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TO: Office of the Assistant Secretary for Health (OASH), and Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS)

FROM: The Center for HIV Law & Policy (CHLP)

RE: Organ Procurement and Transplantation: Implementation of the HIV Organ Policy Equity (HOPE) Act, RIN 0937-AA13, Document ID HRSA-2024-0001

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The Center for HIV Law & Policy (CHLP) welcomes the opportunity to share our analysis and recommendations regarding the Department of Health and Human Services (HHS) proposal to amend the regulations implementing the National Organ Transplant Act of 1984, as amended by the HIV Organ Policy Equity (HOPE) Act.

For nearly 20 years, CHLP has utilized legal advocacy and high-impact policy and research initiatives in collaboration with state and national partners to fight to end stigma, discrimination, violence, and the criminalization of people based on their health status, race, gender identity or expression, and sexual identity. We collaborate with people living with HIV (PLHIV), organizers and base builders, direct service providers, and national organizations to identify, create, and share expertly crafted, intersectional legal and policy strategies to end the criminalization of people living with stigmatized identities, disabilities, and diseases.

Our work is nationally respected and recognized, and our expertise around the criminalization of HIV and its related impacts on bodily autonomy is consistently sought out nationwide. We focus our work on those most deeply vulnerable to discrimination and criminalization by state actors. We are an abolitionist organization that firmly believes that the criminalization of people based on their health status, racial identity, gender, or sexual identity harms rather than protects the public.

To date, CHLP has provided legal and policy technical assistance to state-level coalitions comprised of PLHIV, public health experts, and advocates fighting for racial, disability, and LGBTQ justice in 28 states through the Positive Justice Project (PJP), the first national collaborative formed to end HIV criminalization in the United States. We engage with national

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networks of PLHIV, including groups that center the most marginalized communities affected by HIV criminalization, including Black and brown people, women, queer and trans people, sex workers, people who use drugs, and people affected by housing instability. CHLP has also provided critical legal research and recommendations to the Presidential Advisory Council on HIV/AIDS (PACHA), many of which were incorporated into PACHA's resolution on molecular HIV surveillance (MHS),¹ a public health practice that continues to undermine the health, rights, safety, and human dignity of PLHIV.

When the HOPE Act passed 10 years ago, it catalyzed state legislatures to amend criminal offenses that punished organ donation. States including California, North Carolina, Virginia, Nevada, and Georgia changed or repealed donation-specific crimes used to stigmatize and criminalize PLHIV in the wake of the Organ Procurement and Transplantation Network (OPTN) policy changes. Today, federal HIV policy stakeholders have a similar opportunity to keep pushing for comprehensive change and to address the harmful reality of HIV criminalization affecting so many of the people in our communities.

Removing organ transplant barriers is a respectable goal, but federal HIV policy stakeholders must also work to end HIV criminal laws punishing organ donations to enhance the health and well-being of all

CHLP has a deep-seated interest in how all federal and state-level policies affecting PLHIV are implemented, including the HOPE Act. Patients living with HIV deserve and have every right to access life-saving transplants, and removing clinical research and institutional review board (IRB) requirements for kidney and liver transplants marks a noteworthy step towards that goal. The existing research requirement needlessly singles out PLHIV, fueling stigma, and in turn, worsens health outcomes for PLHIV, like those who die while waiting on the transplant list.² Still, it is also clear other issues are preventing PLHIV from being added to transplant waitlists altogether.^{3,4}

We believe removing barriers to organ donation will increase transplant volumes, and thereby save lives, and spare loved ones, friends, and entire communities from painful, preventable deaths. However, organ donations for PLHIV are not only matters of life and death in clinical terms, since criminal offenses that target PLHIV undermine efforts to increase organ transplant

¹ Presidential Advisory Council on HIV/AIDS, *Molecular HIV Surveillance and Cluster Detection and Response Resolution*, available at <https://files.hiv.gov/s3fs-public/2022-11/PACHA-resolution-on-Molecular-HIV-Surveillance-Cluster-Detection-and-Response-10-17-22.pdf>.

² Jayme E Locke et al, "Survival Benefit of Kidney Transplantation in HIV-infected Patients," *Annals of Surgery* vol. 265,3 (2017): 604-608, doi:10.1097/SLA.0000000000001761.

³ Brittany A Shelton et al, "Access to the Kidney Transplant Waitlist for People With HIV," *Transplantation* vol. 107,5 (2023): e156-e157, doi:10.1097/TP.0000000000004549.

⁴ Ruth O Adekunle et al, "Early steps to kidney transplantation among persons with HIV and end-stage renal disease in ESRD network 6," *Transplant infectious disease : an official journal of the Transplantation Society* vol. 24,1 (2022): e13767, doi:10.1111/tid.13767.

access for PLHIV. Over 30 states have HIV-specific criminal laws that impose heightened criminal penalties on PLHIV for conduct that is either not criminalized or not as severely criminalized for people not living with an HIV diagnosis. In the vast majority of HIV-related arrests and prosecutions, neither HIV transmission nor proof of someone's specific intent to transmit HIV are required. Proof of a substantial risk of HIV transmission is often not a requirement for prosecution, either.

More specifically, at least 10 states and one US territory, the Virgin Islands, explicitly criminalize PLHIV for donating organs, regardless of whether the organ is transplanted.⁵ Additionally, federal law addresses HIV transmission as a criminal offense in only one area: the donation or sale of blood or other potentially infectious fluids or human tissues, although there is an exception in the law regarding donations necessary for medical research or testing.⁶ Data on the enforcement of HIV-specific donation offenses are not widely available and cases can be difficult to track. However, data on enforcement of donation offenses in Missouri, Ohio, and Indiana reveal a persistent threat of arrest and prosecution for PLHIV.⁷

Broadly speaking, HIV criminal arrests and prosecutions are not rare, and in many states, HIV criminal incidents are not trending downwards,⁸ as advances in treatment and prevention might lead one to believe. Black PLHIV, women living with HIV, and especially Black women living with HIV, are dramatically overrepresented in HIV criminal arrests and prosecutions. Specifically examining HIV-specific donation offenses, enforcement similarly targets Black people, with approximately 80% of all people arrested for potential violations of Indiana's donation offense being Black.⁹ These are the same communities most affected by the HIV epidemic since Black

⁵ The Center for HIV Law & Policy (CHLP), *HIV Criminalization in the U.S. A Sourcebook on State and Federal HIV Criminal Law and Practice* (updated January 2024), available at <https://www.hivlawandpolicy.org/sourcebook>.

⁶ 18 U.S.C. § 1122(a).

⁷ See Nathan Cisneros, Carrie Foote, Phoenix Schlebecker, and Brad Sears, *Enforcement of HIV Criminalization in Indiana: Donation Laws*, The Williams Institute, UCLA School of Law (July 2024), available at <https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-Donation-IN-Jul-2024.pdf>; Cisneros, Sears, and Will Tentindo, *Enforcement of HIV Criminalization in Ohio: Analysis of Criminal Incidents from 2000 to 2022*, The Williams Institute, (February 2024), available at <https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-OH-Feb-2024.pdf>; and Sears, Shoshana K. Goldberg, and Christy Mallory, *The Criminalization of HIV and Hepatitis B and C in Missouri: An Analysis of Enforcement Data From 1990 to 2019*, The Williams Institute (February 2020), available at <https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-MO-Feb-2020.pdf>.

⁸ See The Williams Institute, UCLA School of Law, "HIV Criminalization in the United States: Data Interactive," available at <https://williamsinstitute.law.ucla.edu/visualization/hiv-criminalization>. Particular reports that demonstrate HIV-related arrests and prosecutions do not historically trend downwards include their 2018 reports on Georgia and Florida, 2020 report on Missouri, and 2022 report on Louisiana.

⁹ See Nathan Cisneros, Carrie Foote, Phoenix Schlebecker, and Brad Sears, *Enforcement of HIV Criminalization in Indiana: Donation Laws*, The Williams Institute, UCLA School of Law (July 2024), available at <https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-Donation-IN-Jul-2024.pdf>.

and brown people make up 70% of all new HIV diagnoses in the United States.¹⁰ They are the same people confronted by systemic and racist barriers that drive disparities in accessing care preventing us from ending the epidemic.

Furthermore, criminal statutes that punish PLHIV for knowing their health status have clear public health consequences. For example, a study in California showed HIV testing increased after the state reformed its HIV criminal laws in 2018.¹¹ With these laws exacerbating stigma against PLHIV and the communities disparately affected by HIV, HIV criminalization also worsens anti-Black racism and homophobia, further marginalizing Black LGBTQ+ communities from HIV care.¹² For these reasons, hundreds of HIV service providers, HIV advocacy organizations, and other leading nonprofit and governmental organizations have called for an end to HIV criminal laws.¹³

Laws that criminalize PLHIV, including criminal offenses for organ donation, harm public health, promote HIV stigma, discourage HIV testing, and make it more difficult for medical and public health professionals to do their work to end the HIV epidemic. Criminalizing PLHIV for donating or attempting to donate organs causes long-lasting harm by needlessly constricting organ transplant volumes and fuels the further policing and imprisonment of PLHIV. Further, laws that criminalize PLHIV for donating organs may violate the same fundamental legal principle the United States Department of Justice has taken an interest in litigating: that federal antidiscrimination law protects people from criminal prosecutions hinged on an individual's serostatus alone.¹⁴

¹⁰ Centers for Disease Control and Prevention, *Estimated HIV incidence and prevalence in the United States, 2018–2022: HIV Surveillance Supplemental Report*, 2024;29(No. 1), available at <https://www.cdc.gov/hiv-data/nhss/estimated-hiv-incidence-and-prevalence.html>.

¹¹ Jessica M Keralis et al, "HIV: California's 2018 criminalization reform and testing among those reporting risk behavior," *Journal of public health policy*, 10.1057/s41271-024-00517-x, 3 Sep. 2024, doi:10.1057/s41271-024-00517-x.

¹² Amy R. Baugher et al., Black Men Who Have Sex with Men Living in States with HIV Criminalization Laws Report High Stigma, 23 U.S. Cities, 2017, 35 AIDS 1637 (2021), available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9030111/> (describing the differentiated impact of HIV criminalization in distinct geographic regions and noting its intersections with racism and homophobia).

¹³ CHLP, *Positive Justice Project Consensus Statement on the Criminalization of HIV in the United States* (originally published 2012, last updated 2017), available at <https://www.hivlawandpolicy.org/resources/positive-justice-project-consensus-statement-criminalization-hiv-united-states-positive>, and "Collection of Statements from Leading Organizations Urging an End to the Criminalization of HIV and Other Diseases, Compiled by The Center for HIV Law and Policy (2014)," available at <https://www.hivlawandpolicy.org/resources/collection-statements-leading-organizations-urging-end-criminalization-hiv-and-other>.

¹⁴ The United States Department of Justice, "Justice Department Finds That Enforcement of Tennessee State Law Discriminates Against People With HIV," press release, published December 2023, available at <https://www.justice.gov/opa/pr/justice-department-finds-enforcement-tennessee-state-law-discriminates-against-people-hiv>.

HHS can deliver on its mission to improve the health and well-being of PLHIV by delivering thoughtful, high-impact, and proactive programming and using its power to gather PLHIV, advocates, and experts together to develop solutions

Protecting the health, dignity, and well-being of people in the United States goes hand-in-hand with eliminating discrimination as a systematic barrier confronting PLHIV. Discriminatory laws and policies continue to inhibit federal, state, local, and tribal health authorities from delivering services, and hampers efforts to end the HIV epidemic by discouraging people from connecting to testing. HHS administers over 100 programs across its divisions and crafts, collects, and shares information to help people live healthy lives and improve their access to care. We know federal HIV policy stakeholders are working hard to advance solutions to the many problems facing PLHIV. We recommend that HHS, in conjunction with OASH, HRSA, and all federal HIV policymaking partners:

1. Implement a program and provide technical assistance to state, local, and tribal health departments with the goal of adopting policies to firewall all health information from being used in criminal, civil, or immigration legal proceedings
2. Assemble a committee, working group, or advisory body across federal, state, local, and tribal health policy stakeholders, PLHIV networks, HIV advocacy organizations, and public health legal experts to assess strategies on how federal agencies can encourage states to end HIV criminalization

CHLP applauds the effort to remove barriers to organ donations for PLHIV by removing clinical research and institutional review board (IRB) requirements for kidney and liver transplants. That said, criminal laws that punish PLHIV for donating or attempting to donate organs, blood, tissue, and other bodily fluids represent a fundamental threat to the health, well-being, and safety of PLHIV everywhere. Absent concerted efforts by federal and state governments to address these laws, access to organ transplants will remain a persistent problem for PLHIV. This rulemaking process brings with it an opportunity to take full advantage of the resources available to finally end all laws that criminalize PLHIV and prevent any and all health data from being used in criminal, civil, and immigration proceedings.

Thank you for your consideration. We look forward to hearing from you. If you have any questions about these comments, or would like to schedule a follow up meeting, please reach out to me at amir@hivlawandpolicy.org.

Sincerely,



Amir Sadeghi
Policy and Advocacy Manager, CHLP