, and the Senate to vote on. It got signed at five minutes till midnight. And Sannie literally had one of her staffers run it from the Senate chambers into the governor’s office and got it there as the door was closing.”

The governor didn’t sign it, but didn’t veto it either, so Kentucky became the first state in the union to legislatively mandate that insurers cover mito cocktails.

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Mitochondrial disease exemplifies one of the thorniest challenges presented by rare diseases. In the United States, a disease is classified as “rare” when it affects fewer than 200,000 Americans. The vast majority of these are genetic in origin and affect a far tinier fraction. Such small patient populations severely limit the impetus for research and drug development. Yet roughly 7,000 rare diseases have been identified, and the National Institutes of Health estimate that collectively they affect 25–30 million Americans—more than cancer. The FDA has approved treatments for only about 5 percent of rare diseases.

An estimated 80,000 Americans suffer from mitochondrial disease—but mitochondrial dysfunction itself comes in so many flavors that a therapy that benefits one patient might be useless, or even harmful, for another.

The first mitochondrial genetic mutation causing human disease was identi-

fied 30 years ago by Douglas Wallace, who is now a professor of pathology and laboratory medicine at the Perelman School of Medicine, and director of the Center for Mitochondrial and Epigenomic Medicine at the Children's Hospital of Philadelphia (CHOP).

"Now we know of nearly 400 different mutations in the mitochondrial DNA that can cause disease," says Marni Falk, an associate professor of pediatrics at the Perelman School and executive director of CHOP's Mitochondrial Medicine Frontier Program. Animals inherit mitochondria exclusively from their mothers. But the processes by which those organelles produce energy also involve nuclear DNA, which is inherited from both parents. And, says Falk, "we now know of 300 nuclear genes that can cause mitochondrial disease."

The challenge presented by all that complexity is at the center of Falk's research—which was about to expand to a new patient: Katherine Faughn.

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As a medical resident in pediatrics and medical genetics in the early 2000s, Falk sometimes saw children with mitochondrial dysfunction at Case Western Reserve's Rainbow Babies and Children's Hospital in Cleveland.

"Nobody knew what to do," she recalls. "The family would say, 'What do we do about it?,' and [the doctors] would say nothing. And they'd just stay in the ICU until they died. And it could be months."

The geneticists couldn't even counsel the parents about the odds another child would suffer the same fate: "We had no idea."

Around the same time, one of her mentors, an anesthesiologist named Phil Morgan, happened to be part of a team investigating a common class of anesthetics. Volatile anesthetics (also known as inhalation anesthetics, like nitrous oxide) have the remarkable property of immobilizing a wide variety of ani-

mals—from humans to fruit flies to nematodes—at very similar concentrations. But their full mechanism of action remains unknown to the present day.

Looking at nematodes, the investigators found something interesting: a single genetic mutation dramatically increased worms' sensitivity to volatile anesthetics. Morgan remarked that kids with mito disease were also often unusually sensitive. So the team drilled down into the nitty gritty of the gene—dubbed *gas-1* for "general anesthetic sensitive"—and found that it was involved in the manufacture of mitochondrial Complex I.

Excited by the possibility of creating a genetic model that might finally answer the questions of mito disease families, Falk joined the search for other genes involved in Complex I.

240-kb deletion

The mitochondrial respiratory chain converts oxygen and simple sugars into molecules of chemical energy called ATP. The process involves five complexes, which can be envisioned as successive factories. Each factory feeds its product into the next one, while shunting byproducts toward other important cellular processes. Complex I is a "monster," Falk says. It employs 45 subunits to create an enzyme, NADH, whose reduced form is also needed for 500 other reactions in the cell.

NADH is like a "big Lego structure," Falk says, and the NUBPL gene helps some of the Lego blocks snap together.

Consider what that means. A mito patient who has trouble manufacturing a particular block might respond to a therapy that's of no use at all to Katherine, whose difficulty lies not in making blocks but in connecting them. Similarly, if stray blocks are tumbling around Katherine's cells, they could be causing types of trouble utterly foreign to a third mito patient. In a sense, each of those "mito disease" patients actually has a separate disease.

"Sometimes families call me," Falk says, "and they say, 'I read this. I read that. Which drug should I be on?' And I say, 'I don't know. Nobody's ever known.'"

So over the last couple years, she has built a research platform that aims, with an unprecedented level of precision, to find out.

On a sunny day in mid-October, one of her collaborators showed me how.

137-kb duplication

Christoph Seiler is a mutant zebrafish farmer. He breeds and analyzes genetically altered versions of the finger-sized fish, which are a well-established model organism in genetics research. As director of CHOP's three-year-old zebrafish core facility, he oversees the technical wizardry at the heart of Falk's research. Using a cutting edge gene-editing tool called CRISPR/Cas9, Seiler has been able to essentially insert the precise genetic mutations of Falk's patients into zebrafish genomes, creating organisms that enable Falk to assess the resulting functional differences with the ultimate degree of specificity.

Falk uses other tools to make similar alterations to nematodes, which, like zebrafish, are champion reproducers with fast life cycles. (A robotic system dubbed the WorMotel, developed by Christopher Fang-Yen, the Wilf Family Term Assistant Professor of Bioengineering, permits automated analysis of tens of thousands of nematodes at a time—a dramatic leap from the manual observations long performed by sore-eyed graduate students.) She also edits patients' cells, in vitro, to replace mutant genes with normal ones. Since the cells are identical in all other ways, any variations in their function can be attributed directly to the gene in question.

"We have about half a dozen different projects in the lab now that are based upon individual children with specific rare diseases in different parts of this



the third had an obviously malformed and shrunken air sac, and appeared to have liver abnormalities as well.



In October, Falk and Seiler were just beginning to try to create organisms possessing Katherine's mutation. They might show anatomical differences, or might not.

"Mito disease kids often look normal," Falk notes. "When the batteries don't work in a doll, it's not like the arm falls off, right? It's just simply that they don't walk, and they don't talk." Functional problems are more common than structural ones.

That's another advantage zebrafish offer. Seiler flicked the rim of another petri dish and the fry scattered. "You can turn a light on and off to startle them, too," he said. "They have this fast scooting motion with three turns of the tail. And you can study that and see if something's abnormal. You can analyze movement very simply, or look at the trajectory of the swimming and see if that changes." Or you can make zebrafish swim against a current and measure their endurance and recovery.

With anatomical and behavioral baselines established, Falk can then test existing drugs on the model organisms and see if anything has a positive impact. "We're not interested in discovering some new drug," Falk says. "We're interested in an FDA drug, maybe one that exists for some other disease that I could just study in these kids, without having to spend 10 or 20 years developing." That said, there's no reason to rule out screens of novel drug candidates.

Some of the drugs she's interested in don't even target mitochondria at all. "There's a lot of changes that happen outside the mitochondria in the cell when the mitochondria aren't functioning. Maybe

The gene that makes Katherine seem like a one-in-a-billion rarity also illustrates how tightly all humanity is bound.

process," Falk says: "the electron transport chain Complex I subunit; the assembly of Complex IV; in this project, the assembly of Complex I; in another, the function of Complex V."

In his lab in the Abramson Research Center, Seiler pulled out a petri dish swarming with a dozen or so zebrafish larvae. They were five days old, each about the size of a staple snipped in half. As offspring of adults possessing muta-

tions to recessive genes, about a quarter of the juveniles had inherited both mutated copies. Seiler squirted a few drops of tricaine into their water, which quickly and temporarily put them to sleep. Using delicate tweezers, he lined up three fish in the focal field of a microscope.

Through their transparent skin, a difference was immediately clear. Two of the fish looked normal—having inherited at least one normal copy of the gene. But

they're part of the problem—those other changes," she says. "If we could slow down the cell's desire to fix everything by making more and more proteins, we can make the cell a lot healthier—and the organisms and the animals."

"My dream for all this is that ultimately we'll have lots of therapies that work," she says. "But they might be different, or in different combinations, in different people."



Successes with tiny groups of patients— even single patients—could in time have ramifications for far larger groups.

"Complex I not functioning properly is known to happen in Parkinson's disease," Falk notes. "And the dopaminergic neurons in Alzheimer's disease. It happens in ALS. In diabetes. Things like heart attack or stroke, the parts of the brain that are damaged can wind up absolutely having a Complex I defect.

"If we can improve health in kids where the program is abnormal, then maybe we could also improve health" in a broader array of diseases related to aging. "And this is where Big Pharma gets interested."

Orphan therapies, as treatments for some rare diseases are known, "often serve as platform technologies for future expansion across indications," says Brian Corvino WG'11, a managing partner at the healthcare consultancy Decisions Resources Group. "If you look at just the past three years alone, 40 percent of all of the FDA approvals had an orphan drug designation," he adds.

Sometimes drugs developed for a rare disease later find application in a more common one. Sometimes it goes in the other direction.

"Eight out of the top-10-selling drugs in the US in 2016 had some form of orphan drug designation at some point in

its development," Corvino says. "Now, that doesn't represent a majority of the sales—but the orphan drug label collectively is an important one."

Even the gene whose mutation makes Katherine seem like a one-in-a-billion rarity also illustrates how tightly all humanity is bound by our common genetic heritage. This past June, researchers at Harbin Medical University in China discovered that NUBPL plays a "vital role" in the metastasis of colorectal cancer. Modulation of the gene's productivity, they proposed, could provide a novel therapeutic target for the second-leading cause of cancer death worldwide.



The creation of a Katherine Belle zebrafish will depend on laboratory luck and philanthropic generosity. The National Institute of General Medical Sciences supports Falk's research, as does the CHOP Research Institute. She also receives pharmaceutical company funding. But philanthropy is part of the mix. "Families go out and raise money, whether through silent auctions or through lemonade sales," she says. "The money goes for the salaries and the reagents to actually test the models." So far the Faughns have raised about a quarter of the \$178,000 necessary to support Falk's two-year proposal.

There is, of course, no guarantee.

"We don't promise that we're going to cure the disease," Falk cautions. "But we think that this is the best chance to do it rationally and logically."

"All of this is a race against time," Dave says. "Katherine's disease is progressive. We've had two MRIs, and if you look at them, you see the atrophy in the cerebellum. So the brain cells are dying. And when they die, there's no bringing them back."

Cali Spooner's survival into her teens offers hope, but it is tenuous. "We don't

know where this disease is going to lead next," Dave continues. "Mito diseases are generally multi-system diseases. Any part of your body that needs energy starts to be compromised. So you tend to see, over time, heart disease and liver disease and kidney disease. We don't know what the future holds. So we're desperate to find either a cure or a treatment that stops the progression as soon as we can, because we don't know what tomorrow will bring for her."

14q12-NM_025152.2(NUBPL)

When the family visited Philadelphia in October for Katherine to see a phalanx of specialists at CHOP, which now coordinates her care, Katherine showed a small child's mastery of inhabiting the present day.

With the help of orthotic ankle braces, she now walks independently. While I talked with her parents, she scribbled letters and drawings on scraps of paper and pretended she was a mail carrier, delivering them around the table. She fell down half a dozen times, and got back up.

She told me about school: playing games with her friends Delaney and Ally, and counting dominoes for her math homework. Her articulation of words required substantial concentration to decipher, and occasionally Dave or Glenda would interject to make sure I was following. But one thing she said startled me, first by its clarity and later by its symbolic depth.

"What kinds of games do you like to play?" I asked her.

"Baby," she said. "And family. And baby lion."

"How do you play baby lion?" I asked.

"With a mommy lion and a daddy lion and a baby lion," she said. Then, with a smile full of gusto, she expelled a sudden and fierce sound: a savage, exultant hissing growl.

She waited a beat to witness my reaction, and then said, quite clearly, "It's a big roar for a little lion."



who is america?

GOP nativists have taken aim at a fundamental principle defining the American republic: birthright citizenship. Their legal rationale has an unlikely source: a liberal professor who totally opposes their aims. And that's just where things start to get interesting with Constitutional law scholar Rogers Smith.

By Trey Popp

“All persons born or naturalized in the United States, and subject to the jurisdiction thereof, are citizens of the United States and of the State wherein they reside. No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.”

—US Constitution, Article XIV, Section 1

In July 2018, hot on the heels of a 14-month stint as a senior official in President Donald Trump W’68’s National Security Council, Michael Anton authored an arresting op-ed in the *Washington Post*.

Prior to joining the administration, Anton was probably best known as the author of “The Flight 93 Election,” a treatise he wrote under the pen name Publius Decius Mus. Addressed to conservative intellectuals, it posited that failure to defeat Hillary Clinton was tantamount to airline passengers not charging the cockpit of the Al Qaeda-hijacked flight. The essay lauded Trump as the first presidential candidate since Pat Buchanan to campaign against Washington’s “bipartisan junta” on the three “fundamental issues of our time”: opposing free trade, US war-making,

and—most importantly—immigration, which Anton characterized as “the ceaseless importation of Third World foreigners with no tradition of, taste for, or experience in liberty” who pollute American life with “poverty, crime, and alien cultures.”

Anton’s preoccupation with immigration had been evident in his first post-White House *Washington Post* op-ed, titled “Why do we need more people in this country anyway?” (His answers: to ensure oligarchs an “endless influx of cheap labor” and swell the Democratic Party’s voting base—both of which he judged contrary to the national interest.) But it was his second op-ed that sparked a furor, for it targeted the most fundamental principle governing who “We the People of the United States” are: birthright citizenship.

Since the ratification of the Fourteenth Amendment in 1868, US law has automatically conferred citizenship on every person born on American soil. Birthright citizenship had already been customary but had previously been denied to free blacks and slaves. By codifying it in race-neutral terms within the Constitution itself, the Fourteenth Amendment's framers aimed to establish a society without an underclass of people denied the American promise.

In a nation with a long history of exclusion—states had denied suffrage and other political rights to Catholics, Quakers, Jews, and unpropertied white men, and continued to exclude women from civic participation—the Fourteenth Amendment was a high-water mark of the Reconstruction-era Republican Party's drive for inclusiveness. For many it exemplified Lincoln's view of the purpose of the American republic: "augmenting the happiness and value of life to all people, of all colors, everywhere."

But at points during the past 150 years, some have lamented it as overly inclusive. Most recently, voices within the modern Republican Party have decried the US's approach to birthright citizenship for what they consider a critical defect: the fact that it grants citizenship to the newborn children of noncitizens. This is true. Although children of diplomats or enemy soldiers do not qualify, babies born to green-card holders, temporary legal residents, tourists, and others become citizens by dint of a US birth certificate. The class that most agitates many Republicans is unauthorized immigrants.

In proposing that newborns to such parents be excluded from birthright citizenship, Anton wasn't saying anything that party leaders like US Senators Lindsey Graham and Rand Paul hadn't said before. Trump himself had attacked birthright citizenship as a candidate, calling it "the biggest magnet for illegal immigration."

Anton's provocation was to declare that the Fourteenth Amendment had

in fact been misinterpreted for the last 150 years—and that Trump had the authority to issue an executive order specifying that "the children of non-citizens are not citizens."

The ensuing dustup followed a predictable template. Liberal pundits tarred Anton and his fellow travelers as xenophobes and racists. Others—including a fair number of conservatives—cited constitutional scholars to catalogue the ways Anton had misread the law. Consternation flared about whether a wrecking ball was being readied to demolish a central pillar of Lincoln's legacy. After all, Trump had expressed the same unorthodox view of the Fourteenth Amendment in 2015, claiming that "some of the great legal scholars" agreed with him.

In fact, American legal scholars overwhelmingly disagree. Support for the conventional view of birthright citizenship runs from liberal Fourteenth Amendment authority Garrett Epps to originalist James Ho, a Trump-appointed federal circuit judge. But Trump's alma mater happens to house a remarkable exception.

Rogers Smith, the Christopher H. Browne Distinguished Professor of Political Science, is about as far as you can get from Michael Anton or Donald Trump. The self-described "left liberal" has spent his entire professional life preoccupied by the ways race, ethnicity, and gender have been used to privilege some Americans at the expense of others. He has long advocated higher levels of legal immigration. He has argued that the US has incurred special obligations to Mexican nationals including favored "access to American residency and citizenship" as well as "leniency toward undocumented Mexican immigrants."

Smith also pioneered the revisionist view of the Fourteenth Amendment's citizenship clause now being deployed by nativists who stand in stark opposition to so many values he holds dear. This is the story of how that came to be, and why it matters. Moments when the far ends of the political spectrum converge can

clarify the challenges facing a society, and sometimes point to fresh solutions. Moments when they simultaneously converge and clash can be even more revealing. As the United States wrestles anew with the question *Who belongs?*, and citizens confront competing visions of the nation's purpose, there's a lot riding on how we secure the ties that bind us together as a common people.

Portrait of a Teenaged Politico

Rogers Smith was born in 1953 in legally segregated Spartanburg, South Carolina. His family moved the following year to Springfield, Illinois, where his father started a wholesale drug distribution business. It was a typical Eisenhower-era childhood: Sunday School, cowboys and Indians, and brother-vs.-brother battles with World War II toy soldiers. By the time he was in second grade, Smith saw himself as a budding patriot of a familiar "white Anglo-Saxon Protestant" variety: "I knew that, like Lincoln and my parents, I was a Republican, and I watched and thought Nixon won the first debate" of the 1960 presidential campaign.

Smith may or may not have been the only seven-year-old in town with a hot take on the nation's first-ever televised presidential debate. But there can't have been many who fell for politics as hard as he did. After proclaiming himself a Goldwater Republican in 1964—a connection reinforced by an aunt who chaired the senator's campaign in South Carolina—Smith dove headfirst into party politics. Interest morphed into action when his older brother discovered a "faltering and moribund" local teenage Republican club whose bylaws permitted new members to vote upon paying a \$1 membership fee. The Smith boys rounded up a dozen friends with a dozen dollars, turned up at the club's leadership election, and presto: at 13, Rogers became his brother's vice president.

In short order he climbed the ranks to become president of the statewide organization and gained a reputation as an underage field commander in election-

day turnout efforts. He went all in. While his three brothers worked summers for their dad, Rogers took patronage jobs instead. “I like to boast a little bit,” he chuckles, “that by the time I was 16, I had worked in all three branches of the Illinois state government.”

He was a page in the state senate, a clerk in the secretary of state’s office, and a clerk for the state Supreme Court. The experience was part intellectual intoxication, part political culture shock.

“Five Illinois governors during my lifetime have been indicted and convicted,” he reflects, adding that two more probably should have been. The state capitol was a feeding ground for corruption and

At the same time, Smith found inspiration in figures like Lieutenant Governor Paul Simon and Assemblyman Alan Dixon, who combined a glad-handing touch with integrity and intellectual seriousness. “These were guys with whom you could have an intelligent conversation about the ideals of politics, who did read and who did care,” Smith recalls. And it was people like these—both of whom eventually became US Senators—that really influenced policy.

Another brand of evil made an impression too deep to shake.

“Because I was this up-and-coming teenage Republican leader, I would get invited to the formal leadership confer-

The experiences reinforced a lesson he’d taken from his political work as a teen: “People involved in immediate decision-making are very dependent on the universe of ideas around them. They reach for ideas thinking they’re going to be useful for them.”

In other words, original thought is rare in politicians. As John Maynard Keynes quipped: “Practical men who believe themselves to be quite exempt from any intellectual influence, are usually the slaves of some defunct economist. Madmen in authority, who hear voices in the air, are distilling their frenzy from some academic scribbler of a few years back.”

So Smith set out to become such a scribbler.

“I was thrown into shockingly deep morasses of all kinds of evil.”

graft. “My parents were very straight people. I was thrown into shockingly deep morasses of all kinds of evil.”

There was the “impoverished drunk” the Daley machine had installed in the state senate—where older pages were charged with keeping the coffee mugs filled with whiskey—who begged Smith for \$15 to get back to Chicago at day’s end. There were the so-called “monkey girls”: women from country towns who hung onto their jobs in the state capitol “by their tails”—like a fellow page’s mother who frequented the majority leader’s chambers as his mistress. There was Illinois Secretary of State Paul Powell, “drunk out of his mind” at 10 in the morning while signing Smith’s petition for the 18-year-old vote (which the GOP opposed). When Powell died a few years later, a search of his room at Springfield’s St. Nick Hotel revealed \$750,000 in cash stashed behind old whiskey cases.

ences,” Smith recalls, where “the older guys, in their 20s, would hold late-night sessions where you got the real stuff. They would teach you dirty tricks you could play on opponents. And they would get drunk—we would get drunk—and then they would start singing obscene songs.” Like racist ditties set to the tune of “Jingle Bells.”

“And that’s when I began to freak out,” he remembers. There was a “far-right racist element” in the Republican Party that was increasingly impossible to ignore, especially as the Nixon-era GOP “turned away from Lincoln’s cause of civil rights.”

Disillusionment sent him running from the party—but not from politics. As an undergrad at Michigan State University’s James Madison College, and then as a graduate student at Harvard, he worked for legislative and regulatory commissions in Michigan and Illinois.

Liberalism, Republicanism, and America’s Dark Underbelly

The young idealist entered the Ivory Tower—as a professor at Yale—during an idealistic academic debate. On one side were historians who located the US’s fundamental political character in the liberal vision of John Locke, who conceived of government as the product of a social contract designed to protect individuals’ rights to life, liberty, and property. On the other were scholars who argued that America’s founders had been guided more by civic republicanism, which envisioned citizens not simply as rights-bearers engaged in private pursuits of happiness, but as members of a communitarian enterprise that demanded forms of civic service to achieve civic virtues. The rise of “originalist” jurisprudence, which attempts to interpret the Constitution according to the perceived intent of its framers, gave such questions some practical significance.

As a way of contributing to this debate, Smith set out to explore empirically how citizenship had been characterized in federal statutes, legislative debates, and court decisions—surveying some 2,500 cases stretching from colonial times to the early 20th century. A clearer idea of how Americans had officially defined citizenship over time might serve as a

good starting point for contemporary arguments about whether the country was tilting too far toward either the Lockean liberal or communitarian extreme.

But Smith was soon “overwhelmed” by the quantity of statutes, speeches, and decisions that didn’t really belong in either category. “Rather than stressing protection of individual rights for all in liberal fashion, or participation in common civic institutions in republican fashion,” he wrote in *Civic Ideals: Conflicting Visions of Citizenship in US History*, a finalist for the 1998 Pulitzer Prize in history, “American law had long been shot through with forms of second-class citizenship, denying personal liberties and opportunities for political participation to most of the adult population on the basis of race, ethnicity, gender, and even religion.” [Emphasis added.]

The Constitution’s failure to define citizenship was emblematic of this pattern. Tensions over how to classify free blacks, and whether citizenship should be determined by states or the national government, had discouraged the framers from including a clear-cut definition. The result was not only a divide between those with and without citizenship status, but wide disparities in rights and responsibilities among citizens themselves.

Well into the 20th century, for example, a male citizen who married a foreigner conferred automatic citizenship upon her, whereas a female citizen who did so was involuntarily stripped of citizenship, even if she remained in the United States. Citizenship wouldn’t have afforded her all the privileges and immunities it afforded men anyway. Never mind voting rights: American married women lacked the right to enter into contracts, file lawsuits, and control property for much of the 19th century, and couldn’t obtain independent financial credit until the 1970s. Depending on the time and state, meanwhile, men’s access to citizenship’s rights and responsibilities varied according to their race, creed, wealth, or place of birth.

These inegalitarian arrangements arose

from “some very different ideological systems,” Smith concluded, but they had an important commonality: “Against liberal and democratic republican views describing citizenship as a human creation that ought to rest on the consent of all involved,” they assigned (or withheld) political rights on the basis of inalterable characteristics like race, gender, and the religion into which people were born.

Citizenship and Consent

Smith saw consent as the *sine qua non* of a political community’s legitimacy. Like Locke, he believed no one should be coerced into citizenship against their wishes. Especially not in the US, whose Declaration of Independence explicitly repudiated perpetual allegiance and asserted that governments derive “their just powers from the consent of the governed.” And like republican theorists, Smith thought the addition of new members also required the existing community’s consent.

A strong conception of mutual consent is intuitively appealing but not necessarily benign. The tension between popular self-governance and basic human rights was vividly illustrated by the Supreme Court’s 1857 *Dred Scott* decision. Free blacks, Chief Justice Roger Taney reasoned, could not be citizens because the states party to the Constitution had never consented to their membership.

The Fourteenth Amendment’s citizenship clause was specifically drafted to overturn *Dred Scott*, making citizenship a national rather than state determination and guaranteeing it to native-born and naturalized African Americans: “All persons born or naturalized in the United States, and subject to the jurisdiction thereof, are citizens of the United States and of the State wherein they reside.”

The debate about birthright citizenship centers on what, precisely, that middle clause means.

In 1985, Smith coauthored a book with his Yale colleague Peter Schuck advancing an answer. *Citizenship Without Consent* was an unusual blend of antiquar-

ian intellectual history and public-policy brief. The policy question was whether the Fourteenth Amendment mandated birthright citizenship for the children of unauthorized immigrants. It was impossible to know exactly what the amendment’s framers and ratifiers thought, for the simple reason that there was no such category as “unauthorized immigrant” in 1868. Congress did not begin regulating immigration until 1875.

But the legislative record was unambiguous on another count: while its abolitionist framers aimed to extend birthright citizenship to African Americans, they were determined to withhold it from both foreign diplomats and Native Americans who remained members of officially recognized tribes. Since tribal members were not fully subject to US legislative or judicial power—enjoying, for instance, broad immunities from court trials—the jurisdiction clause emerged as a way to exclude them. (The degree to which Native Americans desired or spurned citizenship is an open question, but insistence on tribal sovereignty has been an enduring feature of many tribes’ relationships with the United States.)

Would the framers have considered unauthorized immigrants—who also originate from separate political entities and whose presence on US soil is not invited—as analogous to Indian tribal members?

Again, a definitive answer is elusive. During the legislative debate, Senator Edgar Cowan of Pennsylvania warned his colleagues that the amendment’s language threatened to confer birthright citizenship upon Chinese, Mongols, and Gypsies—which he regarded as undesirable races. Senator John Conness of California answered that this was in fact the amendment’s express intent—“that the children of all parentage whatever, born in California, should be regarded and treated as citizens of the United States.” Yet a racially defined group simply disliked by some or many Americans is legally different, Smith observes, from one whose presence contravenes American law.

Seeking a deeper understanding of the jurisdiction clause, Schuck and Smith turned to the 18th-century Swiss legal theorists Emer de Vattel and Jean-Jacques Burlamaqui, who had influenced the Constitution's framers. They had recognized that birthright citizenship presented a theoretical problem: it was a common-law tradition rooted in a doctrine of perpetual and irrevocable allegiance to a sovereign. That was incompatible with democracy's insistence that government be based on consent. Their innovation was to justify the practice instead on the grounds that "parents should be understood to demand the offer of citizenship to their children as a condition of their own consent to membership," as Smith puts it.

Viewing the jurisdiction clause through the prism of Vattel and Burlamaqui, Schuck and Smith concluded that it made the birthright citizenship guarantee conditional on the presence of mutual consent. They felt the amendment's framers would have viewed unauthorized immigrants in the same light as Native American tribes. At a minimum, that interpretation seemed as supportable as a contrary one.

And "when the Constitution itself does not answer important questions with clarity," as they put it in a 2018 follow-up paper, "decision-making should usually be left to the people's elected representatives in Congress, so long as they do not violate fundamental rights. This properly leaves Congress with the authority to decide the question of birthright citizenship for these children."

An Academic's Agony

One of the ironies of *Citizenship Without Consent* is that its authors advocated higher levels of immigration. Both went on to argue that the children of undocumented immigrants deserved access to citizenship. Schuck proposed "retroactive-to-birth citizenship for the US-born children of illegal-immigrant parents who demonstrate a substantial attachment" to the country by residing here



for some minimum period and completing a certain level of schooling (which would ensure a baseline level of English proficiency and civic knowledge). Smith, who joined Penn's faculty in 2001, has consistently favored retaining the birthright citizenship rule as it has always been applied. (For one thing, birthright citizenship almost certainly pales next to labor opportunities as the "biggest magnet" for illegal immigration. For another, making what has heretofore been a simple universal rule conditional on parents' citizenship status would require an expansive bureaucratic apparatus whose documentary demands would make childbirth even more arduous for citizens than it already is.) But both have steadfastly insisted that Congress be the arbiter—and, in the book, expressed confidence that "after the issues are fully explored, contemporary Americans will decide generously." In 1924, they noted, Congress had granted citizenship to Native Americans by statute.

The book soon went the way of many academic volumes: out of print. Then it experienced an unwelcome revival.

In 1993 US Rep. Elton Gallegly, a California Republican, cited it while introducing a bill and a proposed Constitutional amendment to restrict birthright citizenship to the children of mothers (but not fathers) with citizen or legal-resident status. The proposals failed but kicked off a trend. Similar bills have been introduced in every Congressional term since. They formed a plank of the 1996 Republican Party platform, though one publicly rejected by presidential candidate Bob Dole. In 2003, the influential conservative jurist Richard Posner used a concurring opinion to call for rolling back the birthright citizenship guarantee, pointedly citing Schuck and Smith to suggest that it wouldn't take a Constitutional amendment to do so. Current Vice President Mike Pence introduced Senate legislation restricting birthright citizenship in 2009, and six years later Donald

Trump became the first major party presidential candidate to endorse it.

Smith has long been more comfortable with his critics than his citers. “The argument was used more persistently and prominently by nativist political forces than I ever anticipated,” he says. “And that has been a shadow over my work in life.” His subsequent writing about the issue brims with generous references to scholarly counterarguments. “Garrett Epps is indeed the best of our critics,” he emailed me when I approached him about this article, adding, “Others are good too!”

“I would prefer to read the Citizenship Clause” as some of them do, he wrote in 2008. “Yet I cannot escape [my own] conclusion.”

“The rhetorical triumph of the ideal of democracy is being accompanied by the practical eclipse of democratic practices.”

I had thought too little about the legal framework of birthright citizenship to have an opinion about it at the outset. Reading both Smith and his critics sparked more questions than convictions, but on balance I found his critics more compelling. Does “subject to the jurisdiction thereof” really require such a roundabout historical reading? Couldn’t it simply mean “subject to the nation’s legal authority”—as is the case for any non-diplomat? Unauthorized immigrants can be arrested, imprisoned, and tried in US courts. Undocumented males are even required to register with the Selective Service System for potential military conscription—the ultimate assertion of a government’s jurisdictional authority.

The most relevant Supreme Court ruling, *United States v. Wong Kim Ark* (1898), centered on a child born in the US to parents who were Chinese subjects.

The parents were legal residents—but, under the 1882 Chinese Exclusion Act, had been prohibited from attaining citizenship. The majority ruled that the Fourteenth Amendment guaranteed the child citizenship and that Congress could not alter that guarantee. It interpreted “subject to the jurisdiction” as a geographical condition joined with a requirement to answer to US law (diplomats being exempt from the latter). It did not find Emer de Vattel’s consensual gloss on birthright citizenship germane—though the dissenting opinion did.

Smith contends that since *Wong Kim Ark* involved parents who were legally present in the United States, it has limited relevance to the question of unau-

thorized immigrants. But Congress had expressly excluded Wong Kim Ark’s parents from the US political community—and the Court nevertheless ruled that their child was automatically a part of it. The Fourteenth Amendment’s framers clearly were not “adopting revolutionary new principles of citizenship by consent,” argues legal scholar Gerald Neuman. “Taney had done that in the *Dred Scott* decision ... [and the] framers sought to overturn Taney’s innovation.”

Smith is no Taney acolyte. Why, I wondered, was he so obsessed with consent? And why did he emphasize Congress as the superior vehicle for expressing it, when the Constitution’s amendments offer an arguably even deeper expression of a political community’s will?

The answers to those questions cast Smith’s position in, by turns, a more compelling and provocative light.

Toward a New American Story

Smith started his academic career with a Lockean “individualistic liberal” bent. He gradually came to see himself more as “an Abraham Lincoln, civil rights, small-r republican.” (He notes that many of Lincoln’s policies—which included expansion of the federal government’s role in the economy, progressive income taxation, publicly supported universities, and other initiatives aimed at reducing wealth inequality—typify today’s left end of the political spectrum.) But in America those traditions have never truly been in sharp opposition.

“Everybody was for individual rights, and everybody was for republican self-governance, and everybody was for civic virtue,” he says. In varying combinations, those principles have helped bring about the signal democratic reforms to American life. But each victory has been difficult and susceptible to reversal—in large part due to the other ways Americans have historically tried to order their society. “Almost everybody was for white supremacy, Christian hegemony, patriarchy, et cetera,” Smith inescapably concluded from his exhaustive survey of citizenship laws.

In other words, Americans (like other peoples) have never been content seeing themselves as merely part of a Lockean “arms-length alliance” exercising inalienable rights to which every human being on earth is entitled. They have insisted their nationality has a more particular meaning than can be supplied by universalistic liberal ideals. And too often, Americans have turned to racial, gender, or religious hierarchies in search of it. (And not just in the distant past. A 2016 survey found that a majority of Republicans, and nearly two-thirds of Trump primary voters, considered “being Christian” an important criterion for being an American; 30 percent of Trump primary voters regarded European heritage as another important criterion.)

“The weaknesses of America’s egalitarian liberal republican traditions as civic

ideologies,” Smith writes, “have recurrently permitted and indeed fostered conditions in which illiberal, inegalitarian” policies have flourished. “The clear lesson is that failure to take the political requirements of nation-building seriously may produce morally culpable complicity in malevolent forms of national community.”

Liberalism’s defenders, in short, must supply a compelling alternative to the tribalism lately on the rise in the US and around the world.

Francis Fukuyama, the political theorist who famously suggested in 1989 that the impending “universalization of Western liberal democracy” signaled “the end point of mankind’s ideological evolution,” has lately turned his attention to this very issue. The bind facing modern democracies, he posited during a September campus visit, is that they afford only a “generic recognition” to citizens who demand more. This has fueled an identity politics in which various groups, emphasizing their marginalization from the body politic, advance “group claims of injustice in ways that contradict liberal values.” The adoption of this tactic by right-wing figures, on behalf of majoritarian ethnic or religious groups who have in fact traditionally dominated political life and still have the numbers to do so, has turned it into a particularly dangerous weapon.

It is not good for democracy, Fukuyama contended, if “everyone is aligning into identity groups that are fixed by the way you were born.” The antidote, he declared, lies in cultivating a stronger sense of collective national identity. But “it has to be a civic identity,” he stressed, rooted in “a certain set of universal principles.” In America’s case, he suggested, that would be “belief in the US Constitution, in the rule of law, in the principle of equality embodied in the Declaration of Independence. You would say an American is somebody who believes in these things.”

But if nominal belief in universal principles hasn’t been sufficient in the past,

Walls or Welcome Mats?

Economic Perspectives on Immigration

In 2016, the Wharton Public Policy Initiative published a pair of issue briefs addressing immigration’s impacts on the labor market and the public treasury. According to Howard F. Chang, the Earle Hepburn Professor at Penn Law, “the single most important lesson that economics holds for immigration policymakers is that immigration restrictions are costly.”

Greater labor mobility would be expected to boost global GDP anywhere from 5 to 197 percent, according to a variety of studies. Chang noted that immigration may have a “small” adverse impact on low-skilled domestic laborers, but that US natives gain overall. “To the extent that immigration has any adverse effect on the distribution of income among natives,” he argued, “redistribution through progressive tax reforms rather than through restrictive immigration policies” would yield the optimal economic outcome.

Fears that immigrants overburden the public treasury, Chang observed, are belied by a 1997 National Research Council study that remains the “most comprehensive and authoritative study in the field.” The NRC study was the first to incorporate the projected fiscal effects of immigrants’ descendants—who tend to have higher incomes and pay more taxes—when measuring the overall impact. By that measure, “the average recent immigrant in 1996 has a positive fiscal impact of \$80,000 in net present value.”

But drilling down past the “average” immigrant gives some credence to anxieties over the admission of low-skilled immigrant workers. Workers with more than a high-school education represent a positive fiscal impact of \$198,000 in net present value, and those with only a high-school education are worth \$51,000. But for immigrants who have not completed high school, the fiscal impact drops below zero to -\$13,000.

For the full issue briefs, visit tinyurl.com/PPI-Labor and tinyurl.com/PPI-Treasury.

as Smith argues, the future calls for a stronger supplement in order to achieve a just society. And that is why the issue of consent looms so large in his thinking.

One of the biggest challenges facing democratic citizenship today, he has written, is the prospect that “the rhetorical triumph of the ideal of democracy is being accompanied by the practical eclipse of democratic practices.” The increasing sway of supra-national organizations has fostered feelings of powerlessness in the US and around the world (as entities like the European Union or International Court of Criminal Justice agitate the right, while the World Trade Organization and multinational corporations infuriate the left). There is a gnawing sense that judiciaries have become more assertive and determinative of policy than legislative bodies (hence the conviction that Supreme Court appointments present nothing less than existential stakes).

“The reality of governance in the 21st century is that most citizens experience it as the preserve of a variety of economic and political experts and elites, and they are right to do so,” Smith observes. Global challenges do in fact require expertise and decision-making at levels far removed from “the scale of a New England town meeting.” But there are costs when citizens feel they have lost control—and the US’s approach to illegal immigration has exacted an especially high price.

The original sin of modern US immigration policy, in the eyes of many immigration opponents, was the Reagan-era Immigration Reform and Control Act of 1986, which was taking shape as Schuck and Smith wrote *Citizenship Without Consent*. That “amnesty” failed to stanch the flow of unauthorized immigrants. Schuck and Smith worried that if “an increasing number of newcomers [can] claim political membership only because their parents” were

seen to have exploited the rules, hostility toward them would metastasize into broader xenophobia. The result would be “harsh policies born of resentment and prejudice” targeting a wider spectrum of legal immigrants and citizens. Smith thinks their anxiety has been borne out in developments like the Trump administration’s cancelation of DACA “Dreamer” protections, detainment of juvenile asylum seekers, crack-downs on (high-skilled) H-1B and (low-skilled) H-2B visa admissions, sweeping cuts to refugee resettlement, and the Muslim-targeted travel ban.

These are symptoms, Smith believes, of a perceived loss of control. And they can have negative consequences for citizens as well. The USA Patriot Act, for instance, initially appeared to eliminate certain legal procedural rights for aliens—but the Bush administration argued that citizens under suspicion could be stripped of them too. More recently, the *Washington Post* reported on a “surge” in the number of US citizens thwarted in their effort to obtain passports, because the State Department regarded their birth certificates as “potentially fraudulent.”

“Although economically and politically conservative measures are often advanced in nationalist tones,” Smith notes, “[o]ften they simply reduce the level of rights both [citizens and aliens] can claim.”

The antidote Smith prescribes is a reinvigoration of consensual democratic decision-making where it matters most: defining the national community. If “citizenship laws made nationality as much a matter of choice as possible, then Americans could more genuinely regard their Americanism as something they could define as they saw fit.” They could, in short, regain a sense of control.

In a 2008 article in Penn’s *Journal of Constitutional Law*, Smith made a case that Congress had effectively expressed the electorate’s will regarding birthright citizenship; the repeated and conclusive failure of 15 (now 25) years’ worth of restrictionist

bills amounted to a clear expression that Americans, through their elected representatives, have consented to reading the Fourteenth Amendment as guaranteeing birthright citizenship to children of all aliens born on American soil.

But that is not the only or even primary issue that concerns Smith. Partly because of his experience being subjected to the draft during the Vietnam War, he believes—and argued in *Citizenship Without Consent*—that the government should notify all 18-year-old Americans of their right to expatriate themselves and permit those who do to remain permanent resident aliens.

Measures targeting aliens often make life harder for citizens as well.

Somewhat more provocatively, he argues that the US is not likely to do away with the “differentiated citizenships” that have characterized its history—and should in fact embrace some of the possibilities they present.

“I think we waste a lot of time when we say we just want to do away with all that, when we *don’t* seriously want to do away with all that,” he says. “We just want to do away with certain forms of it.” Someone who cites the ideal of strictly uniform citizenship to oppose special legal safeguards or remedies afforded to historically maltreated racial groups, for instance, may simultaneously prefer to exempt female citizens from mandatory registration for potential military conscription, or excuse religious business-owners from certain obligations that bind secular ones.

“The more honest way to discuss it,” Smith says, “would be to focus on which

forms do we want to do away with and why, and whether we are acting consistently.”

Like James Madison, he sees “robust and explicit contests” among clashing views—including illiberal ones—as salutary to civic health. (Smith departs from some of his liberal brethren by insisting that a meaningful cosmopolitan pluralism must make room for traditional religionists who espouse illiberal principles. Allowing a fundamentalist baker to refuse to make a custom cake for a gay wedding, for instance, may be a “reasonable accommodation” as long as the broader marketplace offers sufficient alternatives. “If so many people refuse

to sell you a cake that you can’t get a cake, then we have to outlaw that. If the truth is you can get a cake from 20 places, but you can’t get it from this one place—and that pisses you off because you don’t like the guy’s attitude, but in fact you can still get a cake—I think we allow that.”)

Legislatures, operating within constitutional guardrails, are superior arenas for forging political consent not only because they are the most democratic but because their decisions are always subject to reversal or refinement. So long as the clashing continues, and combatants believe they have the capacity to shape tomorrow’s outcome if not today’s, perhaps Americans would have better cause to see America’s exceptionalism in terms of an ongoing civic project rather than through the lens of ethnicity, gender, or other criteria that privilege some people over others in morally unacceptable ways.

“The US is not an inherently and automatically liberal democratic nation,” Smith writes. But understanding it as a series “of serious struggles among people, movements, principles, and causes with different aims and interests—struggles in which the actors a particular citizen decides to regard as the ‘good guys’ may not always, perhaps even not often, win” could give “the national story a plot” that energizes citizens with an awareness that it’s up to them to make the next chapter better.

“What you want,” he says, “is to have as democratic a process of defining peoplehood as possible, and to push within that democratic politics to make the choices as inclusive and egalitarian as possible, so that that definition of who we the people are may expand over time—but expand in a way that is sustainable because people have agreed to it, and it hasn’t been imposed on them.”

Maybe that would also foster a mindset more conducive to pursuing supra-national governance in some contexts, sub-national governance in others, and recognizing the reality that growing numbers of people claim membership in multiple polities. More than 2.5 billion people live in countries that permit dual citizenship. Many people legally live and work—be it in corporate suites or poultry plants—in nations not their own. Some countries have granted increased autonomy to sub-units, like Catalonia and Scotland. (And it bears remembering that America’s founders assumed that citizens’ primary loyalties would lie with individual states [See “Gazetteer,” pg. 22.]

“The long-term future of the globe,” Smith hopes, will entail “breaking down a system of nations claiming absolute sovereignty into networks of more cooperative political communities in which movement in and out is accepted [by] semi-sovereign nations that recognize authority in some areas, and in others [acknowledge] the desirability of flexible cooperative memberships and government relationships.”

Further Reading

By Rogers Smith:

- “The Question of Birthright Citizenship” (with Peter Schuck), *National Affairs*. 2018.
- Political Peoplehood: The Roles of Values, Interests, and Identities*. 2015.
- Still a House Divided: Race and Politics in Obama’s America* (with Desmond King). 2011.
- Birthright Citizenship and the Fourteenth Amendment in 1868 and 2008, *University of Pennsylvania Journal of Constitutional Law*. 2008.
- “The Challenges Facing American Citizenship Today,” *Political Science and Politics*. 2005.
- Stories of Peoplehood: The Politics and Morals of Political Memberships*. 2003.
- The Unsteady March: The Rise and Decline of Racial Equality in America* (with Philip Klunkner). 1999.
- Civic Ideals: Conflicting Visions of Citizenship in US History*. 1997.
- Citizenship Without Consent: The Illegal Alien in the American Polity* (with Peter Schuck). 1985.
- Liberalism and American Constitutional Law*. 1985.

About Birthright Citizenship:

- Garrett Epps, “The Citizenship Clause: A Legislative History,” *American University Law Review*. 2010.
- Gerald Neuman, *Strangers to the Constitution: Immigrants, Border, and Fundamental Law*. 2010.
- Cristina Rodriguez, “The Citizenship Clause, Original Meaning, and the Egalitarian Unity of the Fourteenth Amendment,” *University of Pennsylvania Journal of Constitutional Law*. 2009.
- Ayelet Sachar, *The Birthright Lottery: Citizenship and Global Inequality*. 2009.
- James Ho, “Citizenship by birth—can it be outlawed?” *Los Angeles Times*, March 10, 2007.
- Joseph Carens, “Who Belongs? Theoretical and Legal Questions About Birthright Citizenship in the United States,” *University of Toronto Law Journal*. 1987.

That is less an expectation than an aspiration, but one Smith believes to be especially consonant with America’s purpose. And that is to “extend meaningful enjoyment of the basic rights to life, liberty, and happiness to ‘all people of all colors everywhere.’ Those are Lincoln’s words: ‘all people of all colors everywhere,’” Smith stresses. “That’s not just a matter of individual self-interest, or even the exercise of my own rights for my own pursuit of happiness. It’s a claim that we want through our collective endeavors to make sure that all people have these basic opportunities. And

that’s a kind of liberal republicanism,” he says, “that I still think is a pretty good vision.”

When I asked Smith how it felt to find himself on the same side of the Citizenship Clause debate as nativists who espouse quite a different vision, he said, “It feels horrible.” He offered no elaboration. It wasn’t a very good question. Later I asked a better one. Steve Bannon, Trump’s former chief strategist and perhaps the most prominent figure in the rise of the “alt-right,” had recently insisted to journalist Michael Lewis that his movement was not about “ethno-nationalism” but about citizenship. “We’ve got to make citizenship as powerful as it was in the Roman republic,” Bannon told Lewis. When I asked Smith what he thought of that, he grew animated.

“There are some dimensions of citizenship we need to strengthen—and there are some we need to diminish,” he began. “Roman citizenship, after all, became a form of imperial citizenship in which Rome claimed rightful authority to rule the world. We don’t need that. But Roman citizenship also was willing to extend full membership to anyone throughout the empire who became a citizen. If they could make it to Rome, they could participate in the Assembly ... And it also permitted them considerable flexibility in continuing to worship their own gods and pursuing their own customs and law. It accommodated lots of differences. We can use that. And the republican tradition of being willing to make sacrifices for the common good, we can use that, too.

“So there are dimensions of citizenship that we need,” Smith concluded. “But the one that we most need to combat is the sense that the only obligations that matter are to those who are currently juridically my fellow citizens, and that we’re entitled to put the interests of our citizen body over the rest of the world without any concern or doubt. What we don’t need is ‘America first and only.’”

A DEATH IN SOUTH SUDAN

Trying to understand the loss of a young journalist and family friend, who was killed last year while covering the civil war in South Sudan.

By Samuel Hughes

Last winter, in his mother's dream, Christopher Allen LPS'13 came to the table where their family was having dinner. His place mat was a map of the world, the one he had always insisted on having when he was a boy, just as his brother's had always been a map of the United States.

"I don't have much time here, but I needed to see you," he told them. "I needed to be with you again."

"Tell me," his mother said, "in the time we've shared together, what is it that means the most to you?"

He didn't answer—just looked slowly, deeply, first at his brother, then at his father, then at his mother.

"Why do you have to go back?" she asked him. "Why? Can't you just be here? Just stay with us!"

He moved his hands in a circular motion, hovering over the placemat of the world.

"I've got to go be with Helena," he said finally, referring to his Belgian girlfriend. "I don't have much time."

And then, said his mother:
"That was it."

It went from daylight to darkness

and soon a sliver of moon had risen amongst heavy clouds. From dancing to darkness had only taken an hour. Now, we followed the silhouettes in front of us through tall grass, down through the silent valleys with their heavy air and then up again where a cool breeze from the approaching storm made the grass sway. It was silent except for the footsteps of 20 men. Dark, except for the moon, hidden now by clouds.

There was just the silhouette of the man in front—dark and—

—Final words in Christopher Allen's Field Notes Notebook #3, August 25, 2017.

Chris was killed early in the morning of August 26, 2017, during a chaotic dawn attack by rebel forces on the government-held town of Kaya, South Sudan. He was 26 years old, working as a freelance journalist, and had spent the previous three weeks interviewing soldiers and civilians while embedded with the Sudan People's Liberation Movement-in-Opposition (SPLM-IO), that troubled nation's main opposition

faction. The last photo he took of the charging rebel soldiers—he had sprinted ahead of them and appears to have been moving backwards in order to capture their attack face-on—was time-stamped 6:52 a.m. Shortly after that, five high-caliber bullets tore into him, one piercing the side of his head. He probably died instantly.

That is the short, brutal version of his end. Many details of his final days have been uncovered; a few, such as whether he was targeted as a journalist by the South Sudanese government, are murky. On one level, those details are vitally important. On another, they are moot. His name has been etched on the glass Wall of Fallen Journalists in the Newseum in Washington, DC, his final days in Africa probingly chronicled in the *Columbia Journalism Review*. His ashes will be scattered in the Carpathian Mountains of Ukraine. The bottom line is that he's gone, a knife-thrust to the heart of his family and friends, his parents suddenly members of a terrible fraternity of grief. And the question that haunts them and everyone who loved him is not so much *how?* but *why?*



How do I tell a story like this? And why? Those questions are tangled, too. I've wrestled with them since late last fall when Chris's parents, Joyce Krajian and John Allen—close friends of my wife Pat's and mine—broached the idea that I write it. (Chris's brother, who asked that his name not be used for privacy issues, agreed that the *Gazette* was the right place for this piece, partly because it was "probably the only publication Chris wrote for where he didn't want to kill his editor.")

Background is important here. I usually try to keep a low profile in my stories, and while I knew Chris for much of his too-brief life, I was a very minor player in his drama. He and his brother grew up in our Philadelphia suburb of Narberth alongside my two sons, Tristan and Jesse. Chris and Tristan were friends since third grade, and the last time they were home together they went rock-climbing. Chris also became a serious mentor to Jesse, and the two often Skyped when Chris was in Ukraine and Jesse was a student majoring in broadcast journalism at the University of Colorado.

In recent years, our two parental units became increasingly close, with Pat and Joyce bonding deeply over shared worries. Over wine and Joyce's Armenian delicacies, the four of us would fret and laugh and shake our heads over our challenging and often headstrong young men. Increasingly, the worries gravitated toward Chris—who, ironically, was the only one of our sons who never got in trouble with the local constabulary for the kind of dopey things teenagers get in trouble for in places like Narberth. On the Allens' refrigerator was a card with the words: "Raising boys is an extreme sport."

Four years ago I assigned and edited Chris's first magazine article ["With the Donbas Battalion," Nov/Dec 2014], which was a rewarding experience for both of us. Over the next few years I gave him whatever modest advice and encouragement I could, pushing him to write more

for the *Gazette* and writing a recommendation for his 2016 proposal for a Fulbright in Nigeria—which, had it been approved, might have led to a very different outcome.

And so I find myself in a position that's both privileged and fraught.

Fraught because everyone who knew this remarkable, warm, insanely principled young challenger of received wisdom has their own narrative, and because missteps of tone or fact are not easily overlooked. Chris packed a lot of intense living into his brief life, and he hated simplistic storylines. I once had to tell him to stop using the phrase *irreducibly complex* on the grounds that it was a cop-out. I doubt I can reduce his complexities to the storyline he deserves. But let me try.

How else do you think I'm going to climb Mt. Everest?" Chris once said to three women on a SEPTA bus who had been clucking about the fact that he was wearing shorts on a very cold morning. "I'm training!" He wanted to make it clear that the shorts were his decision, not his mother's. He was four years old.

"He was a risk-taker from a very early age," says John, a transplanted Brit and former public school teacher whose polite, deferential manner belies his own adventuring past. (He once took a solo motorcycle trip through some extremely rugged sections of Pakistan, a trip that Chris would later replicate two weeks after Osama bin Laden was killed by American special forces.) "Chris would do things that the average Main Line kid wouldn't dare to do. And we sort of nurtured that, in a way."

That nurturing took many forms, including books and movies about mountain climbers and other adventurers. Chris was fascinated by explorers like Ernest Shackleton and Wilfred Thesiger, who pushed the limits of human endurance.

"He very much identified with Thesiger, right up until his time in South Sudan," says John. "I think in some ways he wished he'd been born in the Victorian age, where people, gentlemen, would explore the Dark Continent. And he loved the world for that, too. He was averse to places that functioned really well."

Polite and respectful in most circumstances, Chris was also quick to challenge authority when he found its reasoning unconvincing. He shared that trait with his mother, a Presbyterian minister whose warm idealism also includes a drive to cut through cant and right injustices. (Joyce's spiritual path began in earnest at age 16, when she left her family's Armenian Orthodox church, frustrated by all the "hocus pocus" and ring-kissing and patriarchal stunting of women and girls. "You ask too many questions!" the priest told her. "Just marry Armenian man and be happy.")

Both parents passed on a relentless questioning of all things status quo.

"Our dinner table was wild with conversation about *why* and *what*," Joyce says. "I felt very strongly that an education would not serve our kids unless they could emerge as independent thinkers and quality writers. The rest felt less significant to me."

By the time Chris began frequenting our house, his questioning mechanism was highly tuned. Pat, who saw her full share of boys in those days, remembers Chris peppering her with question after question, most of which she couldn't answer. He was, she concluded, "the most curious kid I've ever known."

Questions sometimes led to uncomfortable answers, and throughout his elementary and middle school years, he and Joyce often clashed with teachers and counselors. Yet Chris was always a serious student, whose intensely challenging nature played out in the classroom and on the athletic field.

Tristan recalls soccer games where Chris would get his team revved up by "stomping around, waving his arms, and

“You should go and see history being made,” an Oxford professor told him.

singing Queen’s ‘We Will Rock You,’ his face red, his eyes intense with passion.” Yet he never held it against anyone if he lost, Tristan adds. “You wanted to be on his team.”

If his high-tempered sense of principle often got him into scrapes—some comical—Chris nonetheless considered himself “very orderly and civilized, appreciating the structure of society and its conventions—even believing that the American rebels in the Revolution were out of line for attacking British soldiers when they stopped to have tea,” Tristan recalls. “His dad being British, he identified with that sense of orderly British society and would complain about America—until he went there in seventh grade and realized it wasn’t the pinnacle of perfection he thought it was.” A few years later, he became a dual US-British citizen.

By the end of middle school, his teachers appear to have been in two camps.

“I live to teach Chris,” his teacher in the Challenge program told Joyce. “He raises such good questions. They always move the conversation.”

Others found his persistent probing and contradicting annoying. So did some of his classmates. Things came to a head his final year there.

“All he wants to understand are the exceptions to the rule,” his math teacher told Joyce. “It drives me crazy.” His history teacher complained that he had told her: “What you said in class today contradicts what you said two weeks ago.”

“Well, you’ve got a kid who’s really listening,” Joyce responded. “Was he right?” “That’s not the point,” said the teacher.

That did it. Goodbye, Lower Merion School District.

Eddie Einbender-Luks was Chris’s best friend at Germantown Friends School, where Chris thrived throughout his high school years. But it took him a while to warm up to the new kid—who quickly “made himself very known.”

“He was opinionated. Difficult. Incredibly smart,” Eddie says, then hints at a smile. “Kind of an asshole.”

Their friendship grew on the track team. One cold winter afternoon the two, along with a couple of seniors, were running on a path by the Wissahickon Creek, when the older guys casually suggested that Chris wouldn’t jump into the frigid creek for \$50. They kept running—until the others realized that Chris wasn’t there.

“We see him climbing out, drenched in water,” says Eddie. “And we’re like, ‘Holy shit—you’d better go back right now!’ And he’s like, ‘No—I’m going to continue to run with you.’” The others got him back to school before hypothermia set in, but Chris won the bet—and a kind of raised-eyebrow respect.

Academically, “he was like a kid in a candy shop at Germantown Friends,” says Joyce, who had to tap some generous friends and relatives to help with the tuition. “He kept creating these independent things, which would last for the semester, and taking an overload” of classes.

During his junior year there, Chris met his first Penn faculty member: Gareth Darbyshire, a research associate and Gordion archivist at the Penn Museum. He remembers Chris as a “very charismatic person, very sharp.”

“He had to do his junior project, and he was all into archaeology, and could he do it with us?” Darbyshire recalls. “The Penn Museum’s been digging in Gordion, near Ankara, since 1950, and we’ve got a huge amount of legacy data that was in analog format.” Chris began digitizing that data and soon asked if he could do something more focused for his class presentation. The result was a

three-dimensional computer reconstruction of a modern person walking into a Persian period house.

“His computer reconstruction was very good,” Darbyshire notes. “And he did all this very quickly. I was very struck with his dynamic personality, the rapidity with which he grasped information and came up with something new and interesting. He was an avid reader as well, on a wide range of topics. In one month he made a big impression.”

After that, “Chris couldn’t picture himself anywhere but Penn,” says Joyce. He applied Early Decision. Darbyshire wrote a glowing recommendation. It wasn’t enough. Penn turned him down.

Joyce was told that the problem was his GPA, a very good but not outstanding 3.48; the cutoff was 3.5. His advisor at Germantown Friends told Joyce that the school had “done him a disservice” by letting him take an overload every semester, adding: “Everybody wants the spark that he brings to the classroom.”

Fast-forward through an unhappy freshman year at the venerable University of St. Andrews in Scotland, followed by three semesters at Temple University. At first he chafed at some of the unchallenging required courses, then came to admire the urban grittiness of its students, some of whom were working 40-hour weeks to pay the tuition. He also wangled his way into an upper-level philosophy course, which sparked a lasting friendship with the professor and her husband.

But his dream was still to go to Penn, and while the cost was an obstacle, he found what Joyce calls a “back door” entrance: Penn’s College of Liberal and Professional Studies, to which he immediately applied. This time, he got in.

Transferring to a place like Penn is not always easy. Now 21, older than most of his classmates, Chris formed an unlikely friendship with a Vietnam veteran named Alan McIntyre, who audited classes on a regular basis. The two met

in a class on Tolstoy's *War and Peace* taught by Peter Holquist (the Ronald S. Lauder Endowed Term Associate Professor of History) and Ilya Vinitzky (then a professor of Slavic languages and literatures). It was Chris's favorite book, and he reveled in it. Holquist, who remembers Chris as a "very committed student" who did "very well in the course," was struck by the friendship between the 21-year-old Chris and the 70-something McIntyre.

"Despite the difference in our ages, we got along very well," recalls McIntyre, who often came to the Allens' home for dinner. "The fact that he had done so much traveling was of interest to me. And the fact that I had been in Vietnam was of interest to him."

In the spring of his senior year, the *Penn History Review* published a version of his thesis. It was titled "Missions and the Mediation of Modernity in Colonial Kenya." Africa was already calling.

A year later, one of Chris's professors at the University of Oxford gave him some life-altering advice. It was 2014, and he was in his final term of the Europaeum Programme (a master's program in history, divided among Leiden University, Panthéon/Sorbonne, and Oxford). By then he was restless and souring on academe. "You should go and see history being made," his professor told him.

History was then erupting in Ukraine. The Maidan uprising in Kiev had just chased out the country's Russian-supported president, Viktor Yanukovich. Soon after that, pro-Russian forces invaded and annexed Crimea.

"Ukraine was hot," says John. "So Chris decided that for his spring break he wouldn't be going to sunny Greece or Spain. He would go to Ukraine and see what was going on. He ended up right in Donetsk—where things were really hot."

From there he called his parents. "It was very exciting to him," John says.

"Seeing a bunch of guys busting down the police headquarters doors and going up the stairs. He said, 'I'm on the top of the police headquarters building!' I said, '*Get the fuck out of there, Chris.*' But he was in the midst of a revolution, and it was a totally transformative moment for him."

As soon as he finished his classes at Oxford, he returned to Ukraine.

"This was his place," says John. "He eventually moved to Kiev. He felt like it was home. It's a little gritty in places. But that's what he liked—'Oh, there's a demonstration down at Maidan. I want to go and see what's going on.' It wasn't all good—there were some of the more creepy elements there, too, neo-fascist groups and such. And some of the volunteers were a little shadowy. But Chris did like the fact that these people would stand for something."

He also saw the limits of journalism. "They'd write these short articles that didn't really give the background," John says. Chris was keen on providing context, for which few publications have the space and not many readers have patience.

Around that time Pat, who had spent 25 years in newspapers, got a call from Joyce. Chris had decided to become a freelance journalist and was looking for help getting published.

"I was like, 'Does he know anything about freelancing?' 'No.' Ever written a newspaper story?' 'No.' Ever taken a journalism course?' 'No.' And I thought, 'This is kind of crazy. This is a pipe dream.'" But, Pat adds quickly, "I should have known better, because when Chris got an idea in his head, he would not be dissuaded."

On July 17, a Malaysia Airlines passenger jet was shot down over eastern Ukraine, killing all 283 civilians and 15 crew members. (It was later determined that pro-Russian separatists had fired the fatal missile.) One of the first journalists on the scene was Chris. He wrote a breaking-news story that was published by *The Telegraph*, headlined: "MH17: A scene of horror—death and the banalities of life together in a Ukrainian field."

Editors weren't exactly breaking down his door for more stories, though, and when Pat broached the subject one night, I said that Chris, as a Penn alumnus, might be able to write something for the *Gazette*. Then I emailed him. A few snippets:

July 31, 2014

Thanks for the note and the offer. I'm doing my best to stay safe—who knows out here, death seems so random. But this aside, I would definitely be interested—it would be great to be published in the Penn Gazette ...

August 2, 2014

It's been a busy couple days: I got detained overnight for sixteen hours by Ukrainian special services (been detained by both sides now, quite the honor) and then took a train to Kiev to take a break ...

My goal when I came here was to embed with a unit, to follow them, to know them, to see how this war is actually working ... I wouldn't say that is anything more dangerous than I'm doing on a daily basis.

We decided to send Chris a contract for a feature "on the author's travels in Ukraine." I made some suggestions for how he might approach the story and implored him (multiple times) not to take any risks on our behalf. Technically, he probably didn't—by which I mean he would have taken them regardless of whether he had a contract from us.

Vitalii Cherniavskiy, who usually goes by Sava (his nom de guerre), was among the unlikely Ukrainians who carried a gun with the Donbas Battalion during the often-murky conflict between Ukraine and pro-Russian separatists. A self-described "IT guy with glasses," he met Chris in early August, when he was asked to translate during Chris's interview with a deputy commander who didn't speak English.



An unidentified soldier on the frontline, Avdiivka, Ukraine.

“I was quite impressed about how precise were his questions,” recalls Sava, who would become friends and later roommates with Chris in Kiev. “We didn’t need to explain to him a lot. I was eager to help him with everything I could, because I felt he really wants the truth, and he was interested in getting both sides of it. In situations where other journalists would say ‘I have enough,’ he always dug one spade deeper.”

That first stint embedded with Donbas that he chronicled for the *Gazette* was for less than a week. But it was an intense experience. Several members of the rag-tag battalion were killed when their car was ambushed by separatists. Chris was close behind them. He was clearly moved by their deaths.

“The guys he covered in the Ukrainian armed forces and volunteer militias really loved him because he was not the typical journalist,” said Christopher Occhicone, a photojournalist based in New York and Ukraine, in an email to Chris’s brother. “He stayed with them on

“They threatened to hang me and cut my ears off.”

the front line and lived as they lived. He stood next to them in dangerous situations, and he won their respect and friendship ... I can tell you that he was one of the bravest guys I ever met.”

Working with Chris on “With the Donbas Battalion” (from the backlines of West Philadelphia, thank you very much) was one of the most gratifying experiences of my editing career. His first draft was a tad overwritten—understandable for someone who had never tackled a magazine feature before—but the combination of in-the-trenches reportage and

his sharp, sometimes offbeat, observations was riveting. When I’d ask him to flesh out characters or provide background on the conflict, he did so quickly and adroitly. He didn’t even complain when I told him we weren’t going to use his proposed title, taken from a Donbas soldier’s jaundiced view of the fighting: “My Fucking Summer Holiday.”

Both his writing and his refusal to produce overly simplistic storylines about the fighters inspired a letter to the editor from a knowledgeable alumna, Martha Bohachevsky-Chomiak CW’60. She didn’t know Chris, but as a scholar and former director of the Fulbright Exchange Program in Kiev, she wrote, “I appreciated this article greatly, since I know firsthand how difficult it is to write about the complexities that confront contemporary Ukraine.”

Not only did he present a “difficult subject clearly and with feeling,” but he was “concise without simplifying his subject.” Benjamin Franklin, she concluded, “would be pleased by the *Gazette*’s groundbreaking frontline reporting.”

There's so many shades to truth.

There are a million reasons why this war is happening. You ask each person and it's a different reason. It's like Tolstoy said: there's an infinite calculus to history ... But the media has to say something. So they package it to fit their narrative. In history class you do the same thing. You have a thesis, and you pull the facts in order to support that thesis. That's why I don't want to just do journalism. There's more to the truth than that ...

Maybe 'my' truth is the only truth we have access to. Journalism doesn't give you space to tell that story very often.

—From a 2014 Skype interview with Chris by Jesse Hughes.

Shortly after leaving the Donbas Battalion, Chris went to Donetsk, which was still plenty hot. Then he heard that the outfit was leaving for a raid of Ilovaik, some 30 miles away, and tried to rejoin them. It was a good thing he didn't succeed, says Sava, since the battalion got ambushed and a number of men died. But Chris had a close call of his own.

John and Joyce were in San Francisco, enjoying the Bay, when they got a call from Eddie. “Chris is in trouble,” he told them.

According to John, Chris and a Belgian journalist had been trying to locate the battalion when they were stopped by separatists, who arrested them and “bundled them into a makeshift prison. That was very worrying, because they didn't know where they were going. They could have taken them to a field and shot them, and nobody would have known.”

Chris managed to take a picture of an SUV (and its license plate) belonging to a well-known warlord, and texted the photo to Eddie in Philadelphia, along with instructions to contact the State Department and put word of his capture out on Twitter. Chris later told Jesse that the separatists had “threatened to hang me and cut my ears off and nail them to the wall if they found out I was a mercenary” or a spy.

By most people's standards—certainly by mine—this is pretty extreme risk-taking. And yet: for all the risks, Chris was “absolutely not reckless,” in Sava's opinion. “He was brave but always very cautious, and conscious about risks he was taking. He took responsibility to be part of military battalions. If you need to lie down and wait until the shelling is ended, then he did it.” Chris always asked what he could and should not do, Sava adds. “So he took risks, but not more than others did.”

That fall, Mitchell Orenstein, professor and chair of Russian and East European studies, was teaching his Penn class on Russia and Eastern Europe in International Affairs. Acting on a suggestion from Alan McIntyre, who was auditing the class, Chris agreed to talk to the students via Skype from the frontline.

“Chris's presentation was wonderful,” says McIntyre. “He just stood in a field in Ukraine and talked. It showed me he would have been a wonderful teacher.”

At that time Chris was embedded with Right Sector, a far-right militia and nationalist political movement. “He had a lot to say about the people fighting and the conditions,” notes Orenstein. “He mentioned that he thought Right Sector were making their money from cigarette smuggling. He was very informative, though I don't think he was too heavily involved in combat operations.”

One thing did strike him as odd, though: Chris's “obsession with why men go to war zones,” which “seemed to reflect the reasons for his own fascination.”

In a sense, Chris responded to that observation in a lengthy article about European mercenaries published in August 2015 by *Vice*, based on his time with the pro-Ukrainian Azov Regiment.

Those soldiers, he wrote, “have actualized our own very normal fascination with war—one that most satisfy by joining national militaries—or, more passively, through video games and movies—but which, once experienced in real life, cannot be simulated in a training camp, in the cinema, or on a PlayStation.”

Helena Boeykens is sitting in our breakfast room on a cold February afternoon, talking about the Chris she knew, who was slightly different from the Chris his male friends knew. It's her third trip to the States since he died, all spent with Joyce and John. She is gentle and bright-eyed, somewhat girlish in her mannerisms—and also whip-smart, principled, and possessed of a quiet strength.

“I have this completely different sense of who he was on an emotional level,” she says. “He was so romantic, so gentle—he tried to take care of me, and he protected me. Even on a superficial level he was not tough or anything like that. So kind, and such a good heart. And that went really well with who I am.”

They met late in the summer of 2015, when they were both living in Brussels, and Chris was getting over the viral meningitis that had landed him in a Kiev hospital. She was a third-year student at the University of Slavic Studies, feeling somewhat confined in the city of her birth and preparing to go on an exchange program to Warsaw. He was about to return to Ukraine.

“Chris and I often talked about what moment in life made you an adult,” she says. “After that year I could say I grew up a lot.”

They met online. “That's maybe not such a romantic way to meet,” she says with a bit of a smile. Their first date was “awful,” mainly because it didn't last very long. “It was very late, and we talked maybe 45 minutes, and I said I had to go because I had to wake up very early. But it was such an interesting conversation, actually. He made a really big impression on me.”

At first it was the sound of his voice, which she found “really unique.” Then it was “the way he was so comfortable with himself and seemed like he knew what he was going to do in life. He had this will to do things.”

Though she was four years younger, they had a lot of shared interests and



Helena in the mountains of Georgia.

passions. “He talked about Ukraine and about the time he got captured by the separatists,” she says. “I knew about the conflict. We talked about Tolstoy, who was my favorite writer. Chris was crazy about *War and Peace*. When he talked to you, he was really listening to you, and he wanted to hear what you had to say. Everything else disappeared in the background.”

After they both left Brussels for Warsaw and Kiev, “We sort of said goodbye,” she says. “But after a week he texted me. ‘Helena, do you want to meet in Lviv next weekend?’”

Yes, she did. They both drove all night to meet in that city, roughly halfway between their respective locales, and spent “an incredible weekend” together. Then Chris visited her in Warsaw. “We didn’t put on boundaries for each other or anything,” she says, “but we did travel long distances to be with each other. We both felt like this was not just something.”

There is a war being waged in Ukraine, but this one is not being fought from trenches in the east. It is being played out on television sets and in the minds of viewers on an informational frontline where oligarchs and politicians fight for influence.

—From “Who Owns Ukraine’s Media?” in the May 18, 2016, *Al Jazeera*.

BY the time that article was published, Chris was sharing a Kiev apartment with Sava and had reluctantly taken an office job in that city with Boston-based PDFfiller. But his journalism career was foundering.

“He was so frustrated with the fact that people weren’t interested in his stories,” says Helena. “He thought that what he was writing was way more valuable than breaking news. He was there with the people, and the social context or the environment around the story he was writing was sometimes more important than just pitching the story itself.”

The freelancer’s life is a brutal one, and there were only so many stories about Ukraine that someone whose facility with that language was less than perfect could sell, especially now that the fighting had calmed down. He began to cast his net wider.

Early in 2016 he traveled to Nusaybin, Turkey, near the Syrian border, to interview Kurdish volunteers in their struggle with the Erdogan government. In March the *Maghreb and Orient Courier* published his article “Nusaybin: Erdogan’s Private Civil (Kurdish) War.” Two months later the *Courier* published the raw interviews. As always, his questions elicited answers that revealed the soldiers’ variegated reasons for fighting.

“I think Chris was just getting to the point where he would consider himself a journalist,” says Eddie. “He held himself to high standards in that way. He wanted to be part of history, and he believed that history is made up of these micro-stories of normal people. Journalism was a way to really get in touch with these people and to understand them as human beings.”

Heading to Belarus—needed to leave and switch passports/get a new visa anyway, so it was a convenient excuse for a short holiday.

—Email from Chris, October 30, 2016.

It was only recently that I learned the real reason for that holiday in Belarus.

“Chris never talked to us about women,” Joyce says. “He comes back from Belarus, and he calls us and says, ‘Oh, it’s so great—I had such a great time!’ And John and I are looking at each other, thinking, ‘What’s her name?’ Like, who talks about Belarus in November like this? So I said, ‘Did you go with friends?’”

“I know where you’re going with that,” he responded. “When there’s something to tell, I will tell you.”

The budding romance wasn’t always long-stemmed roses, of course.

“We really had some big arguments,” Helena says. “But we would always talk it through. We would really get into the other’s psyche, and it would build up to this climax. Those moments were so intense.”

Once, in Georgia, they hiked up a mountain to visit a monastery. “The whole way up we were discussing this thing and getting more and more heated, until we got to the top, and we were just—angry.” They went through the monastery separately, ignoring each other. Afterwards she found Chris sitting alone on a rock, taking pictures of another couple.

“Well, I admit that I was wrong,” she remembers saying as she sat down beside him. “But why can’t you admit that you were wrong?” Gradually, he did, and they talked it over—and over—and finally worked it out. “And all the way down, we were just laughing and laughing and falling ...”

They had a little saying, almost a mantra, she explains. One of them would say, “We’re good together, aren’t we?” And the other would respond, “We’re *so* good together.”

By the time Joyce and John called him in July 2017, Chris was ready to fess up.

“This is really special,” Joyce recalls him saying. “She’s different from any other woman I’ve ever known. She’s attractive and so smart. She speaks six languages. She’s ready for an adventure.” Then he handed the phone to Helena.

Joyce remembers one thing clearly from that first conversation with the young woman she would soon grow to love. By then Chris had made his plans and would be leaving for South Sudan, by way of Uganda, in less than a month.

“I was just so scared,” says Joyce. “We didn’t want him to go. I said to Helena when I met her on the phone that first time, ‘We’ve got to bring that guy back.’”

As insanely risky as his journey looked to be, no one who knew Chris believes that he had any intention of *not* coming back. He had too many things he was excited about doing, too many places he wanted to go—and now the love of his life to do them with.

Nor, for all his high-minded principles, was he naïve. He saw through people quickly, and given the time he had spent on the frontlines of Ukraine and in Turkey with Kurdish fighters, he knew full well the dangers of war.

But still: Why South Sudan, which is highly dangerous and openly hostile to journalists, some of whom have been killed there, many of whom were banned from the country? Especially since it isn’t on most Westerners’ radars and is thus a much harder sell for a freelancer.

To some extent, he probably saw South Sudan as a place where he could make his mark. Most war correspondents, both freelance and salaried, were heading to places like Mosul to cover the war against ISIS. And a good number of fighters in South Sudan spoke at least some English.

“He was at a point where he really had to make a drastic change,” says Eddie. “We always talked about what holds you back, what factors in life make it difficult to break out of something, to do your own thing and be independent. Chris made his own decisions, regardless of

“I said, ‘You need to take a month or so to get the feel of Africa.’”

what anyone else said. And early that summer he made the decision to go.”

“He felt he needed to broaden his brush a bit and gain more experience,” says John. “This was something that people weren’t covering that he could carve out a little niche for himself, maybe, in a very competitive market.”

Finally, Chris had long been fascinated by Africa, the source of so many explorers’ stories and the subject of his senior thesis at Penn.

“It’s sad to think of his journey to South Sudan as something he did just because he wanted more experience,” says Helena. “He was always drawn to Africa. All the writers he read” had spent time there. “So it was on his path.”

Until Chris was preparing to go, she knew little about South Sudan—or about freelancing in war zones. “He was the freelance journalist and I was a student, so I had the feeling that he knew what he was doing. I never tried to stop him from going.”

It was only when he booked his flight—two weeks before he left—that she started reading up on his destination. Then, she says, “I was just really scared.”

And with good reason. The five-year civil war between the government of South Sudan (which became independent from Sudan in 2011) and the rebel factions had left tens of thousands dead and millions uprooted. Three years ago, President Salva Kiir threatened to kill journalists who reported “against the country.” Seven were killed that year.

During their final days together in Brussels, Helena helped with last-minute preparations, researching medical issues—his biggest concern was getting sick—and accompanying him to the hospital for shots. She recalls sitting next to him when



The photos on these last five pages were taken before and during the attack on Kaya.

he was talking on WhatsApp with Lam Paul Gabriel, spokesman for the SPLM-IO.

“It was all so easy,” she says. “It was like, ‘Okay, let’s meet then, there, and I’ll be in Kampala [Uganda] then. Okay, fine, we’ll leave at 8:00.’ That was it. Just a couple of messages. He could have done more homework, for sure.”

Chris did speak with a number of journalists and got a productive list of contacts. But there were some less tangible things he didn’t get.

“I said to him, ‘You need to take a month or so, just getting the feel of Africa,’” John says. “‘You’ve never been there before. Could you believe everything people say? I regret he didn’t really do that.’”

Some of his fellow journalists were helpful—up to a point. Simona Foltyn, a Dubai-based freelancer who wrote a searching article about his death for the *Columbia Journalism Review*, was one of those with extensive experience in Africa to whom Chris reached out. Though she gave him some contacts, she acknowledged in her article that she

hadn’t volunteered “any other information on how to navigate rebel-held South Sudan, a mistake that has been a great source of guilt.” After speculating that a similar desire for exclusive coverage may have kept him from divulging details of his own plans when he wrote her again, she added: “In the end, we were both freelancers pitching stories to the same few outlets that still cover international conflict ...”

Chris and Helena spent their last moments together hurrying to the train station that would take him to Brussels Airport. As they approached the waiting train, each lugging a heavy bag, Helena voiced their old refrain: “Oh, we’re so good together.”

“We’re *so* good together,” Chris answered. Then they said their goodbyes, as they had so many times over the past two years.

“We were both sad,” she says quietly. “But we just said, ‘Well, we’ll see each other in Ukraine two months from now. It’s going to be over fast.’”

I arrived in South Sudan only a few days after flying from Ukraine, but it feels like ages ago. The contrast between the outside world and this place that I find myself in is stark—and makes Europe feel very far in time and space ... This feeling ... is magnified by the lack of activity here and the perpetual sense of waiting ... I thought relationships with the soldiers would be easy here because most people speak some English, but in fact, I’ve found it somehow more difficult than Ukraine.

—From an unfinished letter to Helena Boeykens, August 18–22, 2017.

Chris arrived at Entebbe International Airport on August 1, after a punishing series of flights, and spent some of his time in Kampala finishing his work for PDFfiller. Three nights later, he and Lam Paul Gabriel took a bus to Yumbe, Uganda, some 20 miles from the border with South Sudan. On August 5, he crossed the border (possibly with



a bribe) into the South Sudanese state of Equatoria. He was now with the rebels of the SPLM-IO.

Matata Frank, the rebel governor of the Yei River state, told Foltyn that Chris’s “only motivation was to find out exactly the truth about the war in South Sudan,” adding: “We had really a lot of hope in him. Everybody was banking on him when he gets back [to tell] their real, actual stories that people are going through.”

But from the outset, Frank told her, “he wanted to cover the actual fighting. He kept on asking me especially, when are we going to the war? Where are we going to attack?”

Complete frustration with this uncivilized backwater ... where even soldiers can't get time distance & direction right. Where everything takes longer than people say by minutes or weeks. Fucking tired and frustrated. How much longer ...

—From Field Notes Notebook #2, August 13, 2017.

Chris spent the bulk of his time in Panyume, which he described in his notes as a “desolate little town deserted except for one merchant who sells biscuits, tobacco, soda, and peanuts.” (When I searched Google Maps for Panyume and the village of Iandu, Chris’s other camp, both came up blank.) He was staying with Matata Frank, who, he wrote, “carries himself with the cocky assurance of somebody who commands respect, but who was only given it late in life.”

Accompanied by guards and Juma, his minder and translator, Chris walked to other villages in the area, interviewing residents about the war and its impact. Judging by the list of “Books Read” in his journal—eight in all, ranging from Ryszard Kapuscinski’s *The Soccer War* to James Joyce’s *A Portrait of the Artist as a Young Man*—he had a lot more down time on his hands than he had bargained for. But at least he had an exclusive.

Then, on the eve of the battle, he learned that the rebels had agreed to let two journalists from Reuters join them.

John and Joyce talked to him the night

before the battle. “He said the communications person lied to him,” says Joyce. “Reuters had made contact even before Chris had, but he was never told that. He said, ‘So now that Reuters is here we’re going out?’ But he was very committed to the men whose stories he’s telling every day.”

“He thought this was his exclusive,” says John. “And these guys had creds—they weren’t even freelancers. We do wonder if he took more risk than he would have because of those guys.”

“Allen, he didn’t want rivals around, so he was not very happy when he saw [them],” Gabriel told Foltyn. “Their presence gave him that pressure, that he wanted to cover something more.”

Unlike the Reuters correspondents, though, Chris had already spent three weeks with the rebels. Even without the battle, he had a lot of singular material.

“We said, ‘You’ve got your story. Just walk from this one,’” says John. “But he didn’t want to [cover] it from a mile back. He wanted to be there with the guys right in front.”



“We said, ‘Look, you have what Reuters could never have, which is three weeks of living with these guys. You can tell a story that nobody else can tell,’” adds Joyce. “He said, ‘It’s not the whole story.’”

25 August — march to attack

The air pressure in the town seems to drop the day the attack is announced in the morning. The vacuum which once existed has been broken but the spirit hasn’t yet rushed in to fill it. The parade is cancelled because of rain but in the late afternoon the attack becomes a reality. As the men distribute ammunition and red arm bands, as they gather together on the open field in front of one of the village’s abandoned schools, they chant and dance, talk excitedly.

Each man has only 20 rounds, 2 magazines. “We are rebels, we don’t have enough [ammunition],” says our roommate. “We will take them from the enemy.”

—From the final entry in Field Notes Notebook #3.

I’m not going to say much about the Battle of Kaya, which appears to have been a foolish, badly planned attack by an under-trained and under-armed rebel force hoping to capture weapons and ammunition. It ended in a rout—one with tragic collateral damage. In her *CJR* article, Foltyn quotes a rebel intelligence officer who had tried to convince the three journalists to stay behind until the town was cleared: “They refused, all of them. I was like, *What can I do?*”

There was apparently a moment of decision that may or may not have been fatal.

“It was a pronged attack, I believe,” says John. “And there was a fork where they divided up, as I understand it, and the two Reuters guys went one way.” Chris went the other.

Despite some reports to the contrary, he was not wearing his bulletproof vest or press badge. As foolhardy as that sounds, the decision to leave the 20-pound vest behind for a hard overnight march was neither illogical nor one he would have made lightly.

“I know he had a conversation with some other journalists about whether or not to wear his flak vest and whether to identify as a journalist,” says his brother. “Ultimately he decided that the bullet-proof vest would slow him down and that the press badge would make him a target.”

There is always a “tradeoff between mobility and protection,” noted Foltyn in the *CJR*, and the vests are “impractical, especially given that the rebels don’t wear body armor and are already difficult enough to keep up with.” And given that he was shot in the head and twice in the neck, it wouldn’t have mattered.

After his death was announced, a South Sudanese information minister told Voice of America that Chris was a “white rebel” who had come into the country illegally. Two days later, the government changed its tone and called his death “regrettable.” But it also ruled out an investigation, despite calls to do so by UNESCO and the Committee to Protect Journalists. “Taking photographs and reporting events is not attacking,” said the CPJ’s Angela Quintal. “It is jour-



nalistic work done by civilians, who are protected under international law.”

Whether the soldier who fired the fatal shots realized that Chris was a journalist is a question that can’t be resolved from West Philadelphia. It’s unlikely to be resolved by anyone who will tell the world. And no answer would change what happened.

Joyce and John were in Southern California, staying at her brother Leon’s house. They had just sold their Narberth home and driven across the country, stopping at Yellowstone and other parks along the way. Their next destination was Colorado, where Chris’s brother and his wife were about to have a baby. Despite the chaos and uncertainty of being homeless for the first time since they were married in 1990, Joyce and John were excited—about the new life they were going to start in Maine (once they found a house), and especially about the prospect of their first grandchild.

When they woke around 7:00, Joyce checked her email and saw there was a

message from the State Department asking them to call a number. There were missed calls from Lam Paul Gabriel and Helena, who had also sent an urgent Facebook friend request. They called the State Department and were put through to the American embassy in Juba.

What they heard next was the message, bluntly delivered, that would change their world forever.

No words can do justice to the slow-motion nightmare they’ve lived through in the year since Chris’s death. Yet somehow they’ve kept moving. In November they arranged a memorial service at Germantown Friends, attended by more than 300 people, some coming from Europe and Australia and Ukraine. Many spoke movingly about their friend, student, mentor—and son. Three months later, Villanova University hosted an exhibition of war-zone photos by Chris and other photojournalists, put together by two freelance journalists (Osie Greenway and Anne Alling) whom Chris had met in Europe. Joyce and John spoke at that event,

too. They met with US Senator Bob Casey, who promised to press the South Sudanese government for answers about Chris’s death, though he couldn’t offer much hope. In March, Joyce, John, and Eddie flew to Ukraine to find a site in the Carpathian Mountains to scatter his ashes, as Chris had requested. (By then Helena was in the Philippines, working for an NGO. She’s still there.) In June Joyce spoke at the Newseum, which honored Chris and 16 other journalists from around the world who had been killed doing their jobs.

“It’s sort of been all-consuming for this time,” admits Chris’s brother. “So in certain ways I feel relief as we get through these chapters. And I feel relief for my parents, just as time goes on.”

His parents are still homeless, house-sitting for friends and kind strangers, still looking for the right house in Maine. Wherever they end up, they want their home to have a place where war-weary freelance journalists can stay. (They also started the Christopher Allen Fund, proceeds for which will support the “work and safety of freelance journalists globally.”)



“Sometimes I just keep expecting him to walk through the door with that love of life and the curiosity,” Joyce was saying last spring. “He was in many ways just—big. I think he got my spirituality—intuited it. I don’t think he could articulate it. But we shared something pretty profound.”

Of course, she’s angry, too, and often confronts Chris in her mind: *Why did you do that? You’ve deprived us of so much. You’ve deprived yourself. And you’ve deprived Helena, who is such a kindred spirit.*

“I don’t think he would have wanted to put us through this,” says John. “I think if he’d been 10 years older he would have known how terrible this is for everybody, how life-altering for everybody around him that would be. I know Joyce said to him that our lives would be changed forever if he died. But I don’t think he really understood that.

“He was very confident he would make it out of there,” John adds, acknowledging that he may have been too confident. “If he’d only held back, been more conservative, he might have made it. If

those [Reuters] journalists hadn’t been there, he might have gone the other way. Who knows?”

“I think his mode of living was going to result in him getting hurt or killed,” says Chris’s brother. And yet, he adds: “Not very many people get to die doing what they’re passionate about doing. He definitely was out there living life to the fullest, and living his life how he wanted to live it.”

Barbie Zelizer Gr’90, the Raymond Williams Professor of Communication and the founding director of the Center for Media at Risk, has a lot to say about the importance of covering dangerous and remote places. Some of it is beyond the scope of this article. But having been a journalist herself, and noting the escalating attacks on journalists everywhere—including the US—she is emphatic about the need to avoid blaming them for daring to cover dangerous parts of the world.

“When we begin to say that it’s okay to go to Ukraine, and it’s not okay to go

to South Sudan, that becomes something of a slippery slope,” she says. “These events, these countries deserve coverage. The problem isn’t with Chris wanting to go there. It’s with the institutions not providing the kinds of requisite protections.”

I ask if she has any words for those still grieving.

“That’s a heavy-duty ask,” she says after a brief pause. “I would only say that it’s not the individual’s fault. It is the individual’s triumph. And if you don’t have individuals who are willing to take these risks, then journalism at large falls short.

“Journalism as an institution can’t do the reporting itself,” she adds. “So the triumph belongs to those who go down there and venture out into dangerous situations. And that’s something I don’t think you can ever take away.”

This is Samuel Hughes’s last article as senior editor of the *Gazette*. He thanks readers for their indulgence over the years and can be reached at smhughes210@gmail.com.