



April 15, 2013

Dear Representative:

On behalf of the American Civil Liberties Union (ACLU), a non-partisan organization with more than a half million members, countless additional activists and supporters, and fifty-three affiliates nationwide, we are writing to urge you to support and co-sponsor the HIV Organ Policy Equity (HOPE) Act (H.R. 698).

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This important, bipartisan legislation, which was introduced by Representative Capps (D-CA), would end the outdated ban on federal research into organ donations from HIV-positive donors to recipients who are living with HIV, as well as provide a pathway to the eventual transplantation of these organs.

The current federal ban on the donation of organs from HIV-positive donors to recipients living with HIV was enacted as part of the Organ Transplant Amendments Act of 1988,¹ during a period of significant and widespread fear and discrimination against those living with HIV/AIDS. While our medical and scientific understanding of HIV/AIDS has vastly increased in the decades that have followed, policies like this serve as harmful relics of the past. With the advent of successful antiretroviral therapy in the mid-1990s, individuals with HIV are living longer lives, but may face chronic conditions, such as liver and kidney failure, requiring organ transplant.

According to the U.S. government, there are more than 100,000 patients actively waiting for potentially life-saving organs.² Due to shortages of donated organs, an average of 18 people die each day across the country while waiting for transplants.³ A study published in the American Journal of Transplantation in March 2011 found that allowing organ transplants between HIV-positive patients could increase the organ donation pool by 500-600 donors per year, as well as reduce the general waiting list for all

¹ Organ Transplant Amendments Act, Public Law 100-607 (1989) (Codified as amended in scattered sections of 42 U.S.C.).

² U.S. Government Information on Organ and Tissue Donation and Transplantation, U.S. Department of Health & Human Services, Homepage, last accessed March 22, 2013, available at <http://www.organdonor.gov/index.html>.

³ *Id.*

patients awaiting transplants.⁴ The study further characterized the ban on the use of organs from HIV-positive donors to recipients living with HIV as “unwarranted and likely harmful.”⁵

In addition, the current ban on the donation of organs from HIV-positive donors and related research is significantly more restrictive than similar policies for other diseases. For example, individuals who test positive for hepatitis C are permitted to donate organs to patients who also have hepatitis C.⁶ Given what is now known about HIV, in addition to the significant support this legislation has received from leading medical organizations including the American Medical Association, the American Society of Transplantation, and the HIV Medicine Association to name but a few, there is a clear need to end the current ban.

By eliminating this outdated policy, the HOPE Act would also further the important goal, outlined in the National HIV/AIDS Strategy, of reducing and eliminating stigma and discrimination against people living with HIV.⁷ This legislation will empower those who are living with HIV to have greater control over their medical care, while ensuring that the federal government’s HIV policy promotes public health and respect and compassion for people living with HIV and AIDS. If enacted into law, the legislation has the potential to save hundreds of lives each year by making more organs available for safe transplantation.

The ACLU urges you to support and co-sponsor the HOPE Act (H.R. 698). For questions, please contact Legislative Representative Ian Thompson at (202) 715-0837 or ithompson@dcacclu.org.

Sincerely,



Laura W. Murphy
Director, Washington Legislative Office



Ian S. Thompson
Legislative Representative

⁴ B.J. Boyarsky, et. al., Estimating the Potential Pool of HIV-Infected Deceased Organ Donors in the United States, *American Journal of Transplantation*, (2011), <http://onlinelibrary.wiley.com/doi/10.1111/j.1600-6143.2011.03506.x/abstract>

⁵ *Id.* at 1216

⁶ Andrew Cray, Public-Health Advocates Should Support the HIV Organ Policy Equity Act, (March 11, 2013), <http://www.americanprogress.org/issues/healthcare/news/2013/03/11/56117/public-health-advocates-should-support-the-hiv-organ-policy-equity-act/>.

⁷ The White House Office of National AIDS Policy, *National HIV/AIDS Strategy for the United States* 35 (2010) <http://www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas.pdf>.