Pair of Aces

Marlene and Margaretha Diaz's prescription for living well

December 1, 1998 By Lark Lands, PhD

POZ welcomes New York City AIDS activist Marlene Diaz to What This Means (see also her profile, "Working Mom"). Each month, we will be alternating coverage of Marlene's test results with those of PWAs Sean Strub and Stephen Gendin. In this issue, Marlene (whose last medical interview was in the August/September 1996 Checking In) fills us in on her treatment philosophy and how she and her daughter Margaretha, age 5, are doing.

Knowledge is power: That's what guides me. When I was diagnosed in 1992, I was scared, stressed and uninformed. As my CD4 counts nosedived, I got terrified. When Margaretha tested positive at two months, all her doctor had to offer was way-too-toxic AZT. That's when I began to educate myself on every aspect of this disease—which has made all the difference. The more I learn about listening to my body, using medicines properly and countering symptoms with nutrients and herbs, the more I'm able to handle it. And the less scared I am when trouble flares.

Gaining this knowledge didn't come overnight; it has taken years. Years of asking questions, reading everything I could get my hands on, going to conferences. And years of experience groping toward solutions for every new problem.

My first impulse after my diagnosis was to think about nutrition. My mother's from Peru, so good food and herbal teas were how you handled illness when I was growing up. That rubbed off on me, so I began taking supplements and herbs. I also try to provide a highly nutritious diet for both of us. The diet/supplement combo has really eliminated symptoms, so we keep it up [see "The Diaz Medicine Chest"]. I also do acupuncture twice a month and body work—shiatsu energy therapy and Swedish massage—when I can.

Taking care of emotional well-being is also key: You deal with loss, fears, constantly being broke. Going to a therapist and participating in a support group helped me greatly in keeping a positive attitude. But recently my therapy program lost its funding, and I no longer have time for the group. So now I use the skills I've learned, and hang onto that all-important belief in the possibility of our survival.

Yes, doing all this is very time-consuming. Plus it can be difficult to get 60 pills a day into Margaretha—intense for a 5-year-old. And with insurance not reimbursing for most supplements, it

runs into big bucks. Margaretha's supplements alone average $150 to $200 monthly.

What keeps me sane is the duo of decent lab numbers and feeling good. Our CD4 percentages have always been a reassuring 30-plus; other numbers have fluctuated, but my current CD4 count is 460, with viral load at 5,000, and Margaretha's counts are 1,299 and 3,000. I've never had an opportunistic infection, although I get three or four bouts of bronchitis a year. As an infant, Margaretha had wasting [reversed with a herbal formula called Bioradiance] and LIP, a type of pneumonia [untreated due to inadequate medical care; resolved with alternative therapies]; she's now fine.

I took Crixivan [indinavir] monotherapy for two years when it was still experimental, but had to stop because of kidney stones. Then I went on 3TC and d4T for 18 months, until neuropathy forced me off them—although the pain has worsened since then. For now, with my lab numbers fairly stable, I feel safe in sticking with a drug-free protocol based on immune-supportive nutrients and herbs.

My philosophy is simple: Take an integrated approach to the disease, both meds and complementary therapies. But don't be hard on yourself and don't get overwhelmed. Step by step, just work everything into your schedule reasonably. And never forget to take time to enjoy your life. It's not just about living long, it's about living well.

The Diaz Medicine Chest

Marlene

Category: Nutrient supplementation
Treatments: Earth Source Multinutrient tablets (with spirulina and wheatgrass)

Category: Antioxidant protection
Treatments: vitamin C tablets,* alpha-lipoic acid capsules, glutathione capsules

Category: Immunity enhancement
Treatments: Maitake mushroom capsules, Enhance herbal tablets, Resist herbal tablets

Category: Wasting prevention, blood-fat normalization
Treatments: Carnitor (carnitine) tablets (prescription paid by insurance)

Category: Liver support
Treatments: milk thistle caps, alpha-lipoic acid

Category: Neuropathy alleviation
Treatments: grape seed extract caps (GLA source)

Category: Absorption improvement
Treatments: glutamine powder

Category: Probiotic maintenance
Treatments: acidophilus capsules

Category: Gas prevention
Treatments: digestive enzyme tablets

Margaretha

Category: Antiretroviral action
Treatments: nelfinavir (Viracept) tablets, ddI (Videx) liquid, d4T (Zerit) capsules

Category: Nutrient supplementation
Treatments: chewable multivitamin, Twinlabs Miquick (multimineral) liquid, black currant oil capsules (for essential fatty acids)

Category: Antioxidant protection
Treatments: Prevail Children’s Antioxidant capsules, chewable vitamin C, glutathione capsules

Category: Immunity enhancement
Treatments: Prevail Children’s Defense capsules** (nutrients, plant enzymes and herbs), homeopathic remedies (cell salts)

Category: Heart fortification
Treatments: Co-enzyme Q-10 tablets

Category: Wasting prevention, blood-fat normalization
Treatments: Carnitor (carnitine) tablets

Category: Liver support
Treatments: milk thistle tincture***

Category: Probiotic maintenance
Treatments: acidophilus powder

Category: Gas prevention
Treatments: Prevail Children’s Digest capsules

Category: Hair brittleness alleviation
Treatments: silica liquid

*7-9 grams per day (tissue-saturation level for her—varies from person to person)
**Taken one week on, one week off
***Taken three times a week*

NOTE: MANY TREATMENTS ARE MULTIPURPOSE; PRIMARY ONES LISTED. OTHER SUPPLEMENTS ARE ADDED AS NEEDED FOR INFECTIONS OR SYMPTOMS.

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