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Consult your doctor! The only purpose of this booklet is to educate and to inform. It is not a substitute for professional care by a doctor or other medical professionals. TheBody.com neither endorses nor opposes any particular treatment option discussed in this booklet. Instead, we encourage you to discuss your options with a health care provider who specializes in treating HIV. We would like to thank Sharon Dian Lee, M.D., for providing a medical review of this booklet. We'd also like to thank Jorge Zepeda, ACSW, Latin Programs Manager at the San Francisco AIDS Foundation, and the members of "El Grupo" for their amazing help in making this booklet.



# Did You Just Test HIV Positive? You're Not Alone!

We don't want to make light of what you're going through. Getting an HIV diagnosis may feel like the worst thing that has ever happened to you. Anger, fear, numbness, confusion, depression—all are completely natural reactions to testing HIV positive. Allow yourself to feel the way you do. Don't be hard on yourself or think you have to be strong. You don't have to be anything. It is your life, your body and your health. Allow yourself to take time to decide what you want to do. Then go do it.

BUT PAY ATTENTION TO THIS: There is life after testing positive. One million Americans are now living with HIV, and approximately 18 percent of those newly diagnosed with HIV are Hispanic. In fact, although they may seem invisible, more than 80,000 HIV-positive Hispanic men and women are estimated to be living with HIV in the United States.

right now, know that there is a big community of people out there ready to provide information, support, advice and many other resources. In this booklet, you'll meet some of these men and women. We hope they will help you fight the fear, ignorance and prejudice about HIV and HIV-positive people that unfortunately still exist. We hope you'll use this booklet to learn more about HIV—and to discover some helpful steps you can take to live a full and happy life with HIV.



Once you find out that you are HIV positive, one of the most important things you can do is get informed.

**THE FACTS ABOUT HIV:** There are hundreds of different kinds of viruses in the world. Some are just annoying, like the viruses that cause colds. Others, like HIV or the hepatitis C virus, can cause serious, even life-threatening, illnesses. How can you prevent HIV-related illnesses? By taking care of yourself—which includes taking HIV medications that can control HIV.

**WHAT HIV DOES TO YOUR BODY:** HIV is dangerous because it sets up shop in your immune system, your body's natural defense against disease. It especially targets your "CD4 cells," also called "T cells," which your body uses to fight infections. HIV takes command of these cells—like a pirate taking over a ship—and uses them to reproduce itself, creating millions of new viruses every day and slowly but surely weakening your immune system, which is what can put you at risk for developing potentially dangerous illnesses.

The stronger your immune system, the longer it can keep up the fight against HIV. If you treat your immune system well—especially by taking care of yourself, reducing stress, avoiding alcohol and not smoking cigarettes or using recreational drugs—your immune system may be able to keep HIV in check for years.

But even if you treat your body well, HIV can still eventually get the upper hand. Then it's time to call in the big guns: HIV medications. We'll talk more about HIV medications later. First, let's dispel some myths about HIV.

"At first, I was scared to start treatment. I knew a little bit about HIV, but I was pretty ignorant. I had heard stuff like, 'medications kill people,' crazy stuff like that. When I started treatment, I had side effects like diarrhea for a couple of months. But it went away and I haven't had any problems at all, after that."

-Raúl Roldán, diagnosed in 2006



## **Myth Versus Reality**

Even though the facts about HIV are well known and agreed upon by every HIV specialist and every single HIV/AIDS organization in the United States, there remains a lot of misinformation about HIV.

## MYTH: HIV can be transmitted through everyday contact.

**REALITY:** There are absolutely **no** documented cases of HIV being transmitted casually through handshakes, hugging, sharing cups or dinner plates or using the same bathrooms.

### MYTH: HIV doesn't cause AIDS.

**REALITY:** After 25 years, there is a mountain of proof that HIV can cause life threatening illnesses and advanced HIV, also known as AIDS. Everyone who ever got sick or died from AIDS had one thing in common: They had HIV.

## MYTH: Taking HIV meds means you don't have to practice safer sex.

**REALITY:** HIV meds can get rid of nearly all the virus in your blood. Although this will decrease the risk of infection to your sex partners, blood, semen and vaginal fluids still contain HIV. This means that protected

sex is the rule to keep your partner safe. Plus, you can get in serious legal trouble if you don't tell your partner about your HIV.

## MYTH: HIV is a gay disease.

**REALITY:** Tell that to the more than 125,000 women living with HIV in the United States. Or to the men who got HIV through heterosexual sex or intravenous drug use.

## MYTH: There's a cure for HIV, but only the rich have it.

**REALITY:** If rich people had a cure for HIV or AIDS, people like Magic Johnson, who is a multimillionaire, would be cured. Yes, Magic looks fantastic and—even with HIV—is healthier than many HIV-negative Americans. But that's because he takes care of himself and is on HIV treatment—the exact same treatment available to everyone with HIV in the United States.



How do you tell friends or family that you have been diagnosed with HIV? It's one of the greatest challenges you'll face—and it's not something to rush into if you're not ready. There are some important personal steps you should take before you disclose your status to others.

#### **FORGIVE YOURSELF**

HIV is a loaded term: An ignorant world has wrongly stuffed those three letters full of shame and judgment. But no matter what anyone tells you, HIV is **not** a **punishment for sin or immorality**. Having HIV is not a crime. HIV is just a virus that causes a disease. It does not discriminate. Anyone can get it.

"In the beginning, I couldn't forgive myself for getting HIV," remembers Heidi Nass, who was diagnosed in 1996. "I felt compassion toward others, regardless of what led them to their infection, but I could not find it for myself."

This changed for Heidi when she spoke with a close female friend, who had gotten HIV long ago from using dirty needles when shooting drugs. Her friend counseled, "If you're looking for reasons to feel shame, you'll always be able to find them. At some point, though, you might want to look for something else

... like forgiveness." That is the moment that Heidi remembered something she had forgotten: "Forgiveness is something we choose; it only happens when someone chooses it."

#### **GIVE YOURSELF TIME**

There's no rule of thumb that can tell you how long you will need to come to terms with your HIV diagnosis. Some people need a few weeks or months; for others, it can take years.

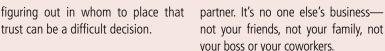
So give yourself time. Everyone adjusts in his or her own way. Let yourself have the time and space you need to find the answers you're looking for.

#### **SEEK OUT SUPPORT**

Once you have taken the time to get used to your new status—and this may take awhile—an important step to take is to find someone you can confide in—someone you can trust who will be there when you need them. Emotional support is essential for your survival. Although

TWhen I told a friend I was positive, she got up off her chair and hugged me. I think at that time, that's all I needed. I needed to see that—even though I had this dreaded disease that everyone was saying was so terrible and only bad people got—I could still get some affection, care or concern from somebody else."

—Bernadette Berzoza, diagnosed in 1989



When Joseph Torres, who was diagnosed in 1995, told his family, they were "shocked, and there were a lot of tears. But there was also a lot of support from cousins and aunts and my brothers and sisters. ... There are a lot of people out there in this world who haven't read about HIV, who haven't really looked into it. They make comments that don't make any sense, whereas my family members and friends, they went and studied HIV."

If you have no one in your immediate circle that you feel you can trust, read Step 3 and contact one of the resources listed on page 19. Once you feel confident that you've got a base of support, you can begin to reach out to the people you weren't ready to talk to at first.

Of course, there is absolutely no reason to tell everyone you know that you have HIV. The only person you are obligated to reveal your status to is your sexual

Some people find that it's an important part of their own healing process to disclose their status to others.

regardless of how they might react.

Ultimately, by forgiving yourself, giving yourself time to deal with your diagnosis and then seeking out support, you'll have been as a place where JUV

and then seeking out support, you'll be able to get to a place where HIV is just another part of your life—not something that defines your life.

Ed Viera Jr., who was diagnosed in 1987, says, "My advice to newly diagnosed people is to develop a support network. It's really important to have one—to have a second and third family. In my case, my family turned their backs on me, closed all doors. I had to develop support networks by going to HIV support groups. Go to a library, just talk to people, get out there and stop being isolated."

"When I told my parents that I was positive, they said, 'You are our daughter, and we love you and we will love you, three months, six years, 10 days ... whatever the time you will live, we will be with you."

—Gracia Violeta Ross Quiroga, diagnosed in 2000



# Dealing With Machismo and Homophobia

If you're Hispanic, you already know how common the culture of "machismo" is among Hispanics. Avoiding condoms, having a lot of sex partners and dominating women are still subtly encouraged. Homosexuality is for the most part still taboo. All of these are reasons why HIV rates are growing in the Hispanic community, researchers say.

Even after you've been diagnosed with HIV, machismo can still have a major impact on your life.



"There's a thick blanket of denial in the Latino community," confides **Enrique** 



**Enrique Franco** 

Franco, an Army veteran who was diagnosed in 2007. "The Latino community accepts my HIV, but it's 'in the family.' They don't talk about

it. ... We treat HIV like the pink elephant in the living room. It's there, but we won't

talk about it or even my homosexuality." Enrique says that when he tells someone that he's homosexual or HIV positive or both, "I can see a change in the look on their face. I transform from Chico to 'this guy.'"

For Enrique, it's not easy to judge others for their stance on HIV. After all, before he was diagnosed, "I was one of them," he admits. "I was like my homeboys. I didn't care about HIV. I hardly knew about HIV. I just knew you got sick and died. But now that I'm a part of it, it's very different on the other side."

Enrique decided that the best way for him to break through the silence and fight stigma is through actions, rather than words. "I'm not going to force it," he states. "I'm just going to live through my actions to demonstrate that not all gay guys try to hit on guys and think about sex all the time, or talk about girly stuff."

**James Nicacio**, who was diagnosed in 2001, has had a similar experience with

**/1** think that the machismo in the Hispanic culture has blocked the progress and acceptance of people who are living with the virus. I know people who say they can't even mention their status to their friends and family members. It's the fear of rejection, of being discriminated or feeling

less than others. That's why you shouldn't reveal your status to another person until you are internally ready." —José Wilson Montoya, diagnosed in 1999



























James Nicacio

his family. "My mom is verv accepting of me and all the decisions that I make in life. She's accepted the fact that

I'm gay, but it's something that was really never talked about," James says. "I think that's pretty common in a lot of Mexican families; it's not discussed. I am who I am and I'm out." However, James realizes he is fortunate: His family has been completely accepting of his homosexuality and his HIV status. "Once I did tell them, once they said that they loved me no matter what and that they were going to support me, and give me every opportunity to take care of myself, then I could move forward."

## **GETTING HELP**

Coming face to face with a lifethreatening disease is daunting for anyone. When the disease is as stigmatized and feared as HIV, it makes it doubly hard. But for many Hispanic men, it's not easy to acknowledge that they may need help. "There's just too much stress to do it alone," says Roger Solar, who was diagnosed in 1999. "In the Hispanic culture, the macho man stands his ground. He supports the family. He takes care of himself. He's the one who goes out and gets that job and gets the money. Whether you are sick or not, you bite your tongue and you don't say anything."

However, Roger is one of many Hispanics who urge people with HIV to fight these social pressures. "It's wrong," he says. "You need people. You need help. You need

to be able to talk to somebody. You need to be able to cry. You need to be able to laugh. That's the only way you can live!"



Roger Solar

# SE UPCLOSE & PERSONAL SE



Name: **Ahmad Salcido** CD4 Count: **545** Viral Load: **Undetectable** Diagnosed: **2007** Age: **23** Job: **Student** 



## WHEN I tested HIV positive, I

felt lonely and deserted," Ahmad Salcido recalls. "There was a pain that wouldn't go away." He knew he wouldn't be able to cope with his diagnosis alone, but he also knew that he couldn't turn to his family: He's never been very close with his Mexican mother or his Arabian father—in fact, they still have no idea that he's gay, and he feels it has to stay that way, at least for now. "My Mexican culture does not approve of HIV, or of being homosexual," Ahmad says. "Being Muslim and being gay? Wow!"

But Ahmad had one person he felt certain he could trust, a close friend living in San Francisco who Ahmad now calls his "little angel." Ahmad's decision to share his HIV status with that friend was a difficult one, but it made all the difference in the world: At

his friend's urging, Ahmad moved to San Francisco, partook of HIV support groups and counseling, and even managed to become part of a clinical trial that provides him with free HIV treatment.

Ahmad also changed his lifestyle: He's eating smarter and making sure his health and happiness are a priority. "I have to take care of myself now more than ever now that my immune system is compromised," he says. "I'm learning how to make the right choices." With help from his therapist, he's putting together a plan for how to come out to his family without hurting them—or himself

Looking back, Ahmad no longer feels the despair he initially felt after he was diagnosed. Living with HIV is not as bad as he feared it would be, he says. "This is a new beginning." n



As we mentioned, nobody should face an HIV diagnosis alone. So, whatever your reservations, make sure you connect with other HIV-positive people. It's a key step towards solving both the emotional and practical problems of living with HIV. Knowing when you need help is vital. An HIV/AIDS organization can be a lifeline. Many such organizations have case managers who can help you move forward on many of your health care issues.

You'll find most, if not all, of the following at HIV/AIDS organizations:

- HIV support groups
- Mental health and substance abuse counseling
- Case managers who can connect you to government aid you may need, such as Medicaid, disability insurance or medication assistance
- Expert information on HIV and nutrition, fitness and other issues
- HIV treatment information and adherence workshops to help with

taking HIV medications

 HIV prevention counseling, safer sex workshops and free condoms

Most big cities have several HIV/AIDS organizations geared to meet the needs of different populations. For help in finding a local organization, go online to www.thebody.com/hotlines.html or call the CDC Health Line at 1-800-232-4636. For online information for anyone just diagnosed with HIV, visit: www.thebody.com/justdiagnosed.

"One of my friends who was sick told me to go to the San Francisco AIDS Foundation. I knew that I could learn a lot over there ... focus on getting healthy and learning about medications. That's why I'm still there, almost every day. They have different classes. Right now I'm taking a class on HIV medications."

—Rubén Echeverría Hernández, diagnosed in 2002







Even if you don't yet need treatment, it's essential that you find a medical professional who is experienced in treating people with HIV. Regular checkups with an HIV health care provider are extremely important, even when you don't feel sick.

You'll need to find a health care provider (this could be a physician, nurse practitioner or physician assistant) with special training in HIV who has treated 20 or more people with HIV, in the past two years. You'll want someone who stays on top of the newest information about HIV medications, tests and other issues.

However, it's just as important to choose someone you like, someone you feel you can trust and be open with. This means you'll need to find someone you can be honest with about

sensitive issues—everything from sex, drugs and alcohol use to missing doses of HIV meds. Communication between you and your health care provider is critical, so if you struggle with English, be sure to find someone fluent in Spanish.

Your health care provider is your partner in fighting the virus. She or he will be your ally for a long time, helping you deal with the ups and downs of HIV disease, the drugs that control the virus, the side effects that may come with the drugs, and many other health issues.



"Get educated. Find a support group, so that if you need to talk to somebody, you can talk there. Because there are people like you who are dealing with the same thing. Also, get a doctor who is a specialist on HIV. That's important, because not every doctor knows about HIV."

—Louis Curbelo, diagnosed in 1987 (pictured with his HIV-negative wife Rosalía)

"It's important that undocumented people know that they should seek HIV treatment and health care and know that they are not going to put themselves at risk for being deported. There is health care for them."

—James Nicacio, diagnosed in 2001





There's a nationwide network of services, programs and resources to help people with HIV remain healthy—even people who may be undocumented or have no insurance or low incomes.

Many big cities have state-of-the-art HIV clinics for people who have no insurance. An HIV clinic will give you better care than other types of health clinics or hospital emergency rooms, since it is staffed by HIV specialists and is equipped specifically to help people with HIV. When you enroll in these clinics, you get medical care from a top team of HIV health care providers as well as counseling and support for mental health, substance

abuse and other issues. You may be assigned to a case manager, who will become the person you can turn to first for whatever help you need—such as figuring out which government programs can pay for your HIV medications and HIV care.

Live in a rural area? Getting the best HIV care possible may mean traveling to the nearest city several times a year—an extra effort, but one that will repay you with better health.

For a list of HIV clinics near you, call the CDC Health Line at **1-800-232-4636** (for Spanish operators, dial 2 on your phone when message begins).

"First things first: Find a good doctor, someone who is an expert on HIV; get checked frequently; get your basic counts at least every three months. Also, begin getting more balanced nutrition. It's also good to get closer to your family, to stop risky behaviors and to get information. If you can, get yourself a computer and get connected to the Internet. There's a lot of information out there."

—Hector Olmo, diagnosed in 2005

















Your HIV-positive test result only lets you know that you've been infected with HIV. To find out if it's time to get HIV treatment, you'll have to visit a health care provider and get two additional tests.

Most HIV-positive people can live many years with HIV before they need to take medications to control it. However, every person who tests HIV positive should immediately have two additional tests: a CD4 count and a viral load test. These tests are the critical measuring tools you and your health care provider will use to see what the virus is doing in (and to) your body.

THE CD4 COUNT TEST

This test, also known as a "T-cell count test," gives an indication of the number of CD4 cells in your bloodstream. The more CD4 cells you have, the stronger your immune system is.

After living with HIV for a while (if you don't take medications), the number of CD4 cells you have will usually fall. This is a sign that your immune system is being weakened.

A normal CD4 count for someone without HIV is usually between 500 and 1,600. Experts generally agree that when your CD4 count goes below 350, you're at a high risk for developing potentially dangerous illnesses, so you should begin taking HIV medications before your CD4 count hits 350.

#### **CD4 COUNT EXPLAINED**

500 – 1,600	
350 – 500	
200 - 350	
0 – 200	

#### THE VIRAL LOAD TEST

Viral load tests provide an estimate of how much HIV is circulating in your blood. Generally speaking, your viral load is not considered as critical as your CD4 count in determining the health "HIV is just three big letters. People hear it and panic. But it's just a big word."

—Beatriz Díaz, diagnosed in 1992



of your immune system. However, once you begin HIV treatment, it is a good measure of how well your HIV medications are working.

A viral load test measures the amount of HIV in a small amount (milliliter or mL) of your blood. Current viral load tests can detect as few as 50 copies of HIV per milliliter of blood. When your viral load test indicates that you have fewer than 50 copies/mL of HIV, your health care provider will tell you that your viral load is "below the limit of detection," or "undetectable."

This does not mean that you no longer have HIV in your body. Even someone who has an "undetectable" viral load can transmit HIV. However, an "undetectable" viral load means that your medications are doing an excellent job of keeping HIV in check.

#### **RESISTANCE TESTING**

Besides a CD4 count and viral load test, your HIV specialist will look at your overall health with a general blood count test. You may also be given something called an HIV drug resistance test. A resistance test will tell you if your HIV has already become resistant to any HIV medications. HIV is "resistant" to a medication if it keeps multiplying rapidly even during the time you are taking the drug. Changes (known as mutations) in the virus, can cause resistance.

How could this happen? The person you got HIV from may have been on HIV treatment and his or her virus may have become resistant to one or more HIV medications. Transmitted along with HIV was their resistance to certain drugs. So before you take treatment, you'll want to be sure your HIV is not resistant to any drugs.

## **DEALING WITH HIV AND OTHER ILLNESSES?**

Be sure to stay on top of HIV as well as any other infections or illnesses. If you are infected, for example, with HIV and hepatitis B or C, your physician may refer you to a liver specialist who also specializes in HIV. If you are seeing other health care providers, besides your HIV specialist, be sure that they are all in contact.





















## WP (LOS) = & PERSONAL SO



Name: **Esmeralda** CD4 Count: **900** 

Viral Load: Undetectable

Diagnosed: **1998** Age: **35** 

Job: Housekeeper



## ESMERALDA

(not her real name) discovered that her husband had HIV only after his death, a few days after he had entered the hospital for the first time. The couple had been living in a small Mexican town. At first, his family didn't tell her what was wrong.

She soon discovered that she too had HIV. She was breastfeeding her baby daughter at the time and, to protect her daughter from getting HIV, she was told to stop breastfeeding. She remembers being "really, really scared" for her baby. Fortunately, her daughter was HIV negative. But Esmeralda discovered that she was pregnant again.

Four days after her husband's death, Esmeralda was encouraged to move out. With little money, one baby, and another on the way, she

had nowhere to go. So, she bravely crossed the border into California to live with her sister-in-law. While she was pregnant with her second baby, a boy, she took medicine to prevent the transmission of HIV and didn't breastfeed him. He is HIV negative.

Esmeralda's life soon took a turn for the better. A social worker, a nurse and a peer advocate helped Esmeralda with services. Through them, Esmeralda met women with HIV who became her good friends. They gave her rides to appointments and supported her.

These days, Esmeralda is happily married to an HIV-negative man. She's doing well medically and she even works full time cleaning houses. On evenings and Saturdays, she takes English lessons. She also volunteers at a women's HIV organization and an HIV clinic.



#### Preferred Anti-HIV Medications for Pregnant HIV-Positive Women

- Retrovir (AZT)
- Epivir
- Viramune
- Kaletra

Anti-HIV Medications to Avoid if You're Thinking About Getting Pregnant or if You Are Pregnant

- Sustiva
- Atripla
- Videx + Zerit

In the dark old days of the late 1980s and early 1990s, when little HIV treatment was available, having HIV dashed all hopes of motherhood. But today, with the right care, a woman with HIV can expect to lead a long and healthy life.

So, if your dream is to become a mother, the likelihood that you'll have an HIV-negative child is greater than it's ever been before. In fact, there's a baby boom among HIV-positive women. What do you need to know about pregnancy and HIV? Turn the

page for answers to some frequently asked questions. Don't forget that regardless of whether or not you want to get pregnant, you need regular gynecological care as well as HIV care.

The biggest challenge in being pregnant and HIV positive is the fear and not knowing, because I didn't know whether my son would be positive or not. At first, I was very uneducated about HIV and pregnancy, because I never intended on getting pregnant ... I cried every day, and prayed every day."

—Jessica Mardis, diagnosed in 1995, mother to an HIV-negative son







# Frequently Asked QUESTIONS About Pregnancy and HIV

Thinking about getting pregnant? Wondering how pregnancy will affect your HIV? Browse through these frequently asked questions and get some answers.

## I DON'T WANT TO GET PREGNANT. CAN I TAKE CONTRACEPTIVES?

Various HIV medications interact with oral contraceptives, making them less effective, so you'll need to also use other contraception to avoid pregnancy if you are taking HIV meds.

## IS IT HARDER FOR HIV-POSITIVE WOMEN TO GET PREGNANT?

Women with HIV may have a harder time getting pregnant. If you've been trying to get pregnant for a while, you may want to see a fertility doctor experienced with HIV-positive women.

## MY PARTNER IS HIV NEGATIVE AND I'M NOT. CAN WE STILL START A FAMILY?

There are many ways to have a baby when you are in a mixed-status relationship. Although there is no method that is 100 percent risk-free, there are many low-risk options, from the at home method

of using a turkey baster to paying top dollar at a fertility clinic. The key is for the HIV-positive partner to have an undetectable viral load.

## I WANT TO BECOME A MOTHER, BUT I'M HIV POSITIVE. WILL MY BABY ALSO BE INFECTED?

The most critical thing is for you to have an undetectable viral load. If your viral load is undetectable, and if you take anti-HIV medication before and during pregnancy and delivery, your baby only has a 1 to 2 percent risk of being infected. If you do not take HIV treatment, the baby has a 20 to 30 percent chance of being HIV infected.

## WILL ANTI-HIV MEDICATIONS HARM ME OR MY BABY?

The majority of HIV medications have been shown not to harm babies. Only Sustiva, which is one of the drugs in the one-pill, once-a-day regimen of Atripla, "I started taking HIV medications after my second child was born. That's when my fight started—fighting to be OK. I needed to be OK, I had to be OK, for these kids. Because I'm not leaving these kids alone."

—Esmeralda, diagnosed in 1998



and the combination of Videx and Zerit should not be taken by any woman thinking of becoming pregnant. Talk to your doctor about which other drugs may be harmful during your pregnancy. If you are already taking anti-HIV medications, the worst thing you can do is stop taking them without consulting your doctor first.

HIV medications for approximately six weeks.

#### **CAN I BREASTFEED?**

Breast milk can transmit HIV, so it's recommended that women with HIV do not breastfeed and instead use infant formula.

#### **C-SECTION OR VAGINAL BIRTH?**

Plan for a normal vaginal birth only if you have an undetectable viral load. If your viral load is above 1,000, plan for a C-section since a C-section would dramatically reduce your chance of transmitting HIV to your baby.

## IS PREGNANCY DIFFERENT FOR HIV-POSITIVE WOMEN?

Research shows little difference between pregnancy in HIV-positive women and negative women. Women taking HIV medications may be more likely to give birth prematurely or have babies that weigh less than average.

## WILL PREGNANCY AGGRAVATE MY ILLNESS?

HIV does not progress any faster in HIV-positive women who get pregnant. It's important, however, that you get your HIV and any other disease, such as diabetes, under control before you get pregnant.

## HOW DO I FIND AN OBSTETRICIAN WHO IS KNOWLEDGEABLE ABOUT HIV-POSITIVE WOMEN?

The best person to ask for a referral is your health care provider, if he or she is an HIV specialist. Otherwise, call the largest HIV organization near you and ask for a referral. It's crucial to your health and the health of your baby that you find someone with lots of experience helping pregnant HIV-positive women.

## WILL MY BABY HAVE TO TAKE HIV MEDICATIONS?

Yes, you will have to give your baby





## WE UP CLOSE & PERSONAL WEEK

Name: **Raúl Roldán** CD4 Count: **496** Viral Load: **Undetectable** Diagnosed: **2006** Age: **41** 

Job: HIV Case Worker



Roldán has lived two lives. There was his life before HIV: Abandoned in Tijuana by his father when he was 11, he later spent years homeless in San Diego, supporting a 17-year addiction to crystal meth with maintenance jobs. A marriage came and went; he barely knew his daughter, born in 2000.

In 2006, Raúl's second life began. Diagnosed with HIV while he was in a substance abuse program, Raúl's CD4 count was already below 300. Yet it took him a while to even accept that he was positive. "That was my main hurdle; I had to overcome the stigma from within," he recounts. "I was uncomfortable with my status because everybody was saying it's a gay disease or it's this or it's that, and I was just as ignorant as they were."

Raúl found a drop-in center that taught him about HIV and connected him to the services he needed. A heterosexual support group at Christie's Place became the family he never had. His HIV is now under control, thanks to his HIV meds.

Raúl quit crystal meth for good in 2006. He now has a steady job as an HIV case manager and is leasing his first apartment. He began paying child support and regularly spends time with his daughter. He even recently found love.

"The most important thing that HIV has taught me is to just live my life," Raúl says. "I have learned that HIV is just a small part of who I am: I have brown eyes; I have black hair; I have tan skin. It's just a part of who I am. It's not everything. Life is what you make it, so I just strive to make life good." n



As we've mentioned, HIV/AIDS organizations can provide invaluable help. There are even a growing number of groups throughout the United States that specifically cater to the needs of Hispanic people living with HIV. All of the groups listed below welcome questions in both English and Spanish.

#### **Nationwide Organizations:**

Call the 24-hour *CDC Health Line* at 1-800-232-4636 for referrals to organizations near you. (For Spanish, dial 2 on your phone when the message begins.)

Another great resource is the bilingual California HIV/AIDS hotline at 1-800-367-2437 or 1-415-863-2437. Call them for referrals and questions about HIV. Or e-mail them at contact-us@ AIDSHotline.org.

For information about HIV treatment, call *AIDS Treatment Data Network*, Monday through Friday, at 1-800-734-7104 or call *Project Inform* at 1-800-822-7422

Women Alive, the country's largest organization for HIV-positive women, offers a bilingual hotline: 1-800-554-4876, Monday through Friday, from 11 to 5

## Hispanic HIV/AIDS Organizations:

No matter where you live, you can get

information or support at any of the organizations listed below:

## Hispanic AIDS Forum (New York)

Offers help managing medical care, rent assistance, emotional support and health education: 1-212-563-4500

## El Grupo at San Francisco AIDS Foundation

The longest-running bilingual support group for HIV-positive Hispanic people in the United States: 1-415-487-8000

#### Mujeres Unidas Contra el SIDA (San Antonio, Texas)

Hosts support groups for HIV-affected Hispanic men, women and families: 1-210-738-3393

## Unión Positiva (Miami, Fla.)

Offers support groups, workshops and referrals tailored to the needs of Hispanic HIVers: 1-305-644-0667

#### Voces Latinas (Woodside, N.Y.)

Provides workshops for immigrant Latinas living with or at risk for HIV: 1-718-593-4528



Once your health care provider recommends that you begin treatment, it's important to consider how treatment will change your life. Are you ready mentally, as well as physically, to take medications every day? Remember: Most HIV specialists say that you have to take your medications exactly as prescribed, at least 95 percent of the time, to keep HIV under control and prevent it from becoming "resistant." HIV that is resistant can make your medications less effective.

This means you have to be certain that taking your medications will become a central part of your daily life. Be honest with your HIV specialist about anything that may make it more difficult for you to take all of your medications on time. If you have a case manager or a counselor, talk with them about this important issue as well.

Without a doubt, the commitment to taking HIV medications will be challenging. This is especially true for women, who generally have lots of family responsibilities to deal with.

However, you have a good chance of keeping HIV under control with the very first combination of medications that works for you. If this combination

successfully controls your HIV, and if you take each and every pill as prescribed, you may not have to change medications for a long time. Here are some things to consider:

## WHAT IF YOU AREN'T ALWAYS ABLE TO TAKE ALL YOUR MEDICATIONS ON TIME?

This may cause your combination of medications to fail. If this happens, it can get harder and harder to keep HIV under control with each new drug combination. It's crucial to identify a combination you can stick to, before you start treatment.

## YOUR MEDICATION SCHEDULE SHOULDN'T BE TOO COMPLEX

One thing is certain: Taking medications

"I've been on my regimen for a little over two years. I've never missed one dosage. I have my big pill organizer for the week. I just fill it once a week with my meds and my vitamins. I always take them. I'd rather skip on my vitamins. But I never skip on my meds."

—Rafael Abadia, diagnosed in 1993



daily will change your life. This is especially challenging when you are taking care of children. Suddenly, you'll have an additional responsibility.

You'll always have to be aware of the time, your schedule and changes in your routine.

In some cases, you may have to schedule taking your HIV medicine around meals or take it with or without certain foods. Even if you are depressed or busy, you will still have to take your medications as prescribed every single day. So, before you begin HIV treatment, you must ask yourself: "Am I really ready?"

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want to give this first combination your best shot, talk to your doctor and read about the possible side effects of the medications you are thinking

of taking. This can help you not only to plan how to manage side effects if they arise, but to choose medications whose possible side effects you can manage. Be sure to let your doctor know before you stop medicines due to side effects.

## YOUR MENTAL HEALTH AND SURROUNDINGS ARE CRITICAL

If you are depressed, using recreational drugs or living on a friend's couch, it may be unrealistic to

assume you'll be able to take all your medications all the time. Remember, it helps a lot to have friends, family, a support group or a therapist you can rely on while you are on a treatment regimen—especially at the beginning when you are still adjusting to taking meds.

## PLAN HOW YOU WILL DEAL WITH SIDE EFFECTS IF THEY OCCUR

All medications can have side effects—even aspirin. Not everyone experiences side effects from HIV medications, which can range from mild to severe. Because you really





HIV researchers have not yet discovered a single combination of HIV medications that's best for everyone. Each combination has its advantages and disadvantages.

For people who are starting on their first HIV treatment combination, each treatment regimen must include at least one drug from two different types, or "classes," of HIV medications. There are currently six classes of HIV medications. Each class of HIV medication stops HIV from making copies of itself at a different moment in its reproductive cycle. You and your provider will consider many issues before deciding on a treatment combination, including:

- Your lifestyle
- Which treatment regimen preserves your future treatment options
- How powerful a regimen it is
- What side effects a regimen can cause
- Other illnesses you may have (such as hepatitis C, kidney problems or diabetes), as these can affect which HIV medications are best for you
- Other medications you may need to take (so that you can be sure there are no interactions between the drugs)
- Which treatment regimen will allow you to get pregnant, if this is what you want
- Financial issues, such as what your insurance will pay for or what medications a clinic can provide

"How do I always remember to take my medications? Every morning I put the pillbox right next to the coffee machine. I can't miss it. I don't leave the house without having my cup of coffee. Actually, I'm looking at it right now. It's on top of a jar, next to the coffee maker. No matter where I am in the apartment, I always see it."

—Ed Viera Jr., diagnosed in 1987



You've made the commitment to begin treatment and settled on your first HIV medication regimen. To ensure that your meds keep working, you'll need to take the exact dose and exact number of pills in your regimen on time, every time. But there may be challenges waiting to trip you up, including:

- Side effects
- Depression, drug addiction or other personal problems
- Remembering to refill your prescription
- Illnesses or injuries
- Family emergencies or travel
- Getting tired of taking meds every day
- Pregnancy

Whatever the reason, and however hard it may be to talk about it, it's extremely important to bring up the problem with your HIV specialist or case manager before the problem interferes with your med schedule.

"If you don't keep up with your meds, and you forget one day, then forget a few days later, you tend to develop resistance to the medication. You don't want to burn your bridges, because then, if there are no other drugs that'll work with you, you're up a creek without a paddle. You don't want to do that. Take your medications first thing in the morning, drink some water, and just go from there."

—Joseph, diagnosed in 1995





Living with a life-threatening disease is no easy feat. It's especially difficult when you've got other problems. We asked HIV-positive Hispanic men and women to tell us some of the things that help them survive day to day.

Here's their advice.

#### **DON'T LET HIV DEFINE YOU!**

"It's only been seven or eight months since I was diagnosed. Initially, I was paranoid. All of a sudden I didn't want to hug people. I felt like I was an alien or whatever. I didn't want to get anybody sick or anything like that. My mom, she still gets on me. She says, 'Your HIV does not make you who you are as a person. It



does not define you.' Today, honestly, I can say that I treat HIV like it's a pebble in my shoe. I have it, and it's going to be there. I can't take off the shoe and dump the pebble out. It bugs me sometimes, but I just have to learn to live with that."

—Enrique Franco, diagnosed in 2007

## **DON'T BE AFRAID TO FIND LOVE!**



"Finding love has been hard, but I am with a man who is also positive and who has been living with HIV longer than I have, so he is an inspiration to keep on going."

—Javier Fontanez, diagnosed in 1999

#### YOU'RE NOT HIV! YOU'RE YOU!

"I went to a women's group. The first thing this lady said was, 'I've been diagnosed for a year, and I don't think I'm ever going to date again and I'm never going to have sex.' I remember I looked at her and I said, 'No, you'll be okay. You watch, in another year you'll be fine.' The next year she met someone



and they're already living together. I said, 'You see!' The person is negative. There's hope. You're not HIV. You are you. You have a soul just like everyone else."

—Damaries Cruz, diagnosed in 1991

### **MAKE THE BEST OF YOUR LIFE!**



"I figure I went down this road, this path of having HIV through my drug addiction, and then through all these complications, for a reason. It's best to do something with that experience, to move forward, maybe help other people in

the same situation that I've gone through. HIV has definitely given me direction, that's for sure. It's made me responsible for my health; it's made me responsible in many different aspects of appreciating life and going forward."

—James Nicacio, diagnosed in 2001

## STAY CALM! DON'T GIVE UP!

"Don't give up! Educate yourself—this is extremely important. Find something that appeals to your psyche, to your inner peace, to help you deal with the information you will be getting, because some of it will be scary as hell. If you have something inside you that keeps you calm, you will navigate through things beautifully."



—Lucia, diagnosed in 1989



















#### **GET ORGANIZED!**



"I would say take things day by day. Feel your sadness, feel your mourning. However, there will come a point when you need to get proactive to see where your viral load, T cells and overall health are so the doctor can determine when you should begin HAART. Write down a list of priorities. If some things

on the list are pulling on your heartstrings more than other things, than do what you need to do, whether that means getting support from friends, family or a significant other. If you are in a housing crisis, don't have insurance, need food, etc., you may want to get hooked up with a case manager right away so that he or she can help you apply for programs you may need."

—Greg Sanchez III, diagnosed in 1985

#### **ADVERSITY CAN HELP YOU GROW**

"Being HIV positive is not an experience one would seek, but you can turn it into something that can make you grow as a human being in terms of knowledge, discipline, being merciful and being compassionate with others. For me, that is crucial."



—Gabriel Santiago, diagnosed in 1990

## **DON'T OBSESS ABOUT YOUR CD4 COUNT!**



"I try to live in the moment and enjoy everything I can. I'm not obsessed with my CD4 count. I know a lot of people who concentrate on their numbers and forget to live their lives. I don't let the disease take over my life—between the morning dose and the evening dose, I have a life to live."

—John Puig, diagnosed in 1986

#### TAKE CARE OF YOUR LOVERS!

"My ex-lover, who is my roommate today, is still negative. I said to him, 'Baby, I give you back exactly the way I found you, because I have never put you at risk.' Protection, that's my message. Protection, love and care. That's what it takes. People with HIV are like negative people, we need love around us."



—Fernando Castillo, diagnosed in 1993

## **LOVE YOURSELF SO YOU CAN THRIVE**



"Do you love yourself enough to take treatment on a daily basis? If you don't love yourself, you won't do it."

—Beatriz Díaz, diagnosed in 1992

#### **USE INSPIRING STORIES TO HEAL**

"I couldn't tell my parents over the phone. I knew I had to fly to Puerto Rico and let them know. ... I was really concerned about how they were going to take it. They're Christian fundamentalists, so I knew my being gay was an issue. I didn't know what to expect. I prepared myself mentally, just in case I was going to get some rejection. Then the day came, and I sat in my parent's living room ... and I told them that I had AIDS. ... My dad, who is what I like to call a true macho Puerto Rican man, who I had never seen cry, ran into his bedroom, crying. Like really, really, crying. I ran after him and I grabbed him. He put his head on my shoulder and we both cried. To my

amazement, they accepted me immediately. I thought they were going to put away the spoons, the cups, so I couldn't use them, because I've heard horror stories from other people. But, no. From day one, they accepted me, and they were there for me. I've been

very blessed with having a very supportive family."

—Rafael Abadia, diagnosed in 1993







"To those who have just been diagnosed with HIV, I want to tell them that life has just begun. One does not have to become ill. This is a chronic, manageable illness and, if you take care of yourself, you can have a long

and good life. In my case, I am happier today than I was before. Taking your meds is like tying your shoelaces. Life is what you make of it."

-Raúl Roldán, diagnosed in 2006

In this booklet, we've talked about some of the most critical steps to take if you've been recently diagnosed with HIV:

- Educate yourself about HIV;
- Find HIV support services and an HIV specialist; and
- Prepare for and start HIV treatment, if necessary.

But perhaps the most important step you can take is the one that makes all the other steps possible: accepting your diagnosis and planning your future as a person living with HIV.

Regardless of the reason you were infected, something as life changing as

an HIV diagnosis usually gives people an unexpected chance to re-examine their lives. Many people with HIV say that their diagnosis turned out to be an opportunity to better their lives. That may sound crazy to you right now, but having to face a serious health problem can motivate you to dig deep and make changes in your life that you may have been putting off, or that you never even realized you needed to make.

Some of these changes, of course, may be staring you in the face. If you drink too much or don't exercise, it's time to change that. If you smoke, it's time to stop. Anything that adds stress, frustration or conflict—be it a bad relationship, a soul-crushing job or trouble paying the

"One of the reasons I thought it was important to tell my story was so that people can see that this can happen to anyone. It has no borders. It doesn't matter what color you are, it doesn't matter what socioeconomic background you come from. HIV/ AIDS impacts everyone, and everyone needs to be educated on it."

> —Evelyn Hernandez Valentino, diagnosed in 1993

> > RFACH OUT

IT WILL

YOU AND

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FOR SUPPORT;

**STRENGTHEN** 

CHALLENGE YOU

TO KEEP GOING.

KFFP GROWING

LIVING LIFF TO

THE FULLEST.



bills—can be a drag on your immune system, or can make it harder for you to commit to taking your HIV medications on time, every time.

Talk to your HIV specialist, a counselor or a support group about these issues, and ask yourself what you can do to

improve the situation. Never underestimate the impact that emotional health can have on your physical health.

You may have to do a lot of work and seek out emotional and maybe spiritual support, before vou can educate friends and family about the realities of HIV, and help them separate the facts from the myths. But know that isolation and silence are hazardous to your health.

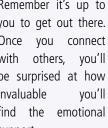
If you don't feel comfortable going to an HIV/AIDS organization for support, the Internet may be a lifesaver. There are an assortment of Web sites where you can learn more about HIV and its treatment, stay on top of the latest HIV news and even meet people. Want to connect with any of the people featured in this booklet? All their stories and e-mail addresses

are featured at www. thebody.com.

Remember it's up to you to get out there. Once vou with others, be surprised at how invaluable you'll find the emotional support.

Don't forget that there are more than one million people from all walks of life living with HIV in the United

States—many in the same position as you. Reach out for that support; it will strengthen you and challenge you to keep going, keep growing and keep living life to the fullest.











"HIV changed my life 100%: it made me more compassionate, more human, more understanding." —Manuel Rochin, diagnosed 2000

