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

JOHN DOE,

Appellant,

v.

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

Appellees.

ON APPEAL FROM THE UNITED STATES DISTRICT COURT FOR THE DISTRICT OF MINNESOTA Honorable Patrick J. Schiltz, United States District Judge

,

BRIEF OF AMICI CURIAE

AID GREATER DES MOINES, INC. d.b.a. AIDS PROJECT OF CENTRAL IOWA, LAMBDA LEGAL DEFENSE AND EDUCATION FUND, INC., MINNESOTA AIDS PROJECT, MINNKOTA HEALTH PROJECT, NATIONAL ASSOCIATION OF PEOPLE WITH AIDS, AND NEBRASKA AIDS PROJECT IN SUPPORT OF APPELLANT'S PETITION FOR REHEARING EN BANC

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INTRODUCTION

This case presents important issues related to the confidentiality afforded federal employees with respect to private, sensitive medical information. Specifically, at issue here is the unauthorized disclosure of an individual's HIV status by a health care provider in the individual's workplace. Amici consist of six national and regional organizations that work with and/or advocate on behalf of people living with HIV, collectively representing and advocating for the rights of thousands of individuals in the United States who are infected with HIV – including many living in the states of Iowa, Minnesota, Nebraska, and North Dakota. Through their long histories of serving and representing the interests of persons living with HIV, amici have gained understanding of and insight into the importance of maintaining HIV-related information in the strictest confidence and of enforcing statutory privacy protections.

The extent to which the Privacy Act, 5 U.S.C. § 552a ("the Act"), protects against unauthorized disclosure of medical history – such as that experienced by the Plaintiff in this case – is a matter of great concern to

¹ Brief descriptions of the *amici* are set forth in the attached Appendix B. By Order dated June 1, 2007, this Court granted permission for these organizations to file *amicus* briefs on behalf of the Plaintiff-Appellant in this case. (Order, June 1, 2007)

those living with HIV. The need to maintain the confidentiality of HIV-related information – a matter with which these *amici* are especially familiar – illustrates the importance and appropriateness of applying the Privacy Act to prohibit unauthorized disclosures by a physician of medical history obtained and recorded during the course of providing medical treatment to a federal employee. *Amici* respectfully suggest that their understanding of the issues at stake in this litigation, as discussed below, will provide helpful background and context for this Court's consideration of how to interpret the Act so as to further its protective purposes. As explained by Judge Hansen in his concurrence, such a reading is consistent not only with the Act's purpose, but also with its language.

ARGUMENT

I. The Privacy Act Was Enacted to Protect Against Unauthorized Disclosure of Sensitive Information Obtained by Federal Employees.

The Privacy Act provides that a federal agency may not "disclose any record which is contained in a system of records by any means of communication to any person, or to another agency, except pursuant to a written request by, or with the prior written consent of, the individual to whom the record pertains," subject to certain enumerated exceptions that are

inapplicable here. 5 U.S.C. § 552a(b). The statute defines the term "record" very broadly to mean:

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

Id. § 552a(a)(4) (emphasis added). A "system of records" is defined as "a group of any records under the control of any agency from which information is retrieved by the name of the individual or by some identifying number, symbol, or other identifying particular assigned to the individual[.]" *Id.* § 552a(a)(5).²

Congress enacted the Privacy Act to "provide certain safeguards for an individual against an invasion of personal privacy" by imposing requirements on federal actors with respect to information gathered and maintained by federal agencies. Privacy Act of 1974, Pub. L. No. 93-579, § 2(b), 88 Stat. 1896 (1974). As Congress stated in its Findings, "[i]n order to protect the privacy of individuals identified in information systems maintained by federal agencies, it is necessary and proper for the congress to

² As found by the District Court below, "[i]t is undisputed that information about Doe's HIV-positive status . . . is contained in records subject to the Privacy Act" *Doe v. Dep't of Veterans Affairs*, 474 F. Supp. 2d 1100, 1102 (D. Minn. 2007), *aff'd*, 519 F.3d 456 (8th Cir. 2008).

regulate the collection, maintenance, use, and dissemination of information by such agencies." *Id.* §2(a)(5) (emphasis added).

The protective purposes of the Act were further explained in the Joint House and Senate Report, which stated that a primary purpose of 5 U.S.C. section 552a(b) is to

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

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

- S. Rep. No. 93-1183 (1974), reprinted in 1974 U.S.C.C.A.N. 6916, 6966 (emphasis added). The importance of preventing disclosures of medical history information was explicitly addressed in the Act, which defines "record" to include an individual's "medical history." 5 U.S.C. § 552a(a)(4).
- II. The Harms Associated with Unauthorized Disclosure of HIV-Related Medical History Illustrate the Importance of the Privacy Act's Protections.

In this case, the author of a federal employee's medical history report disclosed – without the employee's consent – confidential information about the person's HIV status. Because of persistent stigma and discrimination,

people with HIV have a substantial interest in maintaining the privacy and confidentiality of their HIV status. Moreover, the information contained in the medical history records of persons living with HIV are likely to contain other very 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. 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.

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. S.E. Pa. Transp. Auth.*, 72 F.3d 1133, 1140 (3d Cir. 1995))); *Doe v Chand*, 781 N.E.2d 340, 352 (III. 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."). 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.³

Stigma can affect people with HIV in every aspect of their lives, including employment, education, housing, insurance, health care, and personal relationships.⁴ 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, 639 (N.D. Tex. 2003) (noting that people living with HIV "must deal with the social stigma of being HIV-positive" and "will

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³ See, e.g., Gregory M. Herek et al., When Sex Equals AIDS: Symbolic Stigma and Heterosexual Adults' Inaccurate Beliefs about Sexual Transmission of AIDS, 52 Soc. Probs. 15 (2005); D.A. Lentine et al., HIV-Related Knowledge and Stigma – United States, 2000, 49 U.S. DEP'T OF HEALTH AND HUM. SERVS. MORBIDITY AND MORTALITY WKLY. REP. 1062 (2000); Peter A. Vanable et al., Impact of HIV-Related Stigma on Health Behaviors and Psychological Adjustment among HIV-Positive Men and Women, 10 AIDS & BEHAV. 473 (2006).

⁴ For example, "HIV-infected persons who fear being stigmatized . . . may experience real or perceived barriers to prevention and other health-care services." *See* Lentine *et al.* (2006), *supra* note 3.

likely be treated as a[n] outcast by many "); *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."); *Hauser v. Volusia County Dep't of Corrections*, 872 So. 2d 987, 991-92 (Fla. Dist. Ct. App. 2004) (noting that "[t]he stigmatizing effect of being associated with the AIDS virus is so self-evident as to need no further elaboration."). The Centers for Disease Control and Prevention state the need to avoid revealing positive HIV test results even to family and friends "[b]ecause of the risk of stigma and discrimination."

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 29 percent of respondents reported that they would be very comfortable with their child having an HIV-positive teacher and only 41 percent reported that they would be very comfortable working with

⁵ Centers for Disease Control and Prevention, *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings*, 55 (No. RR-14) U.S. DEP'T OF HEALTH AND HUM. SERVS. MORBIDITY AND MORTALITY WKLY. REP. 1, 10 (2006).

someone who has HIV or AIDS. This same survey also revealed that many people still lack basic knowledge about how HIV is, and is not, transmitted.⁶ Such lack of knowledge contributes to stigma and discrimination, but as Justice Scott of the Supreme Court of Kentucky recently 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).

Discrimination against people with HIV also remains prevalent today. Roughly half of those surveyed by the Kaiser Family Foundation in 2006 believed that there is a lot of discrimination against people with AIDS.⁷ 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.⁸ This is only a small decline from the number of claims filed during 1994 to 2001: an average rate of 1.3

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⁶ Attitudes about Stigma and Discrimination Related to HIV/AIDS, KAISER PUB. OPINION SPOTLIGHT (Kaiser Fam. Found., Washington, D.C.), Aug. 2006, http://www.kff.org/spotlight/hivUS/index.cfm, (last visited Apr. 21, 2008) [hereinafter *Kaiser Report*].

⁷ Kaiser Report, supra note 6, at 2.

⁸ ADA Charges Filed with EEOC and State and Local FEP Agencies Where the Alleged Basis Was HIV 10/01/1991 to 12/07/2006 (Dec. 15, 2006) [hereinafter ADA Charges Filed 10/01/99 to 12/07/2006] (unpublished material on file with Lambda Legal Defense and Education Fund, Inc.).

claims per day. 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. 10

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

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⁹ ADA Charges Filed 10/01/99 to 12/07/2006, supra note 8; David M. Studdert, Charges of Human Immunodeficiency Virus Discrimination in the Workplace: The Americans with Disabilities Act in Action, 156 AM. J. EPIDEMIOLOGY 219 (2002).

¹⁰ See CDC HIV Prevention Strategic Plan: Extended Through 2010, CDC REPORTS (Centers for Disease Control and Prevention, Atlanta, GA), Oct. 2007, http://www.cdc.gov/hiv/resources/reports/psp (last visited Apr. 21, 2008)

¹¹ Vanable *et al.* (2006), *supra* note 3, at 479-480.

¹² See Margaret A. Chesney & Ashley W. Smith, *Critical Delays In HIV Testing and Care*, 42 AM. BEHAV. SCI. 1158, 1163-1165 (1999) (discussing research relating stigma to delays in seeking HIV testing and care).

treatment nonadherence.¹³

For all of the above reasons and others, the experience of people with HIV powerfully demonstrates the importance for *all* individuals in having the Privacy Act applied as intended to protect against unauthorized disclosure by federal agency employees of information from medical histories. The need for such protection is especially clear when the information is as sensitive and potentially stigmatizing as the information disclosed about Mr. John Doe. To fail to apply the Act's prohibition to Dr. Samuel Hall's disclosure of Mr. Doe's HIV status would be inconsistent with Congress's protective intent in enacting the Privacy Act. *See* Section I, *supra*; Section III, *infra*.

III. Protecting Against the Disclosure of Information by the Author of a Record Gives Effect to the Language and Purpose of the Act.

The unauthorized disclosure of Mr. Doe's HIV status by Dr. Hall was, as the District Court stated, "a deplorable – indeed, almost incomprehensible – violation of Doe's privacy." *Doe v. Dep't of Veterans Affairs*, 474 F.

Supp. 2d 1100, 1102 (D. Minn. 2007), *aff'd*, 519 F.3d 456 (8th Cir. 2008).

Nonetheless, the District Court – and a three judge panel of this Court – ruled that the Privacy Act was not violated, because Dr. Hall remembered

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

the information that he had previously recorded in Mr. Doe's medical file and did not "retrieve" the information from the file before disclosing it.

However, as discussed below, such a ruling conflicts with the language and purpose of the Act and should be reversed by this Court.

The prior rulings in this case were based on this Court's articulation of the "retrieval rule" in Olberding v. U.S. Dep't of Def., 709 F.2d 621 (8th Cir. 1983). See Doe, 474 F. Supp. 2d at 1103-05; Doe v. Dep't of Veterans Affairs, 519 F.3d 456, 461-462 (8th Cir. 2008). However, since this Court issued its opinion in *Olberding*, other courts have recognized exceptions to the "retrieval rule" where "a mechanical application of [the "retrieval rule"] would thwart, rather than advance, the purpose of the Privacy Act." Wilborn v. Dep't of Health & Human Servs., 49 F.3d 597, 600 (9th Cir. 1995), abrogated on other grounds by Doe v. Chao, 540 U.S. 614 (2004); see also Bartel v. Fed. Aviation Admin., 725 F.2d 1403, 1409-11 (D.C. Cir. 1984). These other courts have found the Act violated when a federal employee disclosed personal information he acquired for inclusion into a record, although he did not review the record before making the disclosure. *Id.*; *Doe*, 519 F.3d at 465-66 (Hansen, J., concurring).

This "scrivenor's exception" to the retrieval rule accords with the

purposes of the Act. Strict adherence to the retrieval rule would "allow[] an official to 'circumvent [the Act] with respect to a record he himself initiated by simply not reviewing [the record] before reporting its contents or conclusions[,]" an interpretation of the Act that "would deprive the Act of all meaningful protection of privacy." Pilon v. U.S. Dep't of Justice, 73 F.3d 1111, 1118 (D.C. Cir. 1996) (quoting *Bartel*, 725 F.2d at 1409, 1411). As Judge Hansen noted in his concurrence, to "exempt[] anyone who creates a record from the disclosure rules as long as he can later remember the information he learned while creating the record without refreshing his memory with the record . . . [is] an absurd result." Doe, 519 F.3d at 465-66 (Hansen, J., concurring). Indeed, Congress noted its intent to protect from disclosure the very information that is *most* likely to be remembered by a federal employee who records it, without refreshing his memory: personal information that is "sensational" or "salacious." See S. Rep. No. 93-1183.

The language of the Act does not require such an "absurd" result. Nor does the grant of summary judgment in *Olberding*. As Judge Hansen noted, in *Olberding* this Court adopted a holding that was "broader than necessary for its underlying facts." *Doe*, 519 F.3d at 464 (Hansen, J., concurring). There, the federal official disclosed information he knew as a result of

having ordered Olberding to submit to a psychiatric exam, not information he learned in connection with creating a record. See Olberding, 709 F.2d at 622.¹⁴ But in its ruling, this Court broadly stated that "the only disclosure actionable under section 552a(b) is one resulting from a retrieval of information initially and directly from the record contained in the system of records." Id. However, as noted by Judge Hansen in his concurrence, the Act does not define the term "disclose." See Doe, 519 F.3d at 464 (Hansen, J., concurring). This Court and several others have read into the Act a requirement that disclosed information be "retrieved" from a "record" for a violation of the Act to occur. See, e.g., Olberding, 709 F.2d at 622; Thomas v. U.S. Dep't of Energy, 719 F.2d 342, 345 (10th Cir. 1983). But that was a judicially created concept rather than an express requirement of the Act. The lack of explicit statutory language mandating the so-called "retrieval rule" requires a narrow formulation of that rule in order to further the protective purposes of the Act.

Furthermore, ruling that the Privacy Act has been violated here would not create the "intolerable burden" that the *Olberding* court sought to avoid.

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¹⁴ If this Court believes that its decision in *Olberding* forecloses finding a violation of the Privacy Act under the facts of this case, *amici* respectfully assert that *Olberding* should be overruled, as providing too restrictive a reading of the Act.

That intolerable burden was tied to Olberding's argument that the Act covers all disclosures of information obtained by any means if the discloser knew or had reason to believe that the information was contained in a "record." See Olberding, 709 F.2d at 622 (quoting Olberding v. U.S. Dep't of Def., 564 F. Supp. 907, 913 (S.D. Iowa 1982)). As the Court of Appeals for the District of Columbia noted in *Bartel*, the "intolerable burden" referenced in Olberding is most likely to arise in situations "where information was inadvertently leaked from a record, became part of general office knowledge, and some time later was disclosed purportedly as a matter within the discloser's personal knowledge." Bartel, 725 F.2d at 1410. Such a scenario is far removed from Dr. Hall's disclosure of information about Mr. Doe's medical history that the physician himself had heard directly from Mr. Doe and had recorded. Applying the Privacy Act to disclosures by those who obtain and record personal medical information does not impose an "intolerable burden" on agency personnel.

Here, akin to the situations in *Bartel* and *Wilborn* but unlike that in *Olberding*, the official who disclosed the information – Dr. Hall – had the power to acquire and store the information he disclosed. He abused that power when he disclosed Mr. Doe's information to the union steward and

violated the Privacy Act's prohibition of unauthorized disclosures.

Applying the Privacy Act to bar Dr. Hall's disclosure furthers the Act's goal of preventing the disclosure of personal information gathered and recorded by agency officials. Moreover, it protects against the significant harms federal employees such as Mr. Doe would face if a physician were permitted to disclose with impunity their confidential medical history in the workplace.

CONCLUSION

For the reasons discussed herein, Appellant's petition for rehearing en banc should be granted and the decision of the District Court should be reversed.

Respectfully submitted, Dated: April 21, 2008

s/ David S. Buckel Lynn Mickelson (#0151178) Bebe J. Anderson* Minnesota AIDS Project

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APPENDIX A: CORPORATE DISCLOSURE STATEMENT

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

APPENDIX B: DESCRIPTIONS OF AMICI

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

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

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

Minnesota AIDS Project ("MAP") is a non-profit organization devoted to educating Minnesotans about HIV prevention, to enhancing the lives of individuals who are HIV positive, and to advocating for the rights of all affected by HIV. A key component of MAP's work is connecting HIV positive Minnesotans such as Mr. Doe with medical care and ensuring ongoing treatment. Based on almost 25 years of experience, MAP keenly understands the impact of stigma and barriers that fear of disclosure of HIV status create in accessing testing and medical treatment.

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

free and available to people living with HIV/AIDS, their partners, families, and caregivers.

The National Association of People with AIDS ("NAPWA"), founded in 1983, is the oldest national AIDS organization in the United States. NAPWA's mission is to advocate on behalf of all people living with HIV/AIDS in order to end the pandemic and the human suffering caused by HIV/AIDS. NAPWA strives to provide current and essential HIV and health treatment information, improve individual ability to access HIV care and treatment, and advocate for the needs of both those with HIV and people at risk for HIV. NAPWA reflects the diversity of HIV/AIDS in America: more than 80% of NAPWA's staff are people of color and living with HIV and the majority of NAPWA's Board of Directors are HIV positive and represent the many communities impacted by the epidemic. These attributes make NAPWA uniquely qualified among national AIDS organizations to represent its constituency.

Nebraska AIDS Project ("NAP") serves the entire state of Nebraska, Southwest Iowa, and Eastern Wyoming through the operation of five offices, three outreach facilities and thirty staff. NAP operates to eliminate the spread of HIV and provide comprehensive services to all people affected by

HIV and AIDS. One of the few statewide AIDS service organizations in the country, NAP is the only community based AIDS service organization in Nebraska. Organized in 1984 to provide compassionate support to those dying with AIDS, the focus now is on helping those living with HIV/AIDS manage the chronic, long term effects of the disease and to provide education to prevent the further spread of HIV. NAP remains true to that mission: prevention and support. Among the services provided by NAP are free HIV testing and counseling; an information and referral hotline; a bilingual education and testing program for Omaha's Latino community; health programs focusing on HIV and STD prevention for men who have sex with men and for gay or bisexual men of color; and an HIV and STD risk reduction program targeting at-risk individuals on the street.

CERTIFICATION IN COMPLIANCE WITH CIRCUIT RULE 25A(a)

I hereby certify that I signed the original version of the **Brief of** *Amici Curiae* in **Support of Appellant's Petition for Rehearing** *En Banc* and that Lambda Legal will maintain the original signed version of the Brief for a period not less than the maximum allowable time to complete the appellate process.

Dated: April 21, 2008 Respectfully submitted,

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CERTIFICATE OF SERVICE

I hereby certify that on April 21, 2008 I electronically filed the **Brief** of *Amici Curiae* in Support of Appellant's Petition for Rehearing *En Banc* with the Clerk of the Court for the United States Court of Appeals for the Eighth Circuit by using the CM/ECF system. I certify that all participants in the case are registered CM/ECF users and that service will be accomplished by the CM/ECF system.

Dated: April 21, 2008 Respectfully submitted,

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