UNITED STATES COURT OF APPEALS FOR THE EIGHTH CIRCUIT CASE No. 07-1576

JOHN DOE,

Appellant,

v.

DEPARTMENT OF VETERANS AFFAIRS OF THE UNITED STATES OF AMERICA; AND THE HONORABLE R. JAMES NICHOLSON, SECRETARY OF THE DEPARTMENT OF VETERANS AFFAIRS,

Appellees.

ON APPEAL FROM THE UNITED STATES DISTRICT COURT FOR THE DISTRICT OF MINNESOTA

Honorable Patrick J. Schiltz, United States District Judge

BRIEF OF AMICI CURIAE

AID GREATER DES MOINES, INC. d.b.a. AIDS PROJECT OF CENTRAL IOWA, LAMBDA LEGAL DEFENSE AND EDUCATION FUND, INC., MINNKOTA HEALTH PROJECT, NATIONAL ASSOCIATION OF PEOPLE WITH AIDS, AND NEBRASKA AIDS PROJECT IN SUPPORT OF APPELLANT

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CORPORATE DISCLOSURE STATEMENT

Pursuant to Federal Rules of Appellate Procedure 26.1 and 29(c), Aid Greater Des Moines, Inc. d.b.a. AIDS Project of Central Iowa, Lambda Legal Defense and Education Fund, Inc., Minnkota Health Project, National Association of People with AIDS, and Nebraska AIDS Project each state that it does not have a parent corporation and that no publicly-held corporation owns any stock in it.

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INTERESTS OF AMICI

Amici consist of five national and regional organizations that work with and/or advocate on behalf of people living with HIV. Amici collectively represent and advocate for the rights of thousands of individuals in the United States -- including many living in the states of Iowa, Minnesota, Nebraska, and North Dakota -- who are infected with HIV or otherwise affected by the HIV epidemic. Based on their experience and knowledge about the discrimination and stigma faced by people with HIV, amici believe that HIV-related information should be maintained in the strictest confidence and that people living with HIV have a substantial interest in having the protections of the Privacy Act enforced against federal employers.¹

INTRODUCTION

In this case, the Court will address whether the federal Privacy

Act was violated when a physician employed by the federal Department of

Veterans Affairs ("VA") obtained HIV-related medical history during the

course of providing medical treatment to a VA employee, recorded the

information in the patient/employee's medical records maintained by the

VA, and subsequently disclosed that information to the employee's union

¹ Brief descriptions of the *amici* are set forth in the attached Appendix.

representative without authorization. *Amici* submit that this unauthorized disclosure undermines the important societal interests in maintaining the confidentiality of medical care for people with HIV and that the Privacy Act provides protection against such disclosure. For these reasons, *amici* request that this Court reverse the decision of the District Court.

ARGUMENT

I. Protecting the Privacy of Information About An Individual's HIV Status Furthers Significant Individual and Societal Interests.

Because of persistent stigma and discrimination, people with HIV have a substantial interest in maintaining the privacy and confidentiality of their HIV status. Further, individual and societal interests in privacy increase exponentially when private information is shared with a health care provider during the course of treatment. Without the assurance of confidentiality from their medical providers, individuals may decline to seek medical care. This is particularly true for people with HIV, and those who believe they may be infected, who may avoid testing and care due to concerns about confidentiality, stigma, and discrimination. Because this potential impact has broader implications for the public health, it is essential that individuals with HIV be able to reveal their private medical and behavioral information to physicians employed by the federal government

without fear that it can be disclosed without their authorization.

A. Due to the Prevalence of HIV Stigma and Discrimination, People Living with HIV Have a Significant Interest in Protecting Their HIV Status from Unauthorized Disclosure.

Because of the societal stigma surrounding HIV, AIDS, and the private behaviors that frequently are associated with HIV infection, the disclosure of HIV-related information can be very harmful, even very dangerous, for people living with HIV. See Doe v. S.E. Pa. Transp. Auth., 72 F.3d 1133, 1140 (3d Cir. 1995) (recognizing that stigma, harassment, and discrimination can result from "non-consensual dissemination of the information that an individual is inflicted with AIDS"). Indeed, "[s]ociety's moral judgments about the high-risk activities associated with the disease, including sexual relations and drug use, make the information of the most personal kind." Doe v. Borough of Barrington, 729 F. Supp. 376, 384 (D.N.J. 1990) (finding that potential for harm after AIDS disclosure is "substantial" and ruling that borough violated family's constitutional right to privacy when police officers revealed information to others in community); see also Woods v. White, 689 F. Supp. 874, 876 (W.D. Wis. 1988) (discussing highly personal nature of information about AIDS and ruling that prison officials violated prisoner's rights by disclosing his status to nonmedical staff and other inmates), *aff'd without opinion*, 899 F.2d 17 (7th Cir. 1990).² Although over 25 years have passed since doctors reported the first cases of HIV in the United States, HIV-related stigma continues to be prevalent and well documented.³

Stigma can affect people with HIV in every aspect of their lives, including employment, education, housing, insurance, health care, and relationships with family, friends, and partners. Such stigma has resulted in harms including the erosion of social support networks, eviction from homes, loss of work, denial of health care, social isolation, depression, and violence. The persistence of stigma for people living with HIV was documented by a recent national survey conducted by the Kaiser Family

² See also Patricia G. Devine et al., The Problem of 'Us' Versus 'Them' and AIDS Stigma, 42 Am. Behav. Sci. 1208, 1208-1219 (1999).

³ See, e.g., Gregory M. Herek & John P. Capitanio, AIDS Stigma and Sexual Prejudice, 42 Am. Behav. Sci. 1126 (1999); Gregory M. Herek et al., HIV-Related Stigma and Knowledge in the United States: Prevalence and Trends, 1991-1999, 92 Am. J. Pub. Health 371 (2002); Gregory M. Herek et al., When Sex Equals AIDS: Symbolic Stigma and Heterosexual Adults' Inaccurate Beliefs about Sexual Transmission of AIDS, 52 Soc. Probs. 15 (2005); D.A. Lentine et al., HIV-Related Knowledge and Stigma – United States, 2000, 49 U.S. Dep't of Health and Hum. Services Morbidity AND Mortality Wkly. Rep. 1062 (2000); Peter A. Vanable et al., Impact of HIV-Related Stigma on Health Behaviors and Psychological Adjustment among HIV-Positive Men and Women, 10 AIDS & Behav. 473 (2006).

Foundation. Although HIV cannot be transmitted through casual contact,⁴ the Kaiser survey revealed that only 29 percent of respondents reported that they would be very comfortable with their child having an HIV-positive teacher. And only 41 percent reported that they would be very comfortable working with someone who has HIV or AIDS. ⁵ This same survey also revealed that many people still lack basic knowledge about how HIV is and is not transmitted. Further, surveys reveal that people with HIV continue to experience significant levels of disapproving moral judgment.⁶

⁴ HIV cannot be transmitted through casual contact or day-to-day interactions at home, work or school. One cannot contract HIV through touching, hugging, kissing, or sharing food utensils, towels, bedding, swimming pools, telephones or toilet seats. *See HIV and Its Transmission*, HIV/AIDS FACT SHEETS (Ctrs. For Disease Control & Prevention, Atlanta, GA), updated Mar. 8, 2007, *available at* http://www.cdc.gov/hiv/resources/factsheets/transmission.htm; Centers For Disease Control & Prevention, *Human Immunodeficiency Virus Transmission in Household Settings – United States*, 43 U.S. DEP'T OF HEALTH AND HUM. SERVICES MORBIDITY AND MORTALITY WKLY. REP. 347 (1994), *available at* http://www.cdc.gov/mmwr/preview/mmwrhtml/00030972.htm.

⁵ Attitudes about Stigma and Discrimination Related to HIV/AIDS, KAISER PUB. OPINION SPOTLIGHT (Kaiser Fam. Found., Washington, D.C.), Aug. 2006, available at http://www.kff.org/spotlight/hivUS/index.cfm [hereinafter Kaiser Report].

⁶ See, e.g., id.; Herek et al. (2002), supra note 3. Several national surveys reveal that stigmatizing attitudes towards people with HIV appear to be greatest among heterosexuals who also express negative attitudes towards gay people. See, e.g., Gregory M. Herek et al., Stigma, Social Risk, and Health Policy: Public Attitudes Towards HIV Surveillance Policies and the Social Construction of Illness, 22 HEALTH PSYCHOL. 533, 536 (2003); Herek & Capitanio (1999), supra note 3, at 1129-1139; Gregory M. Herek & John

The disclosure that a person has HIV frequently wreaks havoc on that person's life. See, e.g., Doe v. City of New York, 15 F.3d 264, 267 (2d Cir. 1994) ("An individual revealing that she is HIV seropositive potentially exposes herself not to understanding or compassion but to discrimination and intolerance, further necessitating the extension of the right to confidentiality over such information."). People living with HIV frequently find themselves discriminated against in employment, victimized by hate crimes, or cut off from family and friends as a result of overwhelming and pervasive stigma. See Doe v. Coughlin, 697 F. Supp. 1234, 1237 (N.D.N.Y. 1988) (recognizing that people living with AIDS may be abandoned by family members); Estate of Behringer v. Med. Ctr. at Princeton, 592 A.2d 1251, 1269-70 & 1272 n.12 (N.J. Super. 1991) (noting that "[u]nauthorized disclosure of a person's serologic status can lead to social opprobrium among family and friends" and citing examples of "hysterical public reaction to AIDS").

P. Capitanio, Symbolic Prejudice or Fear of Infection? A Functional Analysis of AIDS-Related Stigma Among Heterosexual Adults, 20 BASIC & APPLIED SOC. PSYCHOL. 230 (1998). HIV stigma also is exacerbated by negative attitudes about injecting drug users, who are highly stigmatized. See, e.g., Devine et al., supra note 2. For example, a national survey found that 72% of respondents agreed with the statement, "I think people who inject illegal drugs are disgusting." Gregory M. Herek & John P. Capitanio, AIDS-Related Stigma and Attitudes Toward Injecting Drug Users Among Black and White Americans, 42 AM. BEHAV. SCI. 1144, 1148 (1999).

Discrimination against people with HIV remains prevalent today.

Roughly half of those surveyed by the Kaiser Family Foundation in 2006 believed that there is a lot of discrimination against people with AIDS. From 2002 to 2006, HIV-related employment discrimination claims were filed with the U.S. Equal Employment Opportunity Commission ("EEOC") at an average rate of about one per day. This is only a small decline from the number of claims filed during 1994 to 2001: an average rate of 1.3 claims per day.

Inexcusably, discrimination persists within the health care system itself. For example, a 2006 study of specific-service health care providers in Los Angeles County found significant evidence of HIV discrimination. The researchers surveyed 131 skilled nursing facilities, 98 plastic and cosmetic surgeons, and 102 obstetricians in Los Angeles County to determine how many of these institutions practice a policy of blanket discrimination against people living with HIV. They found that of the institutions surveyed, 56

⁷ Kaiser Report, supra note 5, at 2.

⁸ ADA Charges Filed with EEOC and State and Local FEP Agencies Where the Alleged Basis Was HIV 10/01/1991 to 12/07/2006 (Dec. 15, 2006) (unpublished material on file with Lambda Legal Defense and Education Fund, Inc.).

⁹ *Id.*; David M. Studdert, *Charges of Human Immunodeficiency Virus Discrimination in the Workplace: The Americans with Disabilities Act in Action*, 156 Am. J. EPIDEMIOLOGY 219 (2002).

percent of the skilled nursing facilities, 26 percent of the plastic and cosmetic surgeons, and 47 percent of the obstetricians refused to treat people living with HIV and had no lawful explanation for their discriminatory policy. The findings of a 2005 study measuring levels of discrimination perceived by people with HIV corroborate that health care settings remain sites of discrimination. In that study, 26 percent of adults with HIV believed that they had experienced discrimination by a health care provider since HIV diagnosis. Moreover, the researchers noted that these numbers may be low due to underreporting by black Americans and Latinos. 11

The federal government has recognized the reality and prevalence of discrimination against people with HIV. In 1990, Congress enacted the Americans with Disabilities Act of 1990 ("ADA"), 42 U.S.C. § 12101 *et seq.*, whose purpose is to protect people with disabilities from discrimination in employment, public accommodations, and other contexts. Congress clearly intended that the ADA, like the federal Rehabilitation Act, 29 U.S.C.

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¹⁰HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies, WILLIAMS INST. STUDY (The Williams Inst., UCLA Sch. of L., Los Angeles, CA) Dec. 2006, available at http://www.law.ucla.edu/williamsinstitute/publications/Discrimination%20in%20Health%20Care%20LA%20County.pdf.

Mark A. Schuster et al., *Perceived Discrimination in Clinical Care in a Nationally Representative Sample of HIV-Infected Adults Receiving Health Care*, 20 J. GEN. INT. MED. 807, 809-811 (2005).

§ 701 *et seq.*, would provide redress for HIV-related discrimination. *See Bragdon v. Abbott*, 524 U.S. 624, 642-45 (1998) (discussing ADA's legislative history and the treatment of HIV and AIDS under the federal Rehabilitation Act). Amici's experiences indicate that the statutory protections afforded by the Rehabilitation Act and ADA have not eradicated discrimination against people with HIV in the U.S. However, the existence of these statutory protections suggests broad societal recognition of the seriousness of the problem of discrimination against people with disabilities, including people with HIV.

Disclosure of a person's HIV status may have serious ramifications beyond discrimination. Exposure to HIV-related stigma is a significant source of psychological damage and depression. A 2006 study found that higher levels of HIV stigma experienced by the respondent directly correlated with having symptoms of depression and/or having received psychiatric care in the previous year. Stigma has been linked to

¹² The EEOC considers the ADA to protect all people living with HIV. *See* 29 C.F.R. Pt. 1630, App., § 1630.2(j) (HIV is a medical condition that is "inherently substantially limiting").

¹³ Vanable et al. (2006), *supra* note 3, at 479-480.

delays by HIV-positive individuals in seeking medical care,¹⁴ and at least one recent study has confirmed the relationship between stigma and treatment nonadherence.¹⁵ Moreover, depressive symptoms in people with HIV have been correlated consistently with treatment nonadherence, suicidal ideation, disease progression, and mortality.¹⁶ Disturbingly, a 2004 study of nonmetropolitan people living with HIV found that "approximately 60% of participants reported moderate or severe levels of depressive symptomatology."¹⁷

For all of the above reasons and others, people with HIV have a very strong interest in keeping their HIV status private and confidential. Indeed, the U.S. Centers for Disease Control and Prevention ("CDC") has urged that those with HIV be counseled on the importance of keeping their HIV status confidential to avoid discrimination. In 2001, the CDC recommended that "[c]lients who test positive should be referred to legal services as soon as possible after learning their test results for counseling on how to prevent

¹⁴ See Margaret A. Chesney & Ashley W. Smith, *Critical Delays in HIV Testing and Care*, 42 AM. BEHAV. SCI. 1158, 1163-1165 (1999) (discussing research relating stigma to delays in seeking HIV testing and care).

¹⁵ Vanable et al. (2006), *supra* note 3, at 479.

¹⁶ Timothy G. Heckman et al., *Emotional Distress in Nonmetropolitan Persons Living With HIV Disease Enrolled in a Telephone-Delivered, Coping Improvement Group Intervention*, 23 HEALTH PSYCHOL. 94, 97-98 (2004) (discussing studies with these findings).

¹⁷ Heckman et al. (2004), *supra* note 16, at 97.

discrimination in employment, housing, and public accommodation by only disclosing their status to those who have a legal need to know."18

Unauthorized Disclosure of Medical Information by a В. Physician in a Workplace Setting Is a Particularly **Egregious Violation of Privacy.**

Patients' substantial interest in the privacy and confidentiality of private medical information derives from long-standing public policy protecting the confidence of the doctor-patient relationship in order to promote public health and prevent embarrassment, stigmatization, discrimination, and harassment. "[T]here are few matters that are quite so personal as the status of one's health, and few matters the dissemination of which one would prefer to maintain greater control over." Doe v. City of New York, 15 F.3d at 267. Accordingly, courts throughout the nation have recognized the delicacy of medical information and the vital importance of maintaining the confidentiality of that information. See, e.g., Stidham v. *Clark*, 74 S.W.3d 719, 729 (Ky. 2002) (Keller, J., concurring) (ethical code adopted by State Board of Medical Licensure "prohibit[s] the extra-judicial disclosure by a physician of confidential patient communications and

¹⁸ Centers For Disease Control & Prevention, Revised Guidelines for HIV Counseling, Testing, and Referral, 50(RR19) U.S. DEP'T OF HEALTH AND HUM. SERVICES MORBIDITY AND MORTALITY WKLY. REP.: RECOMMENDATIONS & REPS. 1 (2001), available at http://www.cdc.gov/ mmwr/preview/mmwrhtml/rr5019a1.htm.

information unless such disclosure is otherwise authorized or required by law.") (footnotes omitted); Swarthout v. Mutual Serv. Life Ins. Co., 632 N.W.2d 741, 746 (Minn. Ct. App. 2001) (statute prohibiting unauthorized release of medical information did not require existence of doctor-patient relationship); State ex rel. Callahan v. Kinder, 879 S.W.2d 677 (Mo. Ct. App. 1994) (enjoining court rule that permitted judges to obtain medical information about prisoners with HIV and other infectious diseases). Medical professionals and policy makers recognize that a patient must disclose details about "his life and habits . . . in his consultations with his doctor -- even that which is embarrassing, disgraceful, or incriminating. To promote full disclosure, the medical profession extends the promise of secrecy " Hammonds v. Aetna Cas. & Sur. Co., 243 F. Supp. 793, 801 (N.D. Ohio 1965); see also Haddad v. Gopal, 787 A.2d 975, 981 (Pa. Super. Ct. 2002) ("Doctors have an obligation to their patients to keep communications, diagnosis, and treatment completely confidential. Especially when . . . a sexually transmitted disease is in issue."); Wood v. Superior Court, 166 Cal App. 3d 1138, 1147 (Cal. Ct. App. 1985) ("Patients may disclose highly personal details of lifestyle and information concerning sources of stress and anxiety. These are matters of great sensitivity going to

the core of the concerns for the privacy of information about an individual.").

When a patient is infected with HIV, expectations of confidentiality -and the dangers that accompany improper disclosure -- increase exponentially. The treatment of HIV and other blood-borne and sexually transmitted diseases frequently involves discussions of deeply private topics such as a patient's sexual activities, his or her recent sexual partners, drug use, or other high-risk behaviors. Physicians frequently probe into the intimate details of their patients' private lives to ascertain the source of transmission of the virus, to assist patients in protecting themselves and others from infection, and to determine whether patients will benefit from often rigorous and highly structured medication regimens.¹⁹ Therefore, HIV-related medical records tend to reveal intensely personal information, and patients' interests in maintaining the confidentiality of that information is extremely high.

Unless the law maintains and protects the strict confidentiality of

¹⁹ See Centers for Disease Control & Prevention, Guidelines for Using Antiretroviral Agents Among HIV-Infected Adults and Adolescents: Recommendations of the Panel on Clinical Practices for Treatment of HIV, 51 U.S. DEP'T OF HEALTH AND HUM. SERVICES MORBIDITY AND MORTALITY WKLY. REP. 1 (2002), available at http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5107a1.htm.

doctor-patient discussions of these sensitive matters, patients may be dissuaded from seeking proper treatment. *See U.S. v. Hughes*, 95 F. Supp. 2d 49, 60 (D. Mass. 2000) (recognizing, in the context of drug treatment, that assurances of privacy and confidentiality encourage some in "more troubled populations -- populations who have been traditionally suspicious of government programs, medical services and other institutions -- to seek the help they need") (internal quotations omitted); *Anderson v. Strong Mem'l Hosp.*, 531 N.Y.S.2d 735, 740 (N.Y. Sup. Ct. 1988) ("The stigma which comes from the disclosure that a person is a patient at an AIDS clinic will deter a person from seeking treatment or testing, particularly at the early stages of the disease before symptoms develop."), *aff'd* 542 N.Y.S.2d 96 (N.Y. App. Div. 1989).

It is particularly dangerous to chill testing and treatment of people who are HIV-positive or suspect that they might have HIV. Because HIV can be transmitted unwittingly by those who are not aware that they are infected, it is vital that anyone who engages in behaviors that can transmit HIV be encouraged to seek testing and treatment. When assurances of privacy and confidentiality are undermined by the improper disclosure of HIV test results, patients become less willing to seek testing, and private and

public health suffer as a result.²⁰

Furthermore, those individuals who do seek treatment for HIV or AIDS may be less likely to disclose information to their doctors if they fear that their private discussions will be shared with their employers, family members or others. As noted above, a wide variety of highly personal information is often relevant to the treatment of people living with HIV. If patients are afraid to disclose information to their physicians, their doctors will be unable to accurately determine the best course of treatment, and patients' and public health may be compromised.²¹

In sum, the unwarranted disclosure of HIV-related information may have serious negative consequences on a personal level, leading to discrimination and harassment. Additionally, unless promises of privacy and confidentiality are strictly enforced, individuals are less likely to seek HIV testing and treatment or to share vital information with healthcare providers. People with HIV must be able to expect near-absolute confidentiality when they seek medical care. When a physician discloses

²⁰ Patients who believe that medical information will not remain confidential may simply avoid HIV testing and treatment altogether. *See Kaiser Report*, *supra* note 5, at 9.

²¹ See Lentine et al. (2006), supra note 3 ("HIV-infected persons who fear being stigmatized . . . may experience real or perceived barriers to prevention and other health-care services.").

confidential HIV-related information in violation of a patient's trust, that act is an egregious violation of the patient's privacy and also could harm the public health.

In the instant case, Mr. Doe disclosed his HIV status to Dr. Hall, presumably because he believed that an examining physician should have that information. He also disclosed to Dr. Hall private and potentially incriminating information about his use of marijuana for a medical purpose, which is not uncommon for patients with HIV and certain cancers. Individuals like Mr. Doe have a substantial interest in the confidentiality of disclosures to a physician and should be able to expect that such disclosures will remain confidential. Further, the unauthorized disclosure by Dr. Hall was particularly egregious because it occurred in an employment setting, and Mr. Doe was compelled to seek medical treatment from doctors employed by the VA. Because employees with HIV may be subjected to stigma, harassment, and discrimination when their HIV status is disclosed in the workplace, it is essential that employers providing on-site medical care keep private medical information strictly confidential.

II. The Privacy Act Protects Against Unauthorized Disclosure of

Medical Information Provided to Federal Employers.

In this case, a medical care provider, without the consent of his patient, revealed confidential information about the person's HIV status. As the District Court stated, the unauthorized disclosure of Mr. Doe's HIV status was "a deplorable – indeed, almost incomprehensible – violation of Doe's privacy." *Doe v. Dep't of Veterans Affairs*, 474 F. Supp. 2d 1100, 1102 (D. Minn. 2007). For the reasons discussed in Section I, *supra*, significant individual and societal interests are served by maintaining the confidentiality of a person's HIV status. Fortunately, contrary to the District Court's ruling, the Privacy Act *does* protect that confidential information in the situation presented by this case.

Plaintiff Doe alleges that the federal Privacy Act, 5 U.S.C. § 552a, et seq., was violated when a physician working for the Department of Veterans Affairs disclosed confidential, private information about Mr. Doe's medical history. Doe, 474 F. Supp.2d at 1101-02; see also App. 25-26. For purposes of obtaining medical services, Mr. Doe revealed that he was HIV-infected in filling out a medical history form and in providing medical history orally to medical care providers at the Minneapolis Veterans Administration Medical Center ("the Medical Center"), where he worked. 474 F. Supp. 2d at 1101;

App. 138-141, 144, 147-148, 235-239, 332-333, 401-402, 405-406, 409, 412-413. Dr. Samuel Hall, an occupational physician working in the Medical Center's Employee Health Service department, later verbally disclosed that information to Mr. Doe's union steward, without Mr. Doe's written consent. 474 F. Supp. 2d at 1102; App. 155-156, 334, 442. Dr. Hall also verbally disclosed that Mr. Doe used marijuana to treat his HIV appetite symptoms, another fact that Dr. Hall learned in obtaining, and recording, Mr. Doe's medical history. 474 F. Supp. 2d at 1102; App. 147-148, 156, 334, 412-413.

The Privacy Act provides that a federal agency may not "disclose any record which is contained in a system of records by any means of communication to any person, or to another agency, except pursuant to a written request by, or with the prior written consent of, the individual to whom the record pertains," subject to certain enumerated exceptions which are inapplicable here. 5 U.S.C. § 552a(b). The statute defines the term "record" very broadly to mean:

any item, collection, or grouping of information about an individual that is maintained by an agency, including, but not limited to, his education, financial transactions, *medical history*, and criminal or employment history and that contains his name, or the identifying number, symbol, or other identifying particular assigned to the individual, such as a finger or voice print or a photograph.

Id. § 552a(a)(4) (emphasis added). A "system of records" is defined as "a group of any records under the control of any agency from which information is retrieved by the name of the individual or by some identifying number, symbol, or other identifying particular assigned to the individual."

Id. § 552a(a)(5).

The statutory elements of a Privacy Act violation are all present here. Information about Mr. Doe's HIV infection and his use of marijuana comes within the broad statutory definition of "record." See id., § 552a(a)(4). The information was contained in a "system of records": it was contained in the Medical Center's medical file on Mr. Doe, from which information was retrieved by Mr. Doe's name and/or other identifying information. See Doe, 474 F. Supp. 2d at 1102 ("It is undisputed that information about Doe's HIV-positive status and his use of marijuana is contained in records subject to the Privacy Act "). Dr. Hall disclosed the information without a written request from, or the written consent of, Mr. Doe. *Id.*; App. 98-106, 155-156, 334, 442. The Act prohibits disclosure "by any means of communication," including oral communication such as that present here. See 5 U.S.C. § 552a(b); see also, e.g., Olberding v. U.S. Dep't of Defense, 564 F. Supp. 907, 913 (S.D. Iowa 1982) (prohibited disclosure includes

disclosure by oral communication), aff'd 709 F.2d 621 (8th Cir. 1983).

Although finding that all of these statutory elements were satisfied, the District Court concluded that that Privacy Act was not violated because Dr. Hall did not learn Mr. Doe's HIV status from a record, but rather learned it from Mr. Doe. 474 F. Supp. 2d at 1102-05. The District Court concluded that this Court's 1983 *per curiam* decision in *Olberding v. U.S. Department of Defense*, 709 F.2d 621 (8th Cir. 1983), precluded a finding of violation of the Privacy Act. 474 F. Supp. 2d at 1103-05. In the view of the lower court, this Court's interpretation of the Privacy Act meant that "Dr. Hall could have walked down to the [workplace] cafeteria, stood on a chair, and using a megaphone, told the patients and staff that Mr. Doe was HIV-positive and using marijuana -- all without violating the Privacy Act." *Id.* at 1102.

Contrary to the District Court's conclusion, this Court's *Olberding* decision does not foreclose a finding that the Privacy Act was violated based upon the facts of this case. The Act does provide protection in situations such as this: where confidential medical information is obtained from a federal employee for purposes of medical treatment, maintained in medical records covered by the Act, and then disclosed by the medical care provider who obtained and recorded the information.

At issue in *Olberding* was the disclosure by army officers that the plaintiff "had undergone a psychiatric examination and that the examination revealed no mental disease or disorder." Olberding, 709 F.2d at 621. None of the officers obtained that information from Capt. Olberding or from his medical records. *Id.* at 622. Rather, the "disclosures all flowed" from the following sources: (1) Capt. Olberding's superior's order that he report to headquarters with his medical records; (2) Capt. Olberding's superior's knowledge of the psychiatric examination which he ordered that Capt. Olberding undergo; and (3) Capt. Olberding's superior's knowledge of the results of that examination, which the examining psychiatrist had provided to the superior with Capt. Olberding's consent. *Id.* at 622 (quoting Olberding, 564 F. Supp. at 913). In contrast to the instant case, the Olberding district court concluded that the information possessed by Capt. Olberding's superior did not constitute a "record" within the meaning of Section 522a(b) of the Act. *Olberding*, 564 F. Supp. at 913.

The *Olberding* district court also broadly ruled that "the only disclosure actionable under section 552a(b) is one resulting from a retrieval of the information initially and directly from the record contained in the system of records" and concluded that the Privacy Act had not been violated.

Id. The lower court's "retrieval rule," adopted by this Court in *Olberding*, 709 F.2d at 622, was broader than necessary to address the disclosure at issue in that case. ²² Given the different facts presented here, this Court can find in favor of Mr. Doe without concluding that it erred in ruling against Capt. Olberding.²³

In adopting and affirming the reasoning of the *Olberding* district court, this Court was influenced by a few other district court decisions concluding that disclosure is only actionable if the information was retrieved directly from a record before being disclosed and by the absence of any case law supporting Capt. Olberding's contention that a violation of the Privacy Act can occur "where the disclosure of information arose from the personal knowledge of an individual, and not from retrieval of information from a government report." Olberding, 709 F.2d at 622. Since this Court issued its opinion, other courts have read the Privacy Act as providing more protections than rigid application of the "retrieval rule" would allow.

²² Moreover, the language of the Privacy Act does not require that information be "retrieved" for a violation to occur. Rather than constituting an element for liability, "retrieved" is used only as a definitional element for determining if a record is contained in a "system of records." Compare 5 U.S.C. § 552a(a)(5) with id. § 552a(b).

²³ If this Court believes that its decision in *Olberding* does foreclose finding a violation of the Privacy Act under the facts of this case, amici respectfully assert that Olberding should be overruled, as providing too restrictive a reading of the Privacy Act.

The Court of Appeals for the District of Columbia has rejected the view that the Privacy Act is only violated where the disclosure results from retrieval of information from a record. **Bartel v. Fed. Aviation Admin.*, 725 F.2d 1403, 1409 (D.C. Cir. 1984). In that case, an agency official had acquired personal information for inclusion in a record and then, without authorization, disclosed the information, but without actually retrieving it from the record system. 725 F.2d at 1409-10. The court found that the Privacy Act had been violated by that disclosure, ruling that "retrieval" of the information from a protected record was not required where the official who disclosed the information had a primary role in creating and using the record containing that information and acquired the information because of that record-related role. **Id.* at 1409-11. As that court explained,

an absolute policy of limiting the Act's coverage to information physically retrieved from a record would make little sense in terms of its underlying purpose. Nor does the Act's language require such a hypertechnical interpretation. . . . Under the appellees' suggested standard, an official could [avoid application of the Privacy Act] with respect to a record he himself initiated by simply not reviewing it before reporting its contents or conclusions. Ironically, the Act would prohibit dissemination where such an official reviews a record in

²⁴ An earlier district court decision out of the District of Columbia Circuit was one of the three cases that this Court cited in *Olberding* in upholding the District Court's narrow interpretation of the Privacy Act. *Olberding*, 709 F.2d at 622 (citing *King v. Califano*, 471 F. Supp. 180, 181 (D.D.C. 1979)). ²⁵ The FAA officials had revealed information about an internal agency investigation of the plaintiff. 725 F.2d at 1406.

order to ensure the accuracy of a disclosure, but inadvertently mischaracterizes it, yet would immunize dissemination of the same inaccurate information if the official did not even bother to check the disclosure against the record.

Id. at 1409.

The Ninth Circuit Court of Appeals has also held that in some situations the Privacy Act is violated although the disclosed information was not retrieved from a protected record. Wilborn v. Dep't of Health & Human Servs., 49 F.3d 597 (9th Cir. 1995), abrogated on other grounds by Doe v. Chao, 540 U.S. 614 (2004). The Ninth Circuit found the Privacy Act violated where an agency official collected personal information for inclusion in a record, created and then destroyed the record, and then disclosed the existence of the record and its contents without authorization. 49 F.3d at 600-01. Rejecting the argument that the Act was not violated because the person disclosing the information might not have physically retrieved the disclosed information from the plaintiff's personnel file, the court noted that "a mechanical application of [the "retrieval rule"] would thwart, rather than advance, the purpose of the Privacy Act." *Id.* at 600.

Here, as in the cases discussed above, the purposes of the Privacy
Act are furthered by avoiding a hypertechnical reading of the Privacy Act
that would only protect privacy when the confidential information is

physically retrieved from a record prior to disclosure. Clearly the fact that Mr. Doe was the original source of the disclosed information does not make the Privacy Act inapplicable, as information about an individual's "education, financial transactions, medical history, and criminal or employment history," 5 U.S.C. § 552a(a)(4), will frequently come directly from the individual. Whether Dr. Hall remembered or retrieved Mr. Doe's confidential medical history before he disclosed it, his unauthorized disclosure violated the Privacy Act. To conclude otherwise would "thwart, rather than advance, the purpose of the Privacy Act." *Wilborn*, 49 F.3d at 600.

Moreover, applying the Act's prohibition to Dr. Hall's disclosure of Mr. Doe's HIV status is consistent with Congress's protective intent in enacting the Privacy Act. The Act's intent to protect the confidentiality of the type of information disclosed by Dr. Hall is clear from the very definition of "record" in the Act, which explicitly includes an individual's "medical history." 5 U.S.C. § 552a(a)(4). A primary purpose of 5 U.S.C. section 552a(b) is to

require employees to refrain from disclosing records or personal data in them, within the agency. . . . This section is designed to prevent the office gossip, interoffice and interbureau leaks of information about persons of interest in the agency or community, or such actions as the publicizing of information of a sensational or salacious nature

or of that detrimental to character or reputation.

This would cover such activities as . . . reporting personal disclosures contained in personnel and medical records, . . .

S. Rep. No. 93-1183 (1974), *reprinted in* 1974 U.S.C.C.A.N. 6916, 6966 (emphases added). The need for protecting confidential medical history from disclosure by federal agency employees is clear, especially when the information is as sensitive and potentially stigmatizing as the information disclosed about Mr. Doe. ²⁶ *See* Section I, *supra*.

Furthermore, ruling that the Privacy Act has been violated here would not create the "intolerable burden" that the *Olberding* court sought to avoid by rejecting the argument that the Act covers all disclosures of information if the person disclosing the information knew or had reason to believe that the information might be found in a record contained in a system of records. *See Olberding*, 709 F.2d at 622 (quoting *Olberding*, 564 F. Supp. at 913). As the Court of Appeals for the District of Columbia noted in *Bartel*, the "intolerable burden" referenced in *Olberding* is most likely to arise in

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²⁶ For the reasons discussed, federal employees such as Mr. Doe can find such protection within the Privacy Act. In contrast, although the Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (1996), places some limitations on the disclosure of protected health information, that statute does not provide a cause of action for aggrieved individuals. The Rehabilitation Act, 29 U.S.C. § 701 *et seq.*, provides federal employees with protection from discrimination, but not protection against the type of privacy violation at issue here.

situations "where information was inadvertently leaked from a record, became part of general office knowledge, and some time later was disclosed purportedly as a matter within the discloser's personal knowledge." *Bartel*, 725 F.2d at 1410. Such a scenario is far removed from Dr. Hall's disclosure of information about Mr. Doe's medical history that he himself had heard directly and had recorded. Applying the Privacy Act to disclosures by those who obtain and record personal medical information does not impose an "intolerable burden" on agency personnel.

Here, comparably to the situations in *Bartel* and *Wilborn* but unlike that in *Olberding*, the official who disclosed the information -- Dr. Hall -- had it within his power to acquire and store the information he disclosed. He abused that power when he disclosed Mr. Doe's information to the union steward and violated the Privacy Act's prohibition of unauthorized disclosures. Reading the Privacy Act to apply to Dr. Hall's disclosure furthers the Act's goal of preventing the disclosure of personal information gathered and recorded by agency officials. Moreover, it protects against the significant harms federal employees such as Mr. Doe face if their physician may disclose their confidential HIV medical history in the workplace with impunity.

furthers the Act's goal of preventing the disclosure of personal information gathered and recorded by agency officials. Moreover, it protects against the significant harms federal employees such as Mr. Doe face if their physician may disclose their confidential HIV medical history in the workplace with impunity.

CONCLUSION

For the reasons discussed herein, the decision of the District Court should be reversed.

Dated: May 15, 2007

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APPENDIX: DESCRIPTIONS OF AMICI

Aid Greater Des Moines, Inc. d.b.a. AIDS Project of Central Iowa opened its doors in 1991 and became a 501(c)(3) in 1993. Its mission is to assist people living with HIV to achieve the highest quality of life available and prevent future infections in its community. The Project is the largest HIV/AIDS service and prevention agency in the state of Iowa. The agency provides personalized direct care services to hundreds of people living with HIV/AIDS and provides prevention services to thousands of Iowans at-risk for the disease.

Lambda Legal Defense and Education Fund, Inc. ("Lambda Legal") is a national organization committed to achieving full recognition of the civil rights of lesbians, gay men, bisexuals, transgender people and those with HIV through impact litigation, education and public policy work. For over two decades, Lambda Legal has litigated on behalf of people living with HIV in the United States, and it is the only national organization with attorneys dedicated exclusively to the representation of people living with HIV. Through its HIV Project, Lambda Legal's work has included direct representation of people living with HIV in cases involving issues including, inter alia, employment discrimination, confidentiality or privacy concerns,

and access to medical services. In addition, Lambda Legal has filed *amicus* briefs addressing concerns of people living with HIV in many cases in federal and state courts, including before the United States Supreme Court.

Minnkota Health Project provides services for people living with HIV/AIDS, their partners, and their families living in western Minnesota and east-central North Dakota. Services provided by the Project include individual counseling, support groups, care advocacy, information and referral, and social activities. People living with HIV/AIDS within the Project's service area whose income is at or below 300% of the federal poverty level are also eligible for transportation assistance and a monthly food program. The Project's counseling and emotional support services are free and available to people living with HIV/AIDS, their partners, families, and caregivers.

The National Association of People with AIDS ("NAPWA"), founded in 1983, is the oldest national AIDS organization in the United States. NAPWA's mission is to advocate on behalf of all people living with HIV/AIDS in order to end the pandemic and the human suffering caused by HIV/AIDS. NAPWA strives to provide current and essential HIV and health treatment information, improve individual ability to access HIV care

and treatment, and advocate for the needs of both those with HIV and people at risk for HIV. NAPWA reflects the diversity of HIV/AIDS in America: more than 80% of NAPWA staff are people of color and living with HIV and the majority of NAPWA's Board of Directors are HIV positive and represent the many communities impacted by the epidemic. These attributes make NAPWA uniquely qualified among national AIDS organizations to represent its constituency.

Nebraska AIDS Project ("NAP") serves the entire state of Nebraska, Southwest Iowa, and Eastern Wyoming through the operation of five offices, three outreach facilities and thirty staff. NAP operates to eliminate the spread of HIV and provide comprehensive services to all people affected by HIV and AIDS. One of the few statewide AIDS service organizations in the country, NAP is the only community based AIDS service organization in Nebraska. Organized in 1984 to provide compassionate support to those dying with AIDS, the focus now is on helping those living with HIV/AIDS manage the chronic, long term effects of the disease and to provide education to prevent the further spread of HIV. NAP remains true to that mission: prevention and support. Among the services provided by NAP are free HIV testing and counseling; an information and referral hotline; a

bilingual education and testing program for Omaha's Latino community; health programs focusing on HIV and STD prevention for men who have sex with men and for gay or bisexual men of color; and an HIV and STD risk reduction program targeting at-risk individuals on the street.

CERTIFICATE OF COMPLIANCE WITH FRAP 32(a)(7)(C)

Pursuant to Federal Rule of Appellate Procedure 32(a)(7)(C), the undersigned certifies that this brief complies with the applicable typevolume limitation of Federal Rule of Appellate Procedure 32(a). This brief was prepared using a proportionally spaced type (Times New Roman, 14 point) and using the word processing software Microsoft Word 2000. Exclusive of the portions exempted by Federal Rule of Appellate Procedure 32(a)(7)(B)(iii), this brief contains 6,799 words, according to word count functions of Microsoft Word.

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CERTIFICATION IN COMPLIANCE WITH CIRCUIT RULE 28A(D)

A PDF digital version of this *amicus* brief has been furnished on a CD-ROM and produced to this court. Duplicate CD-ROMs have been produced to counsel of the parties. The CD-ROMs have been scanned for viruses using Symantec Antivirus Corporate Edition 2002 and are virus free.

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CERTIFICATE OF SERVICE

I certify that on May 15, 2007 I caused to be served two copies of the brief of *Amicus Curiae* Aid Greater Des Moines, Inc. d.b.a. AIDS

Project of Central Iowa, Lambda Legal Defense and Education Fund, Inc.,

Minnkota Health Project, National Association of People with AIDS, and

Nebraska AIDS Project and one electronic copy of the brief on a CD-ROM on counsel of record for the Appellant and for the Appellees herein by placing said copies in the care of regular U.S. mail, addressed to the following:

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