No. 08-17074

IN THE UNITED STATES COURT OF APPEALS
FOR THE NINTH CIRCUIT

STANMORE CAWTHON COOPER,

***Plaintiff-Appellant*,**

v.

FEDERAL AVIATION ADMINISTRATION,
SOCIAL SECURITY ADMINISTRATION, AND
UNITED STATES DEPARTMENT OF TRANSPORTATION,

***Defendants-Appellees*.**

On Appeal from the United States District Court for the
Northern District of California, No. C 07-1383 VRW

BRIEF OF AIDS LEGAL REFERRAL PANEL, COMMON GROUND–WESTSIDE HIV COMMUNITY CENTER, FACE TO FACE SONOMA COUNTY AIDS NETWORK, GAY CITY HEALTH PROJECT, GUAHAN PROJECT, LIFE FOUNDATION, LIFELONG AIDS ALLIANCE, NATIONAL EMPLOYMENT LAWYERS ASSOCIATION, AND PUBLIC LAW CENTER AS *AMICI CURIAE* IN SUPPORT OF PLAINTIFF-APPELLANT STANMORE CAWTHON COOPER, URGING REVERSAL

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RULE 26.1 DISCLOSURE STATEMENT

Pursuant to Federal Rules of Appellate Procedure 26.1 and 29(c), AIDS Legal Referral Panel, Common Ground–Westside HIV Community Center, Face to Face Sonoma County AIDS Network, Gay City Health Project, GUAHAN Project, Life Foundation, Lifelong AIDS Alliance, National Employment Lawyers Association, and Public Law Center each states that it does not have a parent corporation and that no publicly-held corporation owns any stock in it.

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INTRODUCTION AND INTERESTS OF *AMICI CURIAE*

The illegal release of intensely private information involved in this case caused a typically devastating, documented injury of precisely the kind that the Privacy Act was designed to govern. *Amici curiae*, located in California, Guam, Hawaii, and Washington, have responded because they are nine professional organizations serving thousands of individuals with the human immunodeficiency virus (HIV) throughout the Ninth Circuit. (*See* Appendix, containing full statements of *amici curiae*.) *Amici* have direct knowledge of the intense fear of unauthorized disclosure of HIV status, typically linked to stigma and discrimination. They know the life-changing impact of unauthorized disclosure—typically a severe personal impact, and much more rarely a direct financial one.

Amici seek to make clear to this Court the need for the Privacy Act's protections of personally sensitive information—not for reasons connected to one's finances (where, for instance, employment discrimination law may apply if a job is lost based upon discrimination), but rather for reasons of emotional and sometimes physical safety, community standing, and a range of other extremely important, vividly real, and almost exclusively nonpecuniary consequences. People desire to protect their private medical information because of its personal sensitivity—not because someone else's appropriation of the private medical information might

affect their wallets. For these reasons, as further explained below, *amici* support reversal of the result below.

Counsel for Plaintiff-Appellant and counsel for Defendants-Appellees have consented to the filing of this brief by *amici curiae*.

FACTUAL BACKGROUND REGARDING ILLEGAL DISCLOSURE AND ITS IMPACT

This case arises from the release of private medical information in the form of documentation of Plaintiff-Appellant Stanmore Cawthon Cooper's HIV infection, which three federal agencies (Defendants-Appellees) shared without his consent. Mr. Cooper submitted evidence of the psychic, emotional, and dignitary impact of the unlawful disclosures, including a fourteen-page psychiatric report professionally documenting the impact on Mr. Cooper, three declarations of friends and professionals who knew him well, and his own eleven-page declaration that detailed the resultant stress and anxiety Mr. Cooper experienced.

The court below ruled the disclosures violated the federal Privacy Act, 5 U.S.C. Section 552a ("the Act"), but judged the entirely nonpecuniary impact of the illegal disclosures to fall outside the ambit of the Act's damages provision. The appeal of that harmful determination, to which *amici* have been moved to contribute this brief, ensued.

ARGUMENT

I. Prevailing Stigma and Discrimination Contribute to the Significant Interest People With HIV Have in Protecting Their Serostatus From Unauthorized Disclosure.

Although more than 25 years have passed since physicians reported the first cases of HIV in the United States, HIV-related stigma continues to be prevalent and well documented.[1] "Large segments of the public remain uneducated about HIV and how it is transmitted," which promotes fear and antipathy that can "often translate into biased and discriminatory actions." Katherine R. Waite et al., *Literacy, Social Stigma, and HIV Medication Adherence*, 23 J. Gen. Internal Med. 1367, 1367 (2008); *see also* Brad Sears and Deborah Ho, *HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies* 1-2, Williams Institute, Dec. 1, 2006[2] (reporting that studies conducted from 2003 to 2005 found that 55 percent of obstetricians, 46% of skilled nursing facilities, and

[1] *See, e.g.*, 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); 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); 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); D.A. Lentine et al., *HIV-Related Knowledge and Stigma – United States, 2000*, 49 Morbidity and Mortality Wkly. Rep. 1062 (2000), *available at* http://www.cdc.gov/mmwr/PDF/wk/mm4947.pdf (last visited Feb. 20, 2009).

[2] This document is available at http://www.law.ucla.edu/williamsinstitute/publications/Discrimination%20in%20Health%20Care%20LA%20County.pdf (last visited Feb. 20, 2009).

26% of plastic and cosmetic surgeons in Los Angeles County refused to treat patients living with HIV); Ronald A. Brooks et al., *Preventing HIV Among Latino and African American Gay and Bisexual Men in a Context of HIV-Related Stigma, Discrimination and Homophobia: Perspectives of Providers*, 19 AIDS Patient Care & STDs 737, 738 (2005) (referencing 2003 report of American Civil Liberties Union survey finding that HIV stigma has resulted in denials of medical treatment, privacy violations, and refused admittance to nursing homes).

Research indicates HIV is viewed more negatively than many other stigmatized conditions, and fully one-third of Americans have reported negative attitudes toward people living with HIV. Deepa Rao et al., *Stigma, Secrecy, and Discrimination: Ethnic/Racial Differences in the Concerns of People Living with HIV/AIDS*, 12 AIDS & Behav. 265, 265-66 (2008). The persistence of stigma for people living with HIV was documented by a recent national survey conducted by the Kaiser Family Foundation. Kaiser Fam. Found., *Kaiser Pub. Opinion Spotlight: Attitudes about Stigma and Discrimination Related to HIV/AIDS* 7-8 (Aug. 2006).[3] Although HIV cannot be transmitted through casual contact, 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

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[3] This document, cited hereinafter as "*Kaiser Report*" is available at http://www.kff.org/spotlight/hivstigma/upload/Spotlight_Aug06_Stigma.pdf (last visited Feb. 20, 2009).

only 41 percent reported that they would be very comfortable working with someone who has HIV or AIDS. *Id*. at 6; *see also id*. at 7-8 (forty-three percent of people harbor one or more misconceptions about how HIV is transmitted, and people who harbor misconceptions are more likely to express discomfort about working with someone who is HIV positive). This same survey also revealed that many people still lack basic knowledge about how HIV is, and is not, transmitted. *Id*. at 6-7. Such lack of knowledge contributes to stigma and discrimination, but as Justice Scott of the Supreme Court of Kentucky noted, even having such "knowledge often does not remedy the discrimination towards and the stigma felt by persons infected by the disease." *Melo v. Barnett*, 157 S.W.3d 596, 600 (Ky. 2005) (Scott, J., dissenting).

Courts have repeatedly recognized the stigma experienced by people living with HIV and the link between stigma and discrimination. For example, the district court for the Eastern District of New York observed that "HIV-infected persons necessarily struggle with many stresses in their lives, including . . . rejection of friends and family, stigma, and discrimination." *Henrietta D. v. Giuliani*, 119 F. Supp. 2d 181, 186 (E.D.N.Y. 2000), *aff'd*, 331 F.3d 261 (2d Cir. 2003); *see also, e.g.*, *Poveromo-Spring v. Exxon Corp.*, 968 F. Supp. 219, 228 (D.N.J. 1997) ("A myriad of diseases carry with them social stigma, for example, syphilis or even cirrhosis of the liver. If intentionally disclosed, while a

misfortune, the physician's conduct would likely not fall within the realm of extreme and outrageous. AIDS is different. It has a stigma attached to it unparalleled by any other disease."); *Hauser v. Volusia County Dep't of Corr.*, 872 So. 2d 987, 991-92 (Fla. Dist. Ct. App. 2004) ("[t]he stigmatizing effect of being associated with the AIDS virus is so self-evident as to need no further elaboration"); *Estate of Behringer v. Med. Ctr. at Princeton*, 592 A.2d 1251, 1269-70, 1272 n.12 (N.J. Super. Ct. Law Div. 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"); *cf. 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 non-medical staff and other inmates), *aff'd without reported opinion*, 899 F.2d 17 (7th Cir. 1990). "The particular associations AIDS shares with sexual fault, drug use, social disorder, and with racial minorities, the poor, and other historically disenfranchised groups accentuates the tendency to visit condemnation upon its victims." *Cain v. Hyatt*, 734 F. Supp. 671, 680 (E.D. Pa. 1990) (quoting Susan Sontag, *AIDS and Its Metaphors* 44-46, 54-59 (1989)).

People living with HIV frequently find themselves discriminated against in employment, victimized by hate crimes, or cut off from family and friends. *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). Roughly half of those surveyed by the Kaiser Family Foundation in 2006 believed that there is a lot of discrimination against people with AIDS.[4] They were right: for example, 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.[5] 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.[6] And the Centers for Disease Control and Prevention's strategic plan for HIV prevention for the years 2007 to 2010 recognizes the continuing importance of interventions to reduce both HIV stigma and discrimination.[7]

The federal government has recognized the reality and prevalence of discrimination against people with HIV. In 1990, Congress enacted the Americans

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[4] *Kaiser Report* at 2.

[5] *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.).

[6] *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, 221 (2002).

[7] *See* Centers for Disease Control and Prevention, *HIV Prevention Strategic Plan: Extended Through 2010* 12-13 (Oct. 2007), *available at* http://www.cdc.gov/hiv/resources/reports/psp/pdf/psp.pdf (last visited Feb. 20, 2009).

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 of 1973 ("Rehabilitation Act"), 29 U.S.C. § 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 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. The existence of these statutory protections, however, suggests broad societal recognition of the seriousness of the problem of discrimination against people with disabilities, including people with HIV.

Notably, the ADA and Rehabilitation Act are not privacy laws; privacy protections are left to other laws, prime among them the Privacy Act.
A fair reading of the Privacy Act would find concern for the control of personal medical information that may subject one to stigma and discrimination to lie at the heart of the interest protected by the law.

II. The Harms Associated With Unauthorized Disclosure of HIV-Related Medical Information—Many of Them Nonpecuniary—Illustrate the Importance of the Privacy Act's Protections.

Because of the societal stigma surrounding HIV, AIDS, and the private behaviors frequently associated with HIV infection, the disclosure of HIV-related information can be very harmful—and even dangerous—for people living with HIV. *See, e.g., Doe v. Delie*, 257 F.3d 309, 315 (3d Cir. 2001) ("the privacy interest in information regarding one's HIV status is particularly strong because of the stigma, potential for harassment, and 'risk of much harm from non-consensual dissemination of the information.'" (quoting *Doe v. Se. Pa. Transp. Auth.,* 72 F.3d 1133, 1140 (3d Cir. 1995)); *Doe v. Chand*, 781 N.E.2d 340, 352 (Ill. App. Ct. 2002) (Welch, J., concurring) (discussing importance of remedies for violations of state HIV confidentiality provisions, which were included in the statute because "the legislature . . . recognized the social stigma that attaches" to individuals known to be infected with HIV, who "are pariahs, treated only slightly better than how people used to treat a leper who escaped from the colony.")

The medical records of persons living with HIV are likely to reveal not only data about their HIV disease, but also to contain other very sensitive, private information, because 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. Surveys reveal that people with HIV continue to experience significant levels of disapproving moral judgment.[8] 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).

The disclosure that a person has HIV frequently wreaks havoc on that person's life. *See, e.g.*, *Kinzie v. Dallas County Hosp. Dist.*, 239 F. Supp. 2d 618,

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[8] *See*, *e.g.,* Herek et al. *HIV-Related Stigma and Knowledge*, *supra* note 1; Patricia G. Devine et al., *The Problem of "Us" Versus "Them" and AIDS Stigma,* 42 Am. Behav. Sci. 1208, 1208-1219 (1999). 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); Gregory M. Herek & John P. Capitanio, *AIDS Stigma and Sexual Prejudice*, 42 Am. Behav. Sci. 1126, 1129-39 (1999); Gregory M. Herek & John P. Capitanio, *Symbolic Prejudice or Fear of Infection? A Functional Analysis of AIDS-Related Stigma Among Heterosexual Adults*, 20 Basic & Applied Soc. Psychol. 230, 239 (1998). HIV stigma also is exacerbated by negative attitudes about injecting drug users, who are highly stigmatized. *See, e.g.,* Devine et al., *Problem of "Us" Versus "Them," supra*. For example, a national survey found that 72% of respondents agreed with the statement, "I think people who inject illegal drugs are disgusting." John P. Capitanio & Gregory M. Herek, *AIDS-Related Stigma and Attitudes Toward Injecting Drug Users Among Black and White Americans*, 42 Am. Behav. Sci. 1144, 1148 (1999).

639 (N.D. Tex. 2003) (noting that people living with HIV "must deal with the social stigma of being HIV-positive" and "will likely be treated as [] outcast[s] by many . . . ."), *aff'd*, 106 F. App'x 192 (5th Cir. 2003); *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."). The Centers for Disease Control and Prevention caution health care workers to avoid revealing positive HIV test results even to family and friends of patients "[b]ecause of the risk of stigma and discrimination."[9]

Disclosure of a person's HIV status may have the above serious ramifications and can also adversely impact mental—and even physical—health. 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.[10] Stigma has been linked to

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[9] Centers for Disease Control and Prevention, *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings*, Morbidity and Mortality Wkly. Rep. Recommendations and Reps., Sept. 22, 2006, at 10, *available at* http://www.cdc.gov/mmwr/PDF/rr/rr5514.pdf (last visited Feb. 20, 2009).

[10] Vanable et al., *Impact of HIV-Related Stigma*, *supra* note 1, at 479-80.

delays by HIV-positive individuals in seeking medical care,[11] and at least one recent study has confirmed the relationship between stigma and treatment nonadherence.[12] Moreover, depressive symptoms in people with HIV have been correlated consistently with treatment nonadherence, suicidal thoughts, disease progression, and mortality.[13] Disturbingly, a 2004 study of nonmetropolitan people living with HIV found that "approximately 60% of participants reported moderate or severe levels of depressive symptomatology."[14]

For all of the above reasons and others, people with HIV suffer real—though often not pecuniary—harm when their HIV status is not kept private and confidential. Typically damaging—and disturbingly justified—fears of stigma and discrimination flowed from the illegal disclosure of Mr. Cooper's HIV status, as reflected in his own declaration:

> I had cause to be concerned that many others also knew of my infection, and that the number of people who had this knowledge was no longer limited to the carefully chosen close friends and relatives to

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[11] *See* Margaret A. Chesney & Ashley W. Smith, *Critical Delays In HIV Testing and Care: The Potential Role of Stigma*, 42 Am. Behav. Sci. 1158, 1163-1165 (1999) (discussing research relating stigma to delays in seeking HIV testing and care).

[12] Vanable et al., *Impact of HIV-Related Stigma*, *supra* note 1, at 479-80.

[13] 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).

[14] *Id.* at 97.

> whom I had revealed my infection, but to many, many more. I was mortified, humiliated and terrified. The possibility that some of these unknown persons might cause me physical harm because of prejudices held by them was of great anxiety to me.

Pl.'s Excerpt of Record ("Pl. E.R.") 37 (Cooper Decl. in Supp. of Pl.'s Mot. for Summ. J., Apr. 28, 2008). Therefore, the HIV context in which this case arises provides a clear illustration of the importance of interpreting the Privacy Act consistent with its protective purposes.

The experience of people with HIV powerfully demonstrates the importance for *all* individuals in having the Privacy Act applied as intended, to protect against having federal agency employees make unauthorized disclosures of information from medical histories. The need for such protection is made especially clear through documentation of the typically significant, nonpecuniary impact the disclosure had upon Mr. Cooper: "His medical records, his sexual orientation, and his HIV status inappropriately became public knowledge leading to feelings of humiliation, social withdrawal and ostracism." Pl. E.R. 98 (Psych. Rep. of Dr. Jose R. Maldonado, Sept. 29, 2007). According to the psychiatrist, the unauthorized disclosure was "deeply stressful and upsetting" (Pl. E.R. 91) and caused a "tremendous sense of shame" (Pl. E.R. 92). Other impacts included "loss of appetite, loss of sleep, physical tension and constant emotional distress." Pl. E.R. 93. *See also* Pl. E.R. 104 (Decl. of Alan L. Carter in Supp. of Pl.'s Mot. for Summ. J., Mar. 3, 2008) ("He was in shock that his medical records, given in

utmost confidence to Social Security years before, were now in the hands of agents of a different agency. He felt violated . . . ."); Pl. E.R. 109 (Decl. of Michael Harold Hart in Supp. of Pl.'s Mot. for Summ. J., Mar. 18, 2008) ("Mr. Cooper was obviously stressed by the FAA's action and the releasing of his medical status by the Social Security Administration . . . . I observed less patience and a shorter temper.").

A friend and clinical psychologist provided detailed observations of the effect of the unlawful disclosure:

> I observed an obvious, serious deterioration in his emotional state because, as Stan related it to me, "private records about me have been made public." The significance of this was twofold. The first is that the disclosure, at least in Stan's experience of it, revealed that he was gay, something he has never been completely open about. I would mention his age and cultural background in understanding this. So, he very much felt that he needed control over that information and that it had been taken away from him because what he thought were private medical records were now in the hands of people who had nothing to do with his medical care. I know from my professional work that for many people the discovery that they have HIV brings up *first* the issue of being "exposed" as gay. . . . So part of Stan's anxiety was about losing control over this information; but it was also about his fear that others might use that information in a threatening or harmful way.

Pl. E.R. 116-17 (Decl. of Dr. Walt Odets in Supp. of Pl.'s Mot. for Summ. J., Mar. 4, 2008).

> The second issue of emotional significance for Stan was the loss of control of the narrower information about having HIV. This is a stigmatized infection and one that Stan did not talk about with many people. This can be problematic in a public way (insurance, job, etc.) and also in a private way. Friends and acquaintances often treat

> people differently when they discover that someone has HIV. One loses control of how he is perceived by others and of relationships when the information is divulged. People with HIV are usually very concerned about these issues. I work with a number of them in my clinical practice.

Pl. E.R. 117.

> In summary, what I observed was that his initial reaction was one of anxiety about these two pieces of information suddenly being in the public record and that his anxiety then deteriorated into depression. Both anxiety and a sense of loss of control are very common predicates to depression and they certainly were in Stan's situation.

Pl. E.R. 117.

As the Odets declaration concluded, "While many of his overt symptoms have disappeared, I experience Mr. Cooper as someone who has survived trauma and whose character will be permanently altered by that experience." Pl. E.R. 119.

These predictable consequences of illegal disclosure are at the heart of the interest protected by the Privacy Act. To fail to apply the Act's prohibition to the information-sharing that disclosed Mr. Cooper's HIV status would be inconsistent with Congress's protective intent in enacting the Privacy Act.

III. Restricting Actual Damages Under the Privacy Act to Pecuniary Harms Would Eviscerate the Law's Protections.

Interpretation of the Privacy Act should not diverge from the basic understanding, both logical and legal, of the concept of privacy, its importance, and the mainly nonpecuniary consequences of unauthorized disclosure—as

acknowledged specifically and powerfully throughout legal structures and accompanying case law concerning privacy in this country. It has long been recognized that while laws protecting privacy may use financial compensation as "rough justice" to compensate victims of improper intrusions on privacy, the harms those laws address are primarily nonpecuniary. Privacy has long been valued for reasons that have little to do with one's pocketbook. *See*, *e.g.*, *Time, Inc. v. Hill*, 385 U.S. 374, 385 n.9 (1967) ("In the 'right of privacy' cases the primary damage is the mental distress from having been exposed to public view."); *Fairfield v. Am. Photocopy Equip. Co.*, 291 P.2d 194, 197 (Cal. Dist. Ct. App. 1955) ("The gist of the cause of action in a privacy case is not injury to the character or reputation, but a direct wrong of a personal character resulting in an injury to the feelings without regard to any effect which the publication may have on the property, business, pecuniary interest, or the standing of the individual in the community. . . . The injury is mental and subjective. It impairs the mental peace and comfort of the person and may cause suffering much more acute than that caused by a bodily injury.") Congress itself indeed recognized this, enacting the Privacy Act in order to subject federal agencies to suit for "any damages" resulting from violations of individual rights under the Act (Privacy Act of 1974, Pub. L. No. 93-579, § 2(b)(6), 88 Stat. 1896, 1896 (1974)) and including instructions to federal

agencies to "establish . . . safeguards" protecting against "substantial harm, embarrassment, inconvenience, or unfairness." 5 U.S.C. § 552a(e)(10).[15]

As discussed in Plaintiff-Appellant's Opening Brief (App. Opening Br. at 40 n.10, 43, 46-47), the Fifth Circuit Court of Appeals has recognized that breaches of privacy forbidden by the Act are likely to result in mental or emotional distress without associated pecuniary loss. In *Johnson v. Department of Treasury, IRS*, 700 F.2d 971 (5th Cir. 1983), the Fifth Circuit conducted a painstakingly thorough analysis of the legislative history relevant to the Privacy Act's protection of nonpecuniary interests—including the logical discounting of an earlier Eleventh Circuit opinion (*Fitzpatrick v. IRS*, 665 F.2d 327 (11th Cir. 1982)) that had not delved as deeply. Following the Supreme Court's decision in *Doe v. Chao*, 540 U.S. 614 (2004), the Fifth Circuit further reconfirmed its analysis that actual damages should include compensation for proven mental or emotional distress. *Jacobs v. Nat'l Drug Intelligence Ctr.*, 548 F.3d 375, 378 (5th Cir. 2008). In *Jacobs*, the Fifth Circuit quoted the straightforward point made by the district court judge below, during summary judgment argument:

> [A]ctual damages are actual damages. It is what it is. Surely Congress knew that when they passed this statute. And so, therefore,

[15] The Supreme Court's decision in *Doe v. Chao,* requiring proof of actual damages for an injured party to garner any compensation under the Privacy Act, safeguards the government against awards unsupported by a showing of damages of any type. *Doe v. Chao*, 540 U.S. 614, 618 (2004).

> I don't see how we get around it. I mean, actual damages are traditionally viewed to include [emotional-distress damages]. Under the Privacy Act, that would probably be the main source of damage as far as any actual damages someone might have . . . .

Id. at 377 (alteration in original) (quoting Tr. of Hr'g on Mot. for Summ. J. at 4, 8, *Jacobs v. Nat'l Drug Intelligence Ctr.*, No. 5:01-CV-72 (S.D. Tex. Dec. 7, 2006)); *but see* App. Opening Br. at 46-47 (discussing rulings in other courts).

Scholarly analysis of the Act's legislative history has similarly yielded the conclusion that the Act recognizes nonpecuniary harms as "actual damages" deserving compensation: "Debate on potentially excessive liability, however, focused on establishing the proper level of conduct to trigger such liability and whether punitive damages against the government should be available. There is no indication in the legislative history of congressional intent to limit compensation to proven economic loss." Frederick Z. Lodge, Note, *Damages Under the Privacy Act of 1974: Compensation and Deterrence*, 52 Fordham L. Rev. 611, 626 (1984) (footnotes omitted).

Furthermore, it would create a nonsensical and wasteful scheme if a plaintiff has standing for a Privacy Act claim based on the "adverse effect" of emotional and psychic harm, yet is deprived of any remedy for that harm, once proved. Under that scheme, plaintiffs could set foot in the courthouse and put cases before judges based upon assertions that—even when proven—can never yield a remedy or compensation. Such would be the result, were the opinion of the court below to

stand: "But while allegations of mental distress are sufficient to establish that Cooper meets the 'adverse effect' standing requirement, they are insufficient to meet the requirement of actual damages.'" Pl. E.R. 23 (Order Denying Pl.'s Mot. for Summ. J. and Granting Defs.' Mot. for Summ. J., Aug. 22, 2008).

Separate legal structures exist to protect against pecuniary harms, such as breach-of-contract or antifraud provisions. Violations of the securities and copyright laws inappositely cited by the court below (Pl. E.R. 24) naturally cause economic harm, and thus those laws compensate injuries that are predictably and sensibly financial. In contrast, privacy laws—whether constitutionally-derived, found in tort law, or delineated in specific privacy statutes—center on the dignitary harms, humiliation, psychic pain and mental injury, and sometimes accompanying physical distress naturally and logically suffered by those whose privacy is invaded.

CONCLUSION

In sum, the example of HIV showcases the importance of the Privacy Act's protections against nonpecuniary harms. For all the reasons presented above, *amici curiae* respectfully request that this Court reverse the order below and rule that the Privacy Act protects against nonpecuniary harms resulting from illegal disclosures of private medical information.

February 20, 2009

Respectfully submitted,

s/ Bebe J. Anderson

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<u>APPENDIX: STATEMENTS OF *AMICI CURIAE*</u>

Amicus curiae **AIDS Legal Referral Panel** (ALRP), located in San Francisco, California, is the oldest organization in the country dedicated to meeting the direct legal needs of people with HIV/AIDS. Since its inception in 1983, ALRP has handled more than 50,000 legal matters on behalf of people living with HIV/AIDS throughout the San Francisco Bay area. Through its staff attorneys and Panel of over 700 volunteer attorneys, ALRP provides free or low-cost legal services in over 2,000 legal matters each year, in a wide variety of areas of civil law, including confidentiality matters, government benefits, insurance, and discrimination in credit, employment, housing, or public accommodations. Through its work, ALRP is keenly aware of the importance to individuals living with HIV/AIDS of privacy protections to prevent disclosure of confidential medical information. ALRP urges this Court to address the issues raised in this case in a manner that furthers the protective purposes of the Federal Privacy Act.

Amicus curiae **Common Ground–Westside HIV Community Center** ("Common Ground"), located in Santa Monica, California, provides a full continuum of medical and psychosocial services and programs to youth and adults living with and at-risk for HIV. Since their founding in 1992, they are the only comprehensive HIV agency serving the west side of Los Angeles. As such they provide and manage care for hundreds of positive clients each year and reach

thousands of at-risk teens and adults with proven prevention strategies. In addition to medical care offered in conjunction with their partner Westside Partners at the Venice Family Clinic, Common Ground provides free HIV testing, prevention programs, care management, mental health services, needle exchange, and a multitude of related programs. A large number of their care clients are homeless and/or multiply diagnosed with HIV, mental illness and substance abuse. Common Ground's staff and Board of Directors hold many leadership positions in the community in broader governmental and non-governmental partnerships that help further their mission of bringing diverse communities together on the Westside of Los Angeles in the fight against HIV Disease. Common Ground's experience is that some of its clients are tremendously fearful of violations of confidentiality and privacy—so much so that even a registered client will frequently request that communications from the agency are made without identifying the agency in phone messages or by return address on pieces of mail. For those who have faced violations of their rights to privacy and confidentiality, the resulting stress, fear and harm that results cannot be overstated and can often lead to poor treatment adherence and psychological damage. Common Ground will continue to voice its support for strong privacy and confidentiality protections under the law, without unfair or excessive burdens in claiming damages when a violation occurs.

Amicus curiae **Face to Face Sonoma County AIDS Network** ("Face to Face") is a non-profit organization that provides compassionate care to more than 500 people living with HIV and AIDS and prevention education to the entire Sonoma County, California community. Face to Face has addressed the ever-changing challenges presented by the HIV epidemic in Sonoma County since 1983, and currently has offices in Santa Rosa and Guerneville. Face to Face's support services for people living with HIV include benefits counseling, case management, access to in-home care, low income housing, support groups and volunteer services. Face to Face's team of case managers is led by social workers and nurses with extensive experience in HIV care. Over the course of its work, Face to Face has seen medical advances change HIV from an imminent terminal illness to a manageable disease, but it has observed one constant: lingering confusion and prejudice about HIV significantly affects its clients, who need reliable legal protections to shield them from discrimination.

Amicus curiae **Gay City Health Project** is a multicultural gay men's health organization located in Seattle, Washington and the premiere provider of HIV and STD testing in King County. Its mission is to promote the health of gay and bisexual men and prevent HIV transmission by building community, fostering communication, and nurturing self-esteem. Gay City Health Project's nationally-recognized programming includes health workshops, educational events, social

activities, and meetings, many of which are intended to provide information and support to people living with HIV/AIDS. As an organization that diagnoses and serves many HIV-positive individuals and a population disproportionately affected by HIV/AIDS, Gay City Health Project is aware of the pervasive stigma that people living with HIV/AIDS face, the fear of discrimination and marginalization which weighs heavy on the minds of those seeking testing, and the importance of privacy protections for Americans living with HIV.

Amicus curiae **GUAHAN Project** (Guam HIV/AIDS Network) is Guam's only AIDS service organization. A not-for-profit organization established in 2003, the GUAHAN Project provides services for people living with HIV/AIDS, HIV and other STD counseling and testing services, and culturally sensitive education regarding sexual and other health issues, including tuberculosis, smoking cessation, cancer, diabetes, obesity, and hemophilia. It is also known for its pioneering work in advocating for the end of violence against women and girls in the communities it serves. From its Counseling, Testing and Referral Center and its Pacific Resource and Training Center, both in Tamuning, Guam, the GUAHAN Project serves communities not only on Guam and the Northern Mariana Islands (both of which are part of this circuit, 28 U.S.C. § 41; 48 U.S.C. § 1821(a)), but also in American Samoa and U.S.-affiliated Pacific Jurisdictions (Federated States of Micronesia, Marshall Islands, and Palau), offering educational resources in

numerous Asian and Pacific Islander languages relevant to the region. In collaboration with the Guam Public Health Department, the University of Guam, and various community-based organizations and corporate partners, it provides support groups, home and hospital visits, and personal care items to people living with HIV/AIDS in these areas. As an organization whose clients constantly struggle with public misperceptions and stigma surrounding HIV/AIDS, the GUAHAN Project is acutely aware of the need for robust privacy protections as an essential element in the governmental response to HIV/AIDS. A powerful advocate of those living with, and affected by, HIV/AIDS in the Pacific, the GUAHAN Project takes active measures to ensure, promote and preserve client confidentiality whenever possible, and provides capacity-building assistance to regional entities to promote client confidentiality in the provision of HIV/AIDS services.

Amicus curiae **Life Foundation** is the largest and most comprehensive provider of AIDS-related services in the state of Hawaii. A non-profit organization located in Honolulu, Life Foundation is dedicated to stopping the spread of HIV and to assisting people who are living with HIV and AIDS. Since opening its doors as Hawaii's first AIDS organization in 1983, Life Foundation has been implementing innovative programs such as AIDS case management, peer support for HIV-positive individuals, treatment education, and peer-to-peer HIV-

prevention outreach. Consistent with its goal of maximizing the quality of life of those affected by HIV/AIDS, Life Foundation works with nearly 700 HIV-positive individuals to ensure they are receiving proper medical, financial, and emotional support. Familiar with the significant level of misunderstanding and fear about HIV and AIDS, Life Foundation sees the issues raised in this case as particularly important and relevant to people living with HIV and AIDS in Hawaii and the nation.

Amicus curiae **Lifelong AIDS Alliance** ("Lifelong") is a not-for-profit organization in Seattle, Washington committed to preventing the spread of HIV, and to providing practical support services and advocating for those whose lives are affected by HIV and AIDS. Formed in 2001 through the merger of Chicken Soup Brigade and Northwest AIDS Foundation, Lifelong does whatever it takes to improve the lives of people living with HIV/AIDS: funding health insurance so that people can get the care they need, cooking and delivering meals, ensuring that people have a safe place to live, assisting people in adhering to treatment regimens, and providing trained case managers to assist people in finding appropriate support services. Lifelong envisions a world in which every person living with illness is treated with dignity and respect, and recognizes that privacy protections are an important part of promoting the health and well-being of the community it serves.

Lifelong therefore urges this Court to ensure that those privacy protections remain robust.

Amicus curiae **National Employment Lawyers Association** ("NELA") is the largest professional membership organization in the country comprised of lawyers who represent workers in labor, employment and civil rights disputes. NELA advances employee rights and serves lawyers who advocate for equality and justice in the American workplace. NELA and its 68 state and local affiliates have a membership of over 3,000 attorneys who are committed to working on behalf of those who have been illegally treated in the workplace, including individuals whose privacy rights have been violated. NELA strives to protect the rights of its members' clients and regularly supports precedent-setting litigation affecting the rights of individuals in the workplace. NELA's members litigate daily in every circuit, affording NELA a unique perspective on how the principles announced by the courts in employment cases actually play out on the ground. NELA has a particular interest in the case at hand because of the devastating impact an "actual pecuniary harm" requirement would have in the employment context, where privacy violations are likely to be limited to emotional distress.

Amicus curiae **Public Law Center** ("PLC"), Orange County, California's only *pro bono* law firm, provides civil legal services to low-income persons living with HIV/AIDS through its AIDS Legal Assistance Project. PLC holds monthly

legal clinics at multiple local AIDS services providers and participates in various forums aimed at increasing the continuum of care for people living with HIV/AIDS. PLC provides assistance through the efforts of its staff and the efforts of pro bono lawyers and law students. PLC clients living with HIV/AIDS receive free legal assistance in matters such as discrimination, confidentiality, wills, advance health care directives and other permanency planning, immigration, bankruptcy, landlord/tenant, consumer issues, and family law. Acutely aware of the devastating impact imposed by discrimination and unlawful disclosures, PLC instituted the HIV/AIDS Legal Check-up in 2007, a program designed to educate HIV positive clients about their rights, especially federal and state laws affording protections against discrimination and privacy violations. By helping clients avoid the after effects of discrimination and unlawful disclosures, PLC supports the mental and physical well-being of people living with HIV/AIDS.

CERTIFICATE OF COMPLIANCE PURSUANT TO FED. R. APP. P. 32(a)(7)(C) AND CIRCUIT RULE 32-1 FOR CASE NUMBER 08-17074

I certify that pursuant to Federal Rules of Appellate Procedure 29(d) and 32(a)(7)(C) and Ninth Circuit Rule 32-1, the attached *amicus* brief is proportionally spaced, has a typeface of 14 points or more and contains 6,436 words, excluding the parts of the brief exempted by Rule 32(a)(7)(B)(iii), but including the Appendix, as counted by Microsoft Word 2003, the word processing software used to prepare this brief.

February 20, 2009

Respectfully submitted,

s/ Bebe J. Anderson
Bebe J. Anderson

Attorney for Amici Curiae
AIDS Legal Referral Panel et al.

CERTIFICATE OF SERVICE

I hereby certify that on February 20, 2009, I electronically filed the foregoing with the Clerk of the Court for the United States Court of Appeals for the Ninth Circuit by using the appellate CM/ECF system.

I certify that all participants in the case are registered CM/ECF users and that service will be accomplished by the appellate CM/ECF system.

February 20, 2009

Respectfully submitted,

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