



PHOTOS BY CRAIG F. WALKER/GLOBE STAFF

Lucas Guo's parents, Nathan Guo and Ada Lio, cheered him on as he took steps in his gate trainer at their home in Somerville. Lucas has one of the world's rarest diseases, ZTTK syndrome. Scientists have documented just 60 cases worldwide.

## In Somerville, a family takes on their son's very rare disease

The parents of 19-month-old Lucas Guo hope to raise \$10m to find a cure

By Jonathan Saltzman

GLOBE STAFF

SOMERVILLE — At 19 months old, Lucas Guo has never crawled, walked, or stood by himself. He babbles but can't say words. He struggles to chew and swallow. He gets most of his nutrition through a feeding tube attached to his belly.

Lucas has one of the world's rarest diseases, ZTTK syndrome, a complex neurological disorder caused by a genetic mutation. Scientists have documented only about 60 cases worldwide and estimate that, at most, it afflicts several hundred people — far too few to encourage drug makers to find a treatment.

That economic reality has driven

Lucas's parents, Ada Lio and Nathan Guo, to take things into their own hands. Working through a small foundation, they are trying to raise \$10 million to develop a treatment or cure for ZTTK in five years.

Lio and Guo each spend about 40 hours a week — on top of their full-time jobs — contacting scientists, venture capitalists, nonprofit groups, and parents of children with other rare diseases for advice, support, and donations. They make their pitches with a polished, professional slide deck that they created, outlining potential approaches to treating ZTTK, including gene therapies and gene editing. They scour the scant scientific literature on

RARE DISEASE, Page A17



Lucas regularly sees at least 10 different specialists at Boston Children's Hospital.

## Vt. school's suit draws lines in fight over trans athletes

Says being banned by state from interscholastic sports violates religious freedom

KEVIN CULLEN

AROUND NEW ENGLAND

QUECHEE, Vt. — Last year, Mid Vermont Christian School's girls basketball coach Chris Goodwin worried about his players going up against an imposing player from their opponent in the state tournament.

The Long Trail School player was so good at protecting the basket and blocking shots that her teammates nicknamed her "Not In My House."

At some point, Goodwin learned that the imposing defender was transgender, a fact that chafed against the school's conservative Christian beliefs. After consulting the school's administrators and his



WCAX

Mid Vermont Christian School is suing Vermont after being banned from participating in all state-run athletics.

'From a policy perspective, we as a state have been very clear about our support of transgender and nonbinary students, as well as participation in athletics.'

TAYLOR SMALL, first transgender person elected to Vt. Legislature

players, Goodwin said, everyone at Mid Vermont was in agreement: The girls team would not play against a player they believed to be a boy.

Mid Vermont, a small school of about 100 students, forfeited the game, exiting the tournament and ending their season without taking a shot.

The decision triggered sanctions from the agency that oversees the state's interscholastic sports, which said the refusal to compete violated Vermont's nondiscrimination and public accommodation laws. It banned the school from all sports and academic competitions.

The school, firing back, has now teamed up with a powerful Christian law firm, the Arizona-based Al-

TRANS ATHLETES, Page A16

## Steward's claim on payments questioned

Analysis reveals fees from insurers were the same or better than others

By Liz Kowalczyk

GLOBE STAFF

Steward Health Care executives have repeatedly blamed the financial disaster unfolding at their Massachusetts hospitals on stingy payments from health insurers.

The company is months behind on rent, contractors have repossessed lifesaving medical equipment, and state officials are scrambling to prevent the closure of Steward's hospitals, which serve thousands of patients in Eastern Massachusetts. Steward executives at one point asked for more state money.

But a recent analysis provided to the Globe shows that Steward's hospitals as a group are paid the same as or better than many Massachusetts hospital systems for the medical care they provide. Steward's fees from private insurers are average overall, and prices paid to Steward hospitals by the state's three largest commercial insurers — Blue Cross Blue Shield of Massachusetts, Tufts Health Plan, and Harvard Pilgrim Health Care — rose especially fast from 2014 to 2021. Those increases resulted in average payments higher than

STEWARDS, Page A16

## Haley campaign exposes voter reservations

Moderate Republicans and independents weary of Trump's messaging

By Jess Bidgood

GLOBE STAFF

BLOOMFIELD HILLS, Mich. — Fred Johnson, a retired attorney, voted for Donald Trump in 2016 and 2020, but now says he is "over it."

"He has a lack of knowledge of both the law and the history and tradition of this country. He's so dogmatic, too," Johnson, 93, complained, after casting a vote in Michigan's primary last week for former South Carolina governor Nikki Haley.

But with Trump and President Biden steaming toward a November rematch, Johnson isn't sure what he's going to do in the fall.

"I might not vote," Johnson shrugged. "I just don't like either candidate."

HALEY, Page A12

**Empty offices and vacant storefronts in Boston are wasted opportunities.** Here are some ways to reimagine the city. **Ideas, K1.**

**The Oscars are next Sunday,** and classical critic A.Z. Madonna picks her favorite scores and songs from movies. **SundayArts, N1.**

Just drippy

**Sunday:** Drizzle then clouds. High: 49-54. Low: 42-47.

**Monday:** Same.

High: 47-52. Low: 39-44. Complete report, **A24.**

Deaths, **A18-23.**

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