Reaching an Autistic Son Through Disney

In our first year in Washington, our son disappeared. Just shy of his 3rd birthday, an engaged, chatty child, full of typical speech — “I love you,” “Where are my Ninja Turtles?” “Let’s get ice cream!” — fell silent. He cried, inconsolably. Didn’t sleep. Wouldn’t make eye contact. His only word was “juice.”

I had just started a job as The Wall Street Journal’s national affairs reporter. My wife, Cornelia, a former journalist, was home with him — a new story every day, a new horror. He could barely use a sippy cup, though he’d long ago graduated to a big-boy cup. He wove about like someone walking with his eyes shut. “It doesn’t make sense,” I’d say at night. “You don’t grow backward.” Had he been injured somehow when he was out of our sight, banged his head, swallowed something.

In Terra Bella, Water Only Flows as Tears

At first they called Fred Lujan a gentle-farmer. The retired barber washed his tractor every night and parked it in the garage, a source of gentle amusement to the veteran growers around him. He called his pistachio trees his babies, his girls, and gave them names.

“Come on, Suzanne,” he’d say to his wife in the evenings. “Let’s have a glass of wine and sit outside and watch our girls grow.”

Back when he was still learning to take corners while tilling, he sliced one of the saplings. The other farmers told him to pull it out, the tree wouldn’t make it. But he wrapped the trunk in mud and water and tape the way his grandfather, born on an Indian reservation, had taught him.

He named the tree Survivor.

Eight years later, Survivor and the other trees were ready to give their first mature crop. In February, the 10-acre orchard was sprouting spring leaves.

Then a man from the irrigation district came and sealed off Lujan’s water meter.

New Drugs Tested on ‘Human Lab Rats’

Two years ago, on a gray January afternoon, I visited the Ridge Avenue homeless shelter in Philadelphia. I was looking for poor people who had been paid to test experimental drugs. The streets outside the shelter were lined with ruined buildings and razor wire, and a pit bull barked behind a chain-link fence. A young guy was slumped on the curb, glassy-eyed and shaky. My guide, a local mental health activist named Connie Schuster, asked the guy if he was okay, but he didn’t answer.

“My guess is heroin,” she said.

We arrived at the shelter, where a security guard was patting down residents for weapons. It didn’t take long for the ‘Gay Health Warrior’ of New York City

Dr. Demetre Daskalakis cannot fall asleep. Like they have for many physicians, years of late shifts and early rounds have battered his schedule and etched deep grooves beneath his tired, dark brown eyes. But while his colleagues toss and turn, Daskalakis spends his nights patrolling Paddles—a Manhattan S&M club where men check both coats and clothing at the door and pay $40 to wade through faux smoke and loud music in search of a tryst.

Behind the club’s cavernous

Dr. Demetre, continued on page 2

How a Star Surgeon Gave Richard Norris a New Face

Richard Norris was 22 when he shot himself in the face. This was back in 1997. He doesn’t remember how or why it happened, but his mom, who was three feet away, said it was an accident. She remembers pieces of Richard’s face showering her body. This was in the living room. The gunshot had blown off his nose, cheekbones, lips, tongue, teeth, jaw, and Face, continued on page 3

The Big Business Behind Finding a Cancer Cure

For 85% of kids with a terrible cancer called acute lymphoblastic leukemia, chemotherapy is a cure—but not for Emily Whitehead. Diagnosed at 5, she suffered an infection from her first round of chemo and nearly lost her legs. Then the cancer came back; she was put into remission once more and scheduled for a bone marrow transplant. As she waited, the cancer Cure, continued on page 3

Video | Clay Igo and the Big Texas Heat

“It seems like it is doin’ nothing but getting hotter, and drier, and less rain, yearly,” says Clay Igo, a rancher in Plainview, Texas. His father adds: “These communities are drying up.”
Ron Suskind with his sons Walt (left) and Owen. A sketch made by Owen of the character Abu (inset), from Disney's Aladdin.

Dr. Demetre, continued
common room, lined with ornamental shackles and blush-worthy murals, Daskalakis operates a cramped clinic out of make-shift office space. As men queue up for free HIV and Hepatitis C screenings throughout the night, Daskalakis (whom the men fondly refer to as “Dr. Demetre”) offers his humorous, down-to-earth counsel during their 30-minute wait for the results.

“Demetre’s level of engagement is outstanding,” said Hunteur Vreeland, a promoter and host at Paddles. “He is an amazing fit, a friendly face for people who have questions about their health. He is just what the community needs.”

Dr. Demetre, the self-described “gay health warrior” who fought to bring the clinic to the club, caught some media attention last year when he took to the streets to administer vaccines during New York City’s meningitis scare. In only a matter of days, with the help of the Gay Men’s Health Crisis, a New York City-based non-profit, Daskalakis vaccinated hundreds of high-risk patients and helped stave off the meningitis outbreak.

Now a senior faculty member at Mount Sinai Hospital, and recently named New York City’s assistant health commissioner in charge of HIV, Daskalakis, 40, has undeniable gravitas lurking beneath his boyish features. He recently began to collate lessons learned from those odd office hours at Paddles into a research paper published last month in LGBT Health, which shows that men at high risk for HIV may misjudge their vulnerability to the deadly disease.

Read the story, and more on HIV/AIDS, Hepatitis C and meningitis. ■

Owen, continued
poisonous? It was like searching for clues to a kidnapping.

After visits to several doctors, we first heard the word “autism.” Later, it would be fine-tuned to “regressive autism,” now affecting roughly a third of children with the disorder. Unlike the kids born with it, this group seems typical until somewhere between 18 and 36 months — then they vanish. Some never get their speech back. Families stop watching those early videos, their child waving to the camera. Too painful. That child’s gone.

In the year since his diagnosis, Owen’s only activity with his brother, Walt, is something they did before the autism struck: watching Disney movies. The Little Mermaid, Beauty and the Beast, Aladdin — it was a boom time for Disney — and also the old classics: Dumbo, Fantasia, Pinocchio, Bambi. They watch on a television bracketed to the wall in a high corner of our smallish bedroom in Georgetown. It is hard to know all the things going through the mind of our 6-year-old, Walt, about how his little brother, now nearly 4, is changing. They pile up pillows on our bed and sit close, Walt often with his arm around Owen’s shoulders, trying to hold him — and the shifting world — in place.

Then Walt slips out to play with friends, and Owen keeps watching. Movie after movie. Certain parts he rewinds and rewand. Lots of rewinding. But he seems content, focused.

We ask our growing team of developmental specialists, doctors and therapists about it. We were never big fans of plopping our kids in front of Disney videos, but now the question seemed more urgent: Is this good for him? They shrug. Is he relaxed? Yes. Does it seem joyful? Definitely. Keep it limited, they say. But if it does all that for him, there’s no reason to stop it.

So we join him upstairs, all of us, on a cold and rainy Saturday afternoon in November 1994. Owen is already on the bed, oblivious to our arrival, murmuring gibberish. . . . “Juicervose, juicervose.” It is something we’ve been hearing for the past few weeks. Cornelia thinks maybe he wants more juice; but no, he refuses the sippy cup. The Little Mermaid is playing as we settle in, propping up pillows.

Read the story, more on autism, find tools for parents to detect the disorder, and read about the kids who outgrew autism through therapy ■
Terra Bella, continued

A green tag read “No Irrigation Water Is Available This Year.” There was a $10,000 fine for breaking the seal.

For the first time in the more than half a century that the federal government had been diverting Sierra Nevada water to farmers, there would be no deliveries to most Central Valley irrigation districts. In the third year of drought, there wasn’t enough water to go around.

It was a blow to the entire region, but a possible death knell to Terra Bella, whose pistachio and citrus groves are watered only by rain and the government’s canals.

“How am I supposed to just sit here and watch everything turn brown and die?” asked Lujan, 68. Still, it was February and pistachio trees are drought-resistant. It just had to rain during March and April. He was sure it would.

Sean Geivet had known the news was going to be bad. It had been the driest 13-month period in more than 100 years on the winter day the U.S. Bureau of Reclamation announced water allocations. The Terra Bella Irrigation District manager ran through options in his head.

If the feds said a 25% allocation, most of the area’s 700 citrus growers could still bring in a crop. If it was 10%, that was enough to at least keep the trees alive and try again next year.

Read the story, more on the state’s drought, and its impact on health. ■

Drugs, continued

shelter employees to confirm that some of the people living there were taking part in research studies. They said that the studies are advertised in local newspapers, and that recruiters visit the shelter. “They’ll give you a sheet this big filled with pills,” a resident in the shelter’s day room told me the next day, holding up a large notebook. He had volunteered for two studies. He pointed out a stack of business cards on a desk next to us; they had been left by a local study recruiter. As we spoke, I noticed that the next day, holding up a large notebook.

If you’re looking for poor people who have been paid to test experimental drugs, Philadelphia is a good place to start. The city is home to five medical schools, and pharmaceutical and drug-testing companies line a corridor that stretches north-east into New Jersey. It also has one of the most visible homeless populations in the country.

Read the story, and more on FDA regulations for clinical trials. ■

Cure, continued

returned yet again. There was nothing else to try.

Nothing except a crazy experimental treatment never before given to a child: Blood was taken out of 6-year-old Emily’s body, passed through a machine to remove her white cells and put back in. Then scientists at the University of Pennsylvania used a modified HIV virus to genetically reprogram those white cells so that they would attack her cancer, and reinjected them.

But the cells attacked her body, too. Within days Emily was so feverish she had to be hospitalized. Hallucinating, she asked her father, “Why is there a pond in my room?” She was sent to the intensive care unit and put on a ventilator. A doctor told her family that there was only a one-in-1,000 chance she would survive the night. Then the miracle breakthrough: Doctors gave Emily a rheumatoid arthritis drug that stopped the immune system storm—without protecting the cancer.

Read the story, more on leukemia, and promising new treatments. ■

Face, continued

chin, leaving just his wide brown eyes and a swirl of nameless twisted flesh.

The miracle that would come to define Richard’s life begins with these tragic details. Like most miracles, with each retelling, the edges of the story sharpen, the colors become more vibrant, and the shadows disappear. Ashamed of his appearance, Richard became a hermit, living for nearly a decade on a foggy mountaintop in rural Virginia with his parents. They covered the mirrors in the house so Richard wouldn’t have to look at his hideous face. He stayed in his room even to eat, wore a black mask on the rare occasions he came out.

Then one day, searching on the Internet, his mom found Eduardo Rodriguez, a Baltimore reconstructive facial surgeon. He promised Richard he would make him normal. Over the next few years, Rodriguez performed dozens of surgeries using Richard’s own flesh, fashioning a nose-shaped appendage out of tissue from his forearm and a small chin out of flesh from his legs, but these crude approximations failed to make Richard normal. Meantime, Rodriguez had a grander idea in mind. He was driven to achieve perfection. He had been practicing face transplants on cadavers. What he envisioned for Richard was the most extensive transplant any surgeon had ever attempted: He would give Richard a whole new face.

“It’s showtime,” Rodriguez said one day.

“You’re my godsend,” Richard’s mom said.

The surgery started at dawn on March 19, 2012. The face of a recently deceased 21-year-old man came off as one solid flap, skin, muscle, bone, nerves, blood vessels, tongue—everything as one piece.

Read the story, more on facial transplant procedures, and watch a video report on Richard Norris. ■

Pistachio farmer Fred Lujan remembers rain falling in March. “It smelled so good,” he says. It sounded so pretty. It’s the last time he saw rain.

Michael Robinson Chavez / Los Angeles Times

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