

Growing Up in Public

Justin LiGreci is a typical 15-year-old -- give or take AIDS, a \$20 million lawsuit and a mom on a mission

September 1, 1998 By Clifford Chase

"I'm here to tell you about my life," Justin LiGreci announces to the hundred or so teenagers sitting crosslegged on the wooden floor of Camp Tel Yehuda's gym. We're midway into a two-hour presentation by Staten Island's THE (Teen HIV Educators) Group, of which Justin is the youngest member. Under his spiky, dark hair, his pale, bespectacled face is nervous. He shifts tentatively in his seat as he opens his tale of his illness-plagued childhood -- the fevers of unknown origin, the mystery infections, the loneliness and fright -- his voice barely audible above the kids' own shifting and murmuring. "Finally I went to this other doctor, and he tested me for everything. Stuff that only doctors know. One test came back positive -- the HIV test." Justin pauses as the silent faces register pity, respect, surprise. The luxurious, late-May green of the woods outside fills the windows. Birdsong fills the gym. Now he leans back in his seat, takes a breath and is poised to finish the story he is living.

Justin LiGreci was born in 1983 to a woman who shot up drugs. Because his medical records were kept from the couple who adopted him, Justin was 11 before he was tested for HIV, when he saw a specialist for a swollen lymph gland in his neck. Two years later, his adoptive mother, Melody Moreau, filed a \$20 million lawsuit against the New York Foundling Hospital, the agency that placed him, charging that it had violated New York state law requiring full disclosure of adoptees' medical histories to prospective parents. Justin's is believed to be the first-ever wrongful adoption suit involving HIV.

This litigious saga has supplied the media with all the materials out of which to make the nation's newest AIDS poster boy. In turn, stories in *People* and *The New York Times*, as well as updates on local and national television, have supplied Justin and Melody with a stage for publicizing not only their own cause but that of all youth with HIV. But exposure has its costs. For Justin, this has meant at times being cast as a sort of Tiny Tim for the age of AIDS, showing grace under the pressure of morbid and melodramatic questions. For Melody, there's the added anxiety that the lawsuit may imply she wouldn't have taken Justin had she known his medical background. ("Justin is not damaged goods," is how she put it to *People*, through tears. "He is the best thing that has ever happened to me.") The publicity has also provoked the usual nutty letters and calls, as well as HIV-specific harassment -- Justin tells the kids at Camp Tel Yehuda how one day a driver in a passing car yelled "Die!" and threw a can of shaving cream at him. His dealings with *The Montel Williams Show* were no less annoying. He and Melody canceled an appearance last spring when

they realized, the day before the taping, that the program pitched to them as a sensitive treatment of complex adoption issues was in fact a circus of botched adoptions and bitterness. They say they then became the target of all-hour phone calls -- and even a late-night visit -- from frantic producers.

Riding the Staten Island ferry to meet this mother-son partnership, I'm keenly aware of being one more reporter about to intrude on their privacy. Staten Island has a conservative, old-fashioned, small-town feel. During the cab ride to Justin's neighborhood, the urban scenery gives way to stately trees, bright lawns, azaleas in bloom, even patches of open land. It's a day to be outdoors -- a blindingly blue sky with huge white clouds -- but when I reach Melody's modern gray townhouse, all the curtains are drawn. Justin answers the door in baggy jeans and a Tommy Hilfiger T-shirt, and shakes my hand with a boy's quick formality. He knows the drill.

In the dining room, the cast is waiting: Melody; her mother, Rosalie Moreau ("Call me Nana"), who lives with them; and their lawyer, Matt Titone, who will filter discussion of the lawsuit. The three present a united front: All in T-shirts, jeans and strong New York City accents, smoking red packs of Marlboros. Smiling under her inch-long blond hair with blonder highlights, Nana brings me a Snapple, placing it next to a paper cup on the white lace tablecloth. Melody is sitting on one side of Justin, Matt on the other; Nana finds a place behind me, on the stairs. I'm included in their circle but also surrounded. There's a down-to-earth warmth here, but a wariness in the air.

"I'm proud of Justin," Melody says at the first chance she gets, patting his shoulder. Her vulnerability surprises me. "Here's an adolescent who came forth and wants to educate the world about AIDS. He doesn't care about the repercussions. That takes a special and strong individual."

"Just keep going on and on," he says, shrugging off her hand. He's feigning above-it-all amusement, but basking in his mom's adoring gaze. "Feed my ego."

Melody takes a drag from her cigarette. "Well, I want to feed it," she says. "When a young person stands up and does this, it shows more bravery than when an adult does it. They're just coming into themselves, and they're subjected to the ignorance of others."

For Justin, coming into himself has meant becoming more and more open about his HIV status. He speaks out strongly and frequently about the need for more programs to serve kids with HIV ("There's nothing on Staten Island," he says, waving his hand dismissively), and that's how his busy public-speaking career began, at a local funding hearing a year and a half ago.

His openness about his status is unusual for an adolescent: Justin himself knows of only one other HIV positive teen on Staten Island. When he first learned of his diagnosis, at age 11, "I didn't know what it meant -- and I didn't want to know," he says. But soon enough he became aware of the ignorance all around him concerning HIV. "My friends and I would be watching TV, and they would say, 'That person looks like he has AIDS.' Mean stuff, like he wasn't human. And I'm sitting right there next to them." He shakes his head. "I thought, 'They've got to wise up.'"

Everyone in Justin's family displays the same appealingly tough, no-nonsense attitude. The degree

of normalcy they have achieved is remarkable. Like Ryan White's mom, Jeanne, Melody is a driven, formidable presence; given all she and Justin have been through together, not to mention the uncertainties ahead, their devotion to each other is absolute. But as the afternoon passes, I see both mother and son trying to balance their bond with Justin's growing need for independence. It's a delicate, loving negotiation. A few minutes later, Justin ribs his mother for her constant reminder, "Don't give up." Melody answers, "I only say that when you're sick," and Justin shoots back, "Which is every other day."

On one level this is just a typical teenage banter, but it seems to throw Melody into a spin. Justin's medical history is depressingly complex: Dozens of strep throats and eye and ear infections, thrush, conjunctivitis, tonsillitis, appendicitis, pulmonary hypertension and, last April, a benign tumor in his chest that had to be surgically removed. Triple-drug therapy slashed his viral load to zero, but he's often sick. "We made a vow to each other," Melody says softly, her blond hair falling around her fine cheekbones. "If I passed on first, I'd always be around. And if he passed on first, he'd be there for me. We'd never be apart." Justin is doodling on a newspaper, and I decide not to ask what he's thinking.

Humor helps. Melody's phone message begins, in her smoky voice, "Hi, you have reached the nuthouse ... " -- this to *People* and strangers alike. When I ask for a rundown of Justin's meds, Nana retrieves from the kitchen a cut-glass tray piled high with orange prescription vials, setting it down on the big table with a sardonic "Can you believe it?" grin. She, Melody and Justin take turns ID'ing each prescription, tossing out answers in a kind of Name That Drug: Viracept, AZT, Epivir, Procardia (for his heart), Coumadin (a blood thinner), several formulas for thrush, vitamins, the steroid Megace, and, new this week, Augmentin for his sinus infection. I sigh and write down each name.

Justin points out that my hand looks tired, so we take a break. Leaving the adults behind, he and I go down the few steps to the living room, where he shows me his Sony digital camera and pictures of friends stored on his PC. His computer is the control center for a life lived mostly indoors (he missed more than 100 school days last year). Seeing the stacks of CD-ROMs, I ask him what computer games he likes, and he says, "Anything having to do with *Star Wars* or *Star Trek*," which he plays alone or over the Internet. He also plays chess with his father, John (he and Melody divorced when Justin was small), and Melody's fiancé, Kevin. He reads science fiction, Stephen King and loves *The Hobbit* best. He writes poetry and short stories, though he hopes to study computer science at MIT.

Clicking his mouse and gazing intently at the screen, Justin calls up his self-created Internet page (<http://members.aol.com/Lukesky196/index.html>). "Information about HIV/AIDS by Justin," the site's headline reads, followed by Justin's own story as well as basic facts on the disease and its transmission ("If you had oral sex with a girl and had contact with her vaginal secretions, this is also considered high risk"). I ask Justin if he advocates abstinence or safer sex. "Teenagers are going to have sex," he says. "I want to have sex. Soon."

Justin is bound to enter the world of dating with an unusual awareness of himself as both

stigmatized and potentially dangerous. Like nervous parents, the media coverage of Justin has tended to avoid the issue, preferring to report only the comforting abstraction of his interest in girls. The “innocent victims” born with HIV are coming of age. How will America deal?

As I’m puzzling over this, Melody interrupts us. I’m uneasy about making a teenager discuss sex at a table in front of his mother and his grandmother, let alone a reporter. But on my next visit I ask anyway.

“I’ll meet some girl sooner or later, and I’ll want to have sex,” Justin says without looking up. “If she wanted to, I’d say yes -- if I had a condom with me.”

Melody has grown still. “What about your being HIV infected?” she asks carefully.

Eyes averted, Justin says, “I’d tell them that before.”

I mention a girl he met in an Internet chat room: Will they see each other? “We have it planned,” he says with enthusiasm. “When we get our licenses, we’re going to meet up.”

“Oooh, a rendezvous,” Melody croons.

Justin frowns. “You should go out of the room if you’re going to act so immature.”

Melody shrugs half-apologetically. Justin sits playing with his pen. Mother and son are more at odds today than the last time I visited. Even their T-shirts seem out of sync: Melody’s is Tweety, Justin’s is the Tasmanian Devil. I ask Melody if she has concerns about her son dating.

“I think it’s cool,” she says breezily.

I admire her attempt at nonchalance, but now it’s Justin’s turn to tease: “So I can go out late at night? And stay out all night?”

“Not late at night -- ”

“Sleep all day, party all night,” he adds, and Nana suggests helpfully that Justin could go on a date during the day instead.

Suddenly Melody’s voice cuts through the banter. “I do have a concern,” she says. “If Justin meets a girl and he tells her he’s infected, what if he’s rejected?” That sadness creeps into her voice. “Being a mother, I don’t want him to be hurt.”

Justin says, “I’d make sure she would accept me.” His hair has been cut short since the last time I saw him; gel makes it look moist, as if he’s literally wet behind the ears. “I’d make sure I know what kind of person she is.”

Melody shakes her head. “People can be very fearful,” is all she says, and crushes her cigarette.

Justin already knows a thing or two about rejection: Last year, as if it were still the early terror-filled years of the epidemic, he lost all his school friends when word got out that he had HIV. "Four or five of my friends, some from kindergarten -- we used to call each other every day -- they stopped bothering with me," Justin says, shrugging when I ask if there was ever a confrontation. "No. They grew more distant, and you can, like, feel it." Did that hurt? I ask.

"Yes, but then you have to figure they aren't your friends if they do that." Perhaps Justin can be so philosophical now because he's found new friends at THE Group, which meets weekly at the Staten Island Jewish Community Center. Although no one else in THE Group has HIV, these kids are sensitive to the issues Justin faces. He likes to joke that he was roped into the effort by THE Group's pretty girls, but he stuck with it because of the satisfactions of spreading awareness of AIDS at schools, camps and community centers. "After I talk, I see the reaction on people's faces -- like utter respect," he says. "And I see that I've had an impact."

This renewed sense of belonging followed months of loneliness. Last fall was difficult: Justin had just started high school when a corneal infection landed him on home study with a lot of empty time to fill. "I'd just go into really deep thinking," he recalls, staring ahead a little blankly. "I'd think of every possible outcome for me having HIV. I'm deep into possible outcomes and contradictions." Such as? "Like, what if HIV can be cured? But what if it's not a cure, and it comes back three times worse? Or what if I infect someone accidentally? What would they think of me? I do that a lot -- questioning other people's thoughts."

"He's an old soul," Melody says. She reaches toward Justin and taps the table with her palm. "He has a theory about that. Remember?"

"We're all wacky in this house," he replies, slouching down in his chair. "Strange things are normal to us." But he continues: "I do feel like I'm an old soul. In a group I'm the one who doesn't fool around. At a party I'd definitely be the designated driver." We both laugh. "My friends see me like this -- serious, always thinking, not able to live in the moment."

But is he getting better at that?

"Yeah. It's strange -- the moment. Take it as it is."

Justin has a lot to take as it is. Following *The New York Times* article on him last December, two of his eight siblings succeeded in contacting him. Justin agreed to a meeting in January. The encounter with Tina, 20, was eerie, Justin says, because the two look alike. "There's this feature we share -- our cheeks," he says, patting his own face with both hands. "It's weird -- a person you've never known and they're so much like you." Tina, visiting from Michigan, has since gone off to join the Air Force, but Justin now sees his brother Jason, 17, regularly. Tina also brought the surprising news that -- contrary to what Justin and his adoptive parents had been told -- his birth mother is still alive.

My questions about her prompt Justin's most intense replies. When he first learned she was a drug user, and that he had contracted HIV from her, Justin says his reaction was: "She left me with

something, after all -- oh, joy." Nana gasps. "I never heard him say that."

"Is that harsh?" Justin asks.

Nana shrugs. "No, it's just true."

"I'm so unemotional at times. I'm like 'Whatever,'" he says with a flip of his hand. "I don't like public displays of emotion."

Like most 15-year-old boys, he leaves that to his mom. Melody tells me that with the appearance of Tina and Jason, "the past few months have been an emotional roller coaster. HIV is an emotional roller coaster."

"It's hard to stay 'up,'" Justin says. "Some days it's like, 'Wow, I don't have the energy for anything.'"

He shrugs, but when I ask him if he hopes to meet his birth mother, he reacts strongly: "No!" he exclaims, his blue eyes widening. "There wouldn't be any point. What would I say to her?" Then he adds, "Maybe when I'm old."

It's dinnertime on my last visit, and the four of us sit down at the kitchen table. Nana serves up thick strands of pasta with homemade tomato sauce, freshly grated Parmesan and warm Italian bread. The late-afternoon sunlight filters through white curtains into the pleasantly cluttered kitchen: Family photos, a postcard of Jesus smudged with Melody's lipstick, a guinea pig in a wire cage. Matt, the lawyer, isn't here because he had a rough day in court. Melody talks about the lawsuit as we eat, repeating what Matt told her about this morning's hearing, recalling the various offenses of the other side, speculating about what she and Matt can do to fight back. It remains a mystery why the Foundling Hospital withheld Justin's medical records (the parental-disclosure law was brand new), but according to Melody, the omissions in the information she did get were glaring. A social worker told her only that Justin *may have been* exposed to unspecified drugs through his birth mother -- when in fact he spent the first 24 days of his life in intensive care undergoing heroin and cocaine withdrawal. Doctors ordered that Justin get special follow-up care for drug-addicted newborns, a recommendation that never reached Melody. Complicating the case further is Justin's former pediatrician, Dr. Marina Corpus, a New York Foundling associate who, through the years, treated Justin for an extraordinary number of childhood illnesses without ever testing him for HIV. She, too, is being sued, for malpractice.

The defendants' tactics provide continual fuel for Melody's rage. So far, motions to dismiss have delayed the suit for more than a year and a half; not a single witness has been deposed. Lawyers for the Foundling Hospital and the Archdiocese of New York, which oversees the agency, have argued that the case should be dismissed because the statute of limitations for fraud has run out, and because the ELISA test was not yet available at the time of Justin's adoption; the judge ruled against them, but an appeal is in the works. What happened at this morning's hearing -- and what has Melody near tears over dinner -- is that the Foundling Hospital charged, in a revised motion, that the sketchy outline Melody was provided with about Justin's health was sufficient for her to

pursue HIV testing for her son -- thus placing the blame for a late diagnosis on her.

"Matt nearly lost his temper in court," Melody says, picking up her fork and immediately replacing it. "That's how frustrated he was. It's a good thing I wasn't there."

Nana says to Melody, "You need to calm down."

"I know," she says. "My head is spinning with it."

And soon she starts in on another messy, maddening turn of events involving the case. Through most of the meal Justin concentrates on his plate, eating in silence. But when Melody struggles with a fact or searches for a word, Justin supplies it instantly. He misses nothing.

Even so, Justin's attitude toward these legal battles is as removed as Melody's is absorbed. He chooses his words carefully. Of the Foundling Hospital's behavior at the time of his adoption, he says: "It was an injustice and probably happened to a lot more people." Of the pediatrician's failure to test him for HIV: "She should have thought about every possibility. Apparently she didn't." While for Melody the lawsuit is bound to carry the potent symbolism of a mother defending her sick child, Justin's aims are practical: A favorable settlement will deter the defendants from future missteps, and enable him and Melody to start a foundation to help other kids with HIV.

Similarly, when it comes to AIDS activism, Justin's priorities are in sync with his mom's, but remain distinct. A few weeks earlier, during our first meeting, Melody had told me: "You know how in life you're on a mission? It devastated me when I found out about Justin being infected, but I knew I had to go out and join the fight against AIDS." She was referring to her work at the Staten Island AIDS Task Force and Project BUILD, an organization that serves indigent PWAs.

"I've never had a desire more in my life than to fight this fight."

I asked Justin if he has a mission.

His brow furrowed. "HIV and AIDS is part of it," he said slowly. "But there's ... other stuff."

I waited, pencil poised.

"Don't ask, please," said Nana dryly, and his three protectors at the table laughed.

"Girls, girls, girls," said Matt.

"Relationships," Justin tried. "Friends."

Matt continued, a mock accusation: "He went to the city Friday and spent the day with a girl from THE Group."

"I walked ten miles!" Justin said then. He told how he, his friend Vanessa and two cousins wandered all over Manhattan, finally ending up in the Village. "I thought, 'I wonder how my mom

would react if I got pierced?’’

As Melody and Justin began their banter, I thought about his mission and that “other stuff” and remembered something in his speech for World AIDS Day last December: “What is it that drives children to fight? Adults have come up to me saying they would have quit a long time ago. Is it the hope that one day this nightmare will be vanquished? Or is it that children fight to experience -- to experience what life has to offer?” It’s clear that for Justin, the answer is yes: He fights to be, to put it simply, a 15-year-old.

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