

# EVERY BITE, EVERY DAY

What one Penn family is doing to raise awareness and research funds for celiac disease—and pursue a cure using mRNA technology pioneered by Nobel laureate Drew Weissman.

By Dave Zeitlin

**It's** a warm Friday afternoon in early October, and Jax Bari is doing what an 11-year-old should be doing: he's getting dirty.

Off from school for fall break, Jax is strolling around Penn's campus with his father Jon Bari C'89, mother Leslie, and sister Lexi, a second-year student at Wharton. Several years down the road, the sixth grader at Philadelphia's Penn Charter School hopes to follow in his dad's and sister's footsteps and come to Penn for college. But for now, Jax is simply enjoying Locust Walk, joyfully running down a steep, wet hill outside College Hall—and slipping and getting his hand covered in mud.

"I *am* still a kid," he says as he walks over to a bench between College Hall and the Fisher Fine Arts Library.

Sometimes, it's good to be reminded.

How many kids, after all, have personally met with President Joe Biden Hon'13, governors and senators, and the heads of the US Department of Health and Human Services (HHS) and the US Food and Drug Administration (FDA)? Or have appeared on the *Today* show and ABC

*World News Tonight*, and had their photo plastered across a Times Square billboard? Or have spoken in front of hundreds of people at HHS and National Institutes of Health (NIH) summits?

"It's very funny when I have to say that he has to miss school to go to a meeting," says his mother Leslie, just before popping up from the same Locust Walk bench to wipe dirt off her son.

Jax attends those meetings and talks with politicians as the cofounder (along with his parents and sister) of Celiac Journey, a patient-centric advocacy organization that emphasizes sharing the pediatric perspective of 3.3 million Americans with celiac disease—Jax included. When he was five, Jax was diagnosed with the chronic autoimmune disorder, which disrupts the small intestine's ability to digest gluten, a protein found in wheat, rye, and barley, and which frequently contaminates oats. Celiac Journey has two primary goals: requiring the labeling of gluten as a major food allergen on all packaged foods in the US, just like it is in 87 other countries; and increasing government

funding for celiac disease research to find a cure or treatment options beyond a strict gluten-free diet for life.

"One crumb of gluten can make him violently ill," says Jon, noting he didn't fully realize what "food privilege" meant until his son was diagnosed. "And it's unlike a traditional food allergy. There's no rescue medicine at all for celiac disease. And unlike a traditional food allergy, we are a little bit harder to understand, because celiac is at that intersection of food allergies, autoimmune diseases, and digestive diseases."

What Jon doesn't understand is why more attention isn't given to the disease. According to Celiac Journey, about \$3 million has been allocated annually by the NIH (out of a \$45 billion budget) to celiac research, equating to only about \$1 per American with the disease. The Bari family's organization has stepped up to fill the funding void, helping to raise more than \$1.4 million to fund celiac research, including mRNA research with Nobel Prize winner Drew Weissman, Penn Medicine's Roberts Family Professor in Vaccine Research.



And although wheat is required by law to be labeled on food products, barley, rye, and oats are not—which prompted Jax to file a citizen petition with the FDA last September calling for mandatory labeling of gluten on all packaged foods in the US. “Imagine if you had a tree nut allergy, and only almonds and pistachios were required to be labeled, but not other tree nuts, such as almonds and pecans,” Jax says. “That would create a massive food safety gap that needed to be closed. Fortunately, for those with a tree nut allergy, that scenario is not the case. But that similar safety gap does exist with the voluntary labeling of barley, rye, and oats.”

Jon believes that celiac disease is “not taken seriously in our society” because of biases that gluten-free diets and the voluntary labeling of gluten is all that’s needed, “when that’s all that’s ever been available.” Also, while consuming gluten for celiacs might not be “immediately life threatening,” Jon notes, Jax “can get cancer, he can get heart disease, he can get immunological scarring and malnutrition,” among other debilitating symptoms.

Those frightening prospects—not to mention the burden of scouring labels at the grocery store, worrying about cross-contamination in restaurants, and monitoring every bite of food their son consumes—is why the Bari family launched Celiac Journey in 2019. While other celiac organizations have been providing advocacy and support, Jon found that “the pediatric perspective was not being told” and that “Jax’s story is just one of millions of stories out there.”

“I realized that we couldn’t afford not to do it,” Jon says, “because it’s every bite, every day for him.”

### Losing a Carefree Childhood

It’s August of 2018. The Baris are sitting in a conference room at the Buerger Center for Advanced Pediatric Care, overlooking Penn Park. Jax has been seeing Children’s Hospital of Philadelphia (CHOP) doctors because he wasn’t growing, and an endoscopy has just revealed celiac dis-

ease as the culprit. A CHOP psychologist tells them, “This is going to be really hard for you guys,” but Jon is skeptical.

“I was like, ‘*Oh come on, how hard can it be?*’” he says. “I had no idea.”

That kind of immediate response is normal, notes Arun Singh, Jax’s pediatric gastroenterologist and the codirector, along with Lisa Fahey C’07, of the Center for Celiac Disease at CHOP. “When we first meet families, sometimes they’re a little bit stunned,” Singh says. “They don’t realize the magnitude of gluten being in so many different items. It’s not just bread, it’s not just pasta; it can be in something like a dressing, soup, soy sauce.”

One of the largest programs of its kind in the US, the Center for Celiac Disease is staffed by gastroenterologists, dietitians, nurses, and psychologists to provide support and long-term disease management, “because it’s a really complicated psychosocial type of condition where it affects every day, every meal,” Singh says. “With that, unfortunately, comes more anxiety, more depression at times. Our psychologists are there to help our kids and their families with the adjustment.” From a medical perspective, the disease doesn’t manifest the same way, so the center’s staff has learned to coach their patients differently. “Some kids get symptoms by being terribly sick, with vomiting and stomach pains, and others get sick by just being fatigued and having dizziness,” Singh says. “And there are others that don’t have any symptoms, but they’re still having damage done to their intestine, which can be life threatening down the road.”

When Jax first came to CHOP, just before starting kindergarten, doctors determined that he was anemic, which is a common complication of celiac disease. He also had what’s called Marsh Stage 3 damage to his small intestine—“which is the second worst type there is,” Jax notes. “I was told that the doctors only see Marsh 4 damage when they do an autopsy.” Jax worked through those complications, and “he’s been growing well and gotten stronger,” Singh reports. But if Jax

accidentally ingests a single crumb of gluten, “I can get very sick, living on the bathroom floor with vomiting and diarrhea for days,” the 11-year-old says. “It’s awful.”

During a 2023 spring break ski trip to Colorado, the Baris were en route to the airport when Jax “got glutened” (the informal term for accidental ingestion), forcing them to check back into a Denver hotel and pull a bed next to the bathroom for Jax, who spent two days lying next to the toilet in agony. His parents were distraught, unable to do anything for their son but try to comfort him and wait it out. Singh says that for patients like Jax who experience such severe reactions, nausea medications can possibly help, “but mostly it just has to go through your system.”

According to Celiac Journey, 44 percent of people who follow a strict gluten-free diet still get glutened once a month. But the Baris make painstaking efforts to avoid it. Jax likes to say that his mom is his advance team and his dad is his secret service team. Especially when they travel, which can be a challenge, Leslie spends hours scoping out what restaurants are safe—looking at consumer reviews, calling, and emailing—while Jon makes sure to speak up if, for example, he sees a waiter holding a gluten-free pizza too close to an ordinary one. Many places are accommodating but the Baris have left restaurants due to cross-contamination concerns and they were once booted out of an eatery when Leslie ran through her list of questions. “It was horrible,” recalls Jon, who says his wife started to suffer from chronic migraines shortly after Jax’s diagnosis.

But whenever they get discouraged, they think about how much harder it is for Jax—and the emotional toll he grapples with by not being able to participate in simple things like sharing donuts with his soccer teammates or eating pizza at a party. “As Leslie began this journey of getting Jax on a gluten-free diet, and trying to get him to be safe, you don’t realize exactly how many facets of your life this impacts,” Jon says. “It

impacts school, it impacts camp, it impacts soccer practice, it impacts birthday parties. ... I think the worst part of celiac disease is that it takes the idea of a carefree childhood away from a child.”

The Baris have made great strides in navigating a gluten-free lifestyle and have built strong bonds within the celiac community. Leslie and Jax started a blog called Gluten Free Finds with an Instagram following of more than 17,000. But they’ve also been asking tougher questions beyond what the best gluten-free bakery in town is. They’ve been tirelessly asking about cures and treatments, so that Jax can one day eat at McDonald’s (a slice of “Americana,” Jon notes, that is not considered safe in the US for celiacs) or enjoy a beer with friends in college.

“Here I am, a dad wanting his kid to drink a beer,” Jon says. “Right now, he’s not going to have that until things change.”

### Eating Without Fear

It’s the mid-1990s, long before Lexi and Jax are born. After studying political science at Penn, working in radio advertising, and attending Columbia Business School, Jon has become one of the first employees of Comcast PC Connect—which will later evolve to become what’s now known as Xfinity Internet, serving more than 30 million customers.

“I couldn’t tell anyone what I did,” Jon recalls. “We were in stealth mode. We had 48 homes connected to a broadband network in Lower Merion, and we were crashing people’s computers left and right, trying to develop a business.”

So began an ambitious and eclectic career journey that Jon credits with preparing him to become a celiac advocate. He continued to be on the forefront of the internet, moving over to Time Warner to work on what was called Road Runner High Speed Online. He then became an entrepreneur, starting a cable TV software company that was acquired by Comcast, followed by a single sign-on security software firm, which he sold to Verisign and developed one of two patents around.

Since then, he’s run a consulting group that provides expert witness and consulting services on IP and IT matters. For more than 20 years, he’s also been an adjunct professor at Temple’s business school as well as the founder and head of the Constitutional Walking Tour of Philadelphia, which was designed to emulate Boston’s Freedom Trail and is a leading provider of school field trips in Old City.

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Celiac Journey’s logo includes the Liberty Bell, with the crack replaced by a stalk of wheat, because their mission is to provide celiac patients with the freedom to eat without fear. “We’re an all-volunteer organization where people help us through fits and starts,” Jon says. “But ultimately it’s storytelling. That’s what we do with the Constitutional Walking Tour—we tell America’s story—and that’s what I did in my career through radio advertising and inventing two patents.”

While Jon has leaned on his start-up chops to build Celiac Journey, this time he has a secret weapon: a little kid with a big voice. Jon may help get his son in front of a politician or on television, but Jax—to the surprise of many—has no fear once he gets there. Before appearing on the *Today* show in May, Jax wasn’t nervous about going on live TV but instead mostly excited to think about the celebrities who might have sat in the same green room chair backstage.

“I’m just in awe of him,” his older sister Lexi says. “I think it’s absolutely crazy that an 11-year-old is able to have these intellectual conversations with politicians, and he’s able to advocate for those with celiac. ... I would be so nervous. Maybe he doesn’t have the chance to get nervous. He’s built different.”

Lexi has done her part to help with Celiac Journey, chipping in with research in between her Wharton classes. She helps write and edit posts on their website ([celiacjourney.com](http://celiacjourney.com)) and in the beginning studied NIH appropriations, “creating spreadsheet after spreadsheet,” her dad says, “to inform our research that celiac receives next to nothing.” Like the rest of her family, she’s been learning about the disease on the fly and is amazed by how “super positive” Jax usually is when there are so many reasons to be frustrated. “It honestly feels like common sense for gluten to be required to be labeled,” Lexi says. “When Jax was in London this summer, he was able to eat things like Mentos and M&Ms, which he can’t have here because of the labeling standards. In some ways, I don’t understand why the US is like this.”

The Baris have had help in their quest to change the country’s labeling standards. Virginia Stallings, the director of CHOP’s nutrition center and an emeritus professor of pediatrics at the Perelman School of Medicine, has gone with them to the White House, the HHS, and the FDA. They’ve met with senior FDA leadership, including Patricia Hansen Gr’89, who works in nutrition and food labeling, and have gotten support from politicians like Pennsylvania Governor Josh Shapiro, who in an Instagram post at the end of Celiac Disease Awareness Month in May praised “Pennsylvanians like Jax who have advocated for and delivered real change to improve the quality of life for people with celiac.” In August, Jax passionately spoke about his experience with celiac disease and his advocacy in front of about 125 people at an NIH workshop, where Drew Bremer, the director of the NIH Office of Nutrition Research, said “Jax reminds us why we come to work each day.”

Oftentimes for his meetings and speeches, Jax wears a Travis Kelce jersey because the Kansas City Chiefs star sports the number 87—the same number of countries that require gluten to be labeled. Jax is also a fan of Kelce and the music of his

Jax Bari gives Drew Weissman a Celiac Journey challenge coin after Weissman's lab was presented with a \$375,000 state grant toward research for a celiac disease cure.

girlfriend, Taylor Swift. His other interests include playing soccer, tennis, and squash, skiing, collecting baseball cards, and hanging with his sheepadoodle Ace. He goes to summer camp and Hebrew school. He plays fantasy football with friends. Life is often good for Jax, but he's still had a "really hard road," his father says. "We're grateful every day that Jax can walk and run and talk—but we also do recognize that he has a disability. And it's about eating," Jon says. "We've tried to frame this in a different way than it's ever been framed. We've tried to frame it through the rights of disability, because this is a disability that impacts him and 3.3 million Americans every day."

"Look, our overarching goal of all of this is eating without fear," continues Jon, who believes his son's advocacy work is having an effect despite his frustrations at the FDA's "glacial" pace in making changes. "And that's something that most people take for granted. It's just the luck of the draw. He got a bad draw, but it's amazing what he does. We're super proud of him, and we're hopeful that it brings about change."

### Unlocking Celiac's Mysteries

It's a Monday afternoon in late November. The Baris are in a fourth-floor lobby inside uCity Square, a life sciences research building that was recently built in University City. That's where Drew Weissman—who, along with Katalin Kariko, won the 2023 Nobel Prize in Physiology or Medicine for research that led to the development of mRNA COVID-19 vaccines ["Gazetteer," Nov|Dec 2023]—has set up shop at the newly created Penn Institute for RNA Innovation.

The institute, Weissman said at the November event in which it was given a state grant for \$375,000 for celiac treatment research, "came out of the COVID-19 pandemic, but we've been studying RNA for decades—many decades—and what excites us the most about it is all of the potential things that it can be used for." Turning toward Jax, Weissman contin-

ued: "We're so excited that it has an enormous potential to help treat celiac, which will be the first time ever there's a treatment that will prevent the disease. And maybe—and this is just a maybe—some day allow you to eat bread with flour and other grains in it with your family."

Weissman was joined at the event by Kevin Mahoney, chief executive officer



of the University of Pennsylvania Health System, and Jonathan Epstein, interim executive vice president of the University of Pennsylvania for the Health System and dean of the Perelman School of Medicine. Mahoney called Jax "the special star with us today," and joked that "getting \$375,000 out of Harrisburg and winning a Nobel Prize takes about the same amount of effort." Epstein said that Weissman has one more Nobel Prize than Jax, though the 11-year-old "might have him beat on television interviews." The Perelman School dean then added, to Jax, "You've really been a remarkable advocate in a very important way."

Jax and his family assembled the Penn heavy hitters and helped facilitate the donation due to their relationship with Pennsylvania State Senator Amanda Cappelletti, who presented the \$375,000 grant. Cappelletti had previously worked with the Baris—her constituents in District 17 (which includes parts of Delaware County and Montgomery County)—on a \$100,000 celiac research grant given to CHOP in May 2023.

Singh hopes that CHOP can work with Weissman's lab on potential cures, calling it an "incredible opportunity to put two major forces together." When Jax was diagnosed, Leslie says they were told there would be a cure for celiac disease in five to 10 years. Six years later, Singh maintains that level of optimism, especially with more research funding and fierce advocates like the Baris, who he says are "really moving the needle."

"I do think that we're going to have a treatment on the horizon," predicts Singh, noting the possibilities for both a vaccine for celiac disease as well as an emergency medicine if someone gets glutenated. "We're going to be able to do it. It's just a matter of time."

At the November event, Singh discussed collaborations with Jilian Melamed, a postdoctoral fellow at the Perelman School of Medicine who started working in the Weissman lab in 2022 and will be leading the research into how RNA therapeutics could be used to prevent celiac disease. While Cappelletti and Singh have been in Jax's corner for years, Melamed met the 11-year-old for the first time in November, immediately bonding over their "shared love of Taylor Swift." She admits she didn't have a great appreciation about how debilitating celiac disease can be until learning about Jax and, like Singh, is "cautiously optimistic" about better treatment options for those like him.

Melamed's research will focus on developing an anti-inflammatory mRNA vaccine for celiac disease, using lipid nanoparticles to deliver mRNA encoding Gliadin, which is a protein found in gluten. "We hypothesized that we could sort of engineer an anti-inflammatory immune response to combat the autoimmune destruction of the small intestine found in celiac disease," she says, adding this kind of approach to treating celiac is "niche" and "pretty unique to Penn right now." But her team "already has some encouraging results in a mouse model of multiple sclerosis" using a similar system. She also notes that Weissman—"the smartest and

Jax and his father Jon enjoy the football game toast toss for the first time during Homecoming, thanks to Penn switching to gluten-free bread.

most strategic person I've ever met"—is excited about the project, which he calls a "new era of research."

Jon Bari—who first began talking with Weissman the same day he and Jax met Joe Biden, in October 2022—is "hopeful that mRNA can help unlock the mysteries of celiac disease" and holds onto a "vision that Jax is part of the first generation of celiacs to receive a treatment other than a gluten-free diet, and ideally, one day, a cure."

### A Toast to Dear Old Penn

It's Homecoming 2024, two days before the event at Drew Weissman's lab. Penn is playing Harvard at Franklin Field. The third quarter has just ended and the alumni who've returned to campus rise to their feet in eager anticipation. The Penn Band plays "Drink a Highball," and when they get to the song's conclusion—"Here's a toast to Dear Old Penn"—fans stand up, pick up the pieces of toast they had grabbed when they came into the stadium, and fling it toward the field.

It's a familiar scene for Penn faithful. Students in helmets and "P" sweaters run along the track, trying to catch the toast in baskets. Cheerleaders dodge the starchy projectiles. The occasional stray piece flies over the track and startles a Penn football player sitting on the bench.

As evidenced by the families that make their way for the exits once the fourth quarter begins, Penn people have come to expect and enjoy the quirky, decades-long tradition. It's also one that the Bari family had come to dread.

Although simply touching gluten will not harm someone like Jax, bread flying all around him can still stoke anxiety. "Imagine it being in his hair," Jon says. "And then, you know, he accidentally puts his hand in his mouth." But Jax likes going to Penn football games, so he's taken precautions to avoid the bread-crumbs over the years. At a game last season, he sprinted up to the upper deck of the stadium—only to see students throwing toast from up there. So he ran



down to field level at the west end of the stadium, behind the end zone and far enough away from the student section to feel comfortable. It was a hard scene for Jon to watch, and afterward he wrote a letter to Penn administrators asking to reimagine the toast toss (which has also been criticized by others over the years for its wastefulness). "Imagine what it must feel like to have people all around you throwing toast and showering you with crumbs that can make you violently sick if you happen to ingest one crumb," Jon wrote. "People with life-threatening food allergies do not want to be hit with food allergens, get crumbs thrown on their clothes, on their seats."

In the days leading up to this year's Penn Homecoming game, Jon received a pleasant email. Senior associate athletic director Rudy Fuller G'16 LPS'20, who has two kids with celiac disease, happily reported that for the first time Penn would be providing gluten-free bread for their toast toss (with the hopes of continuing the practice in future seasons). The Baris were thrilled. "Look, we know we're living in a gluten-filled world," Jon acknowledges, but little changes like these

make a world of difference for celiacs.

It's unlikely other fans in the stadium even noticed the change—or the 11-year-old boy in a Wharton sweatshirt and Penn button, leaving his seats to run *toward* the toast. Settling into the first row near the Penn Band, a stack of gluten-free toast in his hand, his mom taking a video and his dad standing behind him, Jax flings several pieces of toast, frisbee-style, toward the field, smiling ear to ear.

Penn is far from perfect in how it deals with food allergies and Jon has been disappointed by the lack of gluten-free options at other events at his alma mater. The country has a long way to go, too. The Bari family's mission won't stop.

But in this moment, for one kid who in two days will tell a gathering of prominent grownups that "celiac is every bite, every day, constant worrying, constant questioning, constant uncertainty," everything just feels right.

"It was awesome," Jax says as he settles back into his seat between his parents to watch the fourth quarter of the game. "I didn't have to hide for the first time in my life."