Recommendations for President Elect Donald J Trump on Hispanic/Latino Communities throughout the United States and U.S. Territories to End the AIDS Epidemic and Address Hepatitis and other Health Disparities

The Honorable Donald Trump Presidential Transition Headquarters 1800 F Street, NW, Room g117 Washington, D.C. 20270-0117

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Dear President-elect Trump,

We have made substantial progress in responding to the HIV epidemic. At the beginning of the epidemic, no one could have predicted the incredible success of anti-retroviral medications that permit people with HIV to live healthy, productive lives with similar life expectancies as those not living with HIV. The United States (U.S.) now has the technological capability to reverse and potentially end the national epidemic. The HIV community, in collaboration with several state and local jurisdictions, is working to implement plans to do so. *Your Administration can now accelerate these gains.*

HIV/AIDS continues to threaten the health and well-being of many communities in the United States, including diverse Latino/Hispanic communities. Latinos overwhelmingly believe, when surveyed, that HIV/AIDS is one of the most urgent health problems facing the nation today. Hispanics or Latinos are the largest racial/ethnic minority population in the United States (U.S.). About 1 in 6 people living in the U.S. are Hispanic/Latino (almost 57 million). By 2035, it is estimated that this ratio could be nearly 1 in 4. Federal resources for HIV/AIDS care have not kept pace with the epidemic and funding to prevent the disease among Latinos has remained largely flat. This reality has impacted the ability to maintain prevention, treatment and care as the most important tools to reduce the spread of HIV/AIDS. When surveyed, Latinos respond that AIDS is the second most urgent health problem facing the nation today after cancer. Almost one-half of Latinos report that HIV/AIDS is even more of an urgent problem in their communities today, than a few years ago, compared to 15% of whites.

A number of challenges contribute to the epidemic in Latino communities, including poverty, injection drug use, stigma and discrimination, limited access to health care, and language or cultural barriers in health care settings. Despite the fact that Latinos comprise about 17% of the population in the U.S. iv and Puerto Rico, they account for 24% of HIV infections in 2014 vand 24.8% of people reported living with AIDS since the beginning of the epidemic. vi

Considering that an estimated 3.3 million people in the United States are living with Hepatitis C, it is urgent to increase funding, as many Latino sub-groups are among the most affected by Hepatitis C, chronic liver disease and HIV co-infection. The rate of Hepatitis C among Hispanics/Latinos increased by 13.6% (from 0.22 cases per 100,000 population in 2013 to 0.25 case per 100,000 population in 2014). Additionally, Hispanics are about 50% more likely to die from diabetes, cancer or liver disease than whites.

According to Centers for Disease Control and Prevention (CDC) data, more than 42% of Latinos were diagnosed with AIDS within a year of testing positive – meaning they didn't become aware of or connected to care for their infection until extremely late in the course of their illness. Latinos have high rates of testing "late" – indicating that they are more likely to test long after first becoming infected. Late testers have a decreased life span by sever all years compared to those that test "early." As late testers go through a longer period of time between becoming infected and finding out their status, they may unknowingly place other sexual partners, or individuals they may share needles with, at risk. When an individual with HIV is unaware of their status, or non-adherent to their medication it is likelier that they have not reached viral suppression and therefore more infectious to others.

This striking health disparity reflects an HIV/AIDS crisis among Latinos that demands immediate attention, understanding, and action at the national level through committed leadership, enlightened policies, and targeted resources. To our dismay, disparities in HIV/AIDS in the U.S. are driven by stigma and social and economic marginalization. To truly move towards ending the epidemic, we must not only achieve public health goals in absolute terms, but also in a manner that reduces all disparities – by focusing efforts on communities bearing the largest burden of the HIV/AIDS epidemic.

Prevention and treatment are cost effective. Numerous studies on prevention and treatment interventions demonstrate that we can save lives and money via prevention tools. In the case of HIV, we have a myriad of resources, including male and female condoms, sterile syringe exchange, HIV treatment as prevention, pre-exposure prophylaxis (Prep) and post-exposure prophylaxis (Pep), and comprehensive sex education. The return on investments in HIV prevention and treatment benefits our national economy. According to a recent estimate, each new HIV infection has a lifetime treatment cost of \$379,668. In 2015 there nearly 40,000 new infections in the United States resulting in lifetime costs of \$15.2 billion for that year alone. Working to prevent new HIV infections in the United States and around the world ultimately results in major savings for the U.S.

Screening and early treatment for those living with Hepatitis C will avoid people needing liver transplants which cost \$500,000 or more per person. We must do what is necessary to save critical resources for our nation. <u>Your Administration can now accelerate these gains and save critical resources</u>.

Recommendations

Your Administration has the opportunity to make history by committing the United States to become the first nation to end HIV/AIDS as an epidemic by the year 2025, and aggressively addressing the hepatitis C crisis and have an impact on health access in Latino communities. We offer the following recommendations to strengthen our nation's response to the HIV/AIDS and hepatitis C epidemics and addressing the health care needs, challenges, and opportunities in Latino communities in order to achieve becoming a health nation.

1. Support and Continue the Implementation of the National HIV/AIDS Strategy (NHAS) and Maintain the Office of National AIDS Policy. We have achieved the development of a comprehensive National HIV/AIDS Strategy, Updated to 2020 in the U.S and the Territories. We need to ensure that the set of priorities identified and strategic action steps are supported and implemented targeting Latino

communities at risk for and Latinos living with HIV/AIDS. We request to be included in decisions and present in numbers that represent the epidemic to provide advice, information, and recommendations regarding programs, policies, and research to promote effective treatment, prevention, and care. We strongly urge you to adopt and support the NHAS goals to avoid a serious setback in our nation's work to end AIDS in the United States and urge the administration to build upon existing plans to end the HIV epidemic in all states and territories.

We strongly recommend that you to maintain the Office of National AIDS Policy and Presidential Advisory Council on HIV/AIDS, both of which are institutional bodies that provide critical coordination in accomplishing the goals set out in the National HIV/AIDS Strategy. This requires strong coordination among federal agencies, states, and public and private organizations responding to the AIDS epidemic. During your transition and first year on office, we ask for your leadership and commitment to move our nation toward ending the HIV/AIDS epidemic by 2025.

2. Maintain and Increase Access to high quality, affordable health care for all those living in the U.S.

The ACA has been a critical vehicle for people living with HIV to obtain comprehensive health care coverage. Prior to the ACA, private insurance coverage was unavailable to many people living with HIV/AIDS because insurers were allowed to refuse coverage to individuals with preexisting medical conditions. Medicaid expansion is a key benefit of the ACA that must be maintained or replaced by a program that will have further reach. At least 40 percent of people with HIV rely on the Medicaid program for their health care coverage. Now, in states that have expanded Medicaid, low-income Americans living with HIV can access Medicaid before becoming disabled, allowing them to improve their quality of life by accessing covered treatments. A well-defined replacement plan that maintains key policies that benefit people with HIV should be in place.

At a minimum, we urge that all benefits currently available to individuals under the ACA and Medicaid be grandfathered into any new or revised health care programs. This will ensure that patients do not lose the benefits upon which they have relied to manage and maintain their health. The undersigned organizations do not support the repeal of the ACA given the potential loss of access to care and coverage for people throughout the United States, including people living with HIV. Should the Administration and Congress move forward in repealing the ACA, we strongly urge that you not move forward until a replacement plan ensures affordable, high-quality health care coverage is in place. We need be mindful that a person living with HIV, without access to treatment or care is likelier to have not reached viral suppression and therefore, likelier to transmit HIV to others.

3. Fully Support the Highly Successful Ryan White HIV/AIDS Program.

The Ryan White HIV/AIDS Program is a worldwide respected program and for many nations a model of care to follow, the Ryan White program has provided critical funding to cities, states, clinics, and local community-based organizations for more than 25 years. The program serves more than 500,000 people—which is more than 50 percent of people with living HIV in care in the United States. More than 83 percent of Ryan White clients achieved viral suppression in 2015, thanks in large part to the Ryan White Program. Achievement of viral suppression is important not only because it allows people to live longer healthier lives, but also because it lowers the risk of transmission of HIV to nearly zero. This is the key to reducing new HIV infections and eventually

ending the AIDS epidemic. We urge the Administration to fully support funding for the vital role of the Ryan White Program in helping states to address the HIV public health crisis, particularly in a changing funding and services environment in the health care field.

4. Employ All Tools, Equipment, and Medications to Respond to the HIV, HCV and Opioid Epidemics.

We have the tools to prevent the spread of HIV, including male and female condoms, sterile syringes, and treatment as prevention, PrEP, and comprehensive sexual education. There is a critical intersection of the opioid, hepatitis, STI and HIV epidemics in the United States. We strongly urge the incoming Administration to take a holistic approach to HIV, hepatitis and STI prevention and ensure that prevention information is available across the nation. This would mean comprehensive, accurate, science-based health education across the U.S., and access to sterile syringes nationwide.

5. Support Efforts to End HIV stigma and to Address Social and Economic Barriers that Negatively Affect People with HIV.

Supportive services improve health outcomes and reduce costs. Studies repeatedly show that in addition to improving individuals' quality of life, supportive services facilitate accessing and staying connected to HIV care and treatment. In turn, supportive services have been shown to improve health outcomes and reduce costs. For people living with HIV, proper nutrition is required to facilitate medication absorption, reduce side effects, and maintain a healthy body weight. Homeless or unstably housed individuals are more likely to delay treatment, less likely to have regular access to care, less likely to receive optimal drug therapy, and less likely to adhere to their medication than are stably housed individuals. We urge sustained federal resources to address social and economic determinants of health, including stable, affordable housing; food support; and other supports that sustain treatment and prevention goals and promote health for people with HIV.

6. Support Ending the HIV Epidemic in the U.S. Territories.

In addition to supporting a strong response to HIV in the 50 states and the District of Columbia, we also strongly urge the Administration to increase efforts to end the epidemic in Puerto Rico, the U.S. Virgin Islands and other U.S. Territories. The U.S. Virgin Islands had the 5th highest rate of new HIV diagnoses in 2014 with 27.4 diagnoses per 100,000 people, while Puerto Rico was the 8th highest at 22.7 per 100,000. It is our hope that the new administration will work with Congress to develop comprehensive and long term solutions to ensure that the territories aim to end the HIV epidemic in their communities. We urge the Administration to increase efforts to end the epidemic in Puerto Rico, the U.S. Virgin Islands and other territories and assure access to culturally and linguistically competent quality care and prevention.

Congress must act immediately to resolve the HIV/AIDS Crisis in Puerto Rico. Congress must stop the deterioration of health care for people living with HIV/AIDS in Puerto Rico. As of 2005, Puerto Rico had the second highest rate of HIV related deaths, over three times the national death rate. Health care for people with HIV/AIDS in some parts of the Island borders on non-existent. We urge Congress to eliminate the "cap" on Medicaid funding in Puerto Rico for people living with HIV/AIDS on the Island. Where states receive Medicaid reimbursements of 50% - 80%, Puerto Rico receives 20% due to a fixed dollar limit on Federal participation, known as the Medicaid cap. This limit leaves Puerto Rico striving to

breach a 30% gap in services funding; the difference between the cap at 20% and the statutory minimum of 50% available in the United States. *Congress must resolve these limitations to facilitate care similar to that of the states.*

- 7. Improve the understanding of factors that contribute to HIV risk among Latinos. CDC and the National Institutes of Health (NIH) must join with community-based organizations, national Latino and HIV/AIDS organizations and coalitions, researchers, Hispanics living with HIV/AIDS, local health resources, health departments and other stakeholders to improve the understanding of the social, cultural, and environmental factors that contribute to HIV risk among Hispanics/Latinos. We need to incorporate contextual variables that increase or decrease the likelihood of infection among Hispanics/Latinos (e.g.: acculturation, substance use, gender roles, poverty, discrimination, isolation, mental health, and immigration status), and improve opportunities to prevent HIV infections and facilitate early access to medical care for Hispanic/Latinos living with HIV/AIDS, Hepatitis and other chronic health conditions.
- **8. Develop Immigration Policies that respect all communities and protect the health care of our nation.** Your administration could be a leader in developing immigration policies that will ensure not only a human solution to the immigration system that is broken, but one that will protect the public health of our nation. We can ensure that more people access HIV and hepatitis services when humane immigration policies are in place that assure communities wellbeing at a national priority.
- 9. Support the Implementation of the National Strategic Plan to address viral Hepatitis in the United States and US Territories and assure that it reflects the needs of all affected communities. We have treatments to cure Hepatitis C, it is estimated 3.3 million people in the United States living with Hepatitis C, is it urgent to increase funding, strategic attentions in the implementation of a comprehensive National Viral Hepatitis Strategy in the U.S. We need to assure that the set of priorities identified and strategic action steps are supported and implemented targeting all communities impacted, including Hispanics.

Conclusion

<u>There is a need to create a heightened, effective and evidence-based national response to address the epidemic among Latinos.</u> HHS should direct all of its agencies to specifically address the Latino HIV/AIDS epidemic, and report annually on steps taken and the impact of those steps. HHS should gather these reports annually and submit them to the relevant Congressional oversight committees and the Congressional Hispanic Caucus and be made available to the public.

The undersigned members of the National Latino Convening Organizations therefore write to urge you and your Administration to sustain and strengthen our national response to the domestic HIV epidemic. Questions regarding these recommendations may be addressed to Luis Scaccabarrozzi (LScaccabarrozzi@latinoaids.org), Judith Montenegro (JMontenegro@latinoaids.org), Oscar de la O (odelao@bienestar.org), Jose Joaquin Mulinelli (Joaquincoai05@gmail.com), and Catalina Soles (csol@lcdp.org).

Thank you for considering our recommendations. We wish you tremendous success and are here to assist and serve and provide your administration assistance.

CC:

Access Support Network, San Luis Obispo and Monterrey Counties (California)

AIDS Alabama (Alabama)

AIDS Education Training Center (AETC) South Central (Texas)

ACQC (New York)

ACT UP (New York)

Action for a Better Community (New York)

AGUILAS, El Ambiente Program (California)

AID FOR AIDS (New York)

AIDS Service Center New York City (New York)

AIDS Services of Austin (Texas)

Alabama Latino AIDS Coalition (Alabama)

ALMA (Illinois)

AltaMed (California)

Amor que Sana (Puerto Rico)

Arianna's Center (Florida)

Association for the Advancement of Mexican Americans (Texas)

Bienestar (California)

Bill's Kitchen (Puerto Rico)

BOOM!Health (New York)

Borinquen Medical Centers (Florida)

Boulder County AIDS Project (Colorado)

Casa Iris/Multicultural AIDS Coalition (Massachusetts)

Center for Latino Adolescent and Family Health, NYU Silver School of Social Work (New York)

CALOR, A Division of the Anixter Center (Illinois)

Cero VIH (Puerto Rico)

Clínica del Pueblo (Washington D.C.)

COAI, Inc. (Puerto Rico)

Entre Hermanos (Washington)

GMHC (New York)

Hispanic Federation (New York)

Hispanic Health Network (New York)

Housing Works (New York)

Latino Commission on AIDS (New York)

Latinos in the Deep South (North Carolina)

Latino Religious Leadership Program (New York)

Latinos Salud (Florida)

LULAC (Washington D.C.)

Mission Neighborhood Health Center (California)

National Hispanic Nurses Association (North Carolina)

National Medical Hispanic Association (Washington, D.C.)

Oasis, Latino LGBTS Wellness Center (New York)

Open Arms (Mississippi)

Pacientes de SIDA Política Sana (Puerto Rico)

PROCEED, Inc. (New Jersey)

Puerto Rican Cultural Center (Illinois)

Puerto Rico CONCRA (Puerto Rico)

Resource Center (Texas)

Southwest Viral Med (Texas)

TransLatin@ Coalition (California)

TruEvolution (California)

University of Mississippi Medical Center (Mississippi)

Valley AIDS Council (Texas)

VIDA (California)

Vida/SIDA (Illinois)

Voces Latinas (New York)

Westbrook Clinic (Texas)





















































































































i Kaiser Family Foundation Survey of Americans on HIV/AIDS (conducted March 24 - April 18, 2006) Chart 2 HIV/AIDS in Your Community.

ii Kaiser Family Foundation Survey of Americans on HIV/AIDS (conducted March 24 – April 18, 2006) Chart 32 HIV/AIDS in Your Community iii Kaiser Family Foundation Survey Chart 39.

^{iv} U.S. Census Bureau Press Release on May 17 2014 Release on Minority Population

^v Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 2015, Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.

vi Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 2015, Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.

vii https://www.cdc.gov/nchhstp/healthdisparities/hispanics.html