A guide to FUZEON®
The First Fusion Inhibitor

A SPECIAL REPORT FROM THE BODY
**Fuzeon Side Effects**

The most common side effect of Fuzeon is an injection site reaction. About nine out of 10 people have one, though it’s rarely severe. An injection site reaction is usually a small, hard bump that shows up right where you injected. It may be a little itchy or painful. Vigorous massage of the site after you inject can help prevent this. The reaction shouldn’t last for more than a few days or get worse over time; if it does, tell your doctor right away.

Other side effects, which are much less common, include:

- Allergic reactions (may be severe; symptoms include trouble breathing, fever, vomiting, skin rash, blood in urine, foot swelling)
- Pain and numbness in feet, legs
- Loss of sleep
- Depression
- Decreased appetite
- Loss of strength
- Muscle pain
- Constipation
- Pancreas problems

Studies have found that HIV-positive people taking Fuzeon tend to get bacterial pneumonia a little more often than those who take other meds, though scientists aren’t sure why this happens.

**Paying for Fuzeon**

All HIV medications are costly, but Fuzeon is the most expensive. However, most people who need to take Fuzeon are also likely to be able to get help paying for it. Here’s how:

**Health Insurance:** Most private insurance companies will cover the full cost of a Fuzeon prescription. For insurance requiring a co-pay, however, Fuzeon may remain expensive. Check with your healthcare provider or insurer to be sure.

**Medicare/Medicaid:** Medicare doesn’t include prescription drug coverage. However, if you’re enrolled in Medicare, you can sign up to receive a discount prescription drug card from one of several different organizations and companies (though in the case of Fuzeon, the discount is unlikely to be enough to make it affordable). Medicaid does provide prescription drug coverage, but the extent varies from state to state, as do the processes you have to go through to get coverage for specific drugs. Your case manager or healthcare provider can provide more info.

**ADAP:** Many state AIDS Drug Assistance Programs (ADAPs) will pay for Fuzeon, but you, your doctor or case manager should contact your state ADAP to make sure. Visit www.TheBody.com/financial/adap.html to find the phone number for your state’s ADAP, or call Project Inform’s treatment hotline at 800-822-7422.

**Patient Assistance Program:** If you don’t have health insurance and can’t receive Fuzeon through any government-funded programs (like Medicaid or ADAP), you may be able to get help through a Patient Assistance Program (PAP) set up by one of the makers of Fuzeon, Roche Pharmaceuticals. To be eligible for PAP, your income needs to be no more than 300% above the federal poverty level, although Roche’s final decision on who’s eligible for the program is made on a case-by-case basis. Talk to your case manager or healthcare provider, or call the Fuzeon Answer Center (877-438-9366) for more info.

If none of these options are available to you, talk with your doctor and your local AIDS organization, or go to www.clinicaltrials.gov and check to see if there are any experimental studies you can join.
You’re Never Alone: Resources at Your Fingertips

Living with any disease is a challenge. Although it’s ideal to have the support of family and friends, sometimes it’s not available — nor is it always enough. But realize that you’re never alone. Here are a few places you can turn to for more information and support:

Your local AIDS organization may offer one-on-one counseling and support groups. Visit www.TheBody.com/hotlines.html for a detailed listing.

The U.S. National AIDS Hotline is open 24 hours a day, 7 days a week. It can provide info on AIDS organizations in your area: 800-342-2437.

The Fuzeon Answer Center is offered by Roche/Trimeris, the makers of Fuzeon. The center’s hotline, 877-438-9366, is open 24 hours a day, every day, and staffed by a nurse who can answer any questions you may have about the drug. You can also reach the Fuzeon Answer Center on the Web at www.fuzeon.com.

www.TheBody.com contains dozens of articles on Fuzeon, as well as online Q+A expert forums and live chats every few months.

AIDSinfo, from the U.S. Department of Health and Human Services, offers comprehensive treatment guidelines and information. The hotline phone number is 800-HIV-0440 (open Monday through Friday). The Web site, www.aidsinfo.nih.gov, includes a live service through which you can chat online with an expert.

Project Inform is a nonprofit HIV treatment advocacy group. The treatment hotline is 800-822-7422 (open Monday through Saturday).

WHAT COMES WITH YOUR FUZEON PRESCRIPTION?

Fuzeon comes in a 30-day supply; each time you fill a prescription, you’ll receive a green box (called a “convenience kit”) that contains:

- 60 vials of Fuzeon powder (which you’ll mix with water to create your Fuzeon dose)
- 60 vials of sterile water
- 60 large (3 cc) sterile “safety” syringes with retractable needles for mixing the drug
- 60 small (1 cc) sterile “safety” syringes for injecting it
- Alcohol pads (to clean the area where you’ll inject)

In addition, the first time your doctor prescribes Fuzeon, you’ll also receive a black “starter kit,” which includes all of the following items in a plain black travel bag:

- A flip chart entitled “Your Guide to Taking Fuzeon”
- A video with instructions on how to prepare and inject Fuzeon
- A planner to help you schedule your doses
- A small mat on which you can prepare your Fuzeon doses
- A practice pad you can use to perfect your injection technique
- A wallet-sized travel card with tips
- A travel-sized container for taking your Fuzeon on the go
- A guide for caregivers who give Fuzeon injections to others (such as friends and loved ones)

If you run into any trouble with your kits, want to change your syringes or have other questions, be sure to talk to your HIV doctor or nurse. And if you don’t receive a starter kit the first time you start taking Fuzeon, you can request one by calling Roche/Trimeris’ Fuzeon Answer Center (877-438-9366).
The Bottom Line

Fuzeon, the first approved fusion inhibitor, represents just one of what we hope will be many new classes of HIV meds. Each new class of meds provides a unique means of fighting HIV, and gives hope to people who are running out of treatment options.

Like any other HIV medication, though, Fuzeon isn’t a cure, and it can’t do the job all by itself. Although it works differently from other HIV meds, and needs to be injected, ultimately, it is just another HIV medication. This means that for it to work best, Fuzeon needs to be taken with other HIV meds. When it is, it can keep the HIV in your body at bay for a long time—possibly many years—and help your immune system rebuild itself.

Fuzeon also has many of the same vulnerabilities that all HIV medications have. HIV can develop resistance to it (especially if you often forget to take all of your doses on time), and it does have side effects, although those side effects are generally milder than those of many other HIV meds.

We hope this booklet has given you a better understanding of how Fuzeon works and why it’s such an important part of the HIV treatment picture. Don’t let this booklet be your only source of information, however. Seek out support groups, do your own research, and make sure that you and your doctor talk—frequently and in detail—about your health, your HIV treatment plans, and the pros and cons of taking a med like Fuzeon. The more you take charge of your medical care and the more you learn about how HIV treatment works, the better off you’ll be.

Stay healthy, and thank you for reading!

Greg Braxton: A Long Journey to Recovery

With a 27-year history of drinking, using drugs and sleeping with hundreds of women, Greg Braxton’s AIDS diagnosis in 1994 came as no surprise. He’d blown through a string of careers because of his addictions: steel mill worker, Chicago police officer, taxi driver, bus driver. Even after his diagnosis, he struggled with his crack cocaine addiction, which would often cause him to skip essential doses of his HIV meds.
A Downward Spiral

Greg’s self-destructiveness continued for several years. During this time he was frequently admitted to his hospital’s intensive care unit. “I was extremely sick, and a few times they didn’t know if I would live or die,” he says. “I was always able to pull myself together eventually, but would get sick again, with pneumonia, histoplasmosis and other opportunistic infections.”

At one point, he even suffered a heart attack, although this didn’t deter him from his crack use. He just thought he’d accidentally taken too much crack at once. It wasn’t until the summer of 2001, seven years after his HIV diagnosis, that Greg finally got his addictions under control. With a laugh, Greg recalls the real reason he entered a treatment program for substance-abuse for what turned out to be the final time: He was trying to escape a drug dealer he owed money.

With a 27-year history of drinking, drugs and sleeping with hundreds of women, Greg Braxton’s AIDS diagnosis came as no surprise.

Although his previous attempts had failed, this time, he says, something “clicked.” He managed to stay focused and struggled to change his life.

The Long Road Back

Greg spent nine months in Haymarket Center, one of the largest substance abuse programs in Chicago. Once he completed the program, he was placed into a transitional community living program called AIDS Care. Since then, Greg has been in an independent-living group home that provides him with the support he needs in order to recover from so many years of drinking and drug use.

“I couldn’t have stayed sober without it,” Greg says. “I needed the structure. If you need something it is always there. I’m pretty independent now, but at first I had to take it slowly.” There are substance abuse counselors and support groups available if he needs them. He tries to attend at least three Alcoholics Anonymous meetings a week.

Once he was in recovery, Greg was finally able to adhere to his HAART regimen. But by then he had exhausted his options: By failing to take his meds on time for so many years, he had become resistant to most of the available medications. His CD4 count continued to drop while his viral load continued to rise. “I never thought beyond two or three years, didn’t make any plans as far as employment and going back to school, because I never expected to live that long,” Greg said. “Then a friend gave me information on this new drug, T-20 or Fuzeon, and that’s when I really got hope.”

Since his medications were no longer working, Greg assumed he had little time left to live. He never imagined he would be around long enough to see the younger of his...
two sons graduate from high school (which he did in the spring of 2004), or his daughter give birth to his first grandson, who is now two years old. “It’s really a miracle for me to see my grandson,” Greg acknowledges. “I didn’t think I would see my kids grow up. I remember telling my kids that I had AIDS and my daughter was crying. I really thought I would die soon.”

From Crack to College

Greg started Fuzeon as part of a clinical trial in November 2002. He took the drug in combination with Epivir (3TC, lamivudine), Norvir (ritonavir), Viracept (nelfinavir) and TMC-114, an experimental protease inhibitor. “At that point I was out of options,” he said. “If my doctor told me to jump off a building I would—as long as I had a parachute!” By sticking to his regimen, Greg has seen his viral load slowly plummet to around 900 and his CD4 count rise from 1 to 100.

The same year he started taking Fuzeon, Greg decided to finish college. He had dropped out of Chicago State University in his junior year in 1974. He was majoring in accounting and had decided it would be more interesting to get a job. He finally graduated in October 2004 with a GPA of 3.8 and a bachelor’s degree in applied behavioral science, which he will put to use in the HIV community. “That’s all because of the Fuzeon, the hope that it gave me,” he says. “I haven’t got to undetectable yet, but to me this is a big improvement from over a million copies to 900!”

Adjusting to Fuzeon

When asked what he thought when his doctor told him that he would have to inject Fuzeon twice a day, Greg didn’t blink. Though he had never injected during his crack addiction, he says, “the thought of injections didn’t bother me too much, because I had experience injecting Procrit for anemia. I wanted to do whatever was necessary to get the virus under control. The first three or four times I injected I had to play the training video to do it. After that it became second nature. It really was no big deal considering the benefit I was trying to get from the drug.”

It was actually the preparation of Fuzeon that concerned Greg. “It seemed a little complicated at first because you have to mix the drug, and I had a little apprehension about that,” he said. “But after my doctor went over the training video with me, I was confident that I could do it.”

How does Greg work the twice-daily injections into his schedule? “It takes an adjustment; you have to plan,” he explains. “I mix two batches at night, inject one and do the other in the morning. You...
have to allow time for it to come out of the refrigerator and warm up. By and large, I’ve adjusted to it quite well. It doesn’t burden me.”

And what about his adherence? “I’ve been on Fuzeon for a year and a half and I might have missed only three doses.”

Although people in Greg’s Fuzeon support group talk about bad injection site reactions, he says that his are pretty much average. “Sometimes I inject and have very little reaction at all, and sometimes I get a little bruise there. On average, it’s just something that’s barely noticeable to me. It’s nothing that would prohibit me from injecting. I have to look around for a fresh site to inject. I have problems injecting in my legs and arms, so I stick to the abdomen area and I seem to do okay.”

So how long will Greg stay on Fuzeon? “As long as necessary, that’s my outlook on it. If medications come out that will allow me to take pills, then I’ll do that. But I’ll inject as long as I have to because I’m getting results from it.”

The Power of Support

For people beginning a regimen that includes Fuzeon or those who are considering it, Greg firmly believes in the importance of attending a support group. “You can get honest feedback on the pros and cons of injections,” he says. “The bottom line is, if this is what you need to do to save your life, then you learn how to manage it, and get over the fears of injecting. If you don’t have a support group in your area, then talk to people who are on it and get feedback, ask questions.”

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The Power of Recovery

Greg’s turnaround in life has been nothing short of remarkable. His health has improved, as has his romantic life: Almost two years ago, he met his current girlfriend, and they’re still going strong. Greg has also discovered a passion for exercise—an obsession that’s yielded several benefits. “My addiction to drugs and alcohol have switched to exercise,” he says. “Even in recovery, my T cells plummeted, my viral load was a million and my T cells were 1. The only thing that kept me going was juicing and exercise.”

Greg makes fresh vegetable juices, he says, with broccoli, carrots, beets and celery or whatever else he has on hand. He also makes strawberry, raspberry, apple and grape smoothies. “The exercise...
Beatriz Diaz: From Silence to Success

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

This is what 49-year-old Beatriz Diaz says to people with HIV who are considering treatment. Beatriz is speaking from personal experience. She learned the painful way how critical loving yourself is to committing to HIV treatment.

In his tiny studio apartment, Greg keeps 10 to 15 pieces of exercise equipment, including a stationary bike, total gym, Power Flex for strength training, a crossbow trainer and a rowing machine.

Despite devoting his time over the past several years to his full-time college schedule, and his exercise regimen, Greg also contributes his time and energy to the HIV/AIDS community. He leads a support group for HIV-positive Alcoholics Anonymous members; he’s a member of various AIDS policy and planning groups; and he serves as a board member of the agency that runs the independent-living group home where he lives in Chicago. Most recently, Greg joined the National AIDS Fund AmeriCorps Program, a yearlong community service program. His assignment: an 11-month stint at Haymarket Center, the same substance-abuse program that started him on his path to recovery. While there, he’ll perform a wide range of duties, including HIV testing, one-on-one counseling, outreach and training.

Whenever he’s asked, Greg speaks freely about substance abuse and HIV—at colleges, at high schools, wherever he can. “It’s a way of giving back; it’s 12-step work,” he says. “Having HIV is something negative, so I can flip it to a positive; I can use my disease to prevent others from getting it. I really get a lot out of doing that.”
The Diagnosis

Before the Fresno, Calif., mother of four was diagnosed in July 1992, after donating blood, she believed all sorts of things about people with HIV: that you had to stay away from “those” people ... that they were bad ... that you couldn’t get near them because they were extremely contagious. “It’s a big factor when you are diagnosed,” Beatriz emphasizes. “You feel a lot of self-hatred.”

What made things worse was that Beatriz had little support. She didn’t tell her parents or her four sons, who ranged in age from three to 14. She confided only in her partner of one year. But he had his own diagnosis to deal with. Although he was supportive, it wasn’t enough. Beatriz also had to contend with a stressful, full-time job as an information officer for the federal government.

She admits that she was completely ignorant about HIV. “I didn’t get a lot of background info at the time. The doctor just said I was positive and, at the beginning, I didn’t ask any questions.”

“I kept the plates I ate on and my cup separate for a year and a half,” she says, thinking she was protecting her children from HIV. “My oldest child kept asking me why I was doing this. He kept pestering me.” Finally, she learned that sharing plates did not put her kids at risk and she stopped. She laughs now at how ignorant she was.

For three long years, from 1992 to 1995, Beatriz lived with her HIV in silence. In that time, Beatriz grew more depressed. She stopped seeing her friends and bringing her kids to their barbecues. She kept herself isolated, just staying home with her children. Though physically she was fine, she had no one to talk to, no one to share her worries with. Those three years, she says, were the worst years of her life. Even though she still had her partner, her previously active social life was at a standstill.

The Turning Point

In 1995, for reasons she can’t explain, it suddenly hit her that she had HIV. She closed the curtains, stayed in bed and for four days couldn’t bring herself to go to work. Beatriz had worked at the same office for 12 years. She had good friends at work. But now she wouldn’t take their calls. When one of her coworkers stopped by to visit, Beatriz pretended nobody was home; she hushed her children and wouldn’t answer the door.

But when her coworker Rosario (not her real name) came to check up on her, it wasn’t as easy for Beatriz to ignore her. Rosario banged and banged at the door. She kept shouting, “I know you’re in there!” Finally, Beatriz reluctantly opened the door.
A normally outgoing person, she was silent. Her house was dark. Still in her robe and nightgown, she just looked numbly at her friend. “What’s wrong?” Rosario cried over and over. “What’s wrong? You haven’t even showered! What’s wrong?”

Finally, Beatriz could stand it no longer. She broke down and sobbed out the story right in the doorway. Together they then walked to her room, sat on the bed and cried. As Beatriz tells it, Rosario, noticing how listless Beatriz was, pulled her into the shower—cold water only—and pushed her in, clothes and all.

Beatriz recalls yelling, “What are you trying to do?” “You gotta shake out of it!” Rosario responded, “It’s not like you’re going to die tomorrow! What are you going to do with these boys? You’ve got to think about your boys! You have to do it for them!”

“That’s what made me snap,” Beatriz says: trying to figure out who would take care of her boys if she died. Her parents? Her sister? Maybe—but she knew that no one could take better care of her kids than she could. “Life is too precious to let it go just like that,” she says.

“I started out slowly,” she admits. “But eventually I got myself doing what I had to do.” What Beatriz says truly changed her life was the special support group for HIV-positive women run by All About Care. “Talking to these women helped me a lot emotionally,” she says. “They showed me ways to deal with the disease. Just by going to the groups and being inspired by the older people and younger people. I kept saying, if they can do it, why can’t I?”

Nine years after joining, Beatriz still goes to the group at least once every few weeks, often with one or two of her kids. She has also taken her family on two of the group’s camping trips in Yosemite National Park.

**Telling Her Family**

Soon after she started reaching out for help, Beatriz finally decided to tell her children she had HIV. One Sunday evening, she gathered her boys into the living room and told them she had a chronic disease called HIV. Although they asked her questions, she says it took time for it to sink in. Her two oldest sons had the most difficult time coping with her diagnosis, but they’re now completely supportive.

She also told her parents. Though it was heartwrenching, she has no regrets about telling her family. “You carry something so heavy for so long,” she says. “It was such a relief to stop carrying this secret around with me.”

Beatriz frequently creates floral centerpieces for weddings and coming-of-age parties for Hispanic girls.
A New Life

In that year of momentous changes, Beatriz also decided to quit her job, accept a reduced pension and live on Supplemental Security Income. It was time for her to take care of herself. Her HIV infection had begun to progress and she had stopped feeling healthy.

Before she left work, though, Beatriz decided to tell eight close work friends that she was HIV positive. They reacted so much better than she imagined, she says. “I got all kinds of prayers in the mail. I couldn’t kick myself for not speaking up sooner. There are people out there who care, and I didn’t give them the chance to show it.”

Once she quit working, Beatriz focused on her kids. While she was working full-time, they had taken the bus to school and eaten cereal and TV dinners. Now she cooked their meals, ate with them and drove them to school.

During this time, she began HIV treatment; it consisted of two medications: Retrovir (AZT) and Videx ( ddl). She suffered through various side effects, including a skin rash and headaches and changed treatments a few times, but she couldn’t find a drug regimen she could stick with. By 1999, her CD4 count had been falling for six months straight. Her emotions seemed tied to her CD4 count; as it fell, she sank into depression. In 2000, her doctor told her that her HIV had become resistant to all the medications available at that time. Her CD4 count was 54, the lowest it had ever been.

Her only hope? To join a clinical trial for an entirely new type of HIV medication called a fusion inhibitor; the drug: Fuzeon (T-20, enfuvirtide). Unfortunately, the clinical trial was in San Francisco, which would mean a three-hour drive each way from her home in Fresno. But Beatriz was motivated. After all, she had her kids to take care of. If she were to let HIV kill her, she thought, “how would they pay for my funeral expenses?”

Beatriz joined the trial, and committed herself to the taxing drive to and from San Francisco. “Sometimes,” she says, “I just didn’t have the money to pay for gas. My kids helped me out.” Her two oldest boys were working at the time and chipped in.

For a year Beatriz drove to San Francisco twice a week, then twice a month for six months, then once a month for a year. She never missed an appointment. Her CD4 count climbed from 54 to 216 after the first year. Now, four years later, it’s at 784. She’s still in the trial and drives to San Francisco once every four months.

“Getting Used to Self-Injections

Before she would agree to take part in the Fuzeon trial, Beatriz told her doctor she would have to see the needles up close. “My father is a diabetic,” she explains, “so I was used to seeing needles. When I saw that they were small like that, I thought, if he could do it, so can I.”

The first time she took Fuzeon, the nurses prepared the medication and injected it for her. Then they gave her a kit containing sterile water, Fuzeon in powder form and clean needles. The
It Takes a Family

What does Beatriz do to keep busy nowadays? She crochets blankets. She creates floral centerpieces for weddings and for quinceanera, the Latin American coming-of-age party for girls. A few times a month Beatriz acts as a court interpreter for Spanish-speaking immigrants.

Beatriz also speaks to audiences around the country about her experiences since being diagnosed with HIV. “I’ve become a very outspoken person,” she admits. “I speak to people about living with HIV and taking Fuzeon. I now know that you are not going to get HIV by touching someone. HIV is just three big letters. People hear it and panic and get scared. But it’s just a big word.”

Now Beatriz says she is happy. A few years ago she bought her own house—“a four-bedroom, two-bath, two-garage house!” she says proudly. All of her sons live with her. A special pleasure is sharing her home with her second oldest, now 23, who is married and has two sons of his own, ages two and four.

“I love my grandkids so much!” Beatriz exclaims. “I went to San Francisco not long ago to speak and they came with me. They give me inspiration. They understand I have an illness. They just see it as a fact of life.”

Through it all, Beatriz says, her sons have been her main support. They often come to her doctor with her, and her youngest son even helps prepare her medications. She says that if she falls asleep at night before taking her meds, he wakes her up to remind her. She says this with pride, grateful her sons have so wholeheartedly accepted HIV as a part of their lives that they’re willing to give so much of themselves to keep her healthy.

nurses taught Beatriz how to prepare the drug herself and inject it under her skin.

Although Beatriz is blasé about injecting now, it took her a while to get used to it, she says. “A lot of people get afraid about Fuzeon. If people with diabetes can do it, we can do it.”

To make sure she never misses a dose, Beatriz incorporates Fuzeon into her daily ritual. Every morning when she gets up, she removes the medicine from the fridge and mixes her morning and evening doses. She puts her evening dose back in the fridge and then leaves her morning dose out so it can reach room temperature, which makes it easier to inject. Then she takes her shower and eats breakfast.

Finally, she fills one of her clean needles with the Fuzeon. “I grab the skin of my thigh and put the needle in, and let it go slowly as I’m putting in medication,” she says. “After I’m done with the medication, I rub the spot for at least a minute. I get a little bump sometimes that lasts three to four days before it’s gone. I also sometimes inject in my stomach and waist.”

BEATRIZ’S TREATMENT HISTORY

- HIV medications: Fuzeon, Kaletra (lopinavir/ritonavir), Viramune (nevirapine), Combivir (AZT/3TC), Viread (tenofovir)
- Other medications: Oyster shell calcium, Tagamet (cimetidine), ibuprofen
- Current side effects: Some skin irritation from the injections
- Lowest CD4 count: 54
- Current CD4 count: 784
- Highest viral load: In the millions
- Current viral load: Undetectable
- How she gets her medications: Through her private health insurance, paid for by her former employer
How Do You Find Out More About Fuzeon?

- Begin by talking to your healthcare professional
- Use this booklet
- Then visit www.TheBody.com

The Body features:

- Continually updated HIV treatment information sorted into hundreds of topics
- More than 20 HIV doctors ready to answer your questions
- An online community where you can connect to others with HIV and browse through a rich assortment of resources

At The Body you can also visit the Fusion Inhibitor Resource Center which features: personal stories, frequently asked questions about Fuzeon and an online Ask the Expert forum with a nurse available to answer your questions.

Come visit us at www.TheBody.com today!

Founded in 1995, The Body is the most comprehensive HIV/AIDS resource on the Internet, serving more than 500,000 visitors a month. Like this booklet, The Body is published by Body Health Resources Corporation.