No. 10-1024

IN THE
Supreme Court of the United States

FEDERAL AVIATION ADMINISTRATION, ET AL.,
Petitioners,
v.
STANMORE CAWTHON COOPER,
Respondent.

On Writ of Certiorari to the United States Court of Appeals for the Ninth Circuit

BRIEF FOR *AMICI CURIAE* AIDS FOUNDATION OF CHICAGO, AIDS LEGAL REFERRAL PANEL, APICHA, INC., GAY AND LESBIAN ADVOCATES AND DEFENDERS, GAY CITY HEALTH PROJECT, GLOBAL NETWORK OF PEOPLE LIVING WITH HIV, HIV LAW PROJECT, INTERIOR AIDS ASSOCIATION, LAMBDA LEGAL DEFENSE AND EDUCATION FUND, INC., LEGAL ACTION CENTER, METRO TEENAIDS, NATIONAL BLACK GAY MEN'S ADVOCACY COALITION, NATIONAL CENTER FOR LESBIAN RIGHTS, NATIONAL IMMIGRANT JUSTICE CENTER, NATIONAL WOMEN'S HEALTH NETWORK, TRANSGENDER LEGAL DEFENSE AND EDUCATION FUND, AND WHITMAN-WALKER HEALTH IN SUPPORT OF RESPONDENT

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STATEMENT OF INTEREST

The mission of the AIDS Foundation of Chicago (AFC) is to lead the fight against HIV/AIDS and improve the lives of people affected by the epidemic. Founded in 1985 by community activists and physicians, AFC is a local and national leader, collaborating with community organizations to develop and improve HIV/AIDS services; fund and coordinate prevention, care, and advocacy projects; and champion effective, compassionate HIV/AIDS

[1] Pursuant to Rule 37.6, counsel for *amici curiae* state that no counsel for a party authored this brief in whole or in part, and no counsel or party made a monetary contribution intended to fund the preparation or submission of this brief. No person other than *amici curiae*, their members, or their counsel made a monetary contribution to its preparation or submission. Pursuant to the letters filed with the Clerk, *amici curiae* have permission of all parties to file.

policy. Medical records contain vital information about a patient's medical history, as well as the medical care provided by hospitals, physicians and other health care providers. A patient's financial and insurance information may also be included in the medical record. AFC believes non-voluntary disclosure of a person's HIV status violates the law. It is also a corrosive social driver that fosters distrust of medical professionals and institutions, particularly amongst people of color, contributing to medical nonadherence among HIV-positive individuals.

AIDS Legal Referral Panel (ALRP) provides free or low-cost legal services to people living with HIV/AIDS in the San Francisco Bay Area. For twenty-eight years ALRP has helped people with HIV/AIDS with a range of civil legal issues, including confidentiality. 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 maintains the protective purposes of the federal Privacy Act.

APICHA, Inc. (APICHA), a community-oriented health center in New York City, provides comprehensive HIV/AIDS services including primary care, mental health services, bilingual case management, HIV risk-reduction counseling, HIV and sexually transmitted disease screening and various supportive services for people living with and affected by HIV/AIDS. APICHA has been providing these services for over twenty-one years. APICHA's patients largely come from the

Asian and Pacific Islander communities and other communities of color where stigma of HIV/AIDS remains quite intense. For this reason, APICHA recognizes the importance of privacy protections to prevent disclosure of confidential medical information. APICHA urges this Court to address the issues raised in this case in a manner that furthers the protective purposes of the Federal Privacy Act.

Gay and Lesbian Advocates and Defenders (GLAD) is a public interest legal organization dedicated to ending discrimination based upon sexual orientation, HIV status, and gender identity and expression. GLAD's AIDS Law Project, founded in 1984, has litigated numerous cases of discrimination and privacy violations involving people with HIV. GLAD was counsel in *Bragdon v. Abbott*, 524 U.S. 624 (1998), which involved a dentist who refused to provide dental care to people with HIV.

Gay City Health Project (GCHP), located in Seattle, Washington, is a multicultural gay men's health organization and the leading provider of HIV testing for gay and bisexual men in Washington State. Founded in 1995, GCHP promotes the health of gay and bisexual men (including those who are transgender) and prevents HIV transmission by building community, fostering communication, and nurturing self-esteem. Through its work, GCHP is keenly aware of the importance to individuals living with HIV/AIDS of privacy protections to prevent disclosure of confidential medical information. GCHP urges this Court to address the issues raised in this case in a manner that maintains

the federal Privacy Act's protection against psychological and emotional harms most commonly caused by disclosures against one's will.

The Global Network of People Living with HIV, North America (GNP+NA), is the only regional organization consisting entirely of, and representing, HIV-positive people in North America. Founded in 1997, GNP+NA's purpose is to improve the quality of life of people living with HIV. GNP+NA works with five other regional networks and a global secretariat to facilitate opportunities for people with HIV to come together to work for human rights protections within their own regions, to work together in solidarity with people with HIV in other regions, to build leadership skills and support empowerment of people with HIV, and to bring attention at home to issues that affect people with HIV around the world. In North America, GNP+NA's work is focused on four areas that are of key importance to people living with HIV: challenging stigma and discrimination, ending legal discrimination against people with HIV, ensuring equitable access to treatment and care for people with HIV across North America, and bringing together the voices of people with HIV to define and defend the human rights agenda for HIV-positive people in North America. Addressing stigma and discrimination is fundamental to all of GNP+NA's work. In GNP+NA's experience as people with HIV, who work with others throughout the U.S. and the region, the stigma and discrimination that accompany an HIV-positive serostatus can be more harmful than the virus itself. Of particular concern to us is the ability for people living with HIV to feel empowered to care for their health, protect their

loved ones from infection, and advocate for their rights and health needs. Good social, legal, and mental health support systems, including strong and reliable privacy protections, are required for this to be reality. Maintaining control over one's private health information is necessary for people with HIV to be able to engage fully in their own treatment, care, and advocacy.

HIV Law Project believes that all people deserve the same rights, including the right to live with dignity and respect, the right to be treated as equal members of society, and the right to have their basic human needs fulfilled. These fundamental rights are elusive for many people living with HIV/AIDS. Through innovative legal services and advocacy programs, HIV Law Project fights for the rights of the most underserved people living with HIV/AIDS. HIV Law Project has represented victims of HIV confidentiality breaches, and has seen first hand the devastation such a breach can cause in the life of an individual. HIV Law Project urges this Court to uphold the protections of the federal Privacy Act.

The Interior AIDS Association (IAA) provides case management and support services to people living with HIV/AIDS in Fairbanks, Alaska. For twenty-one years, IAA has helped people with HIV/AIDS access medical care, housing and other support services. IAA is keenly aware of the importance to individuals living with HIV/AIDS of privacy protections to prevent disclosure of confidential medical information. IAA's clients have experienced the real, negative impact of confidentiality violations on their housing,

employment, and access to care. IAA urges this Court to address the issues raised in this case in a manner that furthers the protective purposes of the federal Privacy Act.

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. Lambda Legal brought and won the first HIV discrimination case in the country, and has a dedicated HIV Project. Lambda Legal was counsel in *Lawrence v. Texas*, 539 U.S. 558 (2003) and regularly files *amicus* briefs with the Supreme Court on issues affecting the rights and interests of people living with HIV.

Legal Action Center (LAC) is a national public interest law firm, founded in 1972, that performs legal and policy work to fight discrimination against and promote the privacy rights of individuals with criminal records, alcohol/drug histories, and/or HIV/AIDS. LAC has a multifaceted approach that involves direct client legal services and impact litigation, technical assistance and training to agencies that serve LAC's clientele, and policy advocacy to create systemic changes that will benefit LAC's constituency. LAC has represented many individuals whose right to privacy in their HIV information has been violated under New York State and federal law – both the Privacy Act and United States Constitutional right to privacy. LAC's clients often have no direct economic harm as a result of these privacy violations, but they suffer tremendous emotional harm. Obtaining redress for such harm is

critical. The question posed in this case is of vital concern to LAC's constituency across the country.

Metro TeenAIDS (MTA) is a community health organization dedicated to supporting young people in the fight against HIV/AIDS. Through education, support, and advocacy, MTA works to prevent the spread of HIV, promote responsible decision-making, and improve the quality of life for young people infected with, or affected by, HIV/AIDS. MTA is the only organization in the Washington DC-metro area focusing all of its efforts on the unique prevention, education, and treatment needs of young people. Since its inception almost twenty years ago, MTA has provided education programs and prevention resources to well over 200,000 young people, family members, and youth workers in Washington, Maryland, and Virginia. MTA is accurately aware of the role confidentiality plays in successfully reaching and helping young people living with or impacted by HIV/AIDS. MTA urges the Court to preserve the protective purposes of the federal Privacy Act when contemplating the issues raised in this case.

The National Black Gay Men's Advocacy Coalition (NBGMAC) is committed to improving the health and wellbeing of black gay men. According to the Centers for Disease Control and Prevention's (CDC) report on HIV incidence in the United States, between 2006 and 2009, black gay men between thirteen and twenty-nine years of age experienced a forty-eight percent increase in new HIV infections. In a five-city study of HIV prevalence, the CDC reported that forty-six percent of black men who have sex with men were HIV-positive, and sixty-seven percent of them were unaware of their HIV

status. Stigma and discrimination caused by loss of privacy are critical barriers to HIV testing and care-seeking. In order to achieve the goals of the National HIV/AIDS Strategy and an end to the epidemic, NBGMAC believes that federal policies must work to eliminate marginalizing, stigmatizing and discriminatory practices. NBGMAC's organizational and individual members are working across the United States to provide culturally competent, high-quality services. NBGMAC encourages the Court to protect the privacy of people living with HIV, which will foster an environment where all persons have knowledge of their HIV status without fear of increased vulnerability caused by unwarranted disclosure of their diagnosis.

The National Center for Lesbian Rights (NCLR) is a national legal organization dedicated to achieving equality for lesbian, gay, bisexual and transgender people and their families through impact litigation, public policy advocacy, and community and public education. NCLR has served as counsel in numerous state and federal court cases securing constitutional rights for LGBT people, including the right to privacy for individuals living with HIV.

The National Immigrant Justice Center (NIJC), a program of Heartland Alliance for Human Needs and Human Rights, is a Chicago-based nonprofit that engages in public-policy advocacy, impact litigation, and direct representation on behalf of immigrants. With the assistance of *pro bono* partners, NIJC provides free and low-cost legal services to approximately 8,000 immigrants, refugees, and asylum seekers each year. NIJC's

work ranges from brief consultations to full representation in immigration proceedings or in federal court. NIJC is invested in the outcome of this case because NIJC has observed significant and consistent privacy violations throughout the immigration system. Particular to this case, NIJC has observed the improper disclosure of the HIV status of immigrants, many of whom have experienced discrimination and even persecution because of their HIV status.

The National Women's Health Network improves the health of all women by developing and promoting a critical analysis of health issues in order to affect policy and support consumer decision-making. The NWHN aspires to a healthcare system that is guided by social justice and reflects the needs of diverse women, including those women living with HIV or AIDS. The NWHN recognizes the stigma associated with HIV/AIDS, the discrimination that many HIV-positive women experience, and the serious harm that can result from nonconsensual disclosure of a woman's HIV status. The NWHN further recognizes that the negative consequences of nonconsensual disclosure for a woman might include damage to her mental health as well as her physical wellbeing. One of the NWHN's core values is the NWHN's belief that the government has an obligation to safeguard the health of all people, including through protection of private health information.

Transgender Legal Defense and Education Fund is committed to ending discrimination based upon gender identity and expression and to achieving equality for transgender people through public education, test-case litigation, direct legal services,

community organizing and public policy efforts. Transgender people are intensely concerned about the unauthorized release of private medical information, including information related to HIV status. Recent studies have found that transgender people have an HIV infection rate more than four times the national average. Transgender women have an HIV infection rate more than seven times the national average. Rates for other segments of the transgender population, including those who are unemployed and people of color, are even higher. For transgender people, the release of HIV-related and other private and sensitive medical information can result in stigma, discrimination and even violence. These consequences are often unrelated to financial loss. For these reasons, TLDEF urges the court to affirm the decision below and rule that the Privacy Act protects people from the disclosure of personally sensitive information without regard to financial loss.

Whitman-Walker Clinic, Inc., d/b/a Whitman-Walker Health (Whitman-Walker), is a nonprofit, community-based health organization serving the Washington, D.C. metropolitan area. Whitman-Walker provides primary health care and HIV/AIDS, lesbian, gay, bisexual and transgender medical care; mental health and substance abuse treatment; dental care; medical adherence case management; legal services; and HIV and sexually transmitted infection testing, counseling and prevention services, to more than 13,000 individuals annually. Over the last three decades, Whitman-Walker has become a nationally known expert in HIV/AIDS treatment and prevention. For twenty-five years, Whitman-

Walker's Legal Services Program has provided *pro bono* legal advice and representation to many thousands of persons living with HIV/AIDS throughout the Washington, DC metropolitan area. Whitman-Walker's practice includes employment discrimination, workplace rights and protection of medical privacy; Whitman-Walker's staff and volunteer lawyers have seen many instances of violations of confidentiality by federal agencies, particularly as employers, and Whitman-Walker has repeatedly invoked the Privacy Act to protect Whitman-Walker's clients and obtain redress for violations. In the experience of Whitman-Walker's doctors, nurses and other healthcare providers, therapists, lawyers and prevention workers, HIV stigma and discrimination remain major problems. Robust legal safeguards for medical confidentiality, including adequate monetary compensation for emotional distress that results from unlawful disclosure of medical information, are vital to encouraging persons with HIV, and those at risk of infection, to be tested and to engage in care.

INTRODUCTION AND SUMMARY

Amici agree with the arguments of Respondent Stanmore Cawthon Cooper ("Respondent") that Congress plainly intended the federal Privacy Act's "actual damages" provision to authorize recovery for precisely the type of harmful disclosures and injuries that Respondent suffered when federal government agencies illegally disclosed his private medical information. The nonconsensual release of intensely private information, including the human immunodeficiency virus (HIV)-related medical information involved in this case, is precisely the kind of injury the Privacy Act seeks to remedy. In providing for the recovery of "actual damages," without specifying any restriction to pecuniary loss (5 U.S.C. § 552a(g)(1)(4)), Congress unambiguously authorized recovery for mental and emotional distress. Settled principles of statutory construction squarely demonstrate that understanding. Should the Court find it necessary to proceed further and delve into the legislative history, that history likewise shows that Congress contemplated coverage for violations of privacy that can cause quite serious nonpecuniary harm, but may not give rise to financial injuries. In sum, all of these factors support Respondent's argument and the holding of the circuit court below that the federal Privacy Act clearly and unequivocally protects against illegal disclosures that cause nonpecuniary harm.

Amici curiae have responded to Petitioners' efforts to overturn the decision below because they are professional organizations serving people throughout the United States who are living with

the human immunodeficiency virus (HIV). *Amici* have direct knowledge of the intense fear that many people living with HIV have of unauthorized disclosure of their HIV status, because such disclosures often lead to intense stigma, discrimination, and psychological injuries. *Amici* know the life-changing impact of unauthorized disclosure—typically a severe personal impact, even though it may more rarely be a financial one.

Amici seek to make clear to this Court the appropriateness of finding that the Privacy Act's protections cover nonpecuniary harms, given standard principles of statutory construction and the understanding of actual damages prevailing at the time of the Act's enactment. Further, *amici* emphasize the significance of Congress' choice to extend the Privacy Act's protections beyond individual finances (where, for instance, employment discrimination law may already provide some relief if a job is lost based upon discrimination), to include impact on 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 largely because of its personal sensitivity—and certainly not just because someone else's appropriation of the private information might affect their wallets. For these reasons, as further explained below, *amici* support affirming the result below.

ARGUMENT

I. The Harm Mr. Cooper Suffered Constitutes Precisely the Type of Injury Congress Contemplated as Giving Rise to "Actual Damages" Recoverable Under the Privacy Act.

Under this case's current procedural posture, it is undisputed that Petitioners engaged in disclosures prohibited by the Privacy Act, that there is evidence that those disclosures were intentional or willful, and that the disclosures caused Mr. Cooper real and appreciable mental and emotional distress. Given standard principles of statutory construction, which the Ninth Circuit Court of Appeals applied thoroughly and skillfully below (*Cooper v. FAA*, 622 F.3d 1016 (9th Cir. 2010)), this Court should recognize the soundness of Mr. Cooper's argument and affirm the decision below. The injuries sustained here are the natural and primary consequence of unlawful disclosures of medical records, are the kind of injuries Congress was concerned about when it passed the Privacy Acct in 1974, and are forms of "actual damages" as that term was plainly defined and understood in common law at that time.

Because Mr. Cooper has ably covered the pertinent statutory construction analysis (see Br. for the Resp't *FAA v. Cooper*, No. 10-1024 (2011) (hereinafter "Resp't Br.") at 12-17, *amici* do not repeat those points and instead highlight some additional material within the legislative history that further confirms Mr. Cooper's analysis. Myriad excerpts from the Act's legislative history indicate that the harms Congress intended to cover where in

the main nonpecuniary. For instance, it is striking that, leading up to enactment, the Congressional Record references the need for privacy protections after the government's 1971 break-in to a psychiatrist's office. *See*, *e.g.,* 120 Cong. Rec. 32,848 (1974) (Sen. Nelson) (citing the invasions as "a clear and dramatic illustration of the problem" of governmental intrusion on matters that should remain private and discussing the particular dangers of government intrusion of privacy); 120 Cong. Rec. 36,901 (1974) (Sen. Nelson) (citing examples of government invasions of privacy). As Senator Gaylord Nelson urged, "A society cannot remain free and tolerate a Government which can invade an individual's privacy at will." 120 Cong. Rec. 36,901 (1974). Sen. Nelson went on to quote Justice Stephen Field's 1888 opinion excerpted in *Interstate Commerce Commission v. Brimson*, 154 U.S. 447 (1894):

> Of all the rights of the citizens, few are of greater importance or more essential to his peace and happiness than the right of personal security, and that involves not merely protection of his person from assault, but exemption of his private affairs, books and papers from the scrutiny of others. Without enjoyment of this right, all others would lose half their value.

120 Cong. Rec. 36,902 (1974) (statement by Sen. Nelson). The Senator concluded, "A right so vital to individual liberty and, indeed, to our constitutional system deserves rigorous protection by Congress—the people's chosen representatives." *Id.*

Other members of Congress echoed these concerns and cogently explained what the law would protect. Fellow Senator Samuel J. Ervin warned of the personal danger of unauthorized information-sharing by the government, stating "The protection of personal privacy is no easy task. It will require foresight and the ability to forecast the possible trends in information technology and the information polices of our Government and private organizations before they actually take their toll in widespread invasions of the personal privacy of large numbers of individual citizens." 120 Cong. Rec. 12,646 (1974). He added, "One of the most obvious threats the computer poses to privacy comes in its ability to collect, store and disseminate information *without any subjective concern for human emotion* and fallibility." 120 Cong. Rec. 12,647 (1974) (emphasis added).

Senator Charles H. Percy likewise urged that the Act was needed to protect sensitive personal information:

> Today, almost every fact about us is on file somewhere in this country. Federal census surveys record our household, family, and personal lives. . . . Hospital and physician files register intimate facts about our physical and mental wellbeing. . . . The list may be virtually endless because new systems of files are constantly being created.

120 Cong. Rec. 36,893 (1974). Tellingly—and logically—these explications of Congressional

concern contained no reference at all to financial consequences of privacy breaches.

Interpretation of the Privacy Act should not diverge from the basic understanding, both in law and logic, of the concept of privacy, its importance, and the ample nonpecuniary consequences of unauthorized disclosure—as acknowledged specifically and powerfully throughout privacy case law 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. 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 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." (internal citations omitted)) Congress itself recognized this, enacting the Privacy Act in order to allow individuals to hold federal agencies accountable 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 specifically including instructions to federal agencies to "establish . . . safeguards" protecting against "substantial harm, embarrassment, inconvenience, or unfairness[.]" 5 U.S.C. § 552a(e)(10).[2]

The Court of Appeals properly relied upon such material, below:

> Congress's intent that the Act offer relief in the form of "any damages" resulting from a violation of one's right of privacy begs the question of what types of injuries typically result from the violation of such a right. The Supreme Court has observed that "[i]n the 'right of privacy' cases the primary damage is the mental distress from having been exposed to public view." *Time, Inc. v. Hill*, 385 U.S. 374, 386 n.9, 87 S. Ct. 534, 17 L. Ed. 2d 456 (1967); *see also Restatement (Second) of Torts* § 652H(b) (1977) ("One who has established a cause of action for invasion of his privacy is entitled to recover damages for . . . his mental distress proved to have been suffered if it is of a kind that normally results from such an invasion . . . ."). The related common-law tort of defamation also

[2] 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).

> provides monetary relief for nonpecuniary harms. In defamation cases, the Supreme Court has stated that "the more customary types of actual harm inflicted by defamatory falsehood include impairment of reputation and standing in the community, personal humiliation, and mental anguish and suffering." *Gertz v. Robert Welch, Inc.*, 418 U.S. 323, 350, 94 S. Ct. 2997, 41 L. Ed. 2d 789 (1974).

Cooper, 622 F.3d at 1029-1030.

Similarly, following this Court's decision in *Doe v. Chao*, 540 U.S. 614 (2004), the Fifth Circuit reconfirmed its analysis that actual damages 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 that the district court had made during summary judgment argument in that case:

> [A]ctual damages are actual damages. It is what it is. Surely Congress knew that when they passed this statute. And so, therefore, 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* Opening Br. of Plf.-Appellant at 46-47 *Cooper v. FAA* 622 F.3d 1016 (9th Cir. 2010) (No. 08-17074) (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). "The drafters of the Privacy Act specifically sought to deter government officials from the exact conduct exhibited by the agencies in *Cooper*.... Because the legislative language and the purpose of the Privacy Act seek to protect citizens from embarrassment and from invasion into their private papers and records, and because not compensating for that emotional harm would lead to a minimal deterrence against such conduct, the phrase 'actual damages' within the Privacy Act should include emotional and mental harms as compensable injuries." Nicole M. Quallen, Damages Under the Privacy Act: Is Emotional Harm "Actual"?, 88 N.C. L. Rev. 334, 356 (2009).

Furthermore, it would create a nonsensical and wasteful scheme if a plaintiff had standing to bring a Privacy Act claim based on the "adverse effect" of emotional and psychic harm, yet was 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—could never yield compensation. The Ninth Circuit recognized that illogic in overturning the trial court's decision. *Cooper*, 622 F.3d 1016.

In contrast to claims for breach of contract, fraud or violations of the securities and copyright laws, which naturally cause economic injuries, 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 suffered by those whose privacy is invaded. It therefore is only sensible that the "actual damages" that violations of privacy give rise to are mental and emotional distress damages, not just those that yield pecuniary loss. The plain language of the Privacy Act and the legislative record confirm that this clearly and unequivocally was Congress's intent.

II. The Nonpecuniary Harm Caused by Unauthorized Disclosure of HIV-Related Medical Information Illustrates Why a Pecuniary Limitation Should Not Be Grafted Onto the Privacy Act's "Actual Damages" Provision.

One cannot understate the significant harm to privacy interests that would be caused by engrafting a "pecuniary" limitation onto "actual damages"—a limitation that Congress did not itself provide in the Privacy Act's text. The impact is easily seen in the

serious and appreciable "actual damages" directly at issue in this case. *Amici* vehemently disagree that the government should be permitted to inflict such injuries with impunity, contrary to the clear and explicit compensation, deterrence and accountability objectives Congress had in adopting the Act.

The medical records of people living with HIV are likely to reveal not only data about their HIV disease, but also other very sensitive, private information. That is so because the treatment of HIV (and other blood-borne and sexually transmitted diseases) and the counseling that surrounds a diagnosis frequently involve discussions of deeply private topics such as a patient's sexual activities, 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.[3] Indeed, "[s]ociety's

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[3] *See*, *e.g.,* 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); Patricia G. Devine et al., *The Problem of "Us" Versus "Them" and AIDS Stigma,* 42 Am. Behav. Sci. 1212, 1212-1219 (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 Toward 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. 1130, 1130 (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

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).

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. As the Third Circuit found in *Doe v. Delie*, "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.'" *Doe v. Delie*, 257 F.3d 309, 315 (3d Cir. 2001) (quoting *Doe v. Se. Pa. Transp. Auth.,* 72 F.3d 1133, 1140 (3d Cir. 1995). *See also, e.g., Matson v. Bd. of Educ. of City Sch. Dist. of N.Y.*, 631 F.3d 57, 64 n.6 (2d Cir. 2011) (even in 2011, with greatly improved treatments, "a person infected with HIV may face an 'unfortunately unfeeling attitude among many in

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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. 1148, 1152 (1999).

this society' and 'expose[] herself not to understanding or compassion but to discrimination and intolerance.'" (quoting *Doe v. City of New York*, 15 F.3d 264, 267 (2d Cir. 1994)); *Doe v. Chand*, 781 N.E.2d 340, 352 (Ill. App. Ct. 2002) (Kuehn, J., concurring in part, dissenting in part) (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.")

Although nearly thirty 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.[4] "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, Williams Institute, *HIV Discrimination in Health*

[4] *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); Herek et al., *HIV-Related Stigma, supra* note 3; 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.

Care Services in Los Angeles County: The Results of Three Testing Studies 1-2 (2006)[5] (reporting that studies conducted from 2003 to 2005 found that 55% of obstetricians, 46% of skilled nursing facilities, and 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 resulted in denials of medical treatment, privacy violations, and refused admittance to nursing homes).

Research indicates that 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. Although HIV cannot be transmitted through casual contact, the Kaiser survey revealed that only thirty-six percent of respondents reported that they would be very comfortable with their child having an HIV-positive

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[5] This document is available at http://escholarship.org/uc/item/1bm2p4gv#page-2 (last visited Oct. 3, 2011).

teacher, and only forty-nine percent reported that they would be very comfortable working with someone who has HIV or AIDS. Kaiser Fam. Found., *Kaiser Fam. Found. 2011 Survey of Americans on HIV/AIDS* 8 (June 2011), *available at* http://www.kff.org/kaiserpolls/upload/8186.pdf (hereinafter "Kaiser 2011"). A Kaiser survey released five years prior showed similar results regarding transmission, including the news that 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. Kaiser Fam. Found., *Kaiser Pub. Opinion Spotlight: Attitudes about Stigma and Discrimination Related to HIV/AIDS* 7-8 (Aug. 2006).[6] The same survey also revealed that many people still lack basic knowledge about how HIV is and is not transmitted. *Id.* at 7. 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

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[6] This document is available at http://www.kff.org/spotlight/hivstigma/upload/Spotlight_Aug06_Stigma.pdf.

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.*, *Matson*, 631 F.3d at 64 (comparing HIV/AIDS to other medical conditions and noting that such a diagnosis is "excruciatingly private and intimate [in] nature" and "likely to provoke . . . an intense desire to preserve one's medical confidentiality" (quoting *Powell v. Schriver,* 175 F.3d 107, 111 (2d Cir. 1999)); *see also 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 Cnty. Dep't of Corr.*, 872 So. 2d 987, 991-92 (Fla. 1st DCA 2004) ("The 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."); *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 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)).

Again and again, the harms of disclosure prove to be primarily nonpecuniary. In the Kaiser 2011 survey, more than three-quarters (77%) of those surveyed for the report said they believe that there is "some" or "a lot" of discrimination against people with HIV/AIDS.[7] They are right: Statistics from the U.S. Equal Employment Opportunity Commission (EEOC) show that over the last decade, the number of HIV-related complaints filed under the Americans with Disabilities Act (ADA) has remained consistent.[8] From 2001 through 2005, there were 1094 complaints received, and from 2006 through 2010, the complaints received numbered about the same: 1081.[9] Moreover, these numbers do not include HIV-related ADA charges filed with state and local agencies.

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[7] Kaiser 2011 at 9.

[8] Equal Employment Opportunity Commission, *ADA Charge Data by Impairment/Bases – Receipts FY 1997 – FY 2010*, *available at* http://www.eeoc.gov/eeoc/statistics/enforcement/ada-receipts.cfm (last visited Oct. 3, 2011).

[9] *Id.*

People living with HIV frequently find themselves discriminated against, victimized by hate crimes, and 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). The Centers for Disease Control and Prevention's strategic plan for HIV prevention for the years 2007 to 2010 recognized the continuing importance of interventions to reduce both HIV stigma and discrimination. [10] The problem persists: the subsequent National HIV/AIDS Strategy for the United States, released in July 2010, reiterated the call to address stigma and discrimination, noting, "[t]he stigma associated with HIV remains extremely high and fear of discrimination causes some Americans to avoid learning their HIV status, disclosing their status, or accessing medical care."[11] Further underscoring the issue, the Centers for Disease Control and Prevention's Division of

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[10] *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.

[11] The White House Office of Nat'l AIDS Pol'y, *Nat'l HIV/AIDS Strategy for the U.S.* ix (2010), *available at* http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf (citing Mahajan AP, Sayles JN, Patel VA, et al. *Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward*, AIDS 2008;22 (Suppl 2):S67-S69.) It follows that if people have appropriate control over information concerning their HIV status, they are more likely to get tested and to undergo treatment. Thus, not having effective remedies for invasion of privacy, which help deter unauthorized disclosures, may have serious adverse public health consequences.

HIV/AIDS Prevention Strategic Plan 2011-2015 mandates investigation of stigma as one of the "drivers of the domestic HIV epidemic."[12]

The disclosure that a person has HIV frequently wreaks emotional havoc on that person's life. *See, e.g.*, *Kinzie v. Dallas Cnty. Hosp. Dist.*, 239 F. Supp. 2d 618, 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."[13] As the Court of Appeals observed, below,

One can readily envision circumstances in

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[12] Centers for Disease Control and Prevention, *Strategic Plan: Division of HIV/AIDS Prevention 2011 through 2015* (2011), *available at* http://www.cdc.gov/hiv/strategy/dhap/pdf/DHAP-strategic-plan.pdf.

[13] 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.

> which these types of injuries might flow from the disclosure of one's confidential medical records, which often contain some of the most sensitive and intimate information about one's physical, mental, and emotional well-being, and sexual orientation. Given the nature of the injuries that most frequently flow from privacy violations, it is difficult to see how Congress's stated goal of subjecting federal agencies to civil suit for *any damages* resulting from a willful or intentional violation of the Act could be fully realized unless the Act encompasses both pecuniary and nonpecuniary injuries.

Cooper, 622 F.3d at 1030.

Disclosure of a person's HIV status may have the above serious ramifications and, due to them, may adversely impact mental—and even physical—health in very serious although nonpecuniary ways. 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 those responding to the study directly correlated with having symptoms of depression and/or having received psychiatric care in the previous year.[14] Stigma also has been linked to delays by HIV-positive individuals in seeking testing and medical care,[15] and at least one recent study has

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[14] Vanable et al., *Impact of HIV-Related Stigma*, *supra* note 4, at 479-80.

[15] *See* Margaret A. Chesney & Ashley W. Smith, *Critical Delays In HIV Testing and Care: The Potential Role of Stigma*, 42 Am.

confirmed the relationship between stigma and treatment nonadherence.[16] Moreover, depressive symptoms among people with HIV consistently have been correlated with treatment nonadherence, suicidal thoughts, disease progression, and mortality.[17] Disturbingly, a 2004 study of nonmetropolitan people living with HIV found that "approximately 60% of participants reported moderate or severe levels of depressive symptomatology."[18]

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. *See, e.g., EEOC v. Ford Motor Credit Co.*, 531 F. Supp. 2d 930, 941 (M.D. Tenn. 2008) ("The plaintiff has alleged—and the defendant has admitted—that Mr. Doe suffered shame, embarrassment, and depression as a result of the disclosure of his HIV status to his coworkers. These are tangible injuries."). Under settled principles of construction, the Act's "actual damages" provision provides for a recovery when such harm is caused by

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Behav. Sci. 1162, 1163-1165, 1167-1169 (1999) (discussing research relating stigma to delays in seeking HIV testing and care).

[16] Vanable et al., *Impact of HIV-Related Stigma*, *supra* note 4, at 479-80.

[17] 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).

[18] *Id.* at 97.

an intentional or willful violation of the Act. The experience of people with HIV powerfully demonstrates the importance for all individuals of having the Privacy Act applied as written and as intended, to protect against having federal agency employees make unauthorized disclosures of information from medical records kept by the agencies. To fail to apply the Act's "actual damages" provision to this case would be inconsistent with Congress's protective intent in enacting the Privacy Act.

CONCLUSION

For the foregoing reasons, and for the reasons stated by Respondent, the Court should affirm the judgment of the Court of Appeals.

Respectfully submitted,

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