Dynamic Duo: Marlene & Margaretha Diaz

Holistic care and activism keep Marlene Diaz and her daughter going

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Marlene Diaz is one of the nation's leading advocates for the rights of mothers and children with HIV -- 85 percent of whom are Latina, Latino or African American. Diaz, 33, maintains an exhausting pace: A board member of the HIV Law Project and Just Kids, pioneering New York City organizations that provide services and advocacy for women and children with HIV, she is active with numerous other AIDS groups -- all while working part time at the Gap. "Fatigue notwithstanding," she says, "I lobby State Assemblypersons, U.S. Congress members and even my mother when she needs it." Diaz is also the nexus of an informal network of HIV positive Latina women who, stigmatized by the disease, anonymously seek her advice on many issues. Her insightful AIDS reporting has appeared in such newsletters as SIDAhora, Treatment Review and Women Alive.

POZ *visited Diaz in the cozy, modest Chelsea apartment she shares with her HIV positive daughter, Margaretha, 3. They were still savoring a recent Surrogate Court victory securing her partner Cheryl's rights as Margaretha's guardian if Diaz dies -- the first such win for a lesbian couple in New York City. Anyone meeting Diaz can't help but be moved by her intelligence, warmth and dedication to serving others.*

In December 1992, after I tested positive at St. Vincent's Medical Center, I was in shock. I knew about AIDS, but never had I heard of HIV. With a 450 T-cell count, I didn't believe I'd live very long. Eight months pregnant and determined not to take any medication that might harm me or my baby, I walked straight to a health food store not one block away. Once inside, too embarrassed to say I was positive, I murmured, "What do you have that's, like, antiviral?" I thought I was being discreet. They gave me an echinacea-goldenseal herbal combination, great for fighting a viral infection lasting a week, but not for battling HIV.

After Margaretha tested positive at age two months, I needed answers Western doctors didn't have. I joined ACT UP's caucus for mothers and children with HIV, which grew into the independent group Just Kids. Now my activism takes many forms. Whether I'm teaching advocacy skills to women or giving input on a federal study, activism gives me a sense of purpose.

Beyond that, the activist community provides me the most important and accurate information on

how to stay alive. At Just Kids, Margaretha and I receive emotional and practical group support from other parents and children affected by HIV. And DAAIR, a PWA buyers club I joined, is a source of both discount nutrients and truly lifesaving alternative treatment information.

Still, sometimes I wish I were anywhere but in my own body. I hate when 99 percent of my day is AIDS-related. Today, I spent the morning at the HIV Law Project telling the press why I oppose a Congressional bill to require HIV testing for newborns. I spent the afternoon convincing Margaretha's doctor that I'm not against traditional medication, but I do want to know the consequences of each option. On days like this I'm reminded to plan small getaways, even to the local park.

When immediate health problems flare up for either of us, Plan A is homeopathy -- a system of nontoxic, over-the-counter remedies that use our bodies' own curative powers. But my overall approach is holistic: Homeopathy, medicines from East and West, diet and nutritional supplements, spirituality, culturally relevant support, mental health -- all help maintain Margaretha's and my health.

We both see several practitioners. We go monthly to Dr. Mary Waldron, an infectious disease specialist at Beth Israel Hospital's Peter Krueger Clinic, which also offers complementary modalities for free. I consult Dr. Robert Schiller, a rare breed of M.D. who accepts Medicaid and incorporates homeopathy into his practice. Under his guidance, I take evening primrose oil, which helps my persistent skin rashes. It also has woman-friendly benefits so I don't ride a broomstick across town during my period.

Every week, we see two compassionate, HIV-experienced licensed acupuncturists, Urayoana Trinidad (for Margaretha) and Jackie Haught (for me). Besides providing acupuncture and herbs, they guide me in using aromatherapy (fragrant aromas absorbed through the nose) and Bach Flower remedies (diluted extracts of various flowers) to heal specific ailments. The Bach remedies are especially helpful when I feel overwhelmed or when Margaretha has night terrors. I also get very affordable massage therapy at the Swedish Institute -- great for managing stress -- and for years have had my head shrunk.

I never took AZT because I heard it makes you upchuck. I did, however, take the protease inhibitor Crixivan for a year when it was experimental. It brought my viral load way down for eight months, but I stopped taking it because of severe joint pains. They still don't know how well it works in most women. Instead, I take SPV-30 (boxwood extract), a natural antiretroviral in French clinical trials. Today the only traditional drugs I take are antibiotics for an aggravating five-month ear infection.

Since my diagnosis, my T-cell count has stayed above 200 (most recently 270), so I haven't needed PCP prophylaxis. I've had no opportunistic infections. My viral load is now 30,000 -- not high at all. After some wrangling, my physician and I cut a deal: If my viral load passes 50,000, I'll start on 3TC and d4T. With my daughter only three years old, if I started taking those drugs now, by the time she's five I might have no pharmaceutical options left.

When the doctors told me Margaretha was positive, they suggested AZT for her. I declined, fearing the toxicity. A clinical trial later found that children on AZT alone died faster than those on ddI or AZT-ddI combo. By then her liver problems ruled out ddI. When SPV-30 came out, I gave her the powder from the capsules. I tried to disguise the sickly green glop floating in her orange juice, but Margaretha -- clever like most kids -- refused to take it. When will drug companies make more kid-friendly AIDS meds?

Margaretha has had excellent results with non-Western medicine. At age 18 months, her liver became diseased, spewing enzymes into her blood at a rate five times normal. After three months of guessing, Western doctors opted for the popular “let’s wait and see” nonapproach to disease management. When you’re a mother, you don’t wait and see. Instead, I chose an approach suggested by DAAIR’s director, Fred Bingham -- a long-term survivor: I placed Margaretha on glycyrrhizin (a licorice root extract approved in Japan for liver ailments), alternated it with thioctic/lipoic acid (a strong antioxidant) and silymarin (milk thistle extract) and waited, fearing the worst. After five weeks, my baby’s enzymes were within the normal range, where they’ve remained. Fred saved her life.

Margaretha’s most nagging health problems now are recurrent bronchitis and poor weight maintenance due to nutrient malabsorption. The biggest challenge is getting her to eat more. It’s not like she’s finicky; food just goes right through her. Besides her meals, I give her protein and carbohydrate supplements that maintain her weight, but it’s still too low.

I’ve come a long way in three years. Today, activism is my driving force. I have a need to make a difference and contribute something larger to life -- a need deeply connected to my love for Margaretha. When you’re responsible for someone else’s future, you want to leave behind a world better than the one you inherited. So I cannot rest in peace. Not yet. There’s more work to be done.

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