BY E-MAIL AND REGULAR MAIL

June 13, 2005

New York City Commission on AIDS
C/o NYCDOHMH
125 Worth Street, CN 28
New York, NY 10013
comments@health.nyc.gov

RE: Comments of SMART, Inc. on the May, 2005 Draft Report of the New York City Commission on HIV/AIDS

Dear Members of the Commission:

We thank the Commission for its draft report, clearly the product of considerable thought, discussion and work, and appreciate the opportunity to comment. The comments which follow are submitted on behalf of SMART, Inc. (Sisters Mobilized for AIDS Research and Treatment), [1] through collaboration with the Center for HIV Law and Policy.

We endorse most of the Commission's basic recommendations, and agree wholeheartedly with the need to make condoms much more widely available; to expand harm reduction programs; to make drug treatment programs more quickly and easily available to all who need them; to improve HIV prevention programs among those who are not yet infected; to improve school-based HIV and sexual health education; to pursue measures which will reduce and eliminate HIV-related stigma; and to more effectively evaluate prevention efforts and support those that work. The report's strong endorsement of condom access in correctional facilities throughout the state is particularly welcome.

[1] Founded in 1998 by a group of women living with HIV in East Harlem, SMART was started to address the gap in health information, effective prevention and support for women living with HIV/AIDS. Providing treatment education in a safe and supportive environment, SMART also works to help women advocate for their needs and those of their peers and communities. SMART University's other programs include prevention initiatives that provide safer sex products and information to women in community venues such as shelters and health clinics. Other SMART programs include SMART's Sewing Circle (which provides therapy, skill-building and social support); SMART Voices (a book club and basic education/GED preparation program); and SMART Body (a nutrition program providing instruction in healthful food preparation and good nutrition).

However, we question the report's increasing reliance on the Prevention for Positives approach; we disagree with the extent to which "normalization" of HIV testing would (and in some settings already does) translate to mass rapid testing without adequate preliminary counseling, confidentiality, or a concrete plan to immediately link those tested to useful services; we question the efficacy and efficiency of reliance on partner notification as a central prevention measure in the absence of data supporting its usefulness; and several of the recommendations (particularly as they relate to institutionalized persons, adolescents, and women of color) need further clarification. Finally, we look for specific plans of action that will promise concrete progress on important goals long recognized and supported, such as school-based education, and HIV health and prevention care at Rikers Island Correctional Center.

Our disagreement is based not on abstract principle, but on the extent to which these recommendations either do not clearly serve, or in fact may actively undermine, the Commission's own stated goals: reduction in the spread of HIV, significantly improved control of the epidemic, and ensuring the highest quality of medical care and support services for people with HIV/AIDS. To some extent our reservations about the recommendations – such as expanded surveillance -- are based on the current failure to resolve problems in the provision of quality care and prevention services to those already identified with HIV, such as care for the incarcerated or the City's ability to effectively administer existing prevention initiatives. In other places, the report identifies problems in meeting important goals without offering clear, concrete solutions. For example, if the reason for the ongoing failure to provide even the legally-mandated school HIV/AIDS education program is inadequate resources, how and when will this inadequacy be addressed? How does this resource shortage affect specific implementation of other Commission goals?

We focus here on several of what we think are the most important issues. We hope that the final draft of the report will expand on the many worthy goals identified with specific plans of action for implementation and monitoring.

Introduction

* Challenges: Areas Where We Must Do Better

While there undoubtedly are multiple potential areas of improvement, we believe the report needs to realistically address the ability or willingness of the NYCDOHMH to efficiently and effectively implement, administer and monitor existing programs and laws affecting basic HIV health and prevention needs. For example, as the report acknowledges, revision of the school-based HIV/AIDS health education program is still underway, while schools are not now nor likely ever have been in compliance with the relatively minimal current legal requirements. Treatment and prevention needs of inmates known to be HIV positive are not adequately addressed. Appropriated funds for prevention initiatives through community-based people of color organizations don't get

distributed.[2] Regardless of the reasons for the inability to ensure these critical services are delivered – inadequate staffing, inadequate skills, or inadequate political will – chronic failures to meet the needs of currently-identified individuals with HIV call for examination and resolution before the Commission calls for expansion of programs, or city agencies take on greater responsibility for treatment monitoring/management of those currently in a doctor's care.

Preventing Risk-Taking Behavior – Prevention plan recommendations should reflect proven approaches to disease prevention (such as campaigns targeting smoking and cancer, never restricted just to those already addicted or diagnosed) and must address the increasingly lopsided focus on only those who already are HIV positive. A comprehensive plan for effective HIV prevention in New York should reflect the reality that has never changed during the course of the epidemic: that every HIV negative individual can protect herself or himself against infection, and that (absent rape or the involvement of children and others without capacity to consent) it takes the actions of two people to cause the sexual transmission of HIV. Moreover, the report's recognition of the impact of HIV on women of color should be reflected in specific recommendations acknowledging that, for many women, marriage and monogamous relationships are the source of numerous infections, and prevention efforts must do more to arm and empower women to take direct responsibility for their health and welfare.[3]

Link People Newly Diagnosed With HIV to Care; Optimally Treat and Care for All of the More than 100,000 New Yorkers Living with HIV/AIDS -- The report offers no explanation as to why, decades into the epidemic and years after the institution of surveillance systems promised to improve care linkages, basic referral and care linkage systems are not in place. While touting expanded rapid testing at Rikers Island Correctional Center, the report does not identify this critical population as the target of significant planned interventions; instead, the report identifies the incarcerated as posing special challenges and moves on. Before NYC health officials attempt to monitor or manage the individual care of thousands of New Yorkers who at least have the ability to visit a health provider without assistance, a plan to optimize the care and prevention services of incarcerated individuals who represent, and return to, populations disproportionately affected by the epidemic should be developed and implemented.

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[2] One small but significant example is the 2004-2005 New York City POC funding initiative administered through NYCDOHMH. The DOHMH has been unable to register contracts, and distribute funds awarded last year to most of the organizations serving severely affected communities, despite the fact that the fiscal year comes to a close in weeks. Although SMART, Inc. was notified that it was awarded a grant under this program in September, 2004 (for the fiscal year July, 2004 – June, 2005), it has yet to receive even a registered contract, let alone the grant funds, despite the fact that SMART has at every step of the process responded in a quick, timely fashion to produce initial and subsequent documentation the NYCDOHMH has requested, requests that repeatedly have been made following DOHMH staff assurances that all paperwork had been completed.

[3] See Luby, Jennifer L., *A community-level HIV prevention intervention for inner-city women: Results of the women and infants demonstration projects,* 90 AM. J. PUB. HEALTH 216 (Feb 28, 2000); see also Hirsch, Jennifer S., *The social constructions of sexuality: Marital infidelity and sexually transmitted disease – HIV risk in a Mexican migrant community*, 92 AM. J. PUB. HEALTH 1227 (Aug. 31, 2002).

*** HIV/AIDS Stigma**

The report's assumptions about the Americans With Disabilities Act's effective protections for HIV positive people against discrimination in employment, housing and other accommodations seem naïve. There's little doubt the ADA was intended to provide blanket protection of those with HIV or AIDS against discrimination in all aspects of life. In application, however, the federal courts have failed to afford clear assurances that asymptomatic individuals will be able to secure the ADA's protection, and have diluted individuals' abilities to effectively enforce its protections against government agencies that discriminate. HIV-specific discrimination aside, people with HIV continue to encounter a host of problems in accessing basic services. Funding of legal services – a key component of adequate prevention – needs to be part of any plan for care and treatment.

A number of surveys on the issue of stigma demonstrate that the availability of effective treatment, not the routinization of testing itself, directly reduces stigma associated with HIV and other diseases. Despite the dramatic improvement in treatment in the past decade, the fact remains that, for many, HIV disease management requires multiple daily pill-taking, regular health complications both major and minor, and widespread physical manifestations of both HIV disease and long-term drug therapy that negatively identifies people with HIV. These facts of life with HIV are significant contributors towards its stigma, and should be acknowledged in the Commission's report and reflected in its recommendations.

Comments on the Report's Recommendations on Prevention

1. *Making Condoms Much More Widely Available* -- We applaud the report's recommendation of expanded condom access for inmates in NY, both in New York City and across the state. However, we think that the recommendations should be expanded to ensure that condom access, both in correctional facilities and in schools, is part of a comprehensive program that works to normalize and standardize condom use. Without such a program offered as part of routine programming for all inmates (and students) the perception of social risk or stigma associated with individual requests for condoms likely will limit their use. The Commission should also address the lack of woman-controlled prevention methods, such as microbicides, and how the NYCHOHMH can support development of such promising alternatives.

2. *Expanding Prevention With Positives Initiatives/Improving HIV Prevention Among HIV-negative People with Continued Risk-Taking Behaviors* -- We take issue with the proposed expansion of the Prevention With Positives initiative, and the ever-increasing overemphasis on conduct and responsibility distinctions between persons who have confirmed HIV positive serostatus and those who believe they are seronegative. The approach that self-protection be based on knowledge of a partner's serostatus or risk-taking behavior, through increasing focus on PFP and partner notification (PN), ignores the reality that precisely this approach is responsible for the HIV infection of many of the

women SMART serves.[4] Considering the difficulty of always ensuring condom use and fidelity of a spouse or partner, it makes sense for local advocates and health officials to more visibly endorse development of user-controlled technology such as microbicides that would make it easier for the HIV negative to stay that way.

Additionally, the promotion of partner notification as "an effective prevention strategy" runs counter to the CDC's own acknowledgement that "[n]o studies have directly shown that PCRS prevents disease in a community;"[5] overlooks long-standing criticisms of PN's confidentiality problems and limited practical value;[6] and misses a very recent national survey of HIV partner notification program coverage and outcomes concluding that PN programs have variable success at best and ultimately affect only a small minority of individuals with HIV.[7] PN does identify new cases of HIV, and to some this may seem sufficient justification for expansion of PN programs. Ultimately, we believe that the program costs and returns do not warrant significant additional investment in PN programs, particularly as many of the women and girls we serve see aggressive use of this method as a counter-incentive to test.

There also is important evidence that MSM prevention initiatives that focus solely on sexual risk ignore significant psychosocial problems that are interrelated with HIV infection risk and occurrence, and occur with disproportionate frequency among MSM regardless of HIV serostatus.[8] The final report's recommendations for resource allocation should reflect this.

Finally, we believe that city health officials should make a priority of improving the provision and monitoring of inmate HIV-related health and prevention services. As has been pointed out repeatedly, jails and prisons create a fertile environment for the spread of HIV, particularly among African Americans who are jailed in disproportionate numbers, make up half of all new HIV infections in the United States, and account for 72% of new HIV cases among U.S. women. High-risk behaviors, including injection drug use and unprotected sex, often go unaddressed in correctional facilities; and drug addiction goes effectively untreated. Such policies feed the very increase of HIV

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[4] See i*d.*

[5] CDC, "Incorporating HIV Prevention into the Medical Care of Persons Living with HIV," Morbidity and Mortality Weekly Report 52, no. RR-12 (2003):1-24

[6] See, e.g., Roger Doughty, "The Confidentiality of HIV-Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic," California Law Review 82 (1994); 111-184, at pages 167-75.

[7] Golden, Matthew R., Hogben, Matthew, Potterat, John J., Handsfield, H. Hunter, *HIV partner notification in the United States: a national survey of program coverage and outcomes*, 31 SEXUALLY TRANSMITTED DISEASES 709 (December 1, 2004).

[8] E.g., Stall, R., *Association of co-occurring psychosocial health problems and increased vulnerability to HIV/AIDS among urban men who have sex with men*, 93 AM . J. PUB. HEALTH 939 (June 1, 2003); Gross, M., *When plagues don't end*, 93 AM. J. PUB. HEALTH 861 (June 1, 2003).

transmission both inside and outside of prison that the Commission and the NYCDOHMH pledge to stem. Any serious plan for HIV prevention in New York will have to address the need to increase community prevention professionals' access to adult and youth correctional and detention facilities, and will include a plan to ensure that the care provided inmates of these facilities reflects the current standard of care outside jail and prison walls. There are few concentrated interventions that could have as significant, effective an impact on communities that are particularly hard hit by the HIV epidemic.

As one public health commentator recently observed, "Perhaps most importantly, somehow we need to immunize prevention science, programs and policies against stigma, political opportunism, and sanctimony."[9]

3. *Improving HIV/AIDS Health Education in Schools* – We strongly endorse the Commission report's recommendation in this regard, but find the lack of specifics disappointing. A plan to improve HIV/AIDS and sexual health education in the schools should include instructional modules that address homophobia; demonstrate cultural competence on issues of age, gender, ethnicity, class, and gender expression; and include condom use demonstrations as age-appropriate. It also should have a specific time frame for implementation and monitoring to ensure that public schools are finally in compliance with the long-standing requirement that an HIV/AIDS education program be in place. Finally, a real plan for improving HIV/AIDS and sexual health education in the public schools should address in more detail what resources will be available for this essential program and what the NYCDOHMH will do to ensure the program's quality and implementation.

The deficiencies in the current school HIV/AIDS education program, and the need to take action, are sadly illustrated in the recent comments of Christina Rodriquez, a 13 year-old living with HIV and the daughter of SMART's co-founder and President: "I don't talk about it – only two of my best friends know I have HIV. It's not that I'm ashamed, it's just some people don't understand. A couple of years ago, this boy at school told everyone you could catch it from sitting where someone with HIV had sat. How can I tell anyone I'm HIV positive when people believe such garbage? It didn't make me angry, just really sad."[10]

4. *Reducing HIV-Related Stigma* – As an organization created by and serving primarily women of color with HIV that includes women both newly diagnosed and those diagnosed more than a decade ago, SMART believes it is simplistic to suggest that "routinizing" testing and getting celebrities to come out as HIV positive will make major inroads against stigma. As long as HIV disease requires significant doses of daily medications to control it; is treated by drugs that cause significant visible physical changes and complications in a significant percentage of those who take them; and is transmitted through intimate sexual conduct and intravenous drug use, it will continue to

[9] Gross, M. *When plagues don't end*, supra n. 8.

[10] *Sugar*, (June, 2005), p. 82 (UK teen magazine).

engender a sense of social risk and stigma. Additionally, homophobia and related stigma remains a major obstacle to successful prevention interventions.[11] Until investment in the research, education, policy and legal reforms necessary to make significant progress in these areas is realized, routine testing will do little to reduce the stigma of testing *positive.*

Recommendations on Testing and Linkage to Care

The Commission's comments and recommendations seem oddly cagey as they relate to the role of pre-test counseling in ensuring that voluntary testing is in fact informed and consensual. The cryptic suggestion that current legal requirements governing HIV testing services, and related notions of confidentiality and autonomy, were rendered irrelevant by treatment developments is unfounded and cause for concern.

The pressures of our health care system and managed care have only exacerbated resistance among many health providers and insurers to the continued role of counseling prior to initiation of disease diagnosis and treatment. It was not just the lack of treatment alternatives and the fear of stigma, social isolation and worse that led to pre-test counseling requirements incorporated into most HIV testing regimes around the country. In fact, it was the activism of people with HIV that lead to unprecedented changes in the health care system, including principles of a right to health care, autonomy and informed participation in decisions related to health care, and large increases in AIDS research and funding. Such activists played the primary role in securing the passage of the Ryan White CARE Act in 1990, which provided significant financing for AIDS services, including primary health care. Indeed, conservatives in Congress initially refused to release the funds, seeing the creation of the RWCA as AIDS "exceptionalism" that took money away from others, and other diseases, that needed it.[12] "Informed consent is the bedrock of bioethics, the tangible evidence of respect for individuals and for autonomous decision-making."[13]

We are very concerned with the report's veiled discounting of the importance of pre-test HIV counseling. Not all counseling is alike, either in approach or competence, a factor that is not addressed in the endorsement of expanded rapid testing to settings where adequate counseling and follow-up services are likely to be difficult at best and impossible at worst, with potentially deadly consequences when used with youth, the homeless or other populations whose needs go beyond HIV diagnosis. The significant difference in approach and related efficacy of HIV counseling techniques, and the unfortunate tendency even among researchers to lump all types together in assessing

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[11] See, e.g., Levi, Jeffrey, *Ensuring timely access to care for people with HIV infection: A public health imperative*, 92 AM. J. PUB. HEALTH 339 (March 31, 2002).

[12] Hoffman, Beatrix, *Health care reform and social movements in the United States*, 93 AM. J. PUB. HEALTH 75 (January 1, 2003).

[13] Woodsong, C., Karim, Q. A., *A Model Designed to Enhance Informed Consent: Experiences From the HIV Prevention Trials Network*, 95 AM. J. PUB. HEALTH 412 (March 1, 2005).

effectiveness, has been recognized before.[14] This should be reflected in the Commission's recommendations, which should reject any adoption of a "one size fits all" approach to HIV testing and counseling.

Limiting the role of testing largely to increased case identification (and the emphasis on this as a basis for funding allocations), appears to ignore years of research affirming the role of counseling and education among HIV negative as well as HIV positive individuals.[15] The impact of HIV on already strapped communities and the pressing need to reduce transmission and eliminate barriers to care calls on public health professionals to use every effective tool possible. Health communication -- the study and use of methods to inform and influence individual and community decisions -- is an important tool in this effort, and counseling and other communications between health providers and patients is a central prong of this tool.[16] Unfortunately, too often "the public health community seems to have a limited understanding of what health communication can offer to the elimination of health disparities… [H]ealth communication can increase the intended audience's knowledge and awareness of a health issue, problem, or solution; influence perceptions, beliefs, and attitudes that may change social norms; prompt action; demonstrate or illustrate healthy skills; reinforce knowledge, attitudes, or behavior; show the benefit of behavior change; advocate a position on a health issue or policy; increase demand or support for health services; refute myths and misconceptions; and strengthen organizational relationships."[17]

Particularly at a time when federal and other resources for *effective* HIV prevention are not likely to substantially increase, responsible resource use dictates that we seize the full potential of all prevention interventions, particularly with populations that are uniquely difficult to reach and maintain in care. The goal of each intervention, particularly HIV testing programs as the potential gateway to an array of services, should be to promote preventive health behaviors and ongoing contact with health services and related programs. Research targeting adolescents is particularly instructive in this regard. Well-designed community-based group interventions, for example, significantly increase *ongoing* preventive health care seeking among female adolescents.[18] Rapid testing

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[14] Kamb, M.L., MD, MPH, Peterman, T., MD, MSc, Wolitski, R. J. MA,, Letter, *Prevention Counseling for HIV Negative Persons*, 90 AM. J. PUB. HEALTH 1152 (July 31, 2000).

[15] D.R. Holtgrave and his colleagues found, for example, that for persons who receive HIV counseling and testing, and for whom these services are effective, the transmission rate is near 0%. They also observe that "[f]or persons who do not receive counseling services as well as testing, or for whom counseling and testing is insufficient to induce behavioral change the HIV transmission rate is between approximately 2 and 4%." *HIV transmission rates higher for people unaware of their serostatus HIV/AIDS Transmission*, AIDS WEEKLY (March 21, 2005).

[16] Freimuth, Vicki S, Quinn, Sandra Crouse, *The Contributions of Health Communication to Eliminating Health Disparities*, 94 AM. J. PUB. HEALTH 2053 (Dec. 1, 2004).

[17] *Id.*

[18] VanDevanter, N. L., Messeri, P., Middlestadt, S.E., Bleakley, A., et al., *A Community-Based Intervention Designed to Increase Preventive Health Care Seeking Among Adolescents: The Gonorrhea*

programs that de-emphasize counseling and the engagement of the target population in ongoing preventive health care is short-sighted and risky. As was reported in a recent study on the topic, "[a]dolescents who use preventive health services have been shown to engage in fewer risk behaviors and more health promoting behaviors and to be in better health… In addition, establishing the habit of seeking preventive health services during this age period can build health behaviors that may continue throughout adulthood."[19]

Finally, the issue of linkage to care for the incarcerated is sufficiently critical to warrant more than a paragraph identifying it as "problematic." If the prioritization and political will that brought rapid testing into Rikers were now focused on providing the care to which these newly-diagnosed individuals have a right, an accomplishment of true public health significance would be realized. At the same time, the conduct of testing in these facilities must be monitored and reevaluated to ensure that confidentiality and informed consent considerations – both of heightened concern in a correctional setting – are properly incorporated into the current testing program.

Recommendations on Treatment, Care and Coordination

Once a model for other city jails, the health care afforded inmates of Rikers Island, specifically including the program of HIV-related monitoring, care and follow-up – has become a national disgrace.[20] One of the world's largest city jails, holding over the course of a year thousands of individuals with or at significant risk of HIV who are returning to communities particularly devastated by HIV, Rikers provides an important opportunity for critical public health interventions. Not only is this opportunity being squandered, but the city has extended a contract for the provider, Prison Health Services, that also is nationally notorious for the substandard quality of care it provides and has, as a consequence, been the repeated subject of law suits around the country.

If the Commission's stated goals are to be credible, they must address in a serious way the problem of health care for the incarcerated in New York. The care provided inmates of Rikers and similar facilities should reflect the current standard of care outside jail and prison walls.

Community Action Project, 95 AM J PUBLIC HEALTH. 331-337 (Feb. 1, 2005). "Sexually active adolescents and young adults have the highest rates of sexually transmitted diseases (STDs) in the United States, yet they are less likely to seek and receive health care than any other age group. If young people delay or avoid seeking health care, they may be at increased risk of transmitting infections to sexual partners…There are many benefits associated with increasing preventive health care seeking on the part of adolescents, including early diagnosis and treatment of illness and the opportunity for preventive health education."

[19] *Id.*

[20] *See, e.g.*, *Medical Care At Rikers Fails in Evaluation*, N.Y. TIMES (June 10, 2005), at B1. Health care at Rikers has been in a pronounced decline since the contract for provision of jail health services was switched from Montefiore Medical Center to PHS, presumably as a cost-cutting measure.

Areas Requiring Additional Review

1. *Barriers to HIV testing:* The report fails to clearly identify, let alone support, how or to what extent current New York law governing HIV testing and counseling creates barriers to earlier HIV testing. The report also fails to adequately address why counseling, despite the considerable research and experience underscoring its importance as a key component of HIV testing, should now be abandoned prior to testing or for all who test negative without specific consideration of the unique needs of different populations and communities (e.g., adolescents, prisoners, immigrants, etc.). If there are actual problems with the current regimen, those problems must be specifically identified, with their application to different populations clearly explained, before alterations of the law are proposed.

2. *What type of surveillance serves the goals of better treatment and prevention?* Before scarce resources are expended on the expansion of any form of HIV surveillance, a thoughtful assessment of what data has in fact been useful to date in actual treatment and prevention planning and implementation, and what additional data would be useful, should be undertaken. As acknowledged by the New Jersey Department of Health -- one of the first states to adopt HIV case reporting – current case reporting misses approximately a third of estimated infections and does not provide true incidence or prevalence rates.[21] There is little documentation, if any, that surveillance data has been used to improve linkage to care or treatment. Before expending additional resources, the Commission and the DOH should more thoroughly consider questions such as the following:

- What additional data would be helpful in determining how to slow HIV transmission and better treat those who are infected, and why? What data unnecessarily complicates and makes more expensive the data collection that actually is needed?
- What information would be helpful in determining how to better treat MDR HIV? How can the DOH work better with physicians and labs to better monitor and expand the use of effective therapies? What data would in fact assist researchers exploring better responses to MDR? There currently are a number of individuals with very resistant virus who nonetheless are successfully managing viral load and disease progression through sophisticated assessment of treatment options, resistance testing, etc – what are the NYCDOHMH, and local research labs, doing to identify and assess these patients and approaches?[22]

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[21] New Jersey Department of Health, HIV/AIDS Surveillance Report, *New Jersey HIV/AIDS Semi-Annual* Newsletter, December, 2004, http://www.state.nj.us/health/aids/qtr1204.pdf.

[22] In the wake of the MDR media blitz earlier this year, one of SMART's advisory board members, John Falkenberg, R.N., attempted to interest Aaron Diamond research staff (who apparently work in close communication with the NYCDOHMH) in his own experience with successful monitoring and treatment of MDR HIV. His email, setting out the key details of his treatment and viral progression history, never received a response. We are appending it to these comments, in the hopes that NYCDOHMH officials

- What assistance from the DOH would be helpful to physicians with large HIV practices in helping to organize and collect data related to disease progression and treatment that has broader application to other clinic/physician practices? Would, for example, DOHMH funds be more efficiently spent assigning field staff to assist physicians in setting up data collection systems that would make it possible to track and report trends? While labs are computerized, many physicians do not use computers for this purpose in their practices. Data collection could protect patient privacy, with reporting based on physician license numbers.

Securing answers to these questions will require the involvement not just of agency officials but of physicians and other health care providers in the trenches, seasoned and actively involved in the care and treatment of people living with HIV and AIDS.

Respectfully,

SMART, Inc.

By:

Susan Rodriguez, President and Co/Founder
J. Maya Iwata, LMSW, Executive Director
John Falkenberg, R.N., Advisory Board Member
Catherine Hanssens, Esq., Advisory Board Member and Founding Executive Director, The Center for HIV Law and Policy

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interested in more focused attention on treatment options for MDR virus will have an interest in following up.

> -----Original Message-----
> From: John Falkenberg [mailto:jfalkenberg@nyc.rr.com]
> Sent: Wednesday, February 16, 2005 5:03 PM
> To: mmarkowi@adarc.org
> Subject: Interesting patient with MDR HIV
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> Dr. Markowitz,
>
> I have had a surprising response to ARV therapy despite
> genotyping and phenotyping which demonstrates triple-class MDR
> HIV infection. I think it might be of value if you took a look
> at the virus I'm growing and the levels of ARV medications which
> result from the combination I'm currently taking.
>
> I have long-term HIV infection, treated with antiretroviral
> medications consistently since 1989. Probably infected more than
> ten years before then (PGL beginning in 1978;), I had a lymph
> node biopsy as part of a study of gay men with PGL in the early
> eighties at New York Hospital when I participated in a study
> conducted by Dr. Craig Metroka, an ID fellow at the time. At
> that time I was working as a nurse at NY Hospital.
>
> Without going through my treatment history in detail in this
> email, I have experience with the three major classes of ARV
> medications and documented high-level resistance to all three
> over many years. My strategy has been to recycle and put together
> combos based on kinetic interactions in hopes of achieving
> partial viral suppression and immune reconstitution.
>
> My baseline viral load off therapy runs between 500,000 and
> 600,000. My previous partially effective combination consisted
> of a boosted PI with a nnRTI and 3TC which reduced my viral load
> to around 50,000 for two years. My CD4 count which was as low as
> 137, bounced above 500 and then settled in between 300 and 400
> for the two years. At that point, I experienced viral
> breakthrough, rapidly back to baseline. A short time after the
> breakthrough, I experienced a rapid decline in CD4 count to 150.
> At that point, I stopped the medications except for 3TC to take
> break from the drug-associated toxicity and researched for
> another combination. Based on very little data but based on both
> kinetic and genetic data, mostly from small numbers of patients
> reported in the literature and at meetings, I chose atazanavir +
> fosamprenavir + ritonavir boosting + d4T + 3TC. By the time I
> began therapy, my CD4 count was at 120.
>
> I have been on that combination for 68 weeks. My viral load is
> 9,567 and appears to be slowly declining. My CD4 counts is 450
> and at 29%, the highest CD4% since March 1993 and appears to be
> slowly rising. I do not know why this is working. Could it be
> that the kinetic interactions yield levels exceeding the
> resistance? Could it be that the mutations have disabled the
> virus? One of the reasons I combined atazanavir and
> fosamprenavir was the suggestion that the mutation each drug
> caused at codon 46, "hypersensitized" the virus to the other
> protease inhibitor. Could this combo be more broadly applicable

> to people with MDR HIV?
>
> Anyway, I am a very involved and fairly well informed patient. I
> am a Registered Nurse and was also a pharmaceutical/biotech
> analyst for a number of years before retiring. I have
> comprehensive records, spreadsheets and graphic representations
> of my lab values beginning in 1989 and multiple
> genotyping/phenotyping results beginning in 1996 (I had to
> personally bring frozen specimens to DHL for shipment to Virco
> in Belgium to have these tests done in the beginning). While
> much of this will be useless info, I just wanted to convey that
> there is very easy access to lots of data. I probably still have
> a record with the lymph node biopsy results from the early
> eighties at NY Hospital where I was both a nursing student and a
> nurse for a number of years.
>
> . . . [personal physician information deleted]
>
> Please let me know. If there is any chance that this antiviral
> response is due to anything that might be more broadly
> applicable, I want to help.
>
> Thank you.
>
> John Falkenberg
. . . [personal address information deleted]