

VIA EMAIL:

HLTtestimony@capitol.hawaii.gov

Committee:

Committee on Health

Hearing Date/Time:

Tuesday, March 24, 2009, 10:00 a.m. State Capitol, Conference Room 329

Place: Re:

Testimony of the ACLU of Hawaii in Opposition to S.B. 932, S.D.2,

Relating to Infectious Disease Testing

Dear Chair Yamane and Members of the Committee on Health:

The American Civil Liberties Union of Hawaii ("ACLU of Hawaii") writes in opposition to S.B. 932, S.D.2, which proposes to expand routine HIV testing by eliminating the safeguards that ensure HIV testing is voluntary and informed. While we agree that increasing access to testing and care is a critically important goal, S.B. 932, S.D.2's proposal to eliminate written consent and counseling requirements is not the answer. HIV testing must remain informed and voluntary.

The ACLU of Hawaii met with S.B. 932, S.D.2's proponents and attempted to resolve our points of disagreement. As a result, the bill's proponents suggested language that we found to be an improvement but which ultimately did not allay our concerns.

Eliminating written consent and counseling requirements threatens Hawaii residents' health and privacy, goes against long-standing principles of patient autonomy in medical decision-making and ignores the important benefits that informed consent and counseling provide to patients being testing for HIV.

1. Involuntary and uninformed medical HIV testing violates the privacy rights of Hawaii's citizens.

The Hawaii Constitution explicitly protects every individual's fundamental right to privacy, including privacy in the informational and personal autonomy sense.

Art. I, §6, of the Hawaii Constitution, as adopted by the 1978 Constitutional Convention and as ratified by the electorate, secures personal privacy as a fundamental right of the highest order. Specifically, the provision states:

American Civil Liberties Union of Hawai'i P.O. Box 3410 Honolulu, Hawai'i 96801 T: 808.522-5900 F: 808.522-5909 E: office@acluhawaii.org www.acluhawaii.org Hon. Rep. Yamane, HLT Committee, and Members Thereof March 24, 2009 Page 2 of 5

The right of the people to privacy is recognized and shall not be infringed without the showing of a compelling state interest. The legislature shall take affirmative steps to implement this right.

Art. I, §6, Haw. Const. The Supreme Court of Hawaii has held that the Hawaii Constitution must be construed with due regard to the intent of the framers and the people adopting it. *State v. Kam*, 69 Haw. 483, 492, 748 P.2d 372, 377 (1988) (citing *State v. Lester*, 64 Haw. 659, 649 P.2d 346 (1982). The fundamental principle in interpreting a constitutional provision is to give effect to that intent. *Id.* (citing *Huihui v. Shimoda*, 64 Haw. 527, 644 P.2d 968 (1982); *State v. Kahlbaun*, 64 Haw. 197, 638 P.2d 309 (1981); *State v. Miyasaki*, 62 Haw. 269, 614 P.2d 915 (1980). In discussing the intent of the framers in adopting the Art. I, §6, of the Hawaii Constitution, the Supreme Court of Hawaii has noted:

The proposal to expressly acknowledge the 'right of the people to privacy' was offered by the Committee on Bill of Rights, Suffrage and Election of the Constitutional Convention of Hawaii of 1978. After reviewing the privacy provision in the Hawaii counterpart of the Fourth Amendment, the committee reported 'it would be appropriate to retain [this] privacy provision ... but limit its application to criminal cases, and create a new section as it relates to privacy in the informational and personal autonomy sense.'

Nakano v. Matayoshi, 68 Haw. 140, 147, 706 P.2d 814, 818 (1985) (citing Stand .Comm. Rep. No. 69, in Proceedings of the Constitutional Convention of Hawaii of 1978 (Proceedings), Vol. I, at 674) (emphasis added).

The plain language of the Constitution, as bolstered by the framers' intent, makes clear that the right to privacy in Hawaii is — in and of itself — a fundamental right. The right of privacy "is so important in value to society that it can be infringed upon only by the showing of a compelling state interest. If the State is able to show a compelling state interest, the right of the group will prevail over the privacy rights or the right of the individual. However, in view of the important nature of this right, the State must use the least restrictive means should it desire to interfere with the right." *State v. Kam*, 69 Haw. at 493, 748 P.2d at 378 (citing Stand. Comm. Rep. No. 69, in 1 Proceedings of the Constitutional Convention of Hawaii of 1978, Vol. I at 674-75).

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S.B. 932, S.D.2 erodes our privacy rights contrary to our State's values and to the stated purpose of Hawaii's privacy clause in that it would allow doctors to invade patients' bodies without their true consent and without informing them of important legal and social consequences, including that Hawaii state law requires doctors to report the names of those who test positive for HIV and that patients are required to pay for the HIV test. The current draft of the bill does not require that patients be informed that anonymous testing (in which the individual's name is not reported) is available in Hawaii. The state of Hawaii should not allow these invasions of privacy without at least ensuring that patients fully understand what they are being asked to do and what their alternatives are before they consent to testing.

2. Obtaining documented and informed consent is the best way to avoid potential liability in malpractice and discrimination lawsuits.

While, on the surface, forgoing written consent and pre-test counseling may seem appealing to medical professionals, the reality is that doctors take the risk that they will later have to prove -- with no written record -- that a patient consented to an HIV test after being informed fully of the implications.

3. People who are tested with their knowledge are more likely to get the care they need.

While diagnosis soon after infection can add to life expectancy, it only applies if people get treatment after testing positive. Patients tested without consent and/or without understanding the possible significance of the test are more likely to be alienated from care.

Similarly, because HIV-positive adolescents are at greater risk of self-destructive behavior without adequate counseling, eliminating the requirements may jeopardize teen health and actually hamper efforts to prevent transmission of HIV.

¹ The bill's proponents may suggest adding the following italicized language to H.R.S. §325-16(b): "A health care provider may subject a person's body or fluids or tissue to a test for the presence of human immunodeficiency virus infection only after affording the patient the opportunity to decline the test and advising the patient that free and anonymous human immunodeficiency virus tests may be available through the department and community agencies." The bill's proponents may also suggest adding the following language to H.R.S. §325-16(g): "department shall make available to health care providers current information on accessing anonymous human immunodeficiency virus testing that may be provided to their patients." While this language improves the bill, it does not go far enough to allay our concerns because it does not guarantee that patients will be provided with the necessary knowledge to inform their consent.

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4. People need more information about why they may be at risk for HIV, not less.

Many people are still in the dark about basic facts regarding HIV transmission. Increased offers of testing provide an excellent opportunity to educate patients about HIV and thus change risk behaviors and reduce the HIV/AIDS stigma that is fueled by misinformation about the routes of HIV transmission. Eliminating pre-test prevention counseling means losing a critical opportunity to educate people about HIV.

5. Tangible benefits result from the doctor-patient dialogue that the informed consent requirement envisions, including increased trust and a greater likelihood that a patient will be linked to follow up care.

Many of the populations that are in the most need of increased testing may already be mistrustful of public-health efforts. Even those who trust the government and their doctors are likely to fear them if they are tested without their knowledge or fully informed consent.

If the Committee finds that the current rules are not effective, then Hawaii should look at successful models that encourage providers to offer HIV testing to a broader range of people without abandoning safeguards that ensure that testing is informed and voluntary. ²

Written consent and counseling need not be barriers to testing. People will be better able to take care of themselves and one another if medical providers routinely offer testing and explain its benefits. When people can make voluntary and informed decisions to protect their health, everyone wins.

For more resources on written informed consent and counseling, see:

 American Bar Association comments on the CDC recommendations, available at http://www.champnetwork.org/media/aba.pdf

² See Centers for Disease Control and Prevention, Revised Recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings, MMWR (No. RR-14), at 6 (2006) [citing Rothman, supra note 8, at 33 (finding that emergency room testing can be increased by streamlining the counseling and providing some information in writing, as well as by involving non-physician staff in counseling)]. Available at http://www.cdc.gov/mmwR/preview/mmwrhtml/rr5514a1.html

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- American Academy of HIV Medicine comments to the CDC, available at http://www.champnetwork.org/media/AAHIVM.pdf
- AIDS Alliance for Children, Youth and Families comments to the CDC, available at http://www.champnetwork.org/media/AIDS-Alliance.pdf
- National Association of People with AIDS (NAPWA) comments on CDC recommendations, available at http://www.napwa.org/documents/routine_testing_counseling.pdf
- Comments on the CDC recommendations by community-based organizations serving people living with HIV, available at http://www.aidschicago.org/pdf/2006/adv testing statement.pdf
- Ann Fisher, Catherine Hanssens & David Schulman, The CDC's Routine HIV Testing Recommendation: Legally, Not so Routine, 11 HIV/AIDS Policy & Law Review 17 (Dec. 2006), available at http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=955

The mission of the ACLU of Hawaii is to protect the fundamental freedoms enshrined in the U.S. and State Constitutions. The ACLU of Hawaii fulfills this through legislative, litigation, and public education programs statewide. The ACLU of Hawaii is a non-partisan and private non-profit organization that provides its services at no cost to the public and does not accept government funds. The ACLU of Hawaii has been serving Hawaii for over 40 years.

Thank you for this opportunity to testify.

Sincerely,

Laurie A. Temple Staff Attorney ACLU of Hawaii

> American Civil Liberties Union of Hawai'i P.O. Box 3410 Honolulu, Hawai'i 96801 T: 808.522-5900 F: 808.522-5909 E: office@acluhawaii.org www.acluhawaii.org



OFFICERS

Gary Okamoto, MD

President

Robert Marvit, MD

President Elect

Tuesday, March 24, 2009, 10:00 AM, CR 329

To: COMMITTEE ON HEALTH

Rep. Ryan I. Yamane, Chair

Rep. Scott Y. Nishimoto, Vice Chair

From: Hawaii Medical Association

Gary A. Okamoto, MD, President

Philip Hellreich, MD, Legislative Co-Chair Linda Rasmussen, MD, Legislative Co-Chair

April Donahue, Executive Director Richard C. Botti, Government Affairs Lauren Zirbel, Government Affairs

Cynthia Jean Goto, MD Immediate Past President

Re: SB 932 RELATING TO INFECTIOUS DISEASE TESTING

Thomas Kosasa, MD Secretary

Chairs & Committee Members:

Jonathan Cho, MD Treasurer

Hawaii Medical Association supports this measure.

April Donahue Executive Director For the sake of patients and to protect the public and health care workers, physicians should be able test for HIV the way they do for all other infectious diseases, such as syphilis, hepatitis, and tuberculosis.

This measure will increase early detection of HIV and help ensure the safety of all our citizens from this infectious disease.

Thank you for the opportunity to provide this testimony.

Hawaii Medical Association 1360 S. Beretania St. Suite 200 Honolulu, HI 96814 (808) 536-7702 (808) 528-2376 fax www.hmaonline.net



GREGORY HOUSE PROGRAMS

Hawaii's Statewide HIV/AIDS Housing and Support Services Provider

Bill:

SB 932, SD2

Relating to Infectious Disease Testing

DATE:

Tuesday, March 24, 2009

TIME:

10:00 a.m.

PLACE:

Conference Room 329

Board of Directors Chair person

Chair person: Rep. Ryan Yamane

healthcare providers

those infected and to our state

treatment

PresidentGuy Merola

David Andreoli

Dear Chair Ryan Yamane and Committee Members:

Treasurer

My name is Jon Berliner, Executive Director of Gregory House Programs, **Hawaii's** statewide HIV/AIDS housing organization. On behalf of Gregory House Programs, I wish to express strong support of SB 932, SD2.

Akiko Hayashida Secretary

Thank you for the opportunity to offer testimony in strong support of SB 932, SD2. This bill will support the reduction in barriers to HIV counseling and testing and is in line with recommendations issued by the Centers for Disease Control and Prevention. Gregory House Programs strongly supports passage of this bill. The following documents the benefits of this bill:

reduce barriers to HIV counseling and testing by make it more efficient for

allow Hawaii to follow the recommendations of CDD and major national

help reduce the estimated 25% of Americans who are HIV positive but do not

help many individuals in Hawaii to learn their HIV status and seek care and

help reduce transmission of HIV in Hawaii and reduce the long term costs to

help make HIV testing by healthcare providers more routine and reduce the

organizations in support of increased testing in health care settings

Board Members

Joe Bock

Jaimie Kahale

Cecile Kendrick

Joe O'Mealy

Donald Munro

Gennitt Simons

Les Ueoka

Leighton Yuen

stigma based on offering testing by perceived risk

make it easier for healthcare providers to offer HIV testing to pregnant women

and other patients

know their HIV status because they have not been tested

 reduce the missed opportunities for individuals to learn their HIV status when they are in contact with healthcare providers

 allow individuals to learn their HIV status earlier and receive early care services which will allow them to stay healthier, maintain employment and reduce the high costs of emergency room and hospital care

 allow individuals to learn their HIV status earlier and receive early prevention services which reduce HIV transmission to others

• ensure that all patients testing HIV positive will receive their results and be offered appropriate counseling

Thank you for the opportunity to provide testimony in strong support of SB 932, SD2.

Sincerely and with aloha,

Jonathon Berliner Executive Director Gregory House Programs

770 Kapiolani Blvd., Suite 503, Honolulu, Hawaii 96813 808-592-9022 Facsimile 808-592-9049 "Housing is Healthcare"

Executive Director
Jonathon Berliner
jonb@gregoryhouse.org



March 23, 2009

TO:

Rep. Ryan I. Yamane, Chair, Rep. Scott Y. Nishimoto, Vice Chair and Members of the Committee on

Health

FROM: Jackie Berry, Executive Director

RE:

SB932, SD2, Relating To Infectious Disease Testing

Hearing: Tuesday, March 24 at 10am

My name is Jackie Berry, Executive Director of Healthy Mothers Healthy Babies Coalition of Hawaii. We strongly support the original intent of increasing access to HIV testing by healthy care providers by removing the barriers imposed by mandated pre test counseling and obtaining informed written consent prior to testing. However, the current version of SB 932,SD2 needs some major revision for this to happen.

We suggest the passage of a bill with the original wording of HB 1114 that was passed out by this committee. HB 1114 will make it easier for healthcare providers to offer HIV testing to pregnant women and other patients. Knowing your HIV status as a pregnant woman is critically important to having a healthy birth outcome.

The original bill allows Hawaii to follow the recommendations of the Centers for Disease Control (CDC) to increase testing in health care settings.

Mahalo for your consideration of this issue and our testimony.

18085211279



WRITTEN TESTIMONY

Hawaii State House of Representatives Committee on Health Tuesday, March 24, 2009, 10:00 a.m. - Room 329

FIGHTING AIDS

IN HAWAI'

AND THE PACIFIC

SB 932 SD 2 RELATING TO INFECTIOUS DISEASE TESTING

Chairman Yamane. Vice Chairman Nishimoto and Members of the Committee on Health:

Life Foundation, Hawaii's oldest and largest HIV/AIDS organization asks to be recorded In Opposition to SB 932 SD 2 and in Strong Support of the original SB 932 and the House companion bill HB 1114, which seek to amend the state's longstanding HIV Informed Consent statute, is to remove barriers to routine HIV testing in healthcare settings. HB 1114 was passed unanimously by this committee on February 13.

Since then, the parties supporting the original form of this measure, the Department of Health and Life Foundation, have had the opportunity to meet with representatives of the ACLU and the Attorney General's office to discuss and address concerns raised by the ACLU. Language proposed at that meeting has been or will be presented to you by the Department of Health with the suggestion that the bill before you be replaced with its original language augmented by the proposed language.

My testimony in previous hearing on the House and Senate bills follows:

In the early years of the AIDS epidemic in Hawaii, the legislature, in its wisdom. enacted a law that prohibited testing anyone for HIV infection without pre and post test counseling and written informed consent by the person to be tested. Given the significant shame, stigma, prejudice and ignorance surrounding AIDS at that time, the approach taken by the state was both commendable and appropriate.

HAWAII

96813

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677 ALA MOANA BIND.

SUITE NO. 226

HÖMÖLÜLÜ

www.lifefoundation.org

The CDC has determined that nearly 25% of people infected by HIV do not know their status and, as a result, are not in a position to seek early medical intervention for the treatment of HIV and related conditions. At the same time, the CDC reports that annual HIV infections in the United States are not declining but remain stable at about 56,000 newly reported cases each year.

The purpose of this legislation is to remove the requirements of pre-test counseling and a separate written informed consent before an HIV test can be administered in a healthcare setting. As with all diagnostic tests, a general consent will still be required before testing.



SB932 SD2 Testimony Life Foundation Page 2 of 2

This legislation only pertains to healthcare settings. Sites that provide anonymous or confidential HIV testing, such as the Life Foundation and the Department of Health, will still be required to offer counseling before and after a test is administered.

Because this legislation will help make HIV testing a routine healthcare practice, it has the potential of finding HIV positive people who would not otherwise seek HIV testing. At the same time, we are confident that existing privacy laws and healthcare practices will continue to safeguard the confidentiality that is so important to people infected with HIV.

It is time for HIV/AIDS to become a health issue and not a moral one.

Paul S. Groesbeck Executive Director ${\bf Email:pgroesbeck@life foundation.org}$

Telephone: 853-3234

FAX: 18085211279

nishimoto2-Bryce

From:

Sheila Beckham [sbeckham@waikikihc.org]

Sent:

Monday, March 23, 2009 10:14 AM

To: Subject: HLTtestimony

SD 932 SD 2

TO:

Representative Ryan Yamane, Chair, Health Committee

RE:

SD 932 SD 2

March 24, Room 329

FROM: Sheila Beckham, RD, MPH

Executive Director

On behalf of Waikiki Health Center, I would like to strongly urge your support of SD 932 SD 2. Many clients are often unsure who or how to ask to be tested for HIV/AIDS; they are often reluctant to discuss issues related to the need to be tested. Therefore, this legislation will offer greater opportunities for clients to receive HIV testing, in a routine, comfortable manner. We feel strongly that by increasing access to testing, the clients will likewise have greater access to prevention education and early intervention.

Thank you for the opportunity to submit this testimony.