aids treatment activists coalition

FUZEON
Frequently Asked Questions for the HIV Community

Q. What is Fuzeon?

A. Fuzeon is an anti-HIV drug from a new class that fights HIV in a different way than other AIDS drugs you may have taken before. When HIV enters the body, it seeks out important immune cells to invade. One target is the CD4 T cell, where HIV attaches, fuses with the outer coating of the cell, and inserts itself into the cell. All of these steps work like a series of locks and keys that get HIV into the cell so it can take it over and make copies of itself, kind of like a copy machine. If one lock or key is out of place or damaged, HIV cannot attach and enter the cell. Fuzeon stops one of those keys from working and prevents HIV from fusing with the human cell.

Q. Who is Fuzeon for?

A. Fuzeon has been approved by the FDA for use in combination with other anti-HIV drugs in treatment-experienced patients unable to fully suppress HIV on their current regimens. For most people, this means that Fuzeon is an option of last resort—if you're resistant to a lot of HIV medications, Fuzeon might be useful in constructing a new regimen, especially if you have one or two other drugs you can take that you're not resistant to. Your doctor will probably use resistance tests to select which drugs may have the best chance of still fighting the virus. Studies show that Fuzeon will work best for people who take it with two other drugs that they have never taken before. In general, people who aren't resistant to a lot of drugs will prefer HIV medications that are easier to take because Fuzeon must be taken as an injection (see next question).

Q. How do you use Fuzeon?

A. Fuzeon is not a pill but a powder that has to be mixed with sterile water (taking up to 30 minutes to dissolve). The solution is then injected with a needle into the upper layer of skin (usually in the abdomen, upper legs, or upper arms) twice a day. This process takes a while to learn and to get used to, but over time, people adjust to it in a similar way as people with diabetes learn to self-inject insulin. Your doctor, pharmacist, and other health care providers can teach and assist you with how to do the injections properly.

Q. Aren't needles tricky? Does the injection hurt?

A. Everyone reacts to needle injections differently. The needle that is used is very small but it may hurt a little going in, like a pin-prick. When the fluid is pushed into the skin, it also can cause some pain. In most people Fuzeon causes a stinging reaction that can cause bumps, itching, redness, and pain. The reactions usually go away, but sometimes can last a few weeks. You have to alternate where you inject yourself to avoid the bumps. Some people who have been using Fuzeon for a long time get hardened layers of skin that limit the sites where they can inject.

Q. What if I have a fear of needles?

A. Fuzeon is not for everyone, so it is your choice to decide whether you want to take it and whether you can tolerate it. Some people get used to the injections. Others simply choose another therapy, if available, or choose to wait for a new therapy to come along that is easier to take.

Q. How do I get Fuzeon?

A. Have a talk with your doctor to decide if Fuzeon is right for you. If so, the process required is different than what happens with the typical prescription and initially most local pharmacies will not carry the drug. First, your doctor should call 1-866-694-6670 or go to the website **www.fuzeon.com** to get a "Prescription Enrollment Form." The doctor fills out and then faxes the form to the "Fuzeon Progressive Distribution Program" at 1-877-428-9520. They will check if you have insurance or coverage by a state AIDS Drug Assistance Program (ADAP) to pay for the drug. You can find out more information about ADAPs, including a listing state-by-state, at **www.atdn.org/access/adap**. Because **Fuzeon is the most expensive AIDS drug ever** ($25,000 per year), some payment plans and prescription drug programs may not pay for it. Once your method of payment is verified, your prescription will be filled. The drug either will be sent to you or will be available for you to pick up at your doctor's office or a Statscript pharmacy in your area.

Q. What if my state's ADAP or Medicaid will not add Fuzeon to its list of AIDS drugs?

A. It depends on your state. ATAC is working with Roche, the company that makes Fuzeon, to ensure that anyone who cannot construct a viable treatment regimen and needs Fuzeon will be able to get it regardless of coverage. Roche has promised to establish a Patient Assistance Program and to find a method of payment for you regardless if you have insurance or not.

Q. This all sounds very complicated! Doesn't it?

A. Yes, it is complicated. Fuzeon is a unique drug, and you will need lots of support to get access to it and to learn how to use it correctly. Because Fuzeon is an injectable drug with unpleasant injection site reactions and is not carried by all insurers, including ADAP and Medicaid, Fuzeon will not be the best choice for everyone. There are seventeen approved drugs for HIV and three more may be added this year. There are new protease inhibitors in *expanded access* (available from drug companies even though they are not yet approved by the FDA) that also work against drug-resistant virus. Also, there are other potential therapies in clinical trials. But for those who have absolutely no other choice, Fuzeon may be the drug of last resort.

ATAC is a national coalition of AIDS activists, many living with HIV/AIDS, working together to end the AIDS epidemic by advancing research on HIV/AIDS. www.atac-usa.org