

## WOMEN'S EXPERIENCES AND SIDE EFFECTS WITH ANTI-RETROVIRAL THERAPIES

### Who Should Fill Out This Survey?

YOU SHOULD - if you are an HIV+ woman who is either taking anti-HIV drugs now or has taken anti-HIV drugs in the past.

We know that women have different experiences with HIV disease than men. With the exception of obvious anatomical differences, scientific researchers often argue that women are no different than men. The result is that anti-HIV studies include very few women. The findings are based on men's experiences, and generalized to women. The goal of the survey is to gather data on the different effects of anti-HIV drugs on women, such as dosage and side effects. Please answer each question the best you can. The survey will be completely anonymous. We will report the results in the future issue of the newsletter. With the results from this survey, we can advocate for better research for women.

1. Gender (*circle one*):    A) Female            B) Male            C) Transgender
2. Race/ethnicity (*circle one*)
  - A. American Indian or Alaskan Native
  - B. Asian/Pacific Islander
  - C. Black/African-American
  - D. Hispanic or Latina/o
  - E. White/Caucasian
  - F. Other
3. Age (*circle one*)
 

A) 15-21                      B) 21-30                      C) 31-40                      D) 41-50                      E) 51-60                      F) Older than 60
4. How much do you weigh, in pounds? (*circle one*)
 

A) Less than 100            B) 100-120            C) 121-140            D) 141-160            E) More than 160
5. Height- . . . \_\_\_\_\_ Feet \_\_\_\_\_ Inches
6. How long have you known you were HIV-positive? (*circle one*)
 

A) Less than 1 year    B) 1-3 yrs    C) 3-5 yrs    D) 5-7 yrs    E) 7-10 yrs    F) More than 10 yrs
7. How long have you been seeing a doctor or other health professional for your HIV treatment? (*circle one*)
 

A) Less than 1 year    B) 1-3 yrs    C) 3-5 yrs    D) 5-7 yrs    E) 7-10 yrs    F) More than 10 yrs    G) N/A
8. Please check off which anti-HIV drugs you have EVER taken, and for how many months. Also check off which anti-HIV drugs you are CURRENTLY taking, and for how many months. Please list the side effects you have experienced with each drug. *If necessary, please use the back to describe and/or list the side effects you have experienced.*

DRUG	PAST		CURRENT		Side effects
	Ever taken	For how Long?	Now Taking	For how long?	
AZT(Retrovir, Zidovudine)					
DDI (Videx, didanosine)					
DdC (Hivid, zalcitabine)					
D4T (Zerit, stavudine)					
3TC (Epivir, Lamivudine)					
ABC (ziagen, Abacavir)					
AZT + 3TC (Combivir)					
Ritonavir (Norvir)					
Indinavir (Crixivan)					
Saquinavir (Invirase, Fortovase)					
Amprenavir (Agenerase)					
Nevirapine (Viramune)					
Effavirenz (Sustiva, DMP-266)					
Delavirdine (Rescriptor)					
Other (specify):					

9. Please check off each side effect you have EVER experienced and indicate how many times per month you experienced the side effect. If you knew your viral load at the time you experienced the side effect, please list.

Side Effect	Check all that apply	How many times per month?	Viral Load (copies/ml)
Diarrhea			
Dizziness			
Headaches			
Lipodystrophy:	-----	-----	-----
Breast Enlargement			
Buffalo hump			
Prominent veins			
Sunken Cheeks			
Truncal obesity ("waist tires")			
Liver/Pancreatitis/kidney problems			
Low blood count (anemia)			
Nausea, vomiting, upset stomach			
Tingling/pain in fingers, toes (neuropathy)			
Tiredness (Fatigue)			
Weight loss			
Other (please specify):			
Have not experienced any side effects			

10. What did you do about the side effects you experienced? *(circle all that apply)*
- A. Nothing, just kept taking the drugs
  - B. Spoke to my doctor about it
  - C. Missed work or other appointments
  - D. Missed doses of my anti-HIV drugs
  - E. Stopped taking my anti-HIV drugs
  - F. Changed my anti-HIV medication
  - G. Other (please specify)
  - H. Have not experienced any side effects
11. If you talked to your doctor about the side effects, what did he/she do? *(circle one)*
- A. Nothing
  - B. Advised me to keep taking my drugs
  - C. Told me how to manage the side effects differently
  - D. Changed my anti-HIV medications
  - E. Told me the side effects weren't related to my medications
  - F. Other (please specify)
  - G. Did not talk to my doctor about the side effects
12. Do you ever take LESS than the prescribed dose of your anti-HIV drugs? *(circle one)*
- A) Yes    B) No
13. If Yes, please describe.

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*(please feel free to use the back to describe your experience)*

14. Please provide us with your ZIP CODE for statistical purposes\_\_\_\_\_.

*\*Anti-HIV drugs are also known as antiretroviral drugs.*

**Thank you so much for your time and effort in completing this survey. The results will appear in an upcoming issue of the Women Alive Newsletter *Awareness is Life - Information is Power***