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Issues - Privacy

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Issue 2: Health Privacy Legislation Hits the Senate

As part of an effort to enact a federal health privacy bill by August 1999, the Senate Health, Education, Labor and Pensions Committee (HELP) will mark-up health privacy legislation on Tuesday, May 25, 1999. AIDS Action is calling on our network's strong grassroots advocacy efforts to ensure that fair and effective privacy legislation is enacted.

The most critical component of federal health privacy legislation is ensuring the non-preemption of stronger state laws. In other words, it is important that any federal legislation enacted on health privacy issues provide states with a strong foundation of privacy protections that will preserve their right to offer even stronger privacy laws tailored to their citizens. For this reason, it is crucial that the Senate HELP Committee's bill *not* include the preemption of stronger state health privacy laws.

It also critical that federal health privacy legislation adequately address the privacy needs of individuals living with HIV/AIDS. In order to guarantee the strongest possible federal privacy protections, the Senate HELP Committee legislation should:

- Restrict the disclosure of individually identifiable information without the informed consent of the individual; (Note: Use of disclosures without informed consent should be permitted only under exceptional circumstances, including a threat to an individual's life, a threat to public health, or if there is a compelling law enforcement need.)
- Include an individual's right to privacy of his/her health information and medical records;
- Include the right to review and amend medical records;
- Before the authorization of the use of medical records, informed consent must be obtained by the individual, and he/she should be notified of who will be using the information and for what purpose;
- Include security safeguards for the use, disclosure and storage of personal health information;
- Guarantee a private right of action for patients as well as consumer and civil monetary penalties and whistleblower protections for violations of privacy;
- While protecting individual privacy rights, legislation should not impede important public health efforts or clinical, medical and quality of care research.

Take AIDS Action: If your senator serves on the Senate HELP Committee (members listed below), urge him/her to establish a strong floor, and not a ceiling, of health privacy protections which **DO NOT** preempt stronger state privacy laws and which include the principles outlined above. If your senator does not serve on this committee, request that your senator weigh in with Senators James Jeffords (R-VT) and Edward Kennedy (D-MA).

Senate Committee on Health, Education, Labor and Pensions:

James Jeffords, (R-VT) – Chairman

Republicans:

Judd Gregg, NH
Bill Frist, TN
Mike DeWine, OH
Michael Enzi, WY
Tim Hutchinson, AR
Susan Collins, ME
Sam Brownback, KS
Chuck Hagel, NE
Jeff Sessions, AL

Democrats:

Edward Kennedy, MA – ranking member
Christopher Dodd, CT
Tom Harkin, IA
Barbara Mikulski, MD
Jeff Bingaman, NM
Paul Wellstone, MN
Patty Murray, WA
Jack Reed, RI

Network News: HIV/AIDS Positions Available...

DEVELOPMENT DIRECTOR – Boulder County AIDS Project, Boulder, CO: Individual sought to coordinate and manage all aspects of fund development within the agency - including grant writing and reporting, special events and benefits planning, corporate solicitation, direct mail campaigns, planned giving, and production oversight of agency annual report and donor newsletter. Qualifications include a minimum of three years experience in grant writing and event planning, excellent writing and organizational skills, experience in a non-profit setting and HIV/AIDS related issues. Position requires local travel. Salary negotiable based on experience (\$30,000 - \$37,000). Interested candidates should send letter of interest, resume, and writing sample to: **BCAP, 2118 14th Street, Boulder, CO 80302.**

HUMAN RESOURCES ADMINISTRATOR – Coastal Bend AIDS Foundation, Corpus Christi, TX: Individual sought to manage and develop human resource duties of a growing non-profit organization. Will work closely with Executive Director to develop sound employee relations and policies for over 30 employees. Qualified candidates will possess: Bachelor's degree in human resources management; minimum of one year experience in human resources environment, experience with non-profits or community-based organizations is preferred; excellent written and oral communication skills; public relations, grant writing, and program development skills are a plus; working knowledge of ADA, EEO, unemployment claims, benefits communication, and maintaining sound employee relation practices. Deadline: 5pm, June 15, 1999. Interested candidates should submit resume and letter of interest to: **J. Jimenez, CBAF, 527 Gordon, Corpus Christi, TX 78404. Or fax to: 361.814.6502**

HEALTH PROGRAM COORDINATOR II, San Francisco Department of Public Health, San Francisco, CA: Individual sought to be responsible for planning, managing and evaluating HIV prevention and HIV CTR/PCRS contracts, and assisting the HIV community planning process assess needs and conduct planning/prioritization for San Francisco's HIV Prevention Services. Salary range is \$48,024 to \$58,360. Interested candidates should submit resume, City and County of San Francisco employment application, and letter of interest by June 4, 1999 to: **Delia Garcia, 25 Van Ness, Suite 500, San Francisco, CA 94102.**