

Testimony of Becky Straus SB 1507A: Consent to HIV Testing House Health Care Committee February 15, 2012

Co-Chairs Thompson and Greenlick, and members of the committee:

My name is Becky Straus and I am here today to testify on behalf of the ACLU of Oregon on SB 1507A, which would replace the current informed consent requirement for HIV testing with an opt-out scheme that allows notice to the patient in a general medical consent form. Our central concern is that the bill allows for notification to be embedded in a general medical consent form. Thank you for the opportunity to provide comments and to detail that concern.

We agree that increasing access to HIV testing and care is a critically important goal. Far too many people do not know their HIV status, and we support efforts to help people living with undiagnosed HIV learn their status and gain access to necessary care and support services.

At the same time, we strongly believe that HIV testing should be truly voluntary and informed. Meaningful informed consent is important because HIV testing has specific legal and social consequences. Test results may be reported to the health authority. And, despite state and federal laws prohibiting it and significant improvements in public awareness, discrimination against people living with HIV is an ongoing real problem. In some states, perfectly healthy men are prohibited from giving blood simply because of their sexual orientation. In other states, women in correctional facilities who are HIV positive are placed in special segregation units. In July of 2010, even the White House Office of National AIDS Policy voiced concern that "the stigma associated with HIV remains extremely high and fear of discrimination causes some Americans to avoid learning their HIV status, disclosing their status, or accessing medical care."<sup>1</sup> The ACLU of Oregon has serious concerns and reservations about a bill that does not recognize the real challenges of social stigma and the risk of discrimination that persons with HIV still face today.

The problem with allowing for notice and the opportunity to decline to be provided in the mix of all other information laid out in a general medical consent form is the risk that patients will not receive true notice of testing. The reality is that many patients do not read, and many other patients attempt to read but do not fully understand, generic medical consent forms. We are concerned that incorporating HIV testing notification into a generic form risks that providers administer tests to many patients without their knowledge and to others who lack understanding

<sup>&</sup>lt;sup>1</sup> White House Office of National AIDS Policy, July 2010 (White House Office of National AIDS Policy, National HIV/AIDS Strategy for the United States ix (2010), http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf

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of the implications of the test, their right to anonymous testing, and their ability to opt out. These problems disproportionately affect people of lower socioeconomic status and people who do not have established relationships with health care providers.

The bill leaves open some unanswered questions. If a patient opts out of testing, how does a provider track that decision? How will patients be aware of their right to consent to all other treatment in the general medical consent form but simultaneously decline HIV testing? How do we ensure that a patient is actually notified of testing if such notice is not conspicuous on the form?

For these reasons, we are opposed to the bill in its current form. We would support any efforts to ensure that, if notice and opportunity to decline is provided in a general medical consent form, that it be clear and conspicuous to the patient. Patients deserve true choice in HIV testing.

Thank you for the opportunity to testify and for your consideration of our position.

Sincerely,

Becky Straus Legislative Director