

# San Francisco Chronicle

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Gabrielle Lurie/The Chronicle

he developer of One Oak in S.F. won permission to add units.

## Developers seeking more, smaller units

### Builders see housing density as solution to costs

At a time when tens of thousands of approved housing units are stalled because of a stormy economic outlook and rising construction costs, Bay Area developers are increasing-

ly looking at a possible solution to breaking the logjam: adding more homes to already-approved projects.

In San Francisco, real estate agency Tishman Speyer is looking to increase the density at 655 Fourth St. — the former site of

the Creamery, a popular tech hangout in the 2010s — from 60 to 111 apartments. In February, spokesman Bud Perrone said that the modification would make the project “better suited to the post-pandemic environment.”

## Winter worries as 3 viruses converge

In the past two years, practices such as social distancing and masking against the coronavirus served also to suppress other respiratory viruses that usually rear their heads in the colder months.

This season is off to a different start. Influenza and respiratory syncytial virus, or RSV, cases are rising earlier than normal in the U.S., already testing pediatric hospitals in some regions.

Add in a potential swell in COVID-19 infections this winter, and health officials are concerned about a convergence of the respiratory viruses — a “triple-demic” — that could tax health care systems this winter.

While flu and RSV, a common virus that can be serious in



Brontë Wittpenn/The Chronicle

Gerri Landman holds her daughter Lucy before bed. Lucy's rare genetic disorder has been found in only 5 cases worldwide.

## Newsom hits fork in road over his role

Gov. Gavin Newsom has long had a stock response when asked about how cities are dealing with issues ranging from homelessness to housing to retail theft: “I’m not the

mayor of California.”

He repeated it after his only re-election campaign debate last

month when I asked him when Californians are going to see real progress on homelessness after the state has spent \$15 billion on it.

“I’m not the mayor of California. I’m not the mayor of 7 cities. We need to see accountability, housing accountability,”

### DID YOU REMEMBER TO FALL BACK?



Daylight-saving time ended at 2 a.m. Sunday. Don't forget to set your clocks back one hour.

## RACE AGAINST TIME FOR LUCY

### East Bay parents of baby with rare genetic disorder raising funds to speed research for treatment, cure

Gerri and Zach Landman have filled their phones with videos of baby Lucy, the youngest of their three girls: Lucy flapping her hand for a high-five, Lucy pulling herself to her feet and taking a single wobbly step, Lucy babbling “dada.”

Someday they may look back on the footage with the sweet nostalgia of any parent. But they know the videos could instead become artifacts of a child they met only fleetingly, before an extremely rare neurological disorder stole her fledgling gestures, her mobility, her voice.

Lucy is now 17 months old, and the Landmans, who live in San Anville, are doing everything they can to alter what her life could become even as they brace for what may be inevitable. They’ve joined an exclusive and unenviable club of parents whose children have been diagnosed with rare genetic conditions for which there is no known treatment or cure — diseases so uncommon that it’s nearly impossible even to predict the course of illness.

“I’m constantly taking videos of her babbling because it’s just so cute,” Gerri said recently as Lucy snoozed in her lap. Her husband thinks she’s obsessed with capturing the little girl’s babbles because they both believe Lucy may never speak. Gerri thinks he’s probably right.

“I’m just going to miss her little voice,” she said.

Lucy’s diagnosis in April, shortly before her first birthday, set the Landmans on a race to find a treatment that could give her a chance to thrive as she grows. They’ve formed a nonprofit to raise money in their hunt for a drug treatment and, ultimately, an experimental gene therapy that could cure her.

The Landmans represent a new age of patient-driven medicine, one that allows parents facing a grim future and no good options for their ill children to harness changing models of research and funding and accelerate work that could directly benefit their family.

The cost, though, will be staggering: at least \$2.5 million, possibly triple that. The outcomes are far from

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WEATHER: Variably cloudy, cool. Highs: 58-64. Lows: 42-50. **A20**



### Antique Appraisal Event January 19, 2022

10am - 1pm (Limit 5 items!)

We are delighted to be offering our Appraisal Events the 1st and 3rd Wednesday of each month. Our specialists will give you an on the spot verbal auction estimate on your art, antiques or collectibles. This is a complimentary service with consideration for consigning.

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Diamond, Platinum Brooch. Sold for \$4,125



Danish Mid Century Modern Booshelf. Sold for \$4,760



Louis Vuitton Vintage Monogram Leather Trunk. Sold for \$4,125



Ernie Barnes (American, 1939 - 2009). Study Sketch, mixed media on paper. Sold for \$24,600

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## RACE AGAINST TIME FOR LUCY



Photos by Brontë Wittpenn/The Chronicle

pediatrician Nicole Glenn speaks with Lucy's mother Geri Landman while helping then-1-month-old Lucy stand during a check-up at Sutter Health in August.

## LUCY

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guaranteed.

Their focus is on Lucy, but the Landmans envision the research potentially helping children with all kinds of genetic disorders for which there are currently few, if any, existing therapies — including children with some types of autism or other neurological conditions.

Lucy's condition is so rare that it doesn't have a name — her medical record uses “Mabry syndrome,” but that's an outdated label that doesn't quite fit, Geri said. Only about 50 other cases have been identified in the world, and only two with the exact genetic mutation found in Lucy's DNA.

She has what's known as a single-gene disorder, in which one dysfunctional protein causes dramatic, system-wide impacts. In Lucy's case, the gene is PGAP3, and the mutation affects her cells' ability to form molecular “antennae” that allow them to communicate adequately with each other.

The impact of Lucy's mutation, though not believed to be fatal, is so fundamental that it can affect her gut and her muscles as well as cognitive function. The neurological effects may be the most profound, partly because nerve cells — which use many more “antennae” than most other cells — are especially vulnerable to the mutation, but also because brain function is so central to identity: to what makes Lucy, Lucy.

There's no question Lucy has advantages over many other children with devastating diagnoses. Her parents are both doctors — her mother a pediatrician, her father a specialist in pain. Her mom in particular was able to identify developmental delays, and advocate for Lucy, months earlier than other parents might have. Lucy started physical therapy when she was 6 months old and having trouble sitting up.

Within three weeks of Lucy's diagnosis, her parents had launched their nonprofit, Moonshots for Unicorns, tapping into a burgeoning industry of “personalized” medical research that partners scientists directly with patients and families to better understand and treat rare conditions.

The Landmans also hired a sort of expert “fixer,” a Bay Area consultant who works with families and scientists to develop and finance research specific to an individual patient's needs. Here, their medical backgrounds helped them avoid less trustworthy actors who sometimes prey on desperate parents.

The family began its effort to help Lucy by testing thousands of known drugs to determine if any might counteract her PGAP3 mutations.

“People ask me, ‘When does she need to get this by?’ And it's now. As soon as possible.”

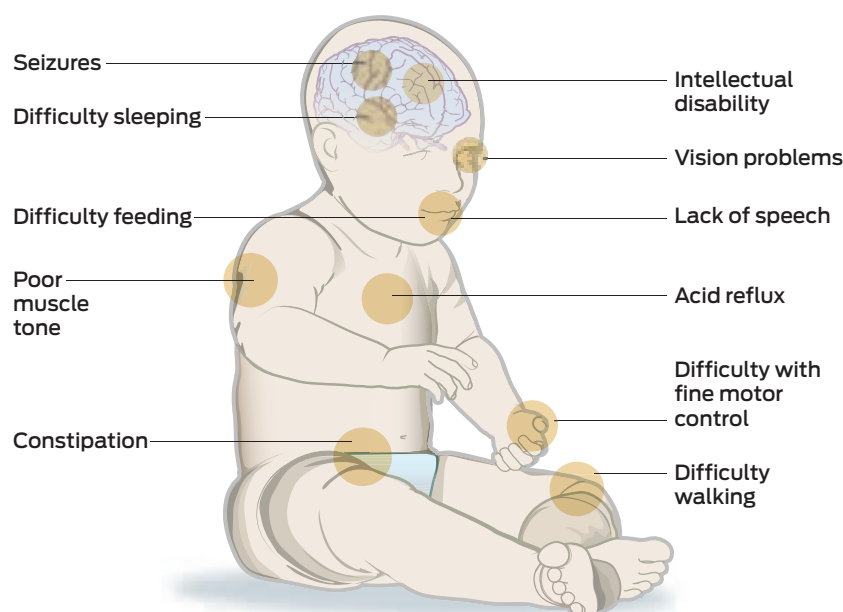
Zach Landman



Gerri Landman works with husband Zach Landman on their nonprofit to find therapies for Lucy's genetic disorder. Moonshots for Unicorns at the family's home in Danville.

## Symptoms of PGAP3 gene disorder

Almost all children with the rare genetic disorder caused by a mutation to the PGAP3 gene have poor muscle tone and intellectual disability, including lack of expressive speech. But the condition can have diffuse effects and involve multiple organ systems. Symptoms usually show up within the first year of life.



Sources: Moonshots for Unicorns, Rare Diseases Clinical Research Network

Todd Trumbull / The Chronicle

Ultimately, though, the Landmans believe gene therapy — essentially replacing Lucy's defective gene with a healthy one — could cure the girl. They've connected with a scientist who has treated other single-gene disorders and has agreed to consider Lucy as a patient.

But that therapy, if deemed feasible for Lucy, is at least 1 months down the line, a crucial time when Lucy could permanently lose her first words or her toddling steps. She is at risk of developing seizures that could yield irreversible brain damage.

Lucy is very young, and her delays are subtle. She's not so obviously behind that other parents at the playground would ask questions. Her big blue eyes are alert. She smiles and laughs with

her sisters.

But her parents notice how she sometimes struggles to sit up when she's tired, how she hasn't mastered waving — a skill her 7-month-old cousin has acquired. Though she babbles “dada” she has no meaningful words, and hasn't managed “mama.” Sometimes she gets a faraway look, her face slack and eyes unfocused, that her mom and dad call her “PGAP face.”

“People ask me, ‘When does she need to get this by?’ And it's now. As soon as possible,” said Zach.

“We want this done yesterday,” Geri said.

“We have to be realistic and do things the right way,” Zach said. “But there's no time too soon, and we don't know how late is too

late.”

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Lucy is a pandemic baby, born in spring 2021. She slept a lot in the first couple of weeks, which both parents noted and worried over her older sisters, Audrey, now 3, and Edna, 6, had been screamers. But then Lucy “woke up” and seemed otherwise normal.

It was at around 6 months old that Geri noticed Lucy lagging a bit on developmental milestones. She was “floppy,” a term used to describe babies lacking the muscle tone to hold their head up or sit unassisted. They started her in physical therapy and she caught up again, but then she got a cold in February and

“just kind of tanked,” Geri said.

After a mild illness, Lucy couldn't sit on her own for more than a minute without falling over. She stopped trying to crawl. She refused solid foods. She was fussier and less interactive.

For a while, Geri and Zach argued over her symptoms and what they might mean. Zach wasn't convinced they were distressing — there's a fairly large range of “normal” for infant development. Geri wavered between feeling like an overreacting “crazy mom” and being convinced something wasn't right.

Eventually, during an episode of profound floppiness when a 7-month-old Lucy refused to sit up at all and cried for hours, inconsolable, they agreed to take her to the emergency room at Stanford. The neurologist on call could find nothing urgent wrong with her, so the family went home. But Geri remained anxious, and a few days later arranged for Lucy to be admitted for more extensive testing.

The neurologist who saw them in the hospital was Dr. Maura Ruzhnikov, a specialist in genetic disorders. Lucy's symptoms were subtle, but taken together, Ruzhnikov found them significant — in particular that she seemed to worsen after illness, which implied that stress on Lucy's body made it harder for her to function.

The brain scans and blood screens and other tests came back normal, and it would have been natural for the doctors and parents to be relieved and hope the problems would resolve on their own. But Ruzhnikov suggested they screen for mutations that might point to an underlying disorder.

When the results came three weeks later, on April 1, Ruzhnikov texted the parents right away.

“Lucy's genetic tests are back and I'm concerned,” she wrote. “Let's meet in an hour.”

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The tests found that Lucy had two bad copies of the PGAP3 gene, inheriting one mutation from each parent — neither knew they were a carrier. Both mutations are thought to be present in less than 0.01% of the population, making her condition extraordinarily uncommon. Lucy's sisters do not have the same disorder, but each has a 2-in-3 chance of being a carrier.

Lucy's condition falls under a broad umbrella known as CMG, or congenital disorders of glycosylation, which refers to the process of building chains of sugars, proteins and fats that attach to the outside of cells.

Problems can arise at any point in the chain-building process — about 160 CMG types have been identified worldwide. Lucy has what is known as a sugar-lipid anchor defect, which means her body is able to build the

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chains but they don't stick to the cells very well. It's not yet clear how profound the disorder is for her, since at least one of her PGAP3 genes may have some function.

A single rare disease may impact anywhere from a few dozen to many thousands of people worldwide, but taken altogether, these conditions are thought to affect up to 10% of the population, according to the National Institutes of Health. Afflicted patients and their families often struggle to meet basic health needs, including finding doctors with expertise in their disorder and securing therapies beyond supportive care to offer a basic quality of life.

Lucy's condition "is an ultra-rare disease," said Dr. Eva Morava-Kozicz, an expert in CPGs at the Mayo Clinic in Rochester, Minn., who has personally seen 20 patients, including Lucy, with anchor disorders. "Most clinicians don't have the chance to see these patients and it's difficult to treat them right if you don't have experience in rare disorders."

With so few cases, doctors struggle to offer a prognosis for patients like Lucy. Most of the people who have been identified with her condition have experienced profound disability, including major cognitive issues and autism-like symptoms. Many don't walk, and those who do are unsteady. None is able to speak.

Yet the most severe patients also tend to be the easiest to find and diagnose, so they may not capture the full range of illness. It's possible Lucy could have a milder case. Much of her prognosis depends on whether she develops seizures, as more than half of children with conditions similar to hers do. If so, can they be controlled with medication?

"Obviously our first question to Maura (Ruzhnikov) was, 'What do we do?'" Geri recalled. "Are there treatments, therapies? What are the major academic centers working on? And she was like, 'No one really is working on it.' This is a rare gene, a rare group of syndromes to begin with. There are no known therapies."

The Landmans joined a Facebook support group launched several years ago by parents of children with PGAP3 mutations. There, they found a 6-year-old girl in New Zealand who, as far as they know, is one of only two others in the world with Lucy's exact mutation. Learning about her case has been unsettling, but has also given them a measure of hope.

"She walks and runs, but she falls a lot. She has no expressive speech at all. She definitely has intellectual disability, and she has some autistic features as well," Geri said of the New Zealand girl. "But you watch videos of her and she definitely has a quality of life — she plays with her brother in a very infantile way, but she takes joy in things."

If that is the best life they can provide for Lucy, too, then that will be enough, the Landmans say. It will be enough for Lucy to be joyful, to go to school and make friends, to run as fast and as far as she can. But it may be that Lucy's condition is more grave than the child on the other side of the world.

Their daughter is not even 18 months old, and they're not ready to commit to the path of acceptance. For now, they fight.

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The first week after Lucy's diagnosis, the Landmans cried a lot. It felt like mourning, relinquishing their preconceived notions of how Lucy would grow up and who she could become.

Then they rallied. They joined support groups for parents of similarly afflicted children. They read every scientific paper published on PGAP3 and similar genetic disorders. They emailed any doctor or scientist they could find who'd been involved in CPG research.

After conversations with experts in gene therapy, including a scientist at Nationwide Children's Hospital in Columbus, Ohio, who has developed treatments for a handful of rare disorders, the Landmans were convinced this might be an option for Lucy. So they signed a contract with Nationwide to develop a therapy for Lucy.

Gene therapy involves taking a defanged virus, loading it with a functional copy of a mutated



**Geri Landman watches then-18-month-old Lucy play in the bathtub in September. On her good days Lucy is cheerful and alert and able to sit up on her own for long stretches.**

*"Our first question ... was, 'What do we do?' ... And she was like, 'No one really is working on it.' This is a rare gene, a rare group of syndromes to begin with. There are no known therapies."*

Geri Landman



**Zach Landman bottle-feeds Lucy in the backyard in August. Lucy's rare disorder also causes problems in her gut. When Lucy is tired or sick she will sometimes refuse to eat solid foods.**

*"We absolutely know that we can fail. As physicians, we're very grounded scientifically and doing everything that science supports. But our hope as parents is that we'll defy the odds."*

Zach Landman



**Nanny Hannah Hurman helps Lucy up the stairs at her home in Danville. Lucy has been getting some form of therapy since she was 18 months old and fell behind on developmental milestones.**

gene and pumping it into a patient. The viral payload transfers into the cells that need it most — In Lucy's case, the cells of her brain and central nervous system. The approach will require at least a year and a half of lab work and jumping through regulatory hoops, including proving efficacy and safety, before scientists can begin a clinical trial and — in theory — get the experimental therapy to Lucy.

The lead Nationwide scientist working with the Landmans, Kathrin Meyer, helped develop a gene therapy for young children with a type of spinal muscular atrophy that was almost always fatal. Geri reached out directly to Meyer after reading about her work in the New England Journal of Medicine.

They don't know if such a treatment will prove safe for Lucy, and if it does, whether scientists will be able to get the healthy gene to all of the right cells in the brain, which are notoriously dif-

ficult to reach.

Additionally, they don't know if there is irreparable damage already happening in their daughter's nervous system. Recently, scientists studying Lucy's cells determined that her astrocytes — spider nerve cells critical for cellular communication — may be actively killing her neurons.

It may be that gene therapy could work for Lucy's condition, but only if it had been provided in the first year of life, or even in utero.

"Will it be worth it? That question is still on the table," Geri said. "This could make zero difference in a neurodevelopmental disorder. But I guess I also think that's a valuable question to answer for science."

Already, studying Lucy's cells in a laboratory has helped experts unlock some of the complex biological mechanisms that may be involved in her disorder — discoveries that could lead to treatments in the future.

At the very least, by contributing to the foundation of gene therapy science, the Landmans believe their efforts will make it more accessible someday for other children.

And if they're able to prove that the therapy could help other genetic neurological disorders, even some types of autism? "Stepping back as a mom and putting my pediatrician hat on," Geri said, "I'm like, damn, that's a question to answer."

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The uncertainty of gene therapy, and the built-in time lag, led the Landmans to pursue a parallel path, one that will hopefully preserve Lucy's healthy cells and developmental progress.

Less than a month after Lucy's diagnosis, they met Ethan Perlstein, whose for-profit company Perlara, based in Oakland, works with families of children with rare genetic disorders to hunt for

medications and other compounds that have proved effective and safe for other conditions, a concept called drug repurposing.

Perlstein's company has been through a few iterations in its eight years. An early investor was Martin Shkreli, the former hedge fund manager and pharmaceutical executive who became notorious for price-gouging. Shkreli was eventually bought out.

Perlstein took a step back from the business during the pandemic, and the Landmans are among his first family partnerships under the next generation of the company. Ruzhnikov, Lucy's neurologist at Stanford, made the introduction.

"It's becoming more common, just in the past five or 10 years, that we have parents who really want to get involved in any type of research," Ruzhnikov said. She keeps in close contact with the Landmans as they consider therapies for Lucy ranging from basic supplements to potentially more experimental drugs.

On the surface, drug repurposing is a fairly simple concept. In Lucy's case, scientists modify various cells and living organisms to express the PGAP3 mutation — to make them "Lucy-like" — and then run thousands of drugs through them to see if any stop or slow the disease.

Drug repurposing is fairly common and was deployed early in the pandemic to identify potential treatments for COVID-19, but it's not often used for rare diseases, in part due to the expense. The Landmans expect their efforts to cost about \$1,000, which they're raising through their nonprofit.

Perlstein collaborates with families to determine which screening tests might work best, how much they'll cost, and where they can be done. He rents lab space to conduct the experiments and hires part-time scientists to run them. A similar collaboration with a family in Michigan five years ago located a drug that dramatically improved the symptoms in a girl named Maggie, whose condition was similar to Lucy's. A phase 3 clinical trial of the drug, which has gone through regulatory approval in Japan but not the U.S., is about to begin.

Perlstein's bid to help Lucy is unfolding at a rented space at SF BioLabs, a cooperative near San Francisco General Hospital. Members of Lucy's team, three young scientists from UCSF and Stanford, share a lab bench and a shelf they've lined with tidy rows of bottled chemicals used for growing yeast. They are currently making "Lucy" yeast, modified to mimic her genetic disorder. They've completed one round of drug screening and plan a second in November.

Yeast are convenient drug screening models because they're sturdy, easy to modify and fast-growing — not unlike the packaged yeast used for bread. Perlara uses a strain that's been grown for lab use for decades.

Perlstein's scientists are growing two types of yeast: one modified to remove the yeast equivalent of the PGAP3 gene, and the other retaining the gene but with Lucy's specific mutation. Both yeast types should be similarly afflicted and show signs of slow growth.

Once they have viable modified yeast, the scientists send it to UCSF for drug screening. Clusters of yeast are placed on plates the size of index cards, with indented wells to separate the samples, which are each exposed to one of at least 6,000 drugs or other molecular compounds. A scientist studies the yeast a day later to see if any show improved growth or other signals of a positive effect from the compound.

There's nuance to the screening. Ideally, they'll find a drug that counteracts problems caused by the mutation and has no side effects. But they're more likely to identify compounds that are less obviously beneficial, or that have concerning side effects, or that haven't been studied in young children.

Depending on what they find, scientists may perform further screens, possibly on Lucy's own cells or on mice that have been genetically engineered with Lucy's PGAP3 mutation. A litter of modified "Lucy" mice, engineered at a lab in Maine, are due to arrive in early November.

"We absolutely know that we can fail," Zach said. "As physi-

## RACE AGAINST TIME FOR LUCY



Scientist Henry Ng moves yeast cultures that will be used to screen for drug candidates as possible treatments for Lucy at a lab in San Francisco in October.



Occupational therapist Kate Delgado taps spoons together during a session in late October with 17-month-old Lucy.



Photos by Brontë Wittpenn/The Chronicle

Zach Landman practices walking with then-15-month-old Lucy while Geri Landman offers encouragement at their home in Danville in August.

## LUCY

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cians, we're very grounded scientifically and doing everything that science supports. But our hope as parents is that we'll defy the odds."

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Early on in their research into gene therapy, the couple learned of the Grays — a film producer, Gordon, and his wife, Kristen, whose two daughters have Batten disease, a rare and fatal neurological condition. The Grays also worked with Nationwide to develop a gene therapy, which both girls have received with mixed results.

Zach posted about the surprising connection on Facebook, and it turned out a friend of a friend knew Kristen Gray and offered to put them in touch. When they spoke, Geri and Zach asked one crucial question that no doctor or scientist could answer: How did they raise the money?

"And she was like well, Madonna tweeted it out, and Chris Pratt tweeted it out, and they got all their followers to donate \$1," said Geri, who had rarely used social media. "And I was like, this cannot be our strategy."

Everything the Landmans are trying to do for Lucy they must pay for themselves — there's no government or industry funding, no academic institutions taking on a disease so uncommon. They'll have to come up with at least \$2.5 million, and possibly as much as \$7 million, for the gene therapy alone.

So far, through Moonshots for Unicorns, they've raised nearly \$300,000, entirely through private donations.

Six months into their fundraising endeavors, Zach said he still gets nervous talking to potential donors, whether it's old friends or people he meets at the local farmers market, where the Landmans have set up an information table most weekends.

When Geri began planning a gala to raise money, her first step was looking up the proper pronunciation — was it gal-luh, gah-luh or gay-luh? (All are acceptable.)

Recently, when one of their older daughter's friends donated 50 cents to Moonshots for Unicorns, the Landmans matched it for a round \$1. "Those little moments give us hope that people care," Zach said.

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One night in early September, Geri was sitting upstairs with Lucy, reading to her before putting her down for bed. She could hear Audrey and Edna playing downstairs, their small voices muffled. Suddenly Geri realized she was crying. It's a thing that still happens, sometimes out of nowhere.

She was thinking about her older girls, "how amazing they are," Geri recalled. "And I just kept thinking, who would Lucy have been if not for this one missing protein? You're here, and we love you, and we derive so much joy from you. But I struggle with the concept of, 'She is who she is.'"

There is so much uncertainty that the parents' biggest challenge some days is balancing hope between wishful thinking and acceptance — striving to love their daughter exactly as she is and still fighting every hour to carve a more promising future for her.

For nearly two excruciating weeks in July, Lucy stopped babbling. Zach and Geri wondered if they'd already captured her last words in their cell phone videos. But then she started again, chatting happily to herself and her parents and her sisters.

It was a largely unnecessary reminder that they face a terrible time pressure, that a day may arrive, fairly soon, when Lucy does stop talking.

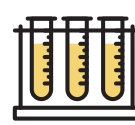
The first drug screening pass, on the yeast with no PGAP3 gene, was done in late September. After a few false starts, including a power outage on a hot afternoon

## Finding a drug for Lucy

Lucy Landman's parents hope that drug repurposing will reveal possible treatments for their daughter's rare genetic condition. The process involves testing many thousands of existing drugs or other molecular compounds on yeast designed to mimic Lucy's DNA, then determining if any appear to slow or stop the disease.

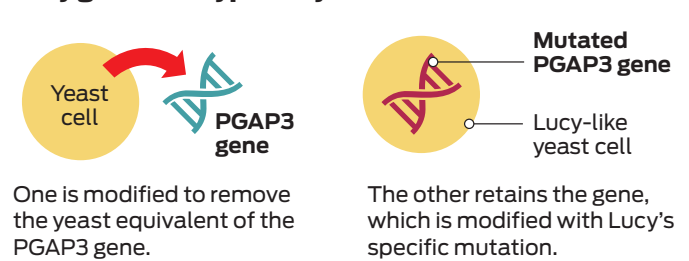


1 Lucy's parents hire Ethan Perlstein, a medical "fixer" who partners families with scientists, to oversee drug repurposing.



2 Scientists modify and grow Lucy-like yeast in a rented lab space in San Francisco.

## They grow two types of yeast:



3 Once they have viable modified yeast, scientists send it to UCSF for drug screening.



4 Clusters of yeast are placed on plates and exposed to one of at least 6,000 drugs or other molecular compounds.



5 A day later, scientists study the yeast to see if any show improved growth.

Source: Chronicle reporting

Todd Trumbull / The Chronicle

in San Francisco that set them back a day, they came up with about a dozen intriguing hits.

A few of the matches don't make much sense, as far as how they might biologically protect Lucy's cells, so the Landmans are waiting for a second drug screen, on the yeast with Lucy's genetic stamp, before considering them. At least one hit was for a prescription drug used to remove excess iron from the body that can cause serious side effects. They

want to see more evidence that it may work before giving it to Lucy.

But three of the possible drug matches were for supplements that are easy to buy and generally considered safe. The Landmans went on Amazon and bought a \$20 bottle of chlorophyll, the pigment that makes plants green and may work as an antioxidant, the day after it showed up in the results, and began adding a few drops to one of Lucy's daily bot-

tlers of milk. It turned her poop forest green, Geri said, and seemed to upset her stomach, so they didn't keep her on it for long.

They started Lucy on the other two supplements — tyrosine and lipoic acid — a few days later, less than a week after getting the screening results.

A week after that, on Oct. 16, Lucy took her first steps.

This is actually a source of friendly debate between Zach and Geri: Geri says it was more of a stumbling fall forward than walking. But Lucy has seemed stronger in other ways, Geri said. Her balance is better. Her babbling has been more consistent and intentional — like she's trying to communicate instead of just making sounds.

For now, they can't say for sure that the drugs are responsible for her progress. She'd been pulling herself up to stand and cruising around tables for weeks, so perhaps she was about to get there anyway. Also, they've now got her in four hours of physical, occupational and speech therapy a week. And sometimes babies make developmental leaps for no obvious reason.

"I don't think any of these things are like magic cures that are going to completely turn things around," Geri said.

Still, a child's first faltering steps are always cause for celebration. More so when she's worked so hard to get there, or when her parents thought that milestone might be ever out of reach.

"They said she'd never walk," Zach wrote in a text message, sent late that Sunday night. In the video he attached, Lucy stood barefoot, smiling around a pacifier. Her dad lifted his hands from her waist, letting her go as she shuffled and bent her knees. Out of the camera's view, her mom and sisters cheered her on.

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