The Continuing HIV/AIDS Crisis in New York: A Course of Action to Advance and Foster HIV/AIDS Research Tailored to the Needs of New Yorkers

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From Article VII SFY 2008-2009

S 31-a. The AIDS advisory council shall prepare a report on the potential for developing an acquired immune deficiency syndrome research initiative. In developing this report, the AIDS advisory council may, at its discretion, consult with appropriate external organizations expert in the development and operation of such research programs. The report shall be submitted to the Department, the legislature and the Governor on or before November 15, 2008.

Executive Summary

The AIDS Advisory Council urges the Governor and Legislature to support the creation of a HIV/AIDS Research initiative. It is proposed that $1 million in start up funding be included for New York State Department of Health (NYSDOH) as part of the 2009-2010 Executive Budget. Following initial start-up it is recommended that $5 million be allocated annually for a period of 2 - 3 years following with an evaluation to assess the effectiveness of the initiative in generating new research and in attracting federal and private research funding to New York State.

In today's complicated financial times, an investment in AIDS research is fiscally sound. Research that leads to greater prevention measures means fewer infections and reduced overall health care costs. Research that leads to better wellness for those already infected will result in improvements in health status and reduced treatment costs. Research in and of itself is a proven economic stimulus, generating employment, grants and patents. This funding would support a growing cadre of New York-trained and practicing research scientists, would allow research priorities to be identified that are specific to, and assure development of, program and policy that is uniquely suited to New York State.

Why an AIDS Research Initiative and Why Now?

During the past 25 years New York has responded to the HIV/AIDS epidemic with bold and proactive programs, and has always been a leader in preventing new HIV infections and in assuring access to quality care. A need for AIDS research was acknowledged 25 years ago with creation of an AIDS Research Council under the New York State Public Health Law. Today, we are at a critical juncture, where research is of paramount importance:

- New York's HIV/AIDS research needs continue as new individuals are infected each year, adding to the population of already infected individuals who are living longer, thanks to the advent of new therapies and treatments.

- National Institute of Health (NIH)-funded research is failing to meet New York's specific needs or to adequately support ongoing generations of New York-based research. New York's current research capacity is constricting due to federal funding

reductions that not only reduces research today but also for the next generation of investigators.

- Building New York's research efforts can address the health needs of New Yorkers and increase federal and private research dollars. A model research program, in place in California, has been hugely successful, not only in stimulating research in the State but also in leveraging significant funding **– nearly seven dollars in Federal and private support for every dollar invested by the state of California.**

- An infrastructure for such an initiative is well in place. Existing expertise is available in the New York State Department of Health, in the Wadsworth Laboratories and in the AIDS Institute. An AIDS Research Council, which exists under statute, would be enlivened and assigned responsibility for development of criteria and standards that would guide the Department in the award of funding.

- New York is home to a wide range of committed researchers who, with continued funding, will continue to conduct research that informs planning, policy and clinical treatment in New York State.

- New York-based researchers are at a competitive disadvantage. California and Massachusetts-based researchers, who are supported in conducting preliminary work of interest to the federal government, are one step ahead in terms of having experience and providing data that renders them more attractive recipients of scare research funding.

- This initiative would accomplish the following:

    - Promote new and novel research that is specific to the needs, care and treatment of New Yorkers
    - Leverage federal and private research dollars and bring research funding to New York State academic and scientific institutions.
    - Assure that New York State researchers can be competitive with researchers in California and Massachusetts – homes to state-sponsored initiatives.

- Funding would be used solely for New York-based HIV/AIDS research and would be used for several independent initiatives, including:

    - Development of innovative research ideas
    - Support for community-researcher partnerships
    - Support for new investigators (e.g., through dissertation awards)
    - Policy analyses and program development.

I. Introduction and Overview

New York State has and continues to be a leader in research and policy development, providing the foundation for many advances in public health. It is home to some of the most esteemed academic and biomedical research institutions in the world, and provides innovative and respected medical, health care, and academic infrastructures, as well as a critical mass of sophisticated researchers devoted to tackling HIV/AIDS. Our scientists have made substantial contributions since the beginning of the epidemic, ranging from early recognition of the problem, the discovery of Kaposi's sarcoma-associated herpes virus to new treatment, and prevention strategies including spectacularly successful pregnancy and risk-based screening approaches to prevention. Since 2002, the New York HIV Research Centers Consortium, consisting of HIV research centers throughout New York State, has led efforts to further an inter-disciplinary research agenda, to address emerging research questions and make efficient use of the broad range of research talent.

Public health policies must be informed by knowledge gained from rigorous scientific investigations. New York State scientists and communities are in the unique position to give attention to the emerging and cross-cutting issues that must be addressed within New York's diverse and demanding environment. It is time for New York to bring its considerable resources to bear in a focused, coordinated way on HIV research. While this will require state funding, the return on the investment will be immeasurable.

II. New York – A History of Successes and Challenges:

For the past 25 years New York has responded to the HIV/AIDS epidemic with bold and proactive programs, providing a comprehensive continuum of HIV services that today is a national model. New York has been a leader in preventing new HIV infections and ensuring access to quality care. Dedicated support of basic, clinical and behavioral research will directly help identify new ways to treat, monitor and prevent HIV infection and in turn help many more New Yorkers living with HIV.

As a State, we can proudly point to multiple successes – successes borne of necessity and invention. Necessity, as New York has been the epicenter of the epidemic in the nation since the first case was diagnosed. Invention, as research conducted in New York State has led to new and effective programs, services and treatment. New York enjoys a complex and multi-faceted policy environment that relies on research to guide policy. Initiatives (such as newborn screening) are closely scrutinized, evaluated and assessed in terms of short- and long-term impact before implementation. Notable policy decisions have resulted in the following:

- The number of deaths reported has sharply decreased, thanks to focused testing programs, widespread access to medications, and strong systems of medical care;
- Since 1990, there has been a 68 percent decline in the number of HIV-positive women giving birth in the State, and since 1983, mother-to-child transmission has been reduced by more than 95 percent; In 2008 to date, there have been two cases of perinatal infection;
- The number of new infections among injection drug users has fallen by 50 percent – 70 percent in the past dozen years;

- HIV/AIDS hospital admissions have declined from 65,000 in 1995 to 48,812 in 2005 – a decrease of 25 percent; and
- The average HIV/AIDS hospital length of stay was 18.9 days in 1990 and 9.3 days in 2005 – a reduction of more than 50 percent.

These successes have bred new challenges. New York continues to face many of the same challenges along with new challenges. The number of persons living with HIV in New York State has tripled since the early 1990s, which poses challenges both to systems of care as well as to our prevention programs; the impact of HIV on communities of color continues to be disproportionate; and the number of persons who are diagnosed late in the progression of their disease (when care and treatment is less effective and transmission more likely) continues to grow – all trends that must be reversed. In fact, as noted in The New York Times:

> "It has been three decades since AIDS made its appearance. There was hope not long ago that the nation was bringing infections under control. The recent bad news means that the crisis is still with us."[1]

Increasing numbers of persons living with the virus, together with the transformation of HIV from an acute, immediately life-threatening disease to a chronic disease with multiple long-term complications demands both programmatic and scientific responses so that the State can continue to provide timely and effective treatment and prevent new infections. A focus on and support of scientific and behavioral research will meet the currently unmet needs of New Yorkers living with the virus will serve to:

- prevent new infections;
- identify infection early in the course of the disease;
- maximize retention in care and treatment; and
- provide critical information and tools to help address the epidemic in New York and nationally.

III. The Importance of Research that is New York State-Specific:

Greater investments in basic and applied HIV/AIDS research are essential, as the demand for care and services continue to increase and until such time that an effective vaccine is developed. Research funding supported by the State of New York will allow for and support maximization of competitive funding by offering essential research facilities seed money to attract and generate additional support. These programs provide an infrastructure and continuous generation of new knowledge which allows for rapid progress toward meeting national needs.

In recent years, our nation's investment in HIV/AIDS research declined, threatening our ability to sustain the vitality of our research portfolio along with our ability to effectively prevent new infections or to treat those already infected. Thus it is imperative that the breadth and competitive nature of the HIV/AIDS research portfolio be expanded to ensure our state and our nation's excellence in prevention, care and treatment of this deadly disease.

[1] "The Real Numbers on H.I.V." *New York Times*, September 3, 2008, p. A24

New York's research needs continue – especially as more persons are living with HIV and are living longer. Moreover, NIH-funded research does NOT address New York-specific needs. A large research establishment in New York State that can continue to achieve successes such as those noted above is diminishing as a result of federal funding reductions. This contraction has long-term consequences as the next generation of investigators are few and far between. Building New York's research efforts can both address health needs and contribute to economic benefits by leveraging increased public and private research funding. New York can look to multiple successful research models – and must do so now.

Now is the time to support an AIDS research initiative in New York; to take proactive steps to assure that New York is a national leader in HIV/AIDS research. This research must reflect and build upon a long history of and strong commitment to basic and clinical research, to persons living with HIV/AIDS and to future research that will improve the lives of persons living with HIV/AIDS and help prevent new infections. Precedent exists for this type of research initiative. Moreover, New York State is uniquely suited to support this type of initiative with both an existing strong research base and a unique and distinct population living with HIV/AIDS.

A. New York State is the HIV/AIDS Epicenter of the Nation

New York continues to be the most disproportionately affected state in the nation with the highest per capita AIDS case rate: 28.5/100,000 as compared with 12.9/100,000 nationwide as of 2006. Only the District of Columbia and Maryland have higher rates. Despite being home to 16 percent of all cases (HIV and AIDS) nationwide, New York received only 8.5 percent of federal research funds in 2004.

New York City is home to the majority of persons living with AIDS in the State, but the magnitude of the epidemic in the State extends well beyond the city's boundaries. In fact, several New York State counties have reported more AIDS cases than have been reported in many other states. Westchester County exceeds 23 states and dependencies in the number of cumulative AIDS cases and in the number of persons living with HIV/AIDS. Monroe and Erie counties each exceed 12 states in the number of cumulative AIDS cases, and Dutchess County exceeds 11 states. Orange, Onondaga, Albany, Rockland, Oneida, Ulster and Sullivan counties each exceed seven or more states in the number of cumulative AIDS cases.

Despite these statistics, federal funding continues to decline. In the past five years, prevention funding has been reduced by almost 20 percent, and the State is anticipating an additional reduction of more than $1 million this year. Ryan White funding directed to the State was reduced by $6.6 million in the last two years, and Ryan White funds directed to the State's eligible metropolitan areas have been reduced by $7.5 million.

New estimates of HIV incidence find New York to be unique. The populations that bear the greatest burden nationally – Blacks and men who have sex with men – are highly represented in New York. In fact, Blacks, whites and Hispanics experienced higher incidence in New York City than nationally. Within New York City, whites were infected at four times the national rate, Hispanics at three times the national rate, and blacks at almost twice the national rate.

New York is home to a unique and diverse population that is not replicated elsewhere in the nation, presenting unique challenges both in terms of caring for those who are infected with HIV-related disease and AIDS, and preventing new infections among those who are at risk. For instance:

- WOMEN: Women in New York State are disproportionately affected by AIDS. Women with AIDS in New York State represent a larger proportion as compared to those living with AIDS in the United States – 30 percent vs. 23 percent. Thus, the need to study the epidemic among women is of particular importance in New York State.

- COMMUNITIES OF COLOR: Among AIDS cases reported in New York State in 2006, the proportion of individuals belonging to racial/ethnic minority groups (primarily African-American and Hispanic) was 78.9 percent compared to 65.5 percent in the United States. In addition, New York State is home to 17 percent of all African-Americans and 24 percent of all Hispanics in the United States living with AIDS.

- IMMIGRANTS: New York State is host to a large, diverse, immigrant population with barriers to prevention and care that include language and significant cultural differences. Many immigrants come from and travel regularly back and forth to their countries of origin, each with their own HIV epidemics, presenting additional considerations.

- DRUG USERS: New York continues to have high rates of drug use, and is ranked fifth in terms of percentage of people infected through injection drug use: 39.2 percent in New York vs. 24.1 percent nationwide through December 2006. Non-injecting drug use (especially stimulants) and alcohol have also been shown to be critical factors in HIV transmission and disease progression.

- DEATHS: New York is second only to Florida in the number of deaths due to HIV, and, in 2005, the rate of death of those infected with HIV-related disease in New York was twice the national average: 8.2/100,000 vs. 4.2/100,000. This suggests persistent challenges in accessing health care[2].

More people, fewer dollars and evolving challenges demand that New York rise to the challenge and support critical clinical and social research that will guide future care, treatment, policy and funding decisions. New York is uniquely suited and qualified to conduct cutting-edge HIV research that will help persons living with HIV infection in New York, prevent new infections and provide a model of care, treatment and prevention that may be used throughout the nation.

B. New York - Home to a Diverse and Well Established Research Community

Research in New York State is supported by a range of diverse organizations and institutions, including academic institutions and medical centers, a state laboratory (Wadsworth); existing research consortiums (NYS HIV Research Centers Consortium,

[2] Kaiser Family Foundation http://www.statehealthfacts.org

private funders) and well-organized medical networks such as HIV SNPs, DACs and HIV Centers of Excellence. New York State has vast and positive experience with sponsored research in traumatic brain injury and stem cell research. In fact, the Wadsworth Center administers legislatively authorized extramural funding programs that support New York State investigators studying specific topics. These include:

Stem Cells - New York Stem Cell Science works to further the agenda of the Empire State Stem Cell Board, established in April 2007 to administer grants for basic, applied, translational or other research and development activities that will advance scientific discoveries in fields related to stem cell biology.

Breast Cancer - The New York State Health Research Science Board has supported breast cancer research studies and education projects since 1996.

Spinal Cord Injuries - The New York State Spinal Cord Injury Research Board, established in 1999, distributes research grants to find a cure for spinal cord injuries.

Recognition of the need to invest in science and technology is well noted in the establishment of the New York State Foundation for Science, Technology and Innovation (NYSTAR). NYSTAR is structured to:

- Create jobs and economic growth in the science, technology, and innovation sectors;
- Invest in academic research programs that advance cutting-edge science;
- Help transfer scientific inventions from the laboratory to the marketplace; and
- Guide the development of the State's overall science and research policy.

New York is a virtual powerhouse of research expertise and resources. As the epicenter of the AIDS epidemic, New York must use its experience and expertise to create an AIDS research initiative that is fiscally prudent and consistent with state research and development goals. Researchers in New York's academic institutions, government agencies, and private organizations must be at the forefront of HIV/AIDS scientific discovery and application, assuring that clinical programs and policy planning are based on the most current and sophisticated science.

Although New York has a vast scientific infrastructure and capacity – academic, governmental, and community-based – these resources are not systemically integrated for HIV research. Sporadically, some institutions and organizations coordinate efforts in clinical trials, to improve prevention and care, and in special projects with investigators, but generally HIV research is fragmented, occasionally using networks that were established for other purposes.

Looking to the future, HIV/AIDS research would focus on New York State-specific HIV services, communities and affected populations. As highlighted by recently released CDC statistics, New York continues to lead the nation in the number of persons impacted by this disease. The new incidence estimate shows that 72 of every 100,000 of New Yorkers were newly infected in 2006, compared to 23 per 100,000 nationally.

This initiative would assure that new researchers who might be years from obtaining a grant from the NIH would have an alternate funding source for new and imaginative studies. It would provide seed money for projects that may not initially be attractive to NIH but might later become so. It would allow experienced researchers to continue basic science, clinical research and support their labs. Similarly, New York-focused research would provide greatly needed information to guide policy development and implementation, such as the debate over written informed consent for HIV testing.

Publicly supported scientific research can give us the tools to stop this epidemic. Small scale interventions and programs have potential for general application. Unique models implemented by agencies throughout the state will have enhanced effectiveness with a centralized clearinghouse able to communicate these models so that they might be implemented by others.

Rigorous scientific investigation has brought substantial increases in our understanding of pathogenesis, disease course, treatment, prevention and transmission, but more must be done. Research is needed in many areas, including:

- Basic and clinical sciences (virology, immunology, vaccine and drug development, and biomedicine)
- Behavioral and social sciences (e.g., determinants of risk behaviors, determinants of access and adherence to care for HIV-infected persons, reduction of late/concurrent diagnoses, prevention interventions ranging from the level of the individual to the community and institutional settings)
- Health service development, policy and evaluation
- Prevention interventions (individual, community and institutional)
- Community empowerment to effectively prevent the spread of HIV and to improve the lives of those who are already infected.

In short, a New York State HIV/AIDS research initiative would serve as an incubator, a catalyst, a hedge against irreparable loss of ideas and professional talent, and, in some cases, a sustaining source of support. A HIV/AIDS research initiative would benefit numerous populations and sectors of the economy. To be successful, the initiative must:

- Be structured to assure linkages between research and prevention;
- Assure that research leads to improved prevention models, clinical care and services;
- Assure timely distribution of funds; and
- Be related to New York State-specific priorities.

IV. The Need for a State-Sponsored Research Initiative

A. Declines in Research Funding

Diminishing federal support of research as noted in recent Congressional testimony (July 16, 2008) when Senator Tom Harkin said that fiscal 2009 "marks the fifth year in a row that NIH funding failed to keep up with the costs of inflation since Congress doubled the NIH budget in a five-year period that ended in fiscal 2003. The average investigator now has a 1 in 5 chance of receiving an NIH grant. It should be no surprise, then that many

young people are deciding against a career in biomedical research, putting this nation at risk of losing a generation of talented investigators."

NIH's budget first expanded and then contracted, doubling between 1998 and 2003 and flattening thereafter. As a result, universities and medical schools built new laboratories and expanded their cadres of researchers, who flooded the NIH with applications. The increased spending helped spur completion of the human genome project and led to new diagnostic tests and therapies for a variety of diseases. Then, beginning in 2003 NIH budgets were flat, which in an era of ever-increasing inflation, resulted in a decrease in purchasing power of between 8-16 percent. The 1995 NIH budget of about $12 billion increased to more than $28 billion in 2007, but that represented only about $19 billion in 1995 dollars. Researchers were told to "curb their appetite for federal funding."[3]

The impact was immediate. Funding for unsolicited, investigator-initiated R01 awards fell from $510 million in 2002 to $351 million in 2005. Currently, only 2 of 10 grant applications are funded. The chance of being funded on the first try dropped from 21 percent in 1998 to 8 percent in 2006.

Many institutes within the NIH quickly adopted changes to minimize the adverse consequences of budget reductions, including reducing the maximum grant term from five years to four years, eliminating cost-of-living increases, and capping the amounts of awards. These changes have had deleterious effects on currently funded research. Moreover, the future of biomedical research is also affected: NIH training grants represent a major source of support for postdoctoral and clinical fellows during their research experiences. Budget limitations affect not only available training slots but also the training climate. As it becomes increasingly difficult for established investigators to renew their grants, their frustration is transmitted to trainees, who increasingly opt for alternative career paths, shrinking the pipeline of future investigators.[4]

Federal spending for biomedical research now amounts to about $97 per capita – a rather modest investment in "advancing the health, safety, and well-being of our people."[5] This downturn threatens to erode the benefits of the investments made between 1998 and 2003. It takes many years for institutions to develop investigators skilled in modern research techniques and to build the costly, complicated infrastructure required. Rebuilding the investigator pool and the infrastructure after a downturn is expensive and time-consuming and weakens the benefits of prior funding.

B. Reduced Funding Allocated to New York State

NIH funding for research conducted by New York State institutions has been declining for 25 years. Between 1984 and 1998, New York's share of funding from the NIH dropped from 15.2 percent to 10.8 percent and has been decreasing ever since, reaching a low of 8.5 percent in 2004. Funding to New York's medical schools between 1984 and 1996 slipped from 8.3 percent to 6 percent of the NIH research budget, a decline of 28

[3] *Science* Magazine, Volume 314: 1088-1090 November 17, 2006 "NIH in the Post-Doubling Era: Realities and Strategies", Elais Zerhouni
[4] Loscalzo J., op. cit.
[5] New England Journal of Medicine, Volume 354: 1665-1667 April 20, 2006 Number 16 "The NIH Budget and the Future of Biomedical Research", Joseph Loscalzo, M.D. Ph.D.

percent.[6] In 2007 New York State trailed California and Massachusetts in of overall NIH funding awarded to the State (New York State, $1.9 billion; Massachusetts, $2.2 billion; and California, $3.2 billion).

Not only has New York State received a decreased proportion of national funds, but funds available for HIV/AIDS research as a proportion of all research funding have also declined over time. The NIH administers approximately 96 percent of all federal HIV/AIDS research funding. Its HIV/AIDS budget in FY 2004 was $2.9 billion, compared to its 1995 funding of $1.3 billion. However, funding for research programs as a share of total federal HIV/AIDS funding declined from 21 percent in 1995 to 16 percent in 2004. In addition, HIV/AIDS research as a share of the overall NIH budget declined from 12 percent in 1995 to 10 percent in 2004.

In the flood of investigators competing for diminishing federal grant support are many researchers who had been encouraged to enter the biomedical sciences during the flush times, as well as senior researchers trying to maintain laboratories and continue promising projects. The implications are no less than a crippling of biomedical research productivity: reduced lab size, abandonment of research in progress, discouragement of young scientists, decreased innovation and risk taking in project conceptualization, less institutional collaboration, and, ultimately, the loss of momentum in the historic U.S. record of biomedical research accomplishment.

V. Why State-Supported Research?

A. Statutory Authority

In 1983, legislation created the AIDS Institute, the AIDS Advisory Council and the AIDS Research Council[7] – an act of great forethought. Throughout the years, policy, programs and resources have been focused on direct care, treatment and support of persons living with HIV infection, rather than research. Today, 25 years later, New York finds itself facing a growing and changing epidemic. Advances in medical treatment have resulted in transforming HIV from an acute disease resulting in untimely death to a chronic disease with changes in the characteristics of affected populations. We can halt this epidemic with science, policy and programs based on contemporary and progressive research. Twenty-five years into the epidemic, New York-specific research is of the highest priority to assure care, access and treatment for those infected and prevention for those at risk.

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[6] NYAM Special Report, Volume 77, Number 1; March 2000

[7] Section 2777 of the Public Health Law – Article 27-E:

1. There shall be established within the Institute a research council composed of seven members to be appointed by the commissioner. The members shall be representative of recognized centers engaged in the scientific investigation of acquired immunosuppressive diseases.
2. The research council shall be responsible for making recommendations to the institute for the purpose of carrying out the provisions of paragraphs (a) and (b) of subdivision one of section twenty-seven hundred seventy-six of this article.
3. The council shall meet at least four times a year. Special meetings may be called by the chairman, and shall be called by him at the request of the commissioner.
4. The members of the council shall receive no compensation for their services, but shall be allowed their actual and necessary expenses incurred in the performance of their duties hereunder.

B. Executive Support and State Health Department Experience

New York State is fortunate to have leadership that has supported research. The New York State Department of Health has significant experience administering research programs and its Wadsworth Center (the Center) is noted among state health laboratories for its historic commitment to research. Today, Center scientists use both classical and contemporary approaches to study topics in environmental and biological sciences related to human health and disease. Their investigations fall into four broad areas with several cross-cutting categories: genes and genomes; molecular and cellular basis of disease; environmental health science; and infectious disease and host defense.

With regard to this critically important research area, Governor Paterson noted:

"Medical research is an area in which new hope and opportunity is found every day in New York State. Our research institutions, teaching hospitals and pharmaceutical companies are world leaders in disease prevention. Thousands of New Yorkers work tirelessly each day in the search for new cures and medicines. However, that critical progress has been hindered by Washington's refusal to fund stem cell research."[8]

An investment in New York State research is needed now and will result in improving the lives of individuals, families and communities and support New York's role as a leader in HIV/AIDS research. New York's leadership will benefit persons infected and affected by HIV and AIDS in New York, and potentially throughout the country. This investment could more than pay for itself in the number of lives saved, diminished health care costs and in attracting federal funds to the state. Moreover, New York State would strengthen its leadership in scientific research devoted to the public's health. This requires New York State support. A modest investment can reap substantial dividends.

VI. A State-Sponsored Research Model: California

California's HIV/AIDS Research Program (CHRP) provides New York State with a successful model. The California program has not only stimulated research in that state but has also **leveraged significant funding – nearly seven dollars in Federal and private support for every state dollar invested by CHRP**. California has an advantage in its ability to secure federal funding. State funding allows the conduct of preliminary work in research areas that are of interest to federal funders so that when federal funding becomes available, California has already started work in the preferred areas – making federal funders more inclined to support their research.

Created in 1983 by the California Legislature, CHRP provides state funding for the support of peer-reviewed, AIDS-related research conducted at nonprofit research institutions and community-based organizations. More than 1,770 research grants have been awarded to more than 50 California institutions since 1983. Start-up funding is provided for the development of cutting-edge research by investigators based in California, offering critical leverage in competing for and bringing subsequent federal and private resources to the state.

[8] "A New Stem Cell Research Fund" Press Release 2008 http://www.ny.gov/governor/press/lt_stemcell.html

To accomplish its mission, the California program established an umbrella of mechanisms to support its HIV/AIDS research. In addition to the administration of investigator-initiated awards, institutional awards, targeted research award and training awards, the program manages a number of special initiatives, which support a broad range of research activities, and allow flexibility to be attentive to the changing needs of HIV researchers in California. CHRP communicates the findings of its funded research to the public through an annual report, a bi-annual Conference on AIDS Research in California, and other publications.

CHRP provides start-up funds for the development of cutting-edge research by investigators based in California, providing critical leverage to investigators to compete for subsequent federal and private grants. The program funding mechanisms are intended to provide a unique niche that can best serve California investigators and communities, and are designed to complement rather than duplicate funding offered by other sources. The CHRP currently administers four types of awards:

- Investigator Initiated Awards
  Innovative, Developmental Exploratory Awards (IDEAs)
  Community Collaborative Awards

- Institutional Awards
  California AIDS Research Centers
  Institutional Support Awards

- Training Awards
  Dissertation Awards
  Postdoctoral/Clinical Fellowships Awards

- Targeted Research Awards

CHRP receives direction from an Advisory Council, the members of which are charged with advising the University of California on the mission, goals and objectives, policies and priorities of the California HIV/AIDS Research Program.

Specifically, the Advisory Council

- Recommends resource allocation across priorities
- Recommends program direction
- Advises on the peer review process
- Assesses the relevance of meritorious grants and recommends grants to be funded
- Evaluates the progress of selected research award programs

Advisory Council recommendations have significant impact on scientists and community members in California. Advisory Council members are intended to be a mix of experts and critical perspectives representing scientific areas and communities concerned with HIV/AIDS research. This collective perspective is essential for the development of a well-balanced program and initiatives that will best serve to advance science in HIV/AIDS.

Since formation of this research initiative, California has led in states awarded NIH funding. While the share of publications by New York biomedical scientists declined by 10 percent, the share from California and Massachusetts increased by 14 percent and 26 percent, respectively.[9] The provision of state funds to California-based researchers has in part accounted for this growing disparity in funding awarded to New York State.

VII. NYS HIV/AIDS Research Initiative Proposal:

It is recommended that $1 million in start-up funding be included for the NYSDOH as part of the 2009-2010 Executive Budget. Following start-up, we propose that New York State allocate $5 million annually for two to three years to evaluate the effectiveness of the initiative.

The AIDS Research Council would function much as an NIH Council and be responsible for establishing priorities and developing criteria to be used by the State in awarding funds. The Council would collaborate with an administrative entity to manage this initiative. Research funds would be used for development of innovative research ideas, support for community-researcher partnerships, and support for new investigators (e.g., through dissertation awards).

The AIDS Research Council could, with the advice and involvement of the Wadsworth Center, the AIDS Institute and an external advisory council, assume responsibility for the development of a competitive peer-reviewed procurement process. *A program administered by the NYSDOH is particularly appropriate to assure oversight of state-funded activities*. Funds would be awarded to non-profit institutions and community-based organizations to support substantive research studies and institutional partnerships that strengthen science and expand the capacity of HIV/AIDS research institutions and organizations throughout the State. The process would draw on state and national expertise to identify the most meritorious proposals, to guarantee an impartial grant award process and assure that the science is of the highest caliber, and is responsive to the needs of New Yorkers.

Priority would be given to proposals which address critical challenges characteristic of or unique to the epidemic in our state. Preference would also be given to projects that have a clear potential for the development of important public policy, of a viable commercial product or patentable intellectual property. A significant proportion of funds would be earmarked for research conducted by community-researcher partnerships that can enhance our knowledge and help to lessen the impact of this epidemic in New York State. Such research may also serve as pilot studies for larger federally funded research awards.

VIII. Goals of a New York Research Initiative

- Generate a stimulus and a platform for innovative research and leadership;
- Provide seed money for research that can be used to attract NIH and private funding;

[9] *Crain's New York Business* Health Care Report March 24, 2008

- Produce research that addresses New York-specific HIV issues, which would assure that New York's HIV clinical and prevention programs are based on science and that reflect New York State-specific populations, programs and service delivery systems;
- Engage New York's many community organizations that are increasingly interested in building research capacity and becoming real research partners in projects that provide timely feedback and clinical application;
- Stimulate economic development; and
- Eliminate the competitive disadvantage that New York-based researchers face due to the California program's advantage in securing federal funding.

Benefits that would accrue to the State and to persons living with HIV/AIDS in New York State are many. Grants awarded would provide start-up funding for the development of cutting-edge research by investigators in New York State, establishing critical leverage in competing for and bringing subsequent private and federal resources into the State.

IX. Recommendation

The AIDS Advisory Council urges the Governor and Legislature to support the creation of an HIV/AIDS research initiative. It is proposed that $1 million in start-up funding be included for the NYSDOH as part of the 2009-2010 Executive Budget. Following initial start-up it is recommended that $5 million be allocated annually for a period of 2 - 3 years following with evaluation to assess the effectiveness of the initiative in generating new research and in attracting federal and private research funding to New York State.

Recognizing New York's difficult fiscal situation and the many competing needs for scarce resources, it is noted that an investment in AIDS research is fiscally sound. Research that leads to improved prevention measures means fewer infections and reduced overall health care costs; enhanced wellness for those already infected similarly will result in improved health status and reduced treatment costs; as has been noted, research is a proven economic stimulus generating employment, grants and patents. This funding would support a growing cadre of New York-trained and practicing research scientists, would allow research priorities to be identified that are specific to the care, treatment and prevention of HIV in New York State, and would assure development of program and policy that is uniquely suited to persons living with HIV/AIDS in New York State.

The public would be supportive of such an initiative (84 percent of New York State residents in a 2006 survey thought health research should be a "very important" priority)[10] and the dividends for New York State that would accrue to people with HIV, to biomedical research overall, and to statewide economic development are immeasurable. The benefit of strengthening the state's reputation for educational and scientific competitiveness are compelling, estimated at many times the modest investment such a commitment would require.

Indeed, California has already proven this to be the case with the establishment of its HIV/AIDS Research Program and Massachusetts has undertaken a similar, aggressive

[10] Health Affairs October 17, 2006 "Understanding the American Public's Health Priorities: A 2006 Perspective", Robert J. Blendon, Kelly Hunt, John M. Benson, Channtal Fleischfresser, Tami Buhr

and successful research initiative. New York State has made progress in developing notable expertise in trauma studies, breast cancer research and stem cell research.

New York must seize the moment and create an opportunity to support and promote critically important research that is necessary if the State and the nation are to effectively halt this epidemic. At the start of the HIV epidemic, New York State had a visionary approach that allowed it to become a model for the nation. Once again, New York can exercise that kind of leadership. As a state with extraordinary research capacity and the largest cumulative and current number of HIV/AIDS cases in the nation, New York State has a scientific and public health responsibility to utilize its enormous resources to nurture and to prioritize HIV-specific clinical, scientific, behavioral and policy research.

Appendix A
New York HIV Research Centers Consortium

Aaron Diamond AIDS Research Center (ADARC)

AIDS Policy Research Group, Rutgers the State University of New Jersey

AIDS Research Program, Montefiore Medical Center

Baron Edmond de Rothschild Chemical Dependency Institute (CDI), Beth Israel Medical Center

Center for AIDS Research (CFAR), New York University School of Medicine

Center for Drug Use and HIV Research (CDUHR), National Development and Research Institutes, Inc.

Center for Health/HIV Intervention & Prevention (CHIP), University of Connecticut

Center for Health, Identity, Behavior & Prevention Studies (CHIBPS), Department of Applied Psychology, New York University

Center for HIV/AIDS Educational Studies and Training (CHEST), Hunter College

Center for Infectious Disease Epidemiologic Research (CIDER), Columbia University Mailman School of Public Health

Center for Interdisciplinary Research on AIDS (CIRA), Yale University School of Medicine

Center for Urban Epidemiologic Studies (CUES), New York Academy of Medicine

Columbia-Rockefeller Center for AIDS Research (CR-CFAR)

Division of Public Health and Policy Research, Montefiore Medical Center

Harlem Health Promotion Center, Columbia University Mailman School of Public Health

HIV Center for Clinical and Behavioral Studies, NYS Psychiatric Institute & Columbia University

HIV Center for Women and Children, SUNY Downstate Medical Center

Hunter College Center for Community and Urban Health

Mount Sinai Center for AIDS Research

New York City Department of Health and Mental Hygiene, HIV Epidemiology Program

New York State Department of Health, Office of Program Evaluation and Research, AIDS Institute

Social Intervention Group (SIG), School of Social Work, Columbia University