It is usually the father who teaches the son. But when a boy is a fraggle he ends up teaching his father — about strength, and courage, and the bone-deep meaning of love.

me & the X man

By Paul Solotaroff
Photographs by Lauren Fleishman

I WAS DOWN IN A CATACOMB KEEP OF DREAMS WHEN the sound of laughter rang through. It woke me by inches — this was the third night running — and sat me up, drunk with rage. Three forty-seven said the bedside clock; it took all my manly rectitude not to scream.

I trudged upstairs, roundly plunking my skull on the tread of our spiral steps. Waiting for the pain to clear, I could hear my son cackling down the hall, drumming his heels in bed. Three months ago it was terror that roused him: a series of nightmares that brought him half around, moaning in fugue-state dread. Now it was hilarity, a joke he couldn't tell me, stand-up from the beyond. As a rule, of course, laughter is better than tears, but at this hour of the morning they're indivisible.

When I opened Luke's door I found him upright,

THE BOYS OF SUMMER The author and his son Luke, last August at the Double D Pool in Brooklyn, New York

A CALL TO ARMS Often the only way his father can calm Luke down is to hold him as tightly as possible and play one of their favorite games, shark attack.

a blanket swaddling his head. In the moonlight he looked like bin Laden as a toddler at terrorist camp. He yanked down the blanket and there was that grin, as though the funniest thing imaginable would have been to waste the night sleeping when we could be up watching Elmo and eating cashews. (Having just discovered nuts, he did a hard-target search for them whenever we were in the aisles of Key Food.) It is useless to describe the effect his smile had on me — picture a man melting like processed cheese — but suffice it to say that I was under its spell. I climbed into bed and curled up with him.

Now that he had me where he wanted me, my four-year-old trash-talked in earnest. As he knew no words beyond the handful of grunts we'd come to interpret as directives — *maaw* for I'm hungry or I want, *buh* for his favorite book of the moment (which had to be read to him 20 times per sitting), and *ahh* for the 12-dollar remote-control cop car that he could watch go in circles for hours and which I would have risked jail time to smash — what came out of him now was a torrent of triphthongs that only the Taco Bell Chihuahua could interpret. "Shhhh," I murmured, though to no known end — nothing short of a ball gag could have muted him now. Besides, how in conscience do you silence a child who is so preternaturally happy?

Still, like a madman I harbored hope of an hour or two's fitful sleep. (My wife was in Texas, teaching a three-day class; otherwise it would have been her turn to shush him.) I sorted through the list of calming techniques we'd learned from Luke's therapists and teachers. Skin brushing was out, as was joint compression — those methods rarely slowed him down even during daylight hours. When he was this far gone on a nocturnal slammer of hilarity and norepinephrine only one thing worked for us, and that only rarely. Turning him sideways, I bundled my child in a straitjacket of a hug, arms crossed firmly at his chest. He giggled and writhed — this was both heaven and hell for a boy so sensorily swamped — then ever so slowly unwound. He fought for every inch, chafing against me, chirping his birdsong dissent. Because he weighed next to nothing and had no muscle to speak of, it didn't take much to subdue him. Still, I could feel the juice coursing through him, uploads of neural current. A doctor once likened Luke's brain wiring to "a jack with ten phones plugged in." As I lay there listening to his nonsense chat, I tried to picture life as a crowded circuit, the world pouring in unfiltered. After a beat, though, I stopped — that way lay madness, a blood-boiling rage against the gods.

At last he fell quiet, his breathing metered, his bony shoulders softened in repose. With the stealth of a burglar I drew back my arms, sliding out from under inch by inch. It was treacherous going — he's the lightest of sleepers — and as I eased away from him I battled the urge to pelt his neck with kisses. A friend once told me that having a child opens parts of your heart you've never used, but this was something else again. It was wild and primitive, a caveman's love. I would have thrown myself at tigers for this boy.

I had just set my second foot on the floor when he rolled over, grinning in spades. Like a shot he was past me and out the door, making for the secret place in the pantry where we hid the cashews.

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Fragile X blunts a child's brain, then superheats his nerves, making him an inmate in his own skin. And for crushing parents' hopes, its power is hard to conjure.

EVERY EXPECTANT FATHER, WHETHER HE ADMITS IT OR NOT, CARRIES around a secret book of fears. Shelved in the unconscious within easy reach at certain sleepless hours of the night, it contains a folio of what-if terrors regarding his unborn child. A botched delivery, an unseen tumor, the innocuous fever that blooms into a stroke — each of these opens into nightmare time, a child so crippled or badly maimed that life for all concerned becomes perdition. If a man indulges these kinds of thoughts — that is to say, if he's anything at all like me — he may find himself, in the run-up to his baby's arrival, engaged in some morbid bargaining. Addressing his nerves, or the god of his choice, he may say, I can handle disfigurement or a kid with Down syndrome, but please, not paraplegia. Or, We'll get through paralysis — there's a cure in the works — but I beg you, no lymphoma. Beyond the unthinkable — the death of an infant — his worst fears tend toward the penny-dreadful: the condition that denies the child a future and renders him a lifelong ward.

But what happens when the next-worst thing occurs, when an otherwise healthy son fails to thrive? How do you hold yourself together when your beautiful, sweet-tempered little boy goes backward as others go forward, trapped in mud and sinking further with every passing month? How do you keep your marriage going in the face of slow-burn loss, grief that seems to replenish daily and grow ever deeper? And how do you competently father a child whose needs outstrip your power to even grasp them?

My son was born, in October 1998, with a single-gene mutation called Fragile X. Though virtually unknown to the general public, FX syndrome is the most common inherited cause of mental retardation, affecting, by some estimates, 100,000 Americans and 2 million people worldwide. It disproportionately afflicts boys — roughly one in 2,000, as opposed to one in 4,000 girls — disrupting neural connections in the brain at some point before birth. More than 80 percent of males with the FX defect suffer mild to severe retardation. The number in FX girls is only 33 percent, though the female sex has other burdens to bear: One in every 250 women in the world is a carrier of Fragile X — without even knowing it, in most cases, until she gives birth to a defective child.

As it's currently incurable and of little or no interest to the drugmakers that fund most research, FX would be catastrophic even if the cellular insult stopped there. But beyond its damage to learning and memory, the defective gene wreaks a host of behavioral woes that blight a child's chance for an engaged life. These often, but not always, include panic, depression, hypomania, attention deficit disorder, sleep disturbance, shyness, impulsivity, generalized anxiety, and hyperactivity, as well as extreme sensitivity to common stimuli, such as noise, light, and touch. Additionally, kids with the Fragile X mutation are much more likely to develop features of autism than are their healthy peers and are at extremely high risk for seizure disorder, which can kill them if it is not treated with powerful medication. FX is, in other words, the perfect storm of genetic sabotage. It seems to blunt a child's brain, then superheats his nerves, making him an inmate in his own skin. And for crushing parents' hopes and wrecking homes, its power is hard to conjure. Well-meaning friends tell me all the time: I can just imagine your pain. No, you can't, I think but don't say. You have no idea.

The science of Fragile X is prohibitively dense, but there are some baseline facts. Boys, to reprise a bit of freshman biology, take an X chromosome at conception from their mother and a Y from their father; girls take an X from both. Unlike many genetic diseases, the mutation that triggers Fragile X starts as a mere molecular instability that lurks silently in families for generations before erupting into full disorder. The weak spot is found near one end of the X chromosome, and it can be transmitted by mothers to children of either sex or (in its latent form) by fathers to their daughters. Girls who inherit the defective gene, however, have a second, presumably healthy X, which may compensate, so even if they have the worst kind of mutation they often show no symptoms at all. Boys, of course, don't have a second X to fall back on and are far more prone to the syndrome's full effects. These include, besides the problems listed above, a set of telltale physical markers: long, oval faces with lantern jaws and large, protruding ears, loose joints and muscles and a flat-footed gait, and, at puberty, the emergence of oversize testicles.

Of the 30,000 genes in human biology, more than half are a thorough mystery to science, performing functions that can only be guessed at. But since it was isolated, 12 years ago, by clinicians in Australia, France, and the United States, the gene that causes Fragile X has begun to yield some secrets. "We know that a defect turns the gene off before it can do its job, which is to make

A PERFECT STORM OF GENETIC SABOTAGE At the William O'Connor School in Brooklyn, Luke tries to sit still with the help of his special assistant, Jackie Fontana. Experts liken Luke's brain to "a jack with ten phones plugged in."

a crucial protein in the brain," says Dr. W. Ted Brown, chairman of human genetics at the Institute for Basic Research (IBR) on Staten Island in New York City, the first and foremost FX clinic in the world. "We think that protein modifies other genes that, collectively, act as editors. Without it — and the ability to tune out stimuli — a child's brain is under constant bombardment, in a more or less standing state of sensory meltdown."

One particular group of FX children, called mosaics, who make limited stores of the crucial protein (which is called FMR1), are considerably higher-functioning than those who don't. They may have mild learning problems and social unease, but they generally learn to read and write tolerably well and, as adults, to hold a job. As protein levels drop, though, so does performance, and in children with none at all the news is grim. "The impairment occurs throughout the brain, and in the networks in the brain that solve problems," says Dr. Randi Hagerman, medical director of the M.I.N.D. Institute at the University of California–Davis and author of the definitive FX text, *Fragile X Syndrome*. "When you add other problems in the hypothalamus, which coordinates and fine-tunes the nervous system, you get a pretty clear sense of why they're besieged. The volume's turned up to ten inside, and they can't turn it down."

In that neurological tumult it's all a kid can do to tolerate being around others, so fixed is he on dumping the energy coursing through his nervous system. FX toddlers, or "fraggles," as my wife calls them, often flap their arms wildly at their sides and bounce on the balls of their feet. They screech rather than talk, emitting a high-pitched squeal that's a menace to eardrums, if not windows. They're virtually incapable of sitting still, twisting and gnashing and chewing their hands till the webbing is calloused and bruised. A change in routine can cause panic, a trip to the shoe store pure suffering. Vacations, even brief ones, are out of the question, triggering in some kids such nervous-system havoc that they can lapse into prolonged seizures. I know of few X-ers over the age of nine who are not on a high-test regimen of drugs, including an adult-strength sedative, a mood pill such as Zoloft, and a stimulant from the Ritalin family. Additionally many take anticonvulsants and top things off with an antipsychotic, such as Risperdal or Seroquel. Even on such a cocktail they are prone to the sort of freakouts that make parents rue their own birth.

"The drugs do help, but better ones are needed, and I'm excited by what's in the pipeline," says Hagerman, who began treating X-ers in the early eighties, when the condition was named. "Things like ampakines, which are in human trials, seem to enhance memory and learning. And though it's several years from being ready for humans there's a class of drugs that work on the glutamate system that may have a far-ranging impact on the lives of these kids as well as on those of Alzheimer's and seizure patients. But the holy grail, of course, would be replacing the FMR1 protein, which would have the greatest impact on FX children."

IT'S THE FIRST FINE SUNDAY IN A LEADEN APRIL, AND WE'RE OUT WITH our son early at a packed Brooklyn playground. Though he's been up since a quarter of four — again — Luke charges away from me when he sees the swings, darting in front of a bus as we cross the street. He lacks all sense

CONSTANT CARING After returning home from a day at school, Luke is still full of energy. Here he plays with pillows as his mother, Elaine Stillerman, watches.

There is magic in my son, and I'm not alone in saying so. By some combination of beauty and temperament, he affects virtually everyone he comes into contact with.

of ambient danger, and if left to his own devices would camp in the crosswalk for a better look at the cars.

My wife bundles him into a toddler swing and takes the first shift pushing him high. Like me, Elaine is haggard and in a filthy mood; neither of us has slept much in days. As a young mom next to her bills and coos, flirting with a baby dressed in Big Bird yellow, Elaine glares murder at the middle distance, perhaps seeing my face in the trees. Five years ago we were sailing through life, the road ahead open for miles. We rarely, if ever, argued, had lots of avid sex, and on weekends slept till the crack of noon, when hunger — or boredom — roused us. Now we go for days barely speaking at all, and we often sleep, if that's the word for it, in separate beds. Each of us has aged a decade in those years, our joints and spirits cracking with fatigue. Occasionally our eyes meet in a moment of dolor, as if to ask the other, How did we get here?

"I'm going to buy juice," she says, meaning, "Your turn." This is how we talk now, in a kind of semaphore.

I take over, pushing him higher and higher, a touch, perhaps, of malice in the act. But if Luke is aware of his parents' oppression, his demeanor gives no hint of it. Today, as always, he's in great form: cheerful, tireless, and in love with the world — or, at any rate, with his insular piece of it. Like a lot of other X kids he has a motor that won't quit, going all week on minimal rest before he crashes in a 12-hour stupor. (It's thought that the part of the brain that runs the circadian rhythm is disabled in FX, a theory backed by studies in mice.) But unlike many X kids he's weirdly serene, a joy at all hours (except 4 A.M.). At William O'Connor–Bay Ridge, a wonderfully humane preschool for special-needs kids of all kinds, he is hugely popular with teachers and classmates, though he has next to no language and even less interest in relating to other kids. Seldom a month passes without a proposal of marriage from some three-year-old ingenue he met at the park, or a fight breaking out between two of his playmates over who will open his juice box. Still, for all his sweetness I know the clock is ticking and that soon these four-year-olds will turn five, then six, and ask the kinds of questions native to six-year-olds everywhere: What's wrong with that kid? Is he retarded?

Elaine comes back from the bagel store with a bag of fresh-made doughnuts. It's exactly the sort of kindness she used to toss off idly, before we became accountants of parental toil, tracking who got up more often with Luke and who had the last night out. That speaks to the childishness that exhaustion spawns, but it's also a register of something poisonous, namely an apportionment of blame. Our lives are in havoc and we're furious about it, burning to hold someone or something responsible for this colossal trick of fate. We've tried hating the doctors who failed for years to correctly diagnose Luke, the hospital for failing to test for FX during the standard prenatal screening, and the insurance companies for their mingy, corporate-minded refusal to pay for such a test. (That $200 bit of bloodwork could have saved them real money: It costs upward of $2 million to care for an X-er over the course of his or her lifetime.)

But when you're up before dawn for the fifth night running, or surrounded in the park by precocious kids while your child can't say his own name, the hunt for scapegoats doesn't range much farther than the person standing beside you. No marriage can withstand that sort of deadening grudge, and we are both in counseling to find a way past it, to hold our home together till help arrives. After months of acrid wrangling about medication — me for, she against — we've come to an agreement, dosing Luke first with a sedative at nighttime, then, in due time, with Zoloft during the day. It's a serious step when you consider his age, but we're past the point of half measures, of herbal baths and cranio-sacral work. There's no firm number for Fragile X parents, but the divorce rate for all couples with special-needs kids is between 80 and 90 percent, or nearly double that of the general population. And if the two of us combined are no match for Luke, I shudder to think how we'd manage apart, with no backup at 4 A.M.

After a half-hour of swinging, Luke crosses his arms, his chosen signal for finished. As I reach to unbuckle him he pulls me close, seizing my neck in a hug. I stand there, love-drunk, soaking him in, imbibing his warmth and little boy scent, his ineffable head-swimming charm. There is magic in my son, and I'm not alone in saying so. By some combination of beauty and temperament he affects virtually everyone he comes into contact with, including bus drivers, matrons, and lunchroom attendants. This summer he'll graduate from his fourth preschool, and if the scene there is anything like the other three, there won't be enough tissues to go around. At last year's ceremony his teacher and her assistant had to duck inside a classroom to have a cry, and they barely managed to croak out their farewells. Only an ogre could begrudge this child, and yet these days my fantasies involve time without him — specifically, the time before his birth.

We were living in a triplex loft back then, with sweeping ceilings, 12-foot windows, and — that needle in a New York haystack — a parking spot. We were both in our forties, had flourishing careers, and were comfortably resigned to childlessness after years of stop-and-start efforts. Then Elaine got pregnant the month her father died, and both of us took it as a blessing conferred, the passing of light to light. The delivery was long, though not dramatic, and as we brought Luke home from St. Luke's–Roosevelt, the drive down Broadway felt like a victory lap.

But with the curse of hindsight, it's clear to us now that something was wrong from day one. Luke wouldn't — or more properly, [*continued on page 135*]

who should be tested?

THE NUMBERS ARE DISCONCERTING: One in 250 women and one in 800 men are carriers of the Fragile X mutation. Each child born to a female carrier has a 50-50 chance of receiving the mutation. A male carrier passes a premutation on to all his daughters, condemning his future grandchildren.

According to the National Fragile X Foundation, any individual with a family history of undiagnosed mental impairment, developmental delay, learning disabilities, anxiety disorders, or autism should be tested. Where Fragile X has been diagnosed, all siblings — children and adults — should be tested. But Katie Clapp, of FRAXA, says that carrier testing should be offered to all young women contemplating having a family. When surveyed, most FX parents of both sexes say they wish they had been given the test. The cost of this simple blood test is $200–$350 and often is not covered by insurance. If a woman is found while pregnant to be a carrier, the fetus can be tested as early as the ninth week. For more information contact the National Fragile X Foundation ***(fragilex.org or 800-688-8765)*** or FRAXA ***(fraxa.org or 978-462-1866)***. —*Christine Penberthy*

couldn't — take his mother's breast, and he lacked the motor strength to use a bottle. At six months he still couldn't roll himself over; at nine months he didn't sit up. Alarmed, his doctor made a referral to a pediatric neurologist at New York University, who watched Luke fumble with tiny blocks and surmised that he had cerebral palsy. Tests were performed that neither proved that diagnosis nor ruled it out. We fired the neurologist and booked another, a star on the Upper East Side. She ordered further tests, including one we refused that involved eight-inch needles. As Luke turned two we got our second diagnosis: mild to moderate autism.

Though of some small help, at least with the insurance company, the label didn't fit our son. He laughed spontaneously; he loved us back; he mimicked Elmo and the Teletubbies, aping their ear-bleed screech. And so we pushed on, seeing a second internist and then a touted child psychologist. Both were stumped, hinting that we might never learn what hindered our son, the malfunctions of the brain being so abstruse as to conceal a pinpoint cause. Anyway, it was best to watch and wait; in a year, they said, the facts might show themselves.

As Luke approached three we all but gave up, coming to terms with his latest diagnosis: pervasive developmental disorder. It's a trashcan label, the doctor who made it readily confessed to us, used to lump together a broad range of kids whose defects stump clinicians. Though it came a bit closer to describing Luke, it offered not even a slender hope of a cure or useful treatment. By then he was finally up and walking, thanks to a fine program in Bay Ridge, Brooklyn, called, poignantly enough, Thursday's Child. Tailored to kids with major learning delays, the program taught Luke to connect with and navigate the world through a series of discrete trials and errors. He began uttering his first crude words there, and he worked like a demon with his therapists.

Then, when we'd stopped looking for it, came our eureka moment, though in retrospect we were happier not knowing. Pressed by Luke's doctor, we paid a grudging visit to our third — and last — neurologist. She took one look at Luke's oval face and blurted out, "Fragile X." "Come again?" said my wife, who'd long since lost patience with doctors who addressed us as if we were colleagues. "Yeah, a mutation of the X chromosome," said the neurologist. "Besides Down syndrome it's the leading cause of mental retardation. Have blood drawn and see me in six months."

Several nights later — on the eve of July 4, when anyone we might reasonably call for support had gone out of town for the weekend — the neurologist phoned to confirm. "It isn't every doctor who'd stay around late to break the news to you," she brayed. My hand went numb; I dropped the phone. I could hear her tinny patter coming up from the floor. When I grabbed the receiver again I screamed obscenities till my lungs, and balance, gave out. By then, though, I was talking to a dial tone, and my child was sobbing in terror down the hall.

IN THE WEEKS AND MONTHS FOLLOWING THE diagnosis Elaine free-dived the FX depths, seldom rising for air. She read every word in the research journals, nagged Luke's therapists to spend their time likewise, and logged long hours corresponding with frantic parents on list-serve sites. Because she was constantly in motion — and I was fogged by grief — I didn't spot her enveloping despair until it had all but swallowed her whole. Formerly unsinkable, she now sobbed over trifles and struggled to get out of bed each day, racked with vagrant pains. One night, after a spat at the dinner table, it all came tumbling out of her: She had broken Luke's brain, he would always be helpless, and someday she would die and leave him.

"I'll be an old hag crossing the street with him, still holding his hand when he's 40," she sobbed. "Who'll look after him and keep him safe? I could go down in a plane tomorrow."

This was in the months following 9/11, and clearly her heartbreak was trading feedback with the hysteria of the day. But it doesn't take a degree in psychology to know that guilt had a part in this too. For all her new acumen in genetic transmission, Elaine was convinced that the gene had mutated in her. That was impossible: The defect builds slowly, growing by increments over many generations until it blooms into full mutation. Still, she kept running the grim statistics: If only she had dealt Luke her healthy X, which he'd had a one-in-two chance of getting; if only she'd given birth to a girl, who'd have had a two-in-three chance of dodging symptoms.

A lot of this I've learned from her over the past few months; at the time she was researching Fragile X she was too embattled to even broach the subject. Nor, out of care for her aging mother, had she shared the news with her extended family, consoled by the knowledge that all the boys she knew were well. Then one day it dawned on her that she was missing half the picture: There could be women on her father's side who were carriers too. A letter went out to her paternal relations, urging them to take the test. Sure enough, a first cousin turned up positive, though the gene had spared her two children. For Elaine that finding seemed to ease the load, retiring the matter of her own inheritance and with it some of her guilt.

"It wasn't just my father who had the premutation: His brother had to have had it too, and both of them had to have gotten it from their mom," she says. "Which leads me to wonder, first, how long it had been hiding before it surfaced in me, and second, how many other women out there are about to pass on that first full mutation?"

IF ANYONE OUT THERE IS GOING TO FIX MY child, it will be a woman like Katie Clapp. She isn't a neuroscientist or a biotech mogul but an unpedigreed housewife in Newburyport, Massachusetts, who won't take no for an answer. Ten years ago she and her husband, Michael Tranfaglia, a psychiatrist, got the hard news about their three-year-old Andy, to which they numbly replied, "Fragile what?" Like my wife and I, they'd been trekking from doctor to doctor, bringing their son to prestigious specialists who should have known better. Unlike us, though, they had grounds for a lawsuit: During the years they were seeking a diagnosis they were told over and over that whatever Andy had, their next child wasn't at risk. And then they had Laura, who, within weeks of her birth, tested positive for the full mutation. (Thanks to good luck, and her second X chromosome, she is mercifully free of symptoms.)

But instead of suing experts up and down the coast, they plowed their outrage into something generative, starting a nonprofit called FRAXA Research Foundation. The foundation had, from its inception in 1994, a couple of bright-line goals: one, to spread the word about Fragile X syndrome to doctors and parents worldwide, and two, to raise a large pot of money fast and fund a search for effective treatments and a cure. By 2002 they'd raised $7 million, most of it from the families of Fragile X kids, and were underwriting dozens of research studies that have advanced the science by leaps. En route they pooled resources with other FX parents — Debbie Stevenson, the wife of a Wall Street baron; David Busby, a powerhouse Beltway lobbyist; and Kathy May, a player in the nonprofit sector — to turn up the heat on Congress. When the group first appeared before the National Institutes of Health, government spending on FX research was less than $2 million annually. Eight years later it was more than $15 million, including funding for three new research centers whose sole purpose is to find a treatment and cure. But Clapp, who is FRAXA's one employee, was just rolling up her sleeves.

"When we first got the news about our son, then learned that all of five people in the entire world were investigating the gene, I said, 'No way, this will not stand. Someone has to help these kids,'" she says, sitting on the deck of her trim colonial on a cul-de-

sac in this seaport town. "That was nine years ago, and we've built the field since, recruiting Nobel laureates, National Academy scientists, and Howard Hughes Medical Institute investigators. And thanks to them, and to the 6,000 people in our network, we stumbled onto a major find: a class of drugs that's going to change all this. It's still in mouse trials and will probably cost $10 million just to bring before the FDA. But I'll get that money somewhere if I have to beg, borrow, or steal — and anyone who says different doesn't know me."

Tranfaglia, her husband, laughs. He's the cool clinician to her firebrand, the guy who works behind the scenes to nudge the research ahead. He's also, by default, the consulting physician to families around the country, freely helping desperate FX parents get the right mix of drugs for their kids. It is vastly complex and can take months or years to find a regimen that calms down a child. But Tranfaglia can count on one hand the number of psychiatrists who are knowledgeable about X-ers, and so he takes the 3 A.M. phone calls from parents at the end of their rope.

"What Katie's talking about is a class of drugs called mGluR5 antagonists," Tranfaglia says. "In Fragile X mice it stops lab-induced seizures 100 percent of the time and also dampens the neuroreceptors that trigger panic and obsessive-compulsion. Then other people found that when mice take it in large doses it blocks addiction, not just to cocaine but to a whole class of opiates and stimulants. Within a decade it'll revolutionize substance abuse treatment and be the drug of choice for Parkinson's and epilepsy and a range of anxiety symptoms. But we can't wait ten years. Our son has almost died three times."

Andy, whose picture is everywhere in the house, is now a handsome boy of 14. Like a quarter of all kids with Fragile X he suffers from a form of seizure disorder, though his is more dire than most. Just one missed dose of anticonvulsants can induce an event called status epilepticus, in which he seizes until he's treated or dies. The last such seizure was nearly fatal; it occurred during a trip to a neuroscience conference and cured his mom of trips for a while.

"Our whole focus now is to find a biotech firm that will underwrite the cost of the drug trials," she says. "Once one's ready to be tested in human subjects, and if we can get the feds to treat it as an orphan drug [i.e., indicated for a small class of potential users], we could bring it to market in three years. A small start-up company that's willing to roll the dice would have things to itself for five to seven years and could make hundreds of millions of dollars for its trouble. They would also earn my undying gratitude, and the gratitude of millions of families."

We talk a while longer about mGluR5's properties, and how it goes to work on the neuropathways, aping the FMR1 protein. (Researchers have produced a synthetic version of the protein but are years away from having a sense of how to deploy it.) Tranfaglia is sketching out glutamate receptors when a bus pulls up to the drive. Down steps a slender, auburn-haired boy with a bashful, meandering gait. He walks in the door, takes a look at me, and instantly begins to shake. My heartbeat skitters as he drops his pants, the preface to a full-on scene. But his mother glides to him and heads things off, parking Andy in the living room with his dinner and a video. When Clapp returns her hands are trembling as she pours herself a drink.

"That's why we put in 60-hour weeks and haven't taken a vacation in ten years. It's not that we're saints whose mission is to save these kids. We're out here trying to save *our* kid, and if we happen to save yours, too, more's the better."

IT IS NIGHT FOUR OF OUR OWN DRUG TRIALS, and nights one through three went beautifully. On a mild combination of an antihypertensive and the over-the-counter sleep-aid melatonin, Luke slept soundly from 9 P.M. till his wake-up at a quarter of seven. Neither Elaine nor I can bring ourselves to raise the subject, tiptoeing around it like the teammates of a pitcher who's throwing a perfect game. So when I click off the tube and head down to bed, it is with a certain amount of giddy stealth, lest I somehow tempt the fates. Sure enough, at 3:15, a loud thump wakes me. Fearing the worst, I race up the steps, expecting to find Luke in a druggy heap after tumbling out of bed. But when I open his door, it's the cat who's spooked, having knocked over a See 'n Say toy. Luke is snoring softly into the trunk of his stuffed elephant; as usual, one of his socks has gone missing. I kneel down, ostensibly to straighten the sheets, but find myself suddenly in prayer. Please, I say to whoever's listening. Please, please, please, I beg you.

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