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## AIDS AT 20; Living With HIV;

People infected with the virus go on with the unfinished business of their lives

By Katti Gray Staff Writer

As much as any sensible gay man alive back then, Jimmy Mack knew AIDS was consuming his kind, rolling over them like fire across dry brush. So, the day in 1987 that his doomsaying doctor told Mack he was HIV-positive, the physician didn't mince words: The outlook was bleak; Mack likely would be dead inside of a couple of years. Mack wept and bolted for the door.

He was 29 at the time, working as an advertising executive, and when he walked out of that doctor's office, he shut the door on medical care for five years. In his despair, he chose his own palliatives: smoking crack, sniffing coke, puffing weed, shooting heroin, popping ecstasy and chasing it all with enough liquor to induce a nightly blackout that he called sleep.

One day in 1992 he awoke in a crack den in Puerto Rico, stripped to his underwear, asking the only other body present who had ripped him off. He got no response, for the body was cold and gray, lifeless after an overdose.

"I had crawled on my hands and knees over to a dead guy. That was a real wake-up call," Mack said.

Soon after, a friend, ravaged to the bone by AIDS, summoned Mack to the bed where he lay dying in San Francisco.

"He told me I needed to get it together," Mack said. An hour later the friend was dead. That was the moment of Mack's turnaround, his finally confronting reality. For 14 years now he has been living with HIV.

The pandemic has claimed almost 440,000 lives in the United States-roughly one-sixth of them in New York City-and more than 23 million around the globe. Most people who are infected with HIV remain asymptomatic for 10 to 12 years, and a few for much longer. But in some, the progression to AIDS is much quicker.

Some who have held off AIDS are celebrities and socialites: Magic Johnson has had HIV for 10 years. So has auto body heiress Mary Fisher, who in 1992 and again in 1996 asked the Republican National Convention to have compassion for people with AIDS.

Jimmy Mack is one who isn't famous. What the survivors acknowledge is that medical advancements have assisted in granting them something of a reprieve. They also suggest there are other forces at play, ephemeral factors that can't be assessed by science's innovations.

Some say they are alive, at least in part, because they have willed themselves to be. They have the unfinished business of life to address: raising children, realizing career dreams or keeping another from being tripped up by AIDS.

Some follow strict diets and exercise routines that they believe have helped fortify them. Meditation, prayer or other spiritual constructs help keep them more centered-and may play a role in reducing stress that is capable of aggravating any illness.

And even if it seems unfathomable to outsiders, some survivors say that life itself has refused to let them go.

"My T-cells are so low," says Mack, referring to the immune system cells that HIV attacks. When they fall below a certain level, AIDS is diagnosed. "I have Kaposi's sarcoma. I just had two lesions removed two weeks ago."

But even as he speaks, he doesn't reveal alarm. "It will be fine. I have no fear, I know that I am here for a reason. This illness is my most amazing blessing." His voice cracks, and his eyes well up.

Mack does not appear sick. No cancerous lesions show on his face, neck, forearms or hands on a recent day. He is speaking in the Park Avenue penthouse where he is a personal assistant to a mega-moneyed family of six. Mack splits his worktime between that Upper East Side abode and his employer's second home in the Hamptons, not far from where he grew up, the son of a radiologist and artist in Westhampton Beach.

Like many in his circle of survivors, Mack maintains a busy schedule. He swims a mile a day; even days after his first hospitalization last December he was back in the pool.

That holiday emergency was the result of a severe reaction to anti-viral drugs that sent Mack's temperature soaring to 105 and covered his entire body with a rash. He had begun taking protease inhibitors, one class of anti-viral medications, in 1995. "I've taken everything that's on the market," Mack says. "One of them always stops working on the way."

Mack is in a relationship with a partner who is HIV-positive, and he maintains his sobriety by meeting with support groups. Over the years since he sobered up he has devoted himself to a host of AIDS-related service projects, from the Gay Men's Health Crisis in Manhattan to the Long Island Association for AIDS Care.

He visits schools in New York City, Long Island and elsewhere, sometimes several times a week, through an AIDS- prevention organization called Love Heals. "I go," he said, "to put a face on alcohol, addiction, AIDS and homosexuality. If I am anonymous, how will people turn to me and say, 'What has your experience been?"

Another member of the Love Heals crew is Niko Flowers, 31, a Brooklyn woman diagnosed when she was 19. She dropped out of a South Carolina college that year but plans to study film-making at Hunter College this fall."

I stay busy with the kids [during visits to schools] because it keeps my mind from going where it ought not go-to my suicidal thoughts, to thoughts of 'If I die will anybody miss me,'" she said.

"When I talk to young people, I tell them about when I was taking 32 pills a day. I say, 'Thirty-two pills versus HIV. Thirty-two pills. HIV...' over and over.

"I am trying to make the point: Is it worth it?" Flowers said of her way of telling young people not to risk becoming infected. The "meds," as she calls her daily pill regimen, give her almost unrelenting diarrhea. But that's a side effect she has become resigned to. "If I don't [keep up the medications], my body loses resistance."

The suffering of survivors goes beyond the physical to the intangible: minute-by-minute vacillations of mood and disposition. On any given day emotions can run the gamut: anger, guilt, self-pity, sorrow. Determination, faith, hope. Feeling up against the world, or that the world is an ally.

Myrna Asia Betancourt was diagnosed with HIV in 1991, having been infected by her boyfriend, Roger Meotti, a former drug addict who believes he contracted the virus from prostitutes. ("I'm still healthy," said Meotti, 36, a Commack native diagnosed 12 years ago.)

The Sunday when Betancourt finally went back to church, a member of her Staten Island congregation announced he had a car to give away. "I didn't even know how to drive, but my hand shot up," Betancourt, now 38, said.

The car, a banged-up 1990 Beretta, has kept Betancourt from relying on others-providing an independence she says is crucial. When she revealed her HIV status, the four or five good friends with whom she used to travel about disappeared. "Now, I take myself to the grocery store," she said. "I take my own kids shopping."

The most obvious outward sign of Betancourt's infection is diminished strength. Her car's stick shift and clutch require effort, but they have their benefit:exercise. Her legs are weakened, and she makes her way through her rent-subsidized apartment by palming the walls, arms of couches and human shoulders to help her stay upright.

For the past five years Betancourt has used a wheelchair. She keeps one in the Beretta's trunk and a second parked by the front door of the home she shares with her two daughters, ages 13 and 15, and the family's two dogs and two cats.

Her girls are scholars, she says, one in a Catholic school and the other in a public school for the academically gifted. She's proud of them-and of her own role, as well, as a dutiful and active mom. Her own parents placed her, at age 3, in an orphanage.

On her walls and shelves are citations attesting to her activism on behalf of half a dozen AIDS organizations.

"My plate is full," she said. "It's called normalcy. It's called getting out there just like anybody else would, whether or not I am depressed.

"It's called hanging on to life."

That can be a hard balance to strike, said Jeff Reynolds, executive director of the Long Island Association for AIDS Care.

"Increasingly, the people you would call long-term survivors are an isolated group. More and more, as protease inhibitors fail, people are dying. [But] there are those who, honestly, no matter what they do, live for a long time," Reynolds said. "We've seen people who said, I didn't think I'd have to worry about my credit cards or going back to the gym or going back to work....For many of them, it's sometimes harder to live with all that uncertainty than to die."

Cynthia is 41, a former intravenous drug user who believes she was infected with HIV from sharing needles with other addicts. She lives in Suffolk County with her husband and 12-year-old son and says it's her desire to see him grow up that keeps her moving forward.

Cynthia, who asked that her last name not be used, said she was diagnosed when her only child was born. (He was HIV-positive at birth but has tested negative since.) She has endured the ups and downs that accompany a compromised immune system: pneumonia, several hospitalizations, the most recent last month. During one serious bout of sickness she lost almost a third of her weight and was down to only 98 pounds.

"I used to be busty, a full 36C," said Cynthia, who has regained some weight. "I have lost a lot of hair, mainly from the medication. I had little hips, a little booty. But my heinie has become concave from all the weight gain and loss."

After one hospital stay, social workers wanted to assign aides to help her with household and personal tasks, from cooking to showering. She refused the offer.

"I could not become too needy," she said, "too dependent on other people."

She's on the rebound right now, up most mornings at 5:45, preparing breakfast, pushing her property- appraiser husband out the door to work-she schedules his appointments-and her son to school. The role of contributing member of the family is significant to her.

"My son and husband play a big part in my being here," she said. "They keep me busy. Being busy keeps my spirits high, but there is always something [hard] going on in my life.

"The hardest part for me now is that, with all the new [medication] cocktails, nothing works for me."

Dr. Bruce Walker, director of the AIDS Research Center at Massachusetts General Hospital in Boston, said long-term survivors cover a broad category. At one extreme are people who qualify simply because they are still alive. At the other are the roughly 1 percent who have thrived for at least 15 years or so with barely a trace of HIV detectable in their blood. Some have never taken any anti-viral medicines but manage to keep their immune systems fully intact.

"Now, we're talking about people who are really beating the odds," said Walker, coauthor of a 1997 study on long-term survivors. His research found that some people "have a genetic predisposition to doing well because the virus cannot enter their cells very well. Some people do really well because the virus that they got infected with is not a very lethal virus. The majority of these people do well because they have a very effective immune system that is doing to HIV what the body is supposed to do with viruses, and that is keep them in check."

As for those other things that survivors cite, the things that cannot be explained by medicine, Walker said, "A lot of this is a mystery...You cannot rule anything out."

Rashonda, Betancourt's elder daughter, is betting on something beyond what the statistics imply about her mother's future.

"In my heart, I honestly say that she will be around when I am in college and when I have kids. Other people say it is impossible. But I believe."

"They say," her mother added, "that God is not going to put more on you than you can bear. Sometimes, I gotta tell you, I'm pushed to the limit, dealing with AIDS services, dealing with doctors. And the medication is really rough.

"Even so, I have more life now than I have ever had before. I love being here. That is what keeps me here. That is what keeps so many survivors here."

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