

BRIEFING PAPER

THE LATEST NEWS AND UPDATES FROM THE CENTER FOR HIV LAW & POLICY

A Civil Rights To-Do List for President-Elect Obama

Advocacy organizations author transition document on civil rights issues for new presidential administration

Civil and human rights have taken a serious hit in the United States over the last eight years, but some of the discrimination against people with HIV has been grinding on for much longer. Stigma and discrimination fuel the HIV/AIDS pandemic; protecting human rights protects the public's health.

The worst kind of discrimination against people with HIV is government-sponsored discrimination. At the very least, we should expect our government officials—federal, state and local—to reject policies that explicitly exclude people living with HIV or AIDS or that are interpreted in a way that marginalizes them. Government discrimination—such as the United States military's exclusion of enlistees with HIV, or many states' exclusion of HIV-positive applicants for trade schools and licensing—reinforces stigma by putting the “official” seal of approval on unsound treatment of those with HIV/AIDS.

Since the beginning of the epidemic, people with HIV and their advocates have been calling on the

President of the United States to take visible leadership in condemning discrimination and supporting adequate services for people with HIV. Protecting the rights and dignity of people with HIV/AIDS must be a central part of a national AIDS strategy.

And so CHLP and Lambda Legal got together to co-chair a working group on civil rights issues that the new administration should address head-on. In this document, the groups identify 15 steps—some requiring little more than a few strokes of the Executive Pen—that President Obama can take in his first 100 days in office to end government support and accommodation of HIV-related stigma and discrimination. The ACLU, Gay and Lesbian Advocates and Defenders (GLAD) and the AIDS Legal Council of Chicago were members of the working group and contributed to the drafting of our civil rights “to-do” list.

The issues identified cover a range of topics—employment and licensing, access to health care and other essential services, the criminal

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Teen SENSE Makes Strides

Advocacy model is prepared for implementation in New Jersey

This year has been an exciting one for Teen SENSE, CHLP's initiative to bring comprehensive sexual health care to youth in state custody.

Real sexual health care has numerous components that are all critical for the protection of the sexual health of youth in state custody. Teen SENSE recognizes that truly comprehensive sexual health care must include medical care, LGBT-inclusive and comprehensive sexuality education, and staff training on sexual health issues to ensure that, when an adolescent approaches a staffer with a concern about sex, sexual identity, or gender issues, that staffer will respond in a

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BRIEFING PAPER

The Newsletter of
the Center for HIV Law & Policy

Winter 2008/2009
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MISSION

The Center for HIV Law and Policy (CHLP) is a national legal and policy resource and strategy center for people with HIV and their advocates. CHLP works to reduce the impact of HIV on vulnerable and marginalized communities and to secure the human rights of people affected by HIV. We support and increase the advocacy power and HIV expertise of attorneys, community members and service providers, and advance policy initiatives that are grounded in and uphold social justice, science and the public health. We do this by providing high-quality legal and policy materials through an accessible web-based resource bank; cultivating interdisciplinary support networks of experts, activists and professionals; and coordinating a strategic leadership hub to track and advance advocacy on critical HIV legal, health and human rights issues.

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The Center for HIV Law and Policy is a project of the National Center for Civic Innovation (NCCI), www.civinnovation.org, a 501(c)(3) organization created by the Fund for the City of New York, 121 Avenue of the Americas, New York, NY 10013-5675. As the Center for HIV Law and Policy's fiscal sponsor, NCCI provides fiscal and administrative support services, allowing the Center to concentrate on program development/operation and fundraising.

A New Year

New developments at CHLP during 2008; preparing for challenges ahead

The Center for HIV Law and Policy started the year with two new, terrific staff members.

Alison Mehlman, previously a senior policy analyst for the HIV/AIDS Bureau at the Massachusetts Department of Public Health and, prior to that, the director of an HIV legal services organization in western Massachusetts, is CHLP's Director of Planning and Policy Research. Margo Kaplan, who joined CHLP as Staff Attorney, is a graduate of New York University School of Law and the Kennedy School of Government at Harvard University, a former Staff

hivlawandpolicy.org's great new look, and expanded content, in May 2008, with many new additions to the Resource Bank; a new blog, *The Fine Print*; and the first of a planned series of primers on critical legal issues facing people living with HIV. We've added more of the best briefs, litigation guides, and issue analyses from organizations around the country, and added nationally-recognized experts to our roster of issue specialists—legal, medical and policy pros who identify useful, quality resources for the Resource Bank and who help review new materials before they are posted. The

The sea change represented in the November 2008 election offers, for the first time in many years, the possibility of systemic change and the beginning of the end of government-endorsed discrimination.

Attorney Fellow with the American Civil Liberties Union, and a published author on the use of international law and cooperation to address human rights violations. Their remarkable smarts, insight, energy, and dedication have been central to the Center for HIV Law and Policy's progress and productivity over this past year.

Another big development here at CHLP has been the transformation of our website and one-of-a-kind Resource Bank. We launched www.hivlawandpolicy.org's

website transformation is now in stage two and scheduled for completion early next year. Stay tuned for detailed issue pages for each of the three dozen topics we cover in the Resource Bank, along with improved search and sorting options, more materials in Spanish and other languages, and lots of new resources—from briefs to medical guides to practice primers for advocates—on issues that matter the most to those in need.

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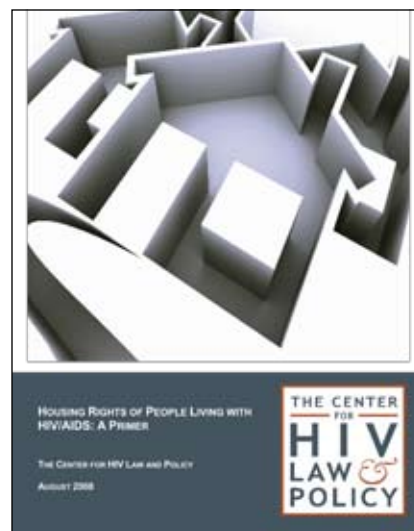
CHLP Introduces Primer on Housing Law

First in a series on pressing legal issues helps to democratize access to information about important HIV laws

CHLP has produced its first in what is anticipated will be a series of primers on the most pressing legal issues for people living with HIV/AIDS. As part of its determination to democratize access to information on important HIV laws, CHLP reached out to consumers and their advocates around the country to come up with a list of priorities for resources that would help them to address their most pressing unmet needs. This is another step in CHLP's efforts to address the lack of resources in the 29 U.S. jurisdictions without a single legal services agency dedicated to people with HIV, and where overtaxed HIV advocates are asked to address more legal issues than they can individually master. The primers allow these advocates—as well as all those living with HIV—to gain needed insight into various areas

study demonstrates the common-sense link between unstable housing and HIV risk or lack of access to HIV care. Yet people living with HIV face daily discrimination in their attempts to obtain and maintain safe, affordable housing.

Housing Rights of People Living with HIV: A Primer, was released this summer and made available on our Resource Bank. The primer outlines the relevant law for advocates whose clients are facing discrimination in housing, or are in need of housing assistance. Specifically, the primer outlines federal housing laws such as the Fair Housing Act (FHA) and cases interpreting it as it relates to tenants with HIV/AIDS. For example, it provides guidance on how to pursue a claim against a landlord who refuses to rent to a prospective tenant who has HIV, and how to circumvent



provides details on how people living with HIV may receive financial assistance to help them find, secure, and maintain safe housing. It also includes information on the effect of past criminal activity on their ability to secure federal housing assistance.

CHLP's second primer, which tackles employment discrimination, is already in the works. The employment primer will outline the federal employment discrimination laws that protect people with HIV/AIDS, focusing on the Americans with Disabilities Act (ADA) and the Rehabilitation Act. The new primer will also discuss how the recent amendments to the ADA, which will take effect in January 2009, increase protections for those living with HIV/AIDS by correcting previous judicial misinterpretations of the ADA.

To see the primer online, visit: www.hivlawandpolicy.org/resources/view/248 on the CHLP web site. ■

The primer outlines the relevant law for advocates whose clients are facing discrimination in housing, or are in need of housing assistance

of law that affect the basic ability to work and live with health and dignity.

Defending housing rights is a critical component of HIV advocacy. Lack of safe housing poses a significant obstacle to HIV treatment and prevention; it seems each year a new

unfounded defenses, such as the argument that renting to someone with HIV would compromise other tenants' safety. The primer also provides information on federal assistance programs such as Housing Opportunities for Persons with AIDS (HOPWA), and

Getting Better All the Time

CHLP unveils improvements to website, highlighting the Resource Bank, special initiatives and news

This summer, CHLP unveiled the first stage of our new and improved website. With a redesigned masthead and improved user friendliness, our new web design highlights CHLP's special initiatives, unique and comprehensive Resource Bank, and news items. Visitors to www.hivlawandpolicy.org now can view and access all topics in the Resource Bank from any page on the website. We also now offer the convenience of online donations—please take advantage of this new feature!

The online Resource Bank also has been expanded to include more depth and breadth than ever before. Covering 33 issue areas, materials from briefs to new regulations to just-released case settlements are added on an almost-daily basis. Increasingly, we hear from HIV advocates in the trenches of client representation and policy work that they keep a direct link to our Resource Bank handy in view because of the frequency with which they refer to it. And the Resource Bank's coverage of international law and human rights now includes more relevant treaties and documents interpreting them as they apply to HIV.

The Resource Bank also now has its first Spanish-language resources and accompanying abstracts, a first step in making the Resource Bank a multi-lingual source of information. Still in the works but coming soon are



The improved CHLP website highlights the Resource Bank, special initiatives and news.

additional retooling of the Resource Bank to allow custom searches that give users enormous flexibility in how they search for resources, and detailed info pages for each of the dozens of issues we cover.

staff as well as guest experts, from Professor Derrick Bell, renowned legal scholar and prominent figure in the study of critical race theory, to Victoria Neilson, Legal Director of Immigration Equality, and Dr. Joseph

Covering 33 issue areas, materials from briefs to new regulations to just-released case settlements are added on an almost-daily basis.

Another great addition to CHLP's website is *The Fine Print*, our new blog of critical analysis and insight into HIV law and policy issues. This is the place where we take on HIV issues, scientific developments, and hot topics that are frequently misrepresented or misunderstood. *The Fine Print* features blogs from CHLP

Sonnabend, one of the world's first and most talented AIDS clinicians.

So bookmark the site, www.hivlawandpolicy.org, visit often, and offer your feedback as CHLP increasingly becomes the go-to source for reliable, high-quality HIV legal and policy resources for advocates around the country. ■

Perinatal Guidelines Update

After CHLP inquiry, new version of recommendations includes stronger statement affirming women's rights

In July 2008, following an inquiry from the Center for HIV Law and Policy, the U.S. Public Health Service (USPHS) Task Force Perinatal Guidelines Working Group issued a revised version of its Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States. The revision reaffirms the right of pregnant women with HIV to control medical decision-making for themselves and their offspring.

The November 2007 version of the guidelines had, without explanation, deleted earlier language protecting a woman's right to refuse HIV medications without penalty, regardless of whether the drugs were recommended to treat her own HIV or to prevent transmission while pregnant.

In response to this change, CHLP submitted an inquiry to the physician at the head of the NIH working group responsible for the guidelines, questioning the group's rationale for removing this important protection. CHLP quickly received assurances that our concern would be taken to the working group for consideration of reinstating the language addressing women's rights to autonomy in treatment decision-making.

The new version of the recommendations now includes an even

stronger statement affirming women's rights in the introduction:

"After counseling and discussion, a pregnant woman's informed choice on whether to take antiretroviral drugs either for her treatment or for prevention of mother-to-child transmission or to follow other medical recommendations intended to reduce perinatal HIV transmission should be respected. Coercive and punitive policies are potentially counterproductive in that they may undermine provider-patient trust and could discourage women from seeking prenatal care and adopting health care behaviors that optimize fetal and neonatal well-being."

An HIV-positive woman's right to decide whether or not to undergo HIV treatment, either for her own health or to prevent transmission to her fetus, is fundamental, and its importance cannot be overstated. We are delighted, and grateful, that the NIH working group respectfully considered our comments, and clearly confirmed the importance of making explicit a woman's basic right to control medical decision-making related to her HIV care and her pregnancy. ▣

Southern Advocacy

CHLP reaches out to target HIV legal advocacy resources

Over the last nine months, CHLP staffers Alison Mehlman and Margo Kaplan have reached out to advocates and consumers in several Southern states to find out how CHLP can help this under-resourced part of the country. Women, who make up the population most disproportionately affected by HIV in the South, are the focus of CHLP's Southern outreach. By meeting with and learning from advocates for HIV-positive women, CHLP has been able to design a set of resources that will reflect and respond to their identified needs.

In April 2008, at the national conference of the ABA AIDS Coordinating Committee in Dallas, Mehlman and Kaplan met with attorneys working in Louisiana, Mississippi, and North Carolina. In June, they traveled to New Orleans and Baton Rouge to meet with more than two dozen legal and community HIV advocates. The following month, Mehlman attended the Southern Access Summit in Birmingham, Alabama, where she met with community advocates and state officials from HIV/AIDS programs in 10 Southern states.

Common themes across the South were the severe limits on state support for the basic health and service needs of people with HIV, and the incredible dedication and creativity of the advocates and agencies determined to serve them. This input has influenced the design of and issue priorities for resources CHLP has planned, created, and will continue to develop over the coming year. Advocates expressed a need for printed information, in a user-friendly format, about issues such as access to obstetrical/gynecological care, disclosure of HIV status, HIV testing, and housing. In December, CHLP will present at the National Association of People with AIDS Women's Institute in Raleigh, North Carolina, and meet with local consumers and advocates about needs and advocacy priorities.

At the outset, the CHLP's mission has been to address the needs of the most marginalized and underserved communities affected by HIV by increasing the legal resources and advocacy capacity of those communities. Our work in the South is an important step in this direction, but it is clear from our travels and conversations that much work remains to be done.

Increasing Advocacy for HIV+ Women

CHLP's Women's Advocacy Resource Connection takes lead in organizing on behalf of women of color, disproportionately affected by HIV

CHLP's Women's Advocacy Resource Connection (WARC) was created to support and increase advocacy by and on behalf of women with HIV. Due to a mix of factors—threats of violence, sexual partners unwilling to negotiate condom use, and socioeconomic disadvantages—women of color are disproportionately affected by HIV. In some communities, unprotected sex with one male partner puts a woman at increased risk for infection. HIV-positive women of color are also more likely to have difficulty obtaining proper health care, to experience disrespect at the hands of their health care providers, and



Margo Kaplan (right), CHLP Staff Attorney, and Hadiyah Charles, community organizer at the HIV Law Project, discuss ways to support sound sexual health care and education following a screening of the new film, "All of Us."

ference in Washington, D.C. in late October, 2008. One study on antiretroviral treatment found that, of 700 women with HIV, 50 percent of African-American women changed their physicians because they believed that communication problems with their doctors were undermining

found that African-American women who were medically appropriate candidates for antiretroviral therapy were twice as likely as white women to remain untreated, regardless of whether they had insurance. Reports such as these reinforce the need for continued outreach and training with health care providers as a critical part of advocacy for women with HIV, and increased urgency

in the calls to make provider training in cultural competence and patient communication a part of a national plan to improve HIV care and reduce new infections.

Much of CHLP's work on these issues is reflected in the developing online collection of research, training, and legal resources launched as part of WARC. The Resource Bank locates and makes available multidisciplinary and hard-to-find studies, advocacy guides, and other back-up for women fighting for a voice in the development of strategies to address the epidemic in their communities. We also launched a legal and policy listserv exclusively for women with HIV and their advocates to identify and share resources and important information, jointly moderated by CHLP's Margo Kaplan and Hadiyah Charles, a community organizer for the HIV Law Project's women's center.

Much of CHLP's work on these issues is reflected in the developing online collection of research, training, and legal resources launched as part of WARC.

to have their decisions about pregnancy and child bearing challenged or judged. WARC addresses issues such as these that are unique to women.

A critical piece of the problem—the level of care that women of color encounter in the health care system—is reflected in studies released at a national infectious disease con-

ference in Washington, D.C. in late October, 2008. One study on antiretroviral treatment found that, of 700 women with HIV, 50 percent of African-American women changed their physicians because they believed that communication problems with their doctors were undermining

Another set of results reported by the Women's Interagency HIV Study

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Civil Rights To-Do List

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prosecution of people with HIV, HIV testing, immigration, HIV prevention, and prisons—and cut across all affected communities. For example, we call for repeal of the ban on federal

spread of HIV is undisputed in the medical and scientific communities and has been endorsed by, among others, the National Institutes of Health, the National Research Council, the

licensing in trades such as barbering, massage therapy, and home health care. And they call for an end to the Department of Health and Human Services' continuing ban on the entry of HIV-positive foreign nationals as visitors or immigrants.

We are now approaching 30 years of this sad and costly epidemic, and it is time to end the judgmental ideology and bigotry that offend the dignity and limits the lives of people with HIV. Now, more than ever, it is time for human and civil rights to be a central part of the U.S. national strategy to end AIDS.

To read the entire HIV Civil Rights Transition Document for the New Administration, go to www.hivlawandpolicy.org/resources/view/298. ■

Now, more than ever, it is time for human and civil rights to be a central part of the U.S. national strategy to end AIDS.

funding of needle exchange/syringe access programs that hinders critical efforts to combat the spread of HIV, Hepatitis C (HVC), and Hepatitis B (HBV). The effectiveness of needle exchange programs in slowing the

Institute of Medicine, the American Medical Association, and the American Academy of Pediatrics. They also call for the end of exclusions of people with HIV from the military, and from pursuing training and

Increasing Advocacy for HIV+ Women

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As part of WARC, CHLP took a leading role in planning, drafting, and securing organizational endorsements to challenge proposed CDC guidance on HIV testing and care in correctional facilities that failed to address the unique needs of incarcerated women. We also are engaged in a collaborative project with Georgetown University Law Center's International Women's Rights Clinic to produce legal resources

such as briefs and expert affidavits that address discrimination against HIV-positive women in treatment and reproductive rights issues while incorporating a human rights framework. Joint projects such as this will allow us to spearhead still more initiatives in the coming year.

In early fall, CHLP organized participation in the screening and discussion of the film *All of Us*, which discusses the rising rates

of HIV among African-American women and highlights the causes of this vulnerability. The film offers a compelling illustration of how unaddressed gender inequality is central driver in HIV's impact on women.

All of Us will be aired on Showtime at 9:00pm on December 1, World AIDS Day. For more about the film, go to www.allofusthemovie.com/endorsements.php. ■

Message from the Executive Director

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Our model of resource sharing has inspired advocates in other parts of the world. Working through Asia Catalyst, a U.S.-based organization that works with community organizers throughout Asia, CHLP is collaborating with activists in China to share and translate many Resource Bank materials for use by Chinese advocates. The considerable time and work dedicated to locating, creating, reviewing, and summarizing the hundreds of quality materials in the Resource Bank will also serve the goal of courageous activists on the other side of the globe to create an AIDS

legal resource center responsive to the needs of advocates throughout China.

This has been a year of extraordinary developments and challenges. We've learned this year that the Centers for Disease Control and Prevention has seriously underestimated the number of Americans affected by HIV, while it continues to categorize nearly half of all new HIV infections among women as the product of "no identifiable risk." After reading the latest evidence of the unconscious bias and communication failures that women of color encounter when they are able to access care, we still sit at national conferences of physicians who insist that legal requirements for counseling and consent pose the primary barrier to HIV diagnosis and care. Meanwhile, the devastating economic situation, unlike much of the boom time that preceded it, has a substantial trickle-down impact on not-for-profit organizations like the Center for HIV Law and Policy. HIV legal services organizations around the country are facing devastating cuts, as the clear connection between protection of rights and preservation of health is minimized or ignored. As these organizations struggle to meet the needs of the communities they serve, the resources provided by CHLP to support and strengthen their efforts are more critical than ever.

At the same time, the sea change represented in the November 2008 election offers, for the first time in many years, the possibility of systemic

change and the beginning of the end of government-endorsed discrimination such as the U.S. Job Corps' and military's continued rejection of people with HIV as unfit for participation. A new federal administration promises at least a new look at live-saving policies such as syringe-exchange and real sexual health programs for our youth, and even a restored respect for the central role of human rights in protecting public health as well as each individual's quality of life. CHLP's central role in developing a transition document that highlights important HIV civil rights measures as first steps for the new Obama administration reflects the importance of weaving individual rights into any national effort to stem the U.S. epidemic.

Clearly, our work is cut out for us as we fight for universal recognition of the undeniable link between human rights and human health. With renewed hope, I'm certain that the dedicated team of advocates at CHLP, and the advocates whom we support and work with across the country and internationally, are up to the challenge. With your continued support, we will continue to scale up resources and advocacy that ensure that challenge is met.

Sincerely,



Catherine Hanssens
Executive Director

Donate Now

The Center for HIV Law and Policy relies on and appreciates the support of individuals and foundations to support our important work. We welcome you to make a donation through our online donation system on our home page.



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If you are interested in other ways you can support us, please call 212.430.6733 or email aburczak@hivlawandpolicy.org.

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Teen SENSE Makes Strides

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way that is sound, non-judgmental, and helpful.

CHLP has made new inroads and partnerships in New Jersey, where it is anticipated Teen SENSE will first be implemented. Earlier this year, CHLP and the Office of the New Jersey Child Advocate hosted a roundtable for Teen SENSE partners to discuss and draft model standards

Understanding Methods of Prevention, Stephanie Witt of Education Training Resource Associates, Terry Zealand of the AIDS Resource Foundation for Children, and Kimberly Page-Shafer of the Center for AIDS Prevention Studies, University of California, San Francisco.

With its Teen SENSE partners, CHLP has formed subcommittees to

Now, more than ever, it is time for human and civil rights to be a central part of the U.S. national strategy to end AIDS.

for the sexual health care of youth in state custody.

Participants included Dr. Robert Johnson, Acting Dean of the New Jersey Medical School, Riki Jacobs of Hyacinth AIDS Foundation, Gary Wright of the African American Office of Gay Concerns, Lori Heninger, Elizabeth Casparian, and Steve Pitts of HiTops, Lanine Tooté of the New Jersey Women and AIDS Network, Guido Sanchez of Hudson Pride Connections, Dr. Kaityi Duffy of Physicians for Reproductive Choice and Health, Melissa Keyes-Digioia of Planned Parenthood of Greater Northern New Jersey, Dr. Paulette Stanford of New Jersey Medical School, Fatima Meadows of New Jersey Medical School's Juveniles

redraft and complete revised standards that will set out best practices for appropriate sexual medical care and sexuality education of youth in state custody, such as juvenile detention facilities. The standards also will provide best practices for staff training to ensure the health and safety of all youth, focusing on the needs of LGBTQ youth and the need of all staff in contact with youth to understand and respect the full spectrum of sexual orientation and gender identity.

Meanwhile, Teen SENSE is moving forward in forging new partners and alliances to implement these standards in New Jersey and beyond. ▣

CHLP presents at International AIDS Conference

For five days in August 2008, the International AIDS Conference convened in Mexico City. The conference, AIDS 2008, was designed to present important new scientific research and as a forum for productive, structured dialogue on the major challenges facing the global response to AIDS. The conference is convened by the International AIDS Society (IAS), the world's leading independent association of HIV professionals.

Executive Director Catherine Hanssens represented CHLP with four separate presentations. The first of these, entitled "Challenges in Democratizing Access to HIV Legal Advocacy Resources," was part of a poster and panel discussion session on HIV and human rights. Addressing the enormous disparity in the resources available to HIV advocates and the people they represent, CHLP outlined its development of the online Resource Bank to provide organized access to quality legal advocacy materials by centralizing HIV advocacy materials on one website, where they are reviewed, synopsized, and contextualized for easier use.

Hanssens also presented two additional posters on CHLP projects, "Sexual Health Care for Youth in State Custody as a Human Right: The Teen SENSE Project" and "Who Decides? Balancing Rights in Perinatal HIV Testing, Prophylaxis, and Treatment." Both generated considerable interest and discussion.

Finally, as a participant in the International AIDS Conference's first Human Rights Networking Zone, CHLP produced a "hot topics" debate on the impact of HIV counseling and documented informed consent on the HIV diagnosis and care of marginalized populations. For the debate, Hanssens moderated a panel that included Adele Webb, Executive Director of the Association of Nurses in AIDS Care, Linda Valleroy of the Centers for Disease Control and Prevention, Walt Senterfitt, a nurse, epidemiologist and long-time HIV activist, and Ronda Goldfein of the AIDS Law Project of Pennsylvania.

For more information on the conference, visit www.aids2008.org.

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