

Consumer Biography Judy Burman by Peter McDonough

Judy Burman's confusion, over the cause of outbreak of herpes that was terrorizing her body, was soon explained to her by her physician. The herpes was a result of her lowered immunological response. Judy had tested positive to the presence of HIV in her blood. As a bonus, she also had pneumonia. "I'll see you in two weeks" the doctor said, while writing Judy's prescriptions. In terror, now, Judy asked the doctor, "But what am I going to do?" Irritated and blunt, the M.D. said, "I told you, I'll see you in two weeks." No counseling, no follow-up advice. At this, Judy started crying. "Please don't do that in my office" was the last help the doctor offered.

The year in which this scene occurred was 1991. It was not a good year for Judy Burman. Within a month of her diagnosis, Judy's weight dropped from 145 lbs to 98 lbs. After telling her husband of her HIV status, he began divorce proceedings against her and threw her out of the house. Now she was sick and homeless. She moved in with her brother, the only member of her family speaking to her. Shortly after the move came the 3 alarm fire that made her homeless once again.

Judy's divorce was at first "good news/bad news." Then it became "bad news/bad news." The good news was the alimony she was paid. It wasn't much, but it was all the money she had. The bad news was the loss of Judy's son Craig. Judy and her husband had adopted Craig when he was a baby. He was later diagnosed as autistic. The subject of institutionalizing Craig was brought up, but Judy refused to consider it. Having grown up with a handicapped sister, Judy knew that a family's love was a much better choice. Placing Craig in an institution might be a future option, but it wasn't a present given.

Now 9 years old, Craig is living with his father and Judy was living wherever she could. After accepting a job in Chicago, Craig and his father moved from Rhode Island leaving Judy behind. The bad news/bad news came a bit later in

the form of a warrant stating that Judy was going to lose her alimony unless she came to Chicago. Ill and with no money, this was not possible for Judy to do. She hired a lawyer and contested the action her x-husband had instigated. The divorce had meant the loss of Judy's health insurance.

Judy's family, refusing to believe she had contracted HIV through the blood transfusions during two major operations in the early 80's, abandoned her. All except her brother Joey. When Judy told her mother about her sero conversion, her mother cold cocked her. In response she cold cocked her back! On the way out Judy angrily told her mother "to educate herself." Over time Judy and her mother managed to re-establish contact. Her mother, however, refused to hug Judy and at first tried sprinkling holy water on her when she would stop by.

Though Judy felt that "life had become a deep, deep hole. I just kept grabbing at roots to pull myself out." Her determination has served her well. Judy entered drug trials in Providence, RI. Although it was a double/blind study, i.e. Judy might receive either drug being tested on a placebo, she began to feel better. She had lucked out and was being given the drug.

Although feeling better, Judy was still very ill and couldn't work. The Dept. of Welfare was not much help. A worker there told Judy to try harder and not to complain; after all, Judy's illness was her own fault.

Dealing with poverty, sickness, rejection and the sullen indifference of bureaucracy made Judy more determined, not less. She

began to question the emphasis placed on profit over the alleviation of a patient's physical and emotional misery. Her mantra became "I will not be defeated!" Judy also began to learn that it was not wrong to focus on oneself. Rather, it was necessary and the affirmation of her worth. Faced with intolerance from others, Judy's response was to become more tolerant herself.

Judy first heard about the Provincetown from a friend. After a short visit here, she fell in love with the town. Soon after, she left Providence and moved here.

Judy feels comfortable being a person with AIDS and living in Provincetown. She feels she doesn't need to explain herself to any-

one here. The acceptance and help Judy finds here has rejuvenated her.

In Judy's words, Provincetown is a place of angels." For two years Judy lived in Foley House. The community spirit she found in the shared meals and shared activities; the privacy of her



efficiency apartment space; the medical support and the friends she has made, give her hope for the future, even if this new-found hope is at times coupled with sadness. The recent loss of her friend Stanley illustrated this. When Judy arrived in P'town, Stanley took her under his wing and taught Judy the ropes. Stanley became a type of mentor for Judy. His loss is deeply felt by her.

Judy now has her own apartment on Beach Point, near the ocean. For Judy, the water is a source of peace and renewal.

Judy has also blossomed artistically. Her creatures made from shells and other found objects, are in constant demand. Her art is rewarding in many ways. The feeling of being productive and the happi-

ness of those receiving the characters a gifts, please Judy to no end. Judy donates her art to the PASG for fund raising purposes and is also a superb envelope stuffer.

If one of Judy's friends is feeling down, Judy creates a character particular to his or her likes or hobbies and surprises the friend with the gift. A lifting of spirits occurs soon afterwards. Judy's shell characters are exuberant in their bizarre whimsy.

For one friend who does drag and likes cats, "I made him a cat in drag and he sees it when he drinks coffee in the morning and it helps him feel better." Many of her pieces she gives away.

For medical treatment, Judy's regime includes: Viramune, Paravachot, Zerit, Epivir. This combination works very well for her. She has been taking Crixivan but due to high cholesterol and extreme nausea was forced to discontinue it. Since she began the new meds, Judy's viral load has dropped to undetectable.

Like everyone else, Judy has good days and bad days, is in a bad temper or good spirits. Life is life. One thing that doesn't change is how deeply touched she is due to all the support and love she receives from the PASG, her friends and the P'town community. These are her family now.

Having AIDS has made Judy keenly aware of life. She refused to give up. At the end of the interview I asked Judy what had been the most vivid impression before her new life here. She recalled the time when a friend and she had been walking along the beach talking about what happens after one dies. Her friend brought up his belief in reincarnation. Judy laughed, explaining that her father, with whom she was extremely close, told her that if he died he wanted to come back as a dolphin. Hearing a noise, they both looked out toward the water and saw a white dolphin arc through the air and re-enter the bay. Not strange, just Provincetown.

Consumer Biography, Mark Baker

Allow me to introduce myself to those who may not know me. My name is Mark Baker, and I tested HIV+ on August 22, 1985 in New York City when I was 28 years old. I would have been diagnosed as having AIDS since my CD4 count was 195, had the CDC (Centers for Disease Control) had a formalized definition for AIDS at that time (by today's CDC definition, CD4 counts under 200 qualify a person for an AIDS diagnosis). Also at the time, there were no approved HIV/AIDS medications; so, my doctor just told me not to drink alcohol, take no drugs whatsoever, eat well and take vitamins. My doctor also gave me 6 months to one year to live. Devastated, I immediately began to learn how to take better care of myself and what having HIV/AIDS meant.

In New York City in October 1985, GMHC (Gay Men's Health Crisis) was conducting its first HIV/AIDS study called "800 Men" - I was #749. There I learned about the HIV virus, how it interacts with the body's immune system, and about safer sex guidelines. In 1987, I came down with the first of two bouts of shingles. Each case (they were about one year apart) was most probably the result of stress from the AIDS-related deaths of close friends. In September 1989, there was a new "P-24" antigen test that supposedly determined the activity of the HIV virus in your body, and there was finally an FDA approved HIV drug - AZT. On September 27th, I received my first prescription for AZT. I was to take 6 capsules a day - 1 every four hours and 2 before bedtime. This was the beginning of a journey that has lasted over 15 years now, and has run the gamut from AZT-mono therapy (now considered a definite "no-no" in the treatment world) to a double-protease inhibitor (PI)/double nucleoside reverse transcriptase inhibitor

(NRTI) antiretroviral "cocktail" to my present PI/NRTI/NNRTI (non-nucleoside reverse transcriptase inhibitor) regimen. From 6 pills a day in 1989 to up to 30 pills a day in 2000!

Along the journey, I have put a lot of faith in complimentary therapy - that is, vitamins, minerals, herbal supplements, massage therapy, acupuncture and good old exercise at the gym. I firmly believe that the body requires some balance to the Western HAART (Highly Active Anti-Retroviral Therapy) medications - and that balance is provided by these com-



plimentary therapies. In my mind, I am alive today because I have always strived to keep my body in balance.

I also attribute my continued well-being to moving to Provincetown, which I did after living in New York City for the decade of the 1980s. On March 1, 1990, my partner, sculptor Tom McCanna, and I moved from NYC and Woodstock, NY, to Provincetown - for more quality of life and less quantity of life. Tom and I bought a small home in the East End and pro-

ceeded to make a life together by building a garden and raising our "family" (our daughter, a Jack Russell Terrier named Cosmos, and then - 5 years later - our son, another Jack named Puck).

My HIV/AIDS journey has been one that I describe as a roller coaster ride - full of the ups and downs one lives through by virtue of taking medications with tremendous side-effects and living with a disease that throws you serious infections every now and then. I was able to continue working for ten years after my HIV+ diagnosis. Then, I had a bad spell with meningitis, which landed me in the hospital, and I stopped working. I have been one of the fortunate ones who have seemingly bounced back (the "Lazarus effect") because of my most recent HAART regimens and complimentary therapies. I have volunteered for a lot of HIV/AIDS-related work with various local, regional, state and, most recently, national organizations. For that I am very grateful, for it keeps me busy and contributing to others who are infected and affected by HIV/AIDS. But still, in the back of my mind, I can't help wondering when the other shoe is going to drop. It's a fear that everyone with HIV/AIDS lives with.

I used to pray just to live long enough to turn 40 (which I did three years ago). Then, it was just to live to see the year 2000 (been there, done that!). Now I pray to live to see the day when PWHAs (people with HIV/AIDS) don't have to take 20 - 40 pills a day to stay alive, to see the day when there is a cure for those infected and a vaccine to prevent any further infections from ever happening again. Let's pray we all see that day come very soon.

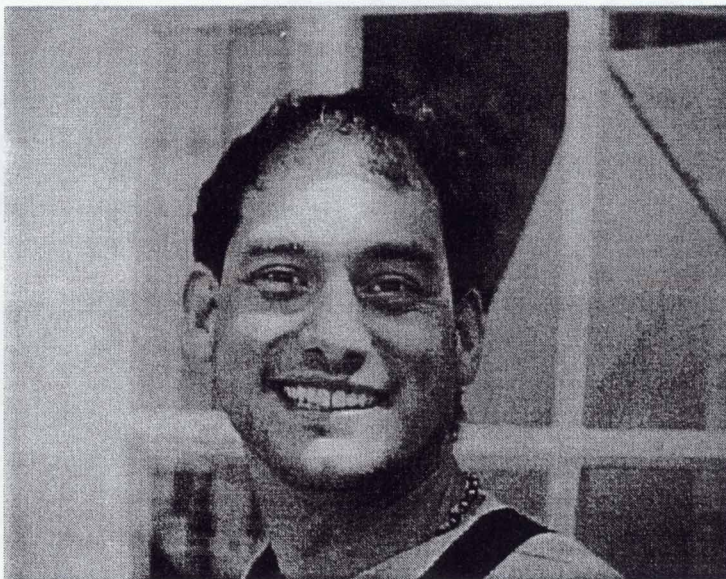
Consumer Biography Tony Tigno by Peter McDonough

In 1995, Tony Tigno was living in Boston where he ran an AIDS Prevention Program for homeless kids. The program dealt with a group that included: street kids, run-aways and hustlers. Trying to help these kids was an intense, high stress job. 1995 was also the year that Tony discovered he carried the HIV virus. He hadn't felt well for sometime, experiencing fatigue to the point of exhaustion on an increasingly regular basis. Tony retired from his job and his life turned from devoting his time and energy in helping others cope with HIV to helping himself cope.

Since protease inhibitors had recently entered the market, he tried them. It became apparent, however, that side effects like: debilitating nausea and diarrhea made it impossible to continue taking them. So he stopped. Tony had also been using acupuncture, massage and Chinese herbs. After some improvement, Tony stopped taking the herbs daily and continued with the massage and acupuncture. Coupled with a life containing significantly less stress boosted his immune system and imparted a feeling of well-being.

Also at that time, Boston Living Center was offering a course teaching

Yoga breathing techniques. Tony took the course, which resulted in even deeper levels of calmness and peace. At the center Tony also met people who introduced him to the teachings of Sri Sri Ravi Shan Kla, which have continued to deeply resonate within. Tony's quest for inner strength in dealing with HIV bit deeply as well with a nourishing of his spirit. On a superficial



level, the breathing techniques, massage, acupuncture and study, have been valuable tools for experiencing a soothing relaxation. On deeper levels, the practice and study has been tremendously beneficial to Tony's outlook and spirit.

Tony describes his life now as a profound encounter with his spirit. He had sensed this possibility before, but was unable to access it due to the type of

life he was living and the unchallenged attitudes, which governed his actions. The self he formally avoided before is now honored and the results fill him with gracious, harmonizing awe. When Tony left his job, he decided to move to Provincetown for the summer. Like many he stayed. In staying he got sober and stays sober via a 12 Step Program.

Last winter Tony

fully aware of the progression of this disease.

Previously, due to its rapid progression, survival of PML was measured in weeks or months. The character played by Eric Roberts in the movie "Its My Party" had PML and died soon after diagnosis with the advent of HAART drugs, however, there is now some qualified hope. These drugs have the ability in some cases to hold the virus at bay. With HAART drugs, the body can sometimes produce T-lymphocytes, which then fight the PML virus. Tony discovered he has these T-lymphocytes and the progress of the PML virus seems to be checked.

Having to take protease inhibitors again has been somewhat easier for Tony than his first experience with them. There are still side effects coupled with depression and a type of disassociative reaction that sometimes leaves Tony feeling removed from what he experiences. Tony never the less continues with his practice of meditative breathing, massage, acupuncture, spiritual study and leading of a sober life. He is glad to be a member of P-town's community and glad too, for the loving friends who nourish his spirit.

noticed a drooping in the left side of his face. Then he began loosing and eventually lost the fine motor functions in his left hand and wrist. Tests confirmed a diagnosis of PML, which stands for Progressive Multifocal Leukoencephalopathy, which was first, discovered in leukemia patients. The virus produces lesions in the white matter of the brain. Since the gray matter is not affected, one is

Consumer Biography Alan Nieman, *by Peter Mc Donough*



When Alan Nieman was 17 years old, he left his hometown of Groton, Ct. and headed to New York. He stayed in New York, working in gay clubs and enjoying a party or two, until he was 33. It was then that he and a boyfriend came to Provincetown for a weekend. On Monday, the boyfriend went back to New York and Alan stayed in Provincetown. That was 1991 Alan is still here.

In August 92', one year and two days after moving to town, Alan's HIV results came back and he found out he was positive. His reaction to the news was not uncommon. "I went a little nuts," he said. He became clinically depressed and gave all his possessions away, feeling that the end was near and he wouldn't be needing them. 1992 was pre-HART. Few HIV medicines were available other than AZT, which did him more harm than good.

Alan describes his

first AIDS Doctor as being "lousy", and never explaining options or diagnosis to him. After nine months, Alan fired him. 1992-93 became a year of crippling depression, bringing on alcohol, drugs, and suicidal ideations. He was hospitalized and placed in the psychiatric ward. Leaving there he entered Gosnold Drug and Alcohol

Rehabilitation Center. In 1993, while working at the Boatslip in Provincetown, Alan became seriously ill, causing a return to being hospitalized. That incident marked his exit from the work force. He was accepted into Social Security Disability.

His need for housing assistance forced him to leave Provincetown- he couldn't find an apartment-and relocate to Hyannis. Getting around Hyannis proved to be much more difficult than getting around P'town. Alan was grateful when he found a place in P'town and was able to return.

Alan's health continued to deteriorate. He had wasting syndrome as well as contracting two different types of cancer. Chemotherapy and radiation therapy forced him to begin wearing adult diapers. He felt so bad, and was in such constant pain, he picked out a room at Hospice, feeling

his time was fast approaching.

Then he started to feel a little better. He progressed from bedridden, to wheelchair, to a few tentative steps using a walker. Protease Inhibitors arrived and Alan began taking them with the result that walking unarmored replaced the walker.

Every three or four months, however, Alan must return for surgery to remove cancerous malignancies. At times, although taking major doses of painkillers, his pain becomes so severe that he has found himself on the floor screaming to die.

Somewhere along the line, the novelty of living the party life disappeared. Alan says that his life has become simplified by necessity. Alan's reaction to HIV meds is refractive. Every six months, or so, their effectiveness in keeping the virus in check begins to diminish, causing his viral load to skyrocket and his T-cells to plummet. Thus he has tried nearly every prescribed medication as well as a number of experimental ones.

Alan's current regimen for HIV as well as other physical ailments is: Androgel/testosterone for wasting, Deoderized Tinctive of Opium- for diarrhea, MS Contin- timed released Morphine, Acyclovir, Ziagen, Eпивir, Neurontin-which allowed him to leave his wheelchair, Paxil for depression,

Megace-for appetite-Alan tried Marinol but it was effective for only two weeks, Zerit, Ultrase-aid in digestion, Lomotil, Reglan, Pepcid, and Percocet.

In spite of or because of everything, Alan's able to maintain, most of the time, a positive out look on things. Things that were bothersome in his past are no longer so. Relationships have changed as well. After several years in an abusive relationship, he decided that he had had enough and left. His taking charge of his life felt good. He is not looking to get married again. Now he accepts that he "makes a better mistress than wife". His free time is used in volunteer work, which includes talking to high school students about the reality of HIV/AIDS. He describes his relationship with his current doctor as "great". He takes his life a day at a time.

Disclaimer:

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