

# Governor's Advisory Council on HIV/AIDS (GACHA)

## Focus on High Risk Youth Public Forum

September 9, 2008

Spokane, Washington



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**Governor's Advisory Council on HIV/AIDS**  
**Focus on High Risk Youth Public Forum**  
**September 9, 2008**  
**Spokane, Washington**

**Background**

The Governor's Advisory Council on HIV/AIDS (GACHA) conducted a public forum on September 9, 2008 in Spokane, Washington focusing on high risk youth, the adequacy of current prevention efforts within that population, and the challenges facing those engaged in delivering treatment services to those already infected with HIV, particularly in rural areas. (A forum agenda and complete list of participants are attached.)

**Summary of Key Findings**

The numbers of newly reported HIV infections statewide, while troubling, have remained relatively stable over the past five years (2003-2007) with roughly 500 new cases reported each year. (The CDC reports an additional 200 cases each year are unreported.) Within the same time frame, however, the number of new cases among young people (under the age of 25) has nearly doubled. The rate of new infections among 13-24 year olds increased from roughly 4 in 100,000 in 2003 to nearly 9 in 100,000 by 2007. There is a sharper rate of increase outside of King County, but regardless of the geography, the majority (77%-89%) of the new cases are among men who have sex with men (MSM) in their early twenties (88%).<sup>1</sup>

The upward trend in HIV infections among high-risk youth could be a reflection of increased testing but is just as likely the result of unsafe sex. There is a lack of data to support either conclusion exclusively and in all likelihood it is a combination of both factors. **Regardless, this increase in infections among high-risk youth is alarming and quite possibly is a crisis-in-the-making which must be addressed.**

Within AIDSNet Region 1, 80% of the HIV epidemic is concentrated within Spokane County. Trends within Region 1 are similar to those statewide: the majority of new cases are white, male and among MSM, although minorities (particularly blacks) are disproportionately impacted. Region 1 witnessed a spike

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<sup>1</sup> *Epidemiology of HIV Disease in Eastern Washington State, September 9, 2008; Jason Carr, MPH, Maria Courogen, MPH, Washington State Department of Health.*

in new cases among males in 2006-07, but epidemiologists require more data over a longer period of time before identifying a trend.<sup>2</sup>

Current prevention campaigns in AIDSNet Region 1 aimed at youth-at-risk include work by the Spokane AIDS Network; Odyssey Youth Group; INMX Young Men's Prevention Group; HIV/AIDS Speaker Bureau, Spokane County Youth Living with HIV and Planned Parenthood. Their individual and collective efforts are tireless and admirable and must continue to be supported.

But young people don't uniformly believe they are at risk. Sex education in the public schools is perceived as both outdated and unbalanced. The messages are seen as either abstinence-only; or, when curriculums do mention condom use, it is discussed solely in terms of preventing pregnancy—a useless message for gay youth.

There are contradictory and confusing messages for young people at risk: "HIV is bad; but you can live a full life with it." *In fact, current evidence is that one will not live a full life with HIV/AIDS, but a shortened more complex life.*

Young people also didn't live through the worst years of the epidemic and thus have no historical context or sense of the seriousness of HIV/AIDS. In the words of a panel participant engaged in prevention efforts, "HIV medications have made the disease invisible."

All these factors, when combined with the vulnerability of a young gay person struggling to come out—particularly in a rural area—and coming of age sexually while desiring an emotional and physical connection are a recipe for risky behavior.

Statewide, there are roughly 10,000 people reported living with HIV disease, more than at any time in the epidemic's history. *Meanwhile, funding for HIV/AIDS programs remains flat.*

Five percent of these prevalent cases are in AIDSNet Region 1.<sup>3</sup>

In addition to private physicians, the region's care services are being delivered by public health; the Spokane AIDS Network, CHAS (a Ryan White Part C funded clinic ; ) the REACH Regional Housing Program and the HASAP Program (substance abuse.)

The challenges facing these providers are similar to those GACHA has identified elsewhere in the state, particularly in rural areas: a lack of participating

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<sup>2</sup> *Epidemiology of HIV Disease in Eastern Washington State, September 9, 2008; Jason Carr, MPH, Maria Courogen, MPH, Washington State Department of Health.*

<sup>3</sup> *Epidemiology of HIV Disease in Eastern Washington State, September 9, 2008; Jason Carr, MPH, Maria Courogen, MPH, Washington State Department of Health.*

(Medicare, Medicaid, WSHIP) specialists; too few doctors in rural counties with adequate HIV experience; too few dentists willing to treat an HIV-infected patient; anti-HIV stigma; and inadequate funds to support the transportation needs of patients who must travel great distances to receive care.

## **Recommendations**

- 1. The governor and other elected leaders must publicly reengage themselves in efforts to raise public awareness of HIV/AIDS, particularly among young persons at high risk.** The Council recommends this message be communicated in a manner designed to attract maximum visibility. For example, the governor could coordinate a media event with one or several of the state's AIDS service organizations at which young persons already infected or at risk could put a human face on this ongoing epidemic and join the governor in warning a new generation of the realities and risks of HIV infection, which, as this report notes, is on the rise among young gay men.
- 2. The governor should support ongoing efforts by AIDS service organizations to increase federal funding for prevention by \$200 million in FFY '09.** National AIDS Service Organizations have requested this increase in funding in a letter to Representative Henry Waxman. When the CDC increased prevention funding in the 1980s, new HIV infections dropped dramatically. Prevention works!
- 3. Youth must be included in the development and delivery of prevention messages.** Young persons are best able to develop prevention messages relevant to their community. This will be a challenge and will require innovative approaches. An increased use of local speaker's bureaus featuring HIV+ youth is one suggestion.
- 4. The governor should encourage the Superintendent of Public Instruction and the Board of Education to include sexual behavior questions in the annual Healthy Youth Survey.** This would require revisiting and revising current WACs which now require active parental consent before such questions are asked. But without such data there is no reliable method to accurately measure changes in sexual behaviors—information critical to prevention efforts.
- 5. The governor should encourage the Superintendent of Public Instruction to appoint a new representative from that office to the Council.** This representative is an important source of information on school curricula and an important conduit for Council efforts.
- 6. GACHA should work with the Superintendent of Public Instruction and the Board of Education to perform a comprehensive assessment of the adequacy and uniformity of HIV education in public schools statewide.**
- 7. GACHA should study the challenges and feasibility of collecting more reliable data on HIV testing in terms of the numbers of tests**

- and reasons for testing.** Currently, only public health collects such data and those tests account for a small share (20%) of all testing done in the state.
- 8. GACHA should explore identifying alternate funding sources for critical transportation needs, particularly in rural areas.** AIDSNETS currently use Ryan White monies but funding is inadequate in relationship to need.
  - 9. To increase access to HIV/AIDS medical expertise more effectively in rural areas, use of teleconferencing and other technologies should be better promoted and, when appropriate, utilized.**
  - 10. GACHA should further investigate how food and nutrition needs of HIV patients are being met.**
  - 11. Increased funding for HIV testing is necessary to increase access to free and low-cost testing for all high-risk individuals, including women.**
  - 12. GACHA reaffirms its support for an increase in reimbursement rates for Medicare, Medicaid and WSHIP providers.** Flat or declining reimbursement rates will only mean fewer specialists willing to treat HIV+ patients dependent on these programs, particularly in rural areas.
  - 13. The governor should appoint a representative of the Washington State Dental Association (WSDA) to the Council. In the interim, the Council should reach out to WSDA and begin a dialogue regarding this report's findings that stigma among some rural dental providers is a barrier to care for HIV+ individuals.**

## **Complete Findings**

This report cites epidemiologic data from the Epidemiology of HIV Disease in Eastern Washington State report, dated September 9, 2008. The key findings have been discussed in the summary; the complete report is included as an addendum.

The Spokane AIDS Network, Odyssey Youth Group; INMX Young Men's Prevention Group, HIV/AIDS Speaker Bureau; Spokane County Youth Living with HIV; and Planned Parenthood are involved in youth prevention efforts. INMX, for example, sponsors discussion groups and movie nights.

Those involved in the prevention efforts believe many teenagers and young adults are engaging in high-risk behavior. They believe current prevention messages are not getting through to those most at risk. There is a general awareness of HIV, but protection isn't consistent. For some who are struggling with their sexuality, just meeting up with someone with whom you can make a connection makes them take risks for fear of losing that connection. Youth also misbelieve that HIV is no big deal; that it can be taken care of with a few pills. HIV medications "have made the disease invisible; you don't see it." There is confusion and contradiction in the current messaging in which youth hear HIV is bad, but it's also something you can live with.

Prevention messages delivered in the school setting are perceived as either abstinence based or heterosexual in orientation. A curriculum which only talks about wearing a condom to prevent pregnancy is going to be tuned out by gay youth. Youth must be a part of developing the message. Development of empowering messages is important, as is networking.

The continued stigma of being gay and living with HIV is still a large factor in rural communities. Gay youth have few role models; few examples of someone their age living with the effects of HIV, or more importantly, for a role model, avoiding HIV.

More HIV awareness in the mass media would help. A Spokane AIDS Network produced PSA focused on youth was judged helpful.

Rapid testing became available at local health district offices within the past five years. But many at risk youth are fearful of going to health district offices. More outreach testing would help; as would more free testing for women.

*The issue of whether an increase in testing was responsible for the documented rise in HIV infections among youth was of great interest to GACHA. While the spike in cases coincides with the increased availability of rapid testing at public health clinics, it was noted that private testing still accounts for an estimated 75% of all testing done in the state. Overall, private testing rates are not measured. Of note is King County's public health experience with testing. It has seen only small increases in testing in recent years; too small to explain the rise in youth infections. Also in King County and likely the rest of the state, very few if any providers are utilizing rapid testing methods outside of public health clinics.*

In addition to private physicians, care services in the region are delivered by public health; the Spokane AIDS Network; CHAS (a Ryan White Part C funded clinic ;) the REACH Regional Housing Program; and the HASAP Program (substance abuse.)

Even in Spokane, HIV-proficient providers are few and in the case of those familiar with pediatric HIV care, non-existent. The shortage is even more acute elsewhere in the region. Specialists are hard to find for those patients who depend on Medicare, Medicaid, and even WSHIP. As elsewhere, low reimbursement rates are the reason.

*The Council learned at the forum that Sacred Heart Hospital will soon open a new HIV clinic in Spokane.*

Dental care would be impossible without EIP or CHAS. Many dentists still don't want to treat HIV patients.

Transportation is a huge barrier to care for patients because of the travel distances required for care. Gas cards are provided but are quickly diminished.

Besides transportation costs, clients see their barriers to care as encompassing all their financial demands. The need to eat and pay for housing take priority over health needs.

Those with mental health issues pose unique challenges, including the very basic need to get them to recognize they need help.

The delivery of holistic care is difficult because funding is 'siloed.'

New Ryan White funding restrictions make it difficult for case managers to spend the time to reach out and do more testing. In fact, there is no funding for prevention case managers.

Free testing is available at public health for those at high risk, but that very often excludes women who may not be perceived as high risk and may be unable to pay the testing fee. Patients (and some providers) are resisting the 20-minute time commitment necessary for a rapid test.

Many case managers have the common frustration of "Groundhog's Day" as they deliver care and services.