



SHAHRAZAD RASEKH

Rachel and Jacob DeConti posed for a portrait in the backyard of their Newington, Conn., home earlier this month. The family recently learned that Jacob would not receive the experimental gene therapy for which they had waited.

PATIENCE RUNNING OUT

As Cambridge-based Sarepta Therapeutics fights for its Duchenne muscular dystrophy therapy, another group of patients feels left behind

By Jason Mast
STAT

Rachel DeConti had been waiting for an announcement from Sarepta Therapeutics virtually every day since the hot summer afternoon she rushed her 4-year-old son, Jacob, to the hospital and learned his muscles were collapsing, spewing their contents into his bloodstream.

Just not this announcement. “Hi,” the email said, “Please see the attached letter.” She felt sick as she read. Jacob, who was about to turn 9, would not receive the experimental gene therapy they had waited for. Nor would anyone else with his ultra-rare disease. “They’ve been telling us for years, ‘It’s coming, it’s coming,’” said DeConti. “And then literally overnight, it’s gone.” There has been no bigger story in biotechnology this summer than the saga of Sarepta and its gene

therapy for Duchenne muscular dystrophy, a spectacle that has played volleyball with the hearts of parents, swung stock prices, and contributed to the brief ouster of a top Food and Drug Administration official. Out of the spotlight, though, another community has been reeling. Even as Cambridge-based Sarepta fought to keep its Duchenne treatment Elevidys on the market, despite the deaths of two teenagers, it pulled out of a nearly decade-long commitment to develop gene therapies for limb-girdle muscular dystrophy, a lesser known collection of over 30 ultra-rare and debilitating muscle disorders. The news devastated patients and families, who for years watched their programs inch along while Sarepta devoted most of its resources to Duchenne, the most well known and universally fatal form of muscular dystrophy. The company had only just started a clinical trial for Jacob’s subtype, LGMD 2D, in January, one of at least four LGMD studies it planned to launch or file this year. The crisis will sound familiar to other rare disease

communities. In the last five years, as history’s second gene therapy bubble burst, many patients and families have been cast adrift by companies that raised hundreds of millions of dollars promising life-changing treatments — before deciding that it was too dangerous, too ineffective, or simply too unprofitable. DeConti still wants Jacob treated. He has experienced little decline, but that won’t last forever. Her friend Faran Day wants the same for her 12-year-old son, Hudson, an aspiring engineer who relies on his wheelchair more each day. Yet given the safety concerns, it’s unknown if any other company would be interested in taking these programs on or if regulators would ever approve them. In addition to the two Duchenne teenagers, a 51-year-old LGMD patient also died in Sarepta’s 2D trial. New companies could develop better treatments with newer viruses, but that would mean starting from scratch, losing years in which Jacob, Hudson, and others may lose muscle they can’t regain.

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JONATHAN WIGGS/GLOBE STAFF

A shopper at the Dorchester Food Co-op on Aug. 8.

Despite promise, some co-op grocers struggle to catch on

By Stella Tannenbaum
GLOBE CORRESPONDENT

Dorchester Food Co-op was a decade in the making when it opened its doors in October 2023. Less than two years later, the community-owned grocery store’s board announced those doors may soon close. The board published a letter Aug. 15 imploring members to shop at the store or donate. If sales don’t increase, the letter says, the Bowdoin Street store will have to close in about two months. Although food co-ops — essentially, grocery stores collectively owned by customers, workers, or both, and often with a mission to tackle food insecurity — have seen massive growth in recent

years, competition with big chains nearby and lack of awareness can make them hard to get off the ground. “We are running against name recognition and habitual practices,” said Darian Leta, co-president of Dorchester Food Co-op’s board. Disappointing sales numbers have been a problem for the co-op since it opened in October 2023, she said. Since sales fell short of expectations, the \$2 million to \$3 million from fundraising and grants obtained over 10 years of advocacy and planning are being poured into operating costs. Another venture, the Charles River Food Co-op, has spent years planning

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Crops grow in Springfield. But for how much longer?

Cuts by the Trump administration threaten efforts to combat hunger in one of Massachusetts’ poorest corners

By Yogev Toby
GLOBE CORRESPONDENT

SPRINGFIELD — When Liz O’Gilvie returned to her hometown of Springfield in 2009, she noticed her husband — a public school teacher — coming home hungry many days. Why? His students who lacked access to consistent food at home and in school, were hungry, too. So he’d give them his lunch. As someone who sometimes went hungry herself as a child, O’Gilvie made it her responsibility to ensure these children, and the greater Springfield community, would not know hunger. Sixteen years later, O’Gilvie leads two local organizations that battle food insecurity in Western Massachusetts, the Springfield Food Policy Council and Gardening the Community. They have launched programs to promote food access, installed more than 500 gardens in schools and backyards, handed out farm shares to about 400 low-income families, and created an organic urban garden and affordable farm store in Springfield. Now, the entire system she weaved could unravel. President Trump’s cuts to the US Department of Agriculture in March, coupled with slashes to the Supplemental Nutrition Assistance Program, or SNAP, in this summer’s Big Beautiful Bill, threaten to end her farm’s opera-

tions, prevent her clients from affording fresh produce, and undo years’ worth of advocacy projects. “We were building a system that enabled us to get the food people in our community needed,” O’Gilvie said. “Now I wake up at night wondering, can I keep the staff I have employed? What will I do next year?” The single biggest move that has O’Gilvie worried is the \$186 billion in

cuts through the next decade for SNAP, along with increased eligibility requirements. About 90 percent of O’Gilvie’s customers use SNAP benefits to buy groceries, as do about one in six people statewide. According to the Center for Budget and Policy Priorities, a Washington think tank, more than 175,000 people in Massachusetts could lose benefits

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SUZANNE KREITER/GLOBE STAFF

Liz O’Gilvie has spent a decade and a half battling food insecurity in Springfield.

TALKING POINTS

TRADE

THESE DAYS, IT'S NOT ALL FUN AND GAMES



Death May Die and Marvel United — have curtailed production and cut staff since April. Several others are struggling to bring in orders in time for the all-important holiday season. At a convention in Columbus, Ohio, in June, about 20 percent of the game publishers who would typically attend were no-shows because they lacked enough product to sell, said John Stacey, the executive director of the Game Manufacturers Association. Those who did attend had fewer games. “Some of your favorite companies may not be here in six months making the games,” Stacey said. Eric Price, president of Japanime Games, based in Portland, Ore., stopped manufacturing new board games about four months ago. He said he was left with little choice as tariffs on China, the source of most of his materials, whipsawed — from 34 percent to 125 percent, then 145 percent, before being scaled back to 30 percent. Even at that lower rate, he said, he would have to raise the price of a \$50 board game to about \$80, a hard sell as tariff uncertainty weighs down consumer spending. **NEW YORK TIMES**

Tariffs have proven to be a roll of the dice that no board game manufacturer can predict. They’re up. They’re down. China’s in. China’s out. Such trade volatility has created an existential threat for independent board game publishers in the United States, virtually all of which employ fewer than 10 workers. At least two prominent publishers — Greater Than Games, which makes the popular strategy game Spirit Island, and CMON Games, whose titles include Cthulhu:

HIGH TECH

MARKET WATCHERS ZOOM IN ON NVIDIA

Traders are breathing easier heading into this week after Federal Reserve chair Jerome Powell indicated interest rate cuts are coming. Now comes Nvidia Corp., which is set to report quarterly earnings on Wednesday after the markets close. Traders are hoping it can shore up fears about artificial intelligence spending and effectively confirm the market’s latest rally isn’t a technology bubble. “Nvidia is crucial for the stock market because any signs of further strength will be the fuel to light this market on fire,” said Eric Beiley, of Steward Partners. “The looming risk is all this AI investment may be peaking if it doesn’t deliver and its outlook is cautious, which would rattle markets.” Nvidia’s size, it’s the biggest weight in the S&P 500, and its position at the center of AI development have made it a bellwether of the broader market. The tech giant’s chips are everywhere, 40 percent of its revenue comes from Meta Platforms Inc., Microsoft, Alphabet, and Amazon. All of which makes Nvidia’s quarterly earnings report, as well as its forward outlook, a major market event. **BLOOMBERG NEWS**

Keurig nears deal to buy JDE Peet’s for about \$18b

May separate drink brands

GLOBE STAFF AND NEWS SERVICES

Keurig Dr Pepper Inc. is close to a deal to acquire European coffee company JDE Peet’s NV for about \$18 billion, a person familiar with the matter told Bloomberg News.

A deal may be announced as soon as Monday, said the person, who asked to not be identified because the discussions were private.

The combined company would later separate its beverage and coffee operations, essentially undoing the 2018 deal that combined Keurig and Dr Pepper, according to The Wall Street Journal, which first reported the talks on Sunday.

Representatives for both companies didn’t immediately respond to requests for comment Sunday night.

Keurig Dr Pepper — formed out of the 2018 merger of Vermont-based Keurig and Dr Pepper Snapple — has its co-headquarters and a research and development facility in Burlington in Massachusetts (its other headquarters is in Frisco, Texas). The beverage conglomerate includes an array of popular soft drink, coffee, and other brands.

The company reported \$15.4 billion in revenue last year and has seen strong growth in its soft drink opera-



KDP was formed in 2018 by a merger of Keurig and Dr. Pepper.

tion, but it is grappling with the impact of tariffs on coffee prices.

Citing inflation and tariffs, Keurig Dr Pepper said in July it expects its US coffee performance to be subdued for the balance of the year.

Last year, the company expanded its holding of energy drinks with a deal for Ghost, starting with a \$990 million investment to take a 60 percent stake in the nine-year-old company.

That deal was the company’s biggest acquisition since Keurig and Dr Pepper originally came together. Other energy drinks in its portfolio include C4, Black Rifle, and Bloom.

JDE Peet’s, based in Amsterdam, owns dozens of brands in addition to its café chain Peet’s Coffee and its retail product of the same name. It has a market value of about \$15 billion.

Material from Bloomberg News was used in this report.

A farm grows in Springfield but for how much longer?

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entirely. Clifton Garner, 66, worries he could be one of them.

“I got no money circulating. It’s tough,” said Garner, a retiree who’s on disability after heart surgery, as he was doing his weekly produce shopping at O’Gilvie’s farm store. “What the president is doing is very scary. I have a cardiac box in my chest and he’s talking about cutting benefits. I need my medication and I need my food.”

Springfield is in Hampden County, where more than 54 percent of households lack geographical or financial access to reliable food. It’s the county in Massachusetts with the highest percentage of food insecurity, according to the Greater Boston Food Bank.

It’s also where O’Gilvie grew up, and went regularly to food pantries with her mother, surrounded by towers of canned beans and rice to quench her hunger. Meanwhile, her father worked two jobs to ensure the family did not go to bed without a meal.

“Food from a pantry will fill you up,” she said. “Healthy food will keep you alive.”

O’Gilvie believes education is key to solving food insecurity. She dedicated her first years in Springfield as a garden instructor in public schools — despite not having much experience gardening herself — and led efforts to bring free breakfast to classrooms. Eventually, O’Gilvie joined Gardening the Community, where youth grow organic produce in a lush oasis amid a concrete desert.

On a Friday this summer, dozens of teenagers donned work gloves and gently weeded the farm’s ground in preparation for the next planting season. In the same green lot, a rust-colored farm store with open walls stood. Workers stocked wooden shelves with vibrant tomatoes and bundles of fresh greens, which were immediately picked up by customers living nearby.

One of them was 16-year-old Judah Cacique. He joined the organization as a summer

youth worker two years ago, and now works there year-round.

“Before I came here, I did nothing with my life. Now I get to be out here, breathe this fresh air, touch these plants,” he said. “I feel like I’m reconnecting with nature.”

Cacique said working at the farm has helped him develop healthier eating habits and carry that tradition back home.

“I always bring fresh vegetables to my mom and tell her what to buy and what not to buy at the store,” he said, tossing a ripe cherry tomato in his mouth. “I used to eat a lot of processed food, but eating here I feel so much better.”

Iyanna Williams, 17, did not think she’d enjoy spending her summers laboring in a field, but said she keeps coming back for the supportive community and the satisfaction of growing her own produce.

“I actually convinced my mom to come to the farm store not too long ago,” Williams said. “She wouldn’t do that before.”

But expanding the food safety net takes money.

In 2017, O’Gilvie joined community members and advocacy groups in Massachusetts to draft an add-on program to SNAP, known as the Healthy Incentives Program, or HIP. The program refunds all SNAP purchases on fresh farm produce at farmers markets, CSAs, and local grocery stores up to \$40.

Last winter, the Legislature downgraded HIP benefits to \$20 due to “insufficient funds” in the state budget. O’Gilvie lost 70 percent of the farm’s revenue that season. HIP regained its funding in June, but O’Gilvie said cutting SNAP could shut down the farm’s operations, since if people lose eligibility for SNAP, they won’t be able to use HIP either.

“We barely held it together,” she said. “But I’ve always been frugal so we could go a few months making no money. Now we’re working hard to get people back into the store.”

O’Gilvie wanted to expand food access to



SUZANNE KREITER/GLOBE STAFF

everyone, including people who were formerly incarcerated. She and the Springfield Food Policy Council won a bid to lease some land in Agawam land that’s owned by the state’s prison system and turn it into a farm that would double as a job training program for people who were formerly incarcerated.

“This project was especially close to my heart,” she said. “As a descendant of people who were enslaved in Massachusetts, to hold that lease was coming full circle.”

In 2024, the project won a \$750,000 grant that would span five years from the US Department of Agriculture, through a program that increases access to land for underserved farmers.

But in March, amid \$1 billion in cuts to USDA’s budget, the agency terminated the program. O’Gilvie was still able to raise private donations to lease the land, but there’s no money to launch a farm there right now.

“All of a sudden, we don’t have the money to support the farm’s operations,” O’Gilvie said. “We can’t buy seeds, cultivate the land, or pay a stipend for the farmers.”

Despite the growing risk to her educational programs, community service initiatives, and especially her client base, O’Gilvie remains steadfast in her belief that she will continue to fight hunger and its roots. And, indeed, even amid new challenges her efforts are bearing fruit.

In July, Massachusetts Governor Maura Healey launched a Hunger Task Force — more than 30 leaders in the state’s food justice system, food bank executives, and state Cabinet secretaries — to try and deal with the effect of federal cuts to the food system. One member: O’Gilvie.

While she doesn’t know if she will be the one to bring systemic change, O’Gilvie is adamant that it’s her responsibility to try.

“When you’re watering the ground and it’s super hard, the first pass just softens it, then the second pass softens it more,” she said. “I’m hoping that I’m softening the systemic crust.”

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Hildamar Velazquez, 17, is a young farmer with Gardening the Community, in Springfield. The organization and others are already facing impacts from federal cuts.

Despite promise, some area co-op grocers struggle to catch on

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for a co-op in Newton, Waltham, or Watertown to replace the shuttered Russo’s Market.

Having amassed almost 1,000 members, organizers were initially hopeful that they could open quickly, said Treasurer Kathryn Loup. But finding a suitable space has proved difficult, Loup said, and they’ll need to raise at least \$7 million to get up and running — and to get the word out.

“You feel like, ‘Wow, we have all these members,’” she said, “But the amount of money you need is just a lot. It’s gonna take some time.”

JQ Hannah, executive director of the Food Co-op Initiative, which helps launch food co-ops across the country, said it’s not unusual for new co-ops to take a few years to reach profitability, and rely on grants and donations until they do.

“I can point to numerous food co-ops

startups that didn’t perform quite as hoped at first ... who had the time and opportunity to course-correct and figure out their business model a little more precisely and get to profitability because of different forms of outside support that may not be available to Dorchester right now,” Hannah said.

It’s a tricky time for independent grocery stores as costs continue to rise. Dorchester-based nonprofit grocery store Daily Table, which had four locations, closed in May citing inflation and rollback of government programs that had helped fund their work.

“I like to think that Daily Table, when it closed, it didn’t fail as much as its success just couldn’t continue,” said Doug Rauch, Daily Table’s founder and a former president of Trader Joe’s. “We ran out of funds.”

Attracting customers without a marketing budget is a challenge for any small, independent grocer, Rauch said, and the solution is to “get your customers to be your ambassadors”

‘I like to think that Daily Table, when it closed, it didn’t fail as much as its success just couldn’t continue.’

DOUG RAUCH, founder

by offering something specific that addresses their needs, whether that’s significantly lower prices, innovative local products, or a unique store experience.

Labor is Dorchester Food Co-op’s biggest cost, Leta said. Rent is significant too, although it’s lower than market-rate because it’s in an affordable housing community.

Since the store opened, Dorchester Food Co-op has made lots of improvements: They’ve introduced bulk discounts — 5 percent for non-members and 10 percent for members — and expanded catering services. They’ve reduced the prices of popular items to draw in more customers, Leta said, and they could lower prices even further if more people shopped at the store.

Leta said the co-op generates \$10,000 to \$13,000 in sales each week. To cover operating costs, that figure would need to be at least triple, she said. She estimates they’d need \$500,000 to survive long enough to reach

next summer’s grant application period. But relying on future grants is far from a safe bet.

Leta said the board has notified members in newsletters over the past several months that the co-op was not reaching its goals. The letter was a “challenge” to people to “shop their values.”

When you spend \$300 on groceries at a mega chain, she said, “you’re giving money to a space that doesn’t necessarily give back to your community.”

And, Leta notes, when big grocery chains’ egg shelves were bare and what little was available high-priced, the locally-sourced Dorchester Food Co-op had plenty.

“We posted, ‘hey, we have eggs for \$7,’ and we were sold out by the end of that night,” she said. “People just need to remember that we’re there.”

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Accompaniment to the silent movies

WHEN MY FATHER retired from the practice of medicine at the age of 76, he had to find things to do to occupy himself. There was, and always had been, golf, and that would continue until his death at age 95. But in the beginning of his retirement, he searched for other things as well.

He began reading voraciously. Histories and biographies, which he loved to discuss if you were willing. There was bridge, which he took up at the Springfield Bridge Club on Sumner Avenue. And there was something else, which he tried to hide away as he perfected



CHRISTINE WHITE

his technique — playing the violin, which he hadn't done in decades and decades.

I could hear him, up in a walk-in closet in his bedroom, quietly bowing away, a bit squeaky, but I could sense his joy in making music. When he felt that he had mastered the

instrument enough to bring it out of the closet, he asked me to play a piece with him — me on the piano, he on the violin.

The problem was, I hadn't played in years, and had never, ever played with another instrument. I got all bollixed up and walked away in disgust.

So he went in search of a small group of musicians, which I gathered he never found.

As I've written before, I was one of the younger kids in a large family that stretched out in time. In my mind, my father was always old, but I loved him dearly. As the only girl, he was very sweet and protective of me.

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HOLYOKE

Holyoke Community College celebrates 78th commencement

In his commencement remarks to the Holyoke Community College class of 2025, President George Timmons told a story about an experience he'd had during spring break that "truly captures what makes our HCC community so special."

Walking down the nearly empty hallways, he noticed a student sitting alone in a study lounge. Curious, he asked why the student was on campus during spring break.

"This place has always felt like a sanctuary to me," the student said. "No matter what's happening in my life, I know I can come here and feel welcome."

"This moment reminded me of something foundational and unique about an HCC education," Timmons said. "It's not just about the classroom, but about creating spaces where people feel they belong. As you leave HCC, I hope you will carry this sense of belonging with you and create it for others wherever your path leads."



Ramon Maldonado, of Springfield, celebrates his graduation from Holyoke Community College on May 31. (SUBMITTED)

HCC held its 78th commencement on May 31 at the MassMutual Center in Springfield. The cold rain falling outside did little to dampen the spirits inside, as graduates celebrated the occasion alongside their families, friends, HCC faculty and staff, with all the traditional pomp and circumstance.

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SPRINGFIELD

GOLF FOR A NEW GENERATION



Program at Franconia Golf Course introduces middle schoolers to the sport

BY CAROLYN ROBBINS
Special to The Republican

Franconia Golf Course manager and professional golfer Steven Carle had some gentle advice for his young middle school protégés from Van Sickle who gathered around him on the course on the green on a late Tuesday afternoon.

"As long as the ball goes in the right direction, that's all I care about," Carle, a PGA-trained golf pro, said as he instructed his eight beginners on the proper golf stance and the difference between irons and woods. Irons are for shorter distances

requiring a V-shaped swing and woods are for long shots requiring a U-shaped swing, he explained.

The students from Van Sickle Academy and Van Sickle Prep, who range in age from 12 to 14, are enrolled in a four-week instructional golf program sponsored by the Springfield Parks and Recreation Department in conjunction with the Springfield Public Schools.

The students didn't disappoint, Carle said. "As beginners, I expected they would miss a lot of balls, but they are hitting them all," he said.

"Nice job, perfect," he called as each of the four boys and three girls practiced their swings.

Parks Department Superintendent Thomas Ashe said the "learn-to-golf" program, now in its second year, is designed to expose inner-city kids — whose prior experience was limited to miniature golf — to the basic skills need to play the professional sport.

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Steven Carle, top and above, PGA pro and manager at Springfield's Franconia Golf Course, teaches middle school students from Van Sickle how to golf twice a week. The program is to spark interest in the sport in youth that might not think about the game. (DOUGLAS HOOK / THE REPUBLICAN)



Samantha Hernandez, 12, left, sets up a shot during a lesson at the Franconia Golf Course, and Cameron Hansel-Cobham, 14, right, focuses intently on the golf instruction. Both are middle school students at Van Sickle and get a lesson from a PGA professional at the golf course twice a week. (DOUGLAS HOOK / THE REPUBLICAN)



SPRINGFIELD

Students blossom through Gardening the Community

At first glance, the urban farm just a half-mile from the Springfield Technical Community College campus may seem like an unlikely launching pad for future leaders in social justice.

But for Kami Trushaw and Malahny Wedderburn, Gardening the Community (GTC) has been more than a job. It's been the foundation for growth, purpose and a path toward higher education.

STCC students Wedderburn and Trushaw are preparing to transfer to the University of Massachusetts Amherst in the fall, continuing their studies in fields rooted in their passion for sustainable agriculture and community equity. Trushaw, an STCC Class of 2025 general studies graduate, will pursue a degree in sustainable food and farming at the Stockbridge School of Agriculture. Wedderburn, a chemistry transfer major at STCC, has been accepted into the

UMass food science program.

The food science program and the Stockbridge School are widely regarded as among the best in the country, drawing students from across the nation for their rigorous academics and strong focus on innovation, sustainability and real-world application.

For 42-year-old Trushaw, returning to college after two decades was no small feat. "Twenty years ago, I did about three different majors and half a degree not knowing what I wanted to do with my life," she says. But after falling in love with farming in her early 30s, she discovered that working the land was more than a job: It was a calling.

Now the farm manager at GTC, she leads the daily operations, teaching youth workers aged 14 to 18 how to grow food and engage in conversations around racial and food justice. "This area right here in Springfield is a food desert. There's not enough

access to grocery stores and healthy food," she said. "At GTC, we grow food and sell it at reasonable prices, give some away and partner with programs to hand out boxes of fresh produce."

Her return to school was fueled by Mass-Reconnect, a state initiative that removes financial barriers for adult learners 25 and older. "A major barrier for me going back to school for years was finances. I've mostly been a waitress, bartender and farmer," she says. "Now that I work more in the food justice world, I know a degree is helpful."

Trushaw was diagnosed with ADHD in her mid-30s, a revelation that helped her reframe her academic struggles. "In high school, I was smart enough to understand it all, but they called me lazy. I was a B/C student who never wanted to do homework," she recalls. "Now I have a

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Malahny Wedderburn, left, and Kami Trushaw work with plants in the greenhouse as part of Springfield Technical Community College's Gardening the Community program. (SUBMITTED)