

**Statement Submitted to the New York State Assembly Health Committee
Amending Article 27F's Provisions Guaranteeing Pre-test
and Post-test Counseling and Written Evidence of Patient Consent**

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I am Susan Rodriguez, the President and Co-Founder of SMART, Sisterhood Mobilized For AIDS/HIV Research and Treatment. SMART was created 9 years ago to provide treatment education and support for women living with HIV/AIDS. Since the beginning, the overwhelming majority of SMART women are women of color. We also now have SMART Youth, a support program for adolescents living with or at risk of HIV.

I appreciate the opportunity to present testimony to the Assembly Health Committee on the important issue of how HIV testing is conducted, and the so-called ancient history of HIV stigma. I was shocked to learn that one of the bills this Committee is considering includes the statement that HIV is no more stigmatized than “any other transmissible disease.” As a woman living with HIV, as a mother of a young teenage girl with HIV, as a someone who has spent years helping women with HIV pick up the pieces after learning their status, I have to conclude that only someone with no direct experience of our lives could be such an AIDS stigma denialist. In fact, when SMART was looking for office space in Harlem in 2004, the door was closed in our face by landlords when they found out it was a program for HIV+ women.

The statement overlooks the many drugs we must take, how sick my daughter and other women I know get, the strange things the virus and the drugs do to our bodies, the continuing ignorance of people old and young about how dangerous we are, or how the virus is transmitted. We will have this virus for life, and many of us are deprived of real intimacy as a result.

The sponsor of this bill knows nothing about E., who barely spoke for weeks when she first came to SMART, who is struggling with her daughter’s rejection of her because of HIV. She doesn’t know T., who was in this country only a short time when her uncle, a doctor, threw her out of the house because she is HIV positive. She doesn’t know M., who is sick a lot and who lost her

husband; or D., who took many months to get up the courage to tell her boyfriend about her status only to have him abandon her in response. She doesn't know V., a woman from Barbados who was infected in her 50's by a man she trusted who then went on his way. These are just a few of the real things that have happened this year in one small program. Does that sound just like "any other transmissible disease" to you?

The proposal to eliminate all counseling before HIV testing reduces a patient's opportunity for involvement in the HIV testing decision to saying "no" or coming up with questions about a test process or disease they may not understand and will feel too intimidated to ask about, especially if it's their first HIV test. Many people are intimidated by their doctors, and if a doctor says "I'm going to do this HIV test, any questions?" many will feel unable to say no or ask questions because that would be challenging their doctor. I think that people proposing this change are fully aware of that fact, and may even be counting on it, as a way to get HIV testing numbers up.

In the 9 years since I co-founded SMART, I continually meet people who don't trust their clinics or doctors, at least not at first and not until they believe that the doctors are being "real." I can tell you from this experience, as well as my own, that the best way to make sure someone never comes back is to treat them in a way that allows them to think the clinic staff is not giving them the full story.

I don't actually think that this is all that different from the way many people feel about their health care. Most people already feel that they get rushed through, or don't get enough clear information about their health conditions. Getting rid of a health care provider's obligation to make sure a patient is informed and ready to get tested may appeal to some doctors – the way it might appeal to anyone who is told their job duties are being scaled back – but no one

could reasonably believe that this approach, especially for adolescents or others who are vulnerable, is being done to make it easier or better for people with HIV, in the short or the long term.

What someone says to you before you test for HIV is very important, because the chances are you won't hear what they say afterwards. If you hear that you are positive, much of what you hear in those first moments will have to be repeated, because you will be in shock. If you are told that you are negative, you probably will go away thinking that whatever you were doing isn't putting you at risk and so you can keep on doing the same thing. Either way, you may not pay much attention to a doctor or nurse who treated the whole testing process like it is nothing worth talking about.

I think it is possible that if you get rid of HIV counseling for all but those who test positive, if you get rid of written informed consent, you may get higher testing numbers, just like you would if you went and tested everyone without even telling them. I don't think that this means that you will necessarily get more people into care, or that this will be worth the trauma you cause people who find out they are positive without being ready for that information. I don't think that this means there will be better health care for people of color with HIV, or that the people still struggling to get into their own housing will have it any easier. I believe that many people support these changes because they think their clinic or their program will get more money, and that that is worth taking away a few rights that community people in the past have literally fought and died for. I am a woman of color living with HIV, and I disagree with changes to Article 27F.