

No. 02-50380

UNITED STATES COURT OF APPEALS
FOR THE NINTH CIRCUIT

UNITED STATES OF AMERICA,
Plaintiff-Appellee,

vs.

THOMAS CAMERON KINCADE,
Defendants/Appellant.

ON APPEAL FROM THE UNITED STATES DISTRICT COURT
FOR THE CENTRAL DISTRICT OF CALIFORNIA

**MOTION FOR LEAVE TO FILE BRIEF OF AMICUS CURIAE
IN SUPPORT OF DEFENDANT/APPELLANT**

Melinda Bird (No. 102236)
Michelle Uzeta (No. 164402)
Protection & Advocacy, Inc.
3580 Wilshire Blvd., Ste. 902
Los Angeles, CA 90010-2512
(213) 427-8747; *Fax: (213) 427-8767*

MOTION FOR LEAVE TO FILE BRIEF OF AMICUS CURIAE

Pursuant to Federal Rule of Appellate Procedure 29, Protection and Advocacy, Inc. (PAI), respectfully applies on its own behalf for leave to file the Amicus Curiae brief in support of Appellant/Defendant Thomas C. Kincade (“Kincade”), which is lodged concurrently with this motion. This motion is filed after discussion with and the consent of Monica Cox, counsel for Mr. Kincade.

A central issue in the briefing by the parties is the privacy interest associated with DNA profiles contained in government DNA databanks. The Appellee/Plaintiff United States (hereinafter, “the Government”) repeatedly asserts that the DNA profile is a mere record of identity, in which individuals have no greater a privacy interest than in their fingerprints. Mr. Kincade argues that greater privacy interests attach to DNA sampling because it is obtained through a intrusive blood draw, but does not dispute the Government’s underlying claim that DNA profiles reveal only identity.

Through its brief, Amicus will show that DNA profiles and the biological samples retained indefinitely in state DNA databases implicate far more than mere identity. Amicus will discuss how even the limited DNA profiles in the federal database can reveal medical history, propensity for disease, race and ethnic origin. Although the collection and banking of DNA samples and the creation of DNA data banks may have legitimate medical, scientific and forensic purposes, the

current trend is to move away from limited-purpose forensic data banks and to expand the groups subjected to involuntary DNA sampling. As technology advances, some researchers believe that DNA profiles, such as those at issue in this case, will be used by law enforcement authorities to identify a propensity for traits associated with criminal behavior, such as alcoholism. Because the purposes and target populations of involuntary DNA testing are changing rapidly, the weight this Court accords the privacy interests associated with DNA profiles will impact the civil rights of many groups of individuals, not merely probationers such as Mr. Kincade.

Amicus will also show that there is a long history of genetic discrimination in the U.S., and that the rapid expansion of involuntary DNA testing will only facilitate and encourage future discrimination. Amicus will show that federal and state laws offer little, if any protection from genetic discrimination, while at the same time failing to limit the storage and authorized uses of DNA samples. Given the incalculable amount of information that can be acquired from a DNA sample, the longevity of a DNA sample, and the ease with which DNA data bases can be shared and accessed, the potential for abuse, misuse and discrimination related to expanded testing is dangerously high.

INTERESTS OF AMICUS CURIAE

Protection & Advocacy, Inc.

PAI is a private non-profit agency established under federal law to protect, advocate for and advance the human, legal and service rights of Californians with disabilities.¹ PAI works in partnership with people with disabilities, striving towards a society which values all people and supports their rights to dignity, freedom, choice and quality of life.

PAI works with people with all categories of disability - sensory, physical, medical, learning, cognitive, genetic, emotional and psychiatric. Services provided by PAI are client-directed, and include information and referral, technical assistance and direct representation in administrative and court proceedings. PAI has extensive experience working with people with disabilities in a wide variety of settings, including jails, prisons and other institutions.

In addition to the provision of direct services to Californians with disabilities, PAI staff conducts outreach and training activities throughout the state

¹ PAI provides services pursuant to the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §15001, PL 106-402; the Protection and Advocacy for Mentally Ill Individuals Act, 42 U.S.C. §10801, PL 106-310; the Rehabilitation Act, 29 U.S.C. §794e, PL 106-402; the Assistive Technology Act, 29 U.S.C. §3011,3012, PL 105-394; the Ticket to Work and Work Incentives Improvement Act, 42 U.S.C. §1320b-20, PL 106-170; the Children's Health Act of 2000, 42 U.S.C. §300d-53, PL 106-310; and the Help America Vote Act of 2002, 42 U.S.C. §15461-62, PL 107-252.

to increase consumer knowledge of anti-discrimination laws and disability services, and to promote self-advocacy and empowerment.

PAI has a direct interest in the outcome of this case. PAI's current goals and objectives include advocacy on behalf of persons with disabilities whose rights to privacy are being threatened, and to ensure that persons with disabilities are not subjected to unnecessary treatments and procedures without their express consent. Moreover, the mission and overriding goal of PAI's work is to combat discrimination on the basis of disability and/or medical or genetic condition generally. The outcome of this case will have significant consequences on the privacy rights of people with disabilities and/or medical or genetic conditions, and on their rights to employment, insurance and health care.

NEED FOR AMICUS PARTICIPATION

PAI seeks permission to participate as Amicus in order to present a perspective broader than that of the individual petitioner. As noted above, neither party has addressed the broader privacy interests at issue in DNA profiling, or the impact that this Court's characterization of these interests will have on other groups.

Amicus has considerable knowledge and experience regarding privacy rights in medical and genetic information, especially as these relate to individuals with disabilities. Amicus also has considerable knowledge and expertise regarding

actual and potential discrimination based on an individual's disability and/or genetic or medical condition. Michelle Uzeta, who is the Associate Managing Attorney of Protection and Advocacy, Inc.'s Los Angeles Regional Office, drafted the brief. She has read the briefs of the parties and the decision of the three judge panel, now vacated. Ms. Uzeta has specific expertise and knowledge with regard to the issue of genetic privacy, genetic discrimination and employment discrimination. Four years ago Ms. Uzeta drafted an Amicus Curiae brief to the California Supreme Court regarding genetic testing and discrimination. See, *Galanty v. Paul Revere Life Ins. Co.* (2000) 23 Cal.4th 368.

Dated: March 3, 2004

Respectfully submitted,

PROTECTION & ADVOCACY, INC.

By: Michelle Uzeta
Amicus and Attorneys for Amicus

I. INTRODUCTION

Every person, with the exception of an identical twin, has a unique DNA profile that can be used for identification purposes. The ability of DNA profiles to successfully and accurately identify individuals allows such evidence to be used both as a means of convicting the guilty and exonerating the innocent.² Over the last 15 years, DNA profiling has become more common for law enforcement purposes, spawning enormous societal debate. Hundreds of scholarly³ and

² Kenneth Jost, *DNA Databases: The Issues*, Congressional Quarterly Researcher, May 28, 1999, at 451.

³ See, e.g., law review articles and legal publications: Dan L. Burk & Jennifer A. Hess, *Genetic Privacy: Constitutional Considerations in Forensic DNA Testing*, 5 Geo. Mason U. Civ. Rts. L.J. 1(1995); Lindsay A. Elkins, *Five Foot Two With Eyes Of Blue: Physical Profiling And The Prospect Of A Genetics-Based Criminal Justice System*, 17 Notre Dame J.L. Ethics & Pub. Pol'y 269 (2003); Jeffrey S. Grand, *The Bleeding of America: Privacy and the DNA Dragnet*, 23 Cardozo L. Rev. 2277 (2002); Ronald M. Green & A. Mathew Thomas, *DNA: Five Distinguishing Features for Policy Analysis*, 11 Harv. J.L. & Tech. 571 (1998); Mark Hansen, *The Great Detective*, A.B.A. Journal, April 2001; Debra A. Herlica, *DNA Databanks: When Has A Good Thing Gone Too Far?* 52 Syracuse Law Review 951, 975-76 (2002); Michelle Hibbert, *DNA Databanks: Law Enforcement's Greatest Surveillance Tool?*, 34 Wake Forest L. Rev. 767 (1999); Michael Higgins, *Acid Test: DNA Databases Help Nail Slippery Criminals, but Their Potential Uses Make Privacy Advocates Nervous When it Comes to Arrestees and Ordinary Citizens*, A.B.A. Journal, Oct. 1999; Eric T. Juengst, *I-DNA-Fication, Personal Privacy, and Social Justice*, 75 Chicago-Kent L.Rev. 61 (1999); Harold J. Krent, *Of Diaries and Data Banks: Use Restrictions Under the Fourth Amendment*, 74 Tex. L. Rev. 49 (1995); Martha L. Lawson, *Personal Does Not Always Equal "Private": The Constitutionality of Requiring DNA Samples from Convicted Felons and Arrestees*, 9 Wm. & Mary Bill Rts. J. 645 (2001); Michael J. Markett, *Genetic Diaries: An Analysis of Privacy Protection in DNA Data Banks*, 30 Suffolk University Law Review 185 (1996); Mark Rothstein and Sandra Carnahan, *Legal and Policy Issues in Expanding the Scope of Law Enforcement*

scientific⁴ articles have been authored on the topic, weighing the benefits of DNA testing to law enforcement against the impact on individual privacy rights

A central issue in the briefing by the parties is the privacy interest associated with DNA profiles contained in government DNA databanks. The Plaintiff/Appellee United States (hereinafter, “the Government”) repeatedly asserts that the DNA profile is a mere record of identity, in which individuals have no

DNA Data Banks, 67 Brook. L. Rev. 127 (2001); E. Donald Shapiro & Michelle L. Weinberg, *DNA Databanking: The Dangerous Erosion of Privacy*, 38 Clev. St. L. Rev. 455 (1990); Aaron P. Stevens, *Arresting Crime: Expanding the Scope of DNA Databases in America*, 79 Texas Law Review 921 (2001); Nachama L. Wilker et al., *DNA on Trial: Genetic Identification and Criminal Justice*, in DNA Data Banking and the Public Interest 146 (Paul R. Billings ed. 1992); Yale H. Yee, *Criminal DNA Data Banks: Revolution for Law Enforcement or Threat to Individual Privacy?*, 22 American Journal of Criminal Law, Winter 1995, at 461; Laurie Stroum Yeshulas, *DNA Dragnet Practices: Are They Constitutional?* 8 Suffolk J. Trial & App. Advoc. 133 (2003).

⁴ See U.S. Congress, Office of Technology Assessment, *Genetic Witnesses: Forensic Uses of DNA Tests*, OTA-BA-438 (U.S. Government Printing Office, July 1990). See also other scientific and medical publications: George J. Annas, *Privacy Rules for DNA Databanks: Protecting Coded “Future Diaries,”* 270 Journal of the American Medical Association (JAMA) 2346-2350 (1993); Marc A. Lappe, *Justice and the Limitations of Genetic Knowledge*, in Justice and the Human Genome Project, 153-168 (Murphy & Lappe, eds. University of California Press, 1994); Elinor J. Langfelder & Eric T. Juengst, *Social Policy Issues in Genome Research*, 8 Forum for Applied Research and Public Policy, Fall 1993, at 14-18; Jean E. McEwen, *DNA Data Banks*, in Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era, 231, 237 (Mark Rothstein ed., 1997); Madison Powers, *Privacy and the Control of Genetic Information in The Genetic Frontier: Ethics, Law, and Policy*, 77-100 (Mark S. Frankel & Albert Teich, eds., American Association for the Advancement of Science, 1994); Ronald Walters, *Genetics, Crime, and Individual Rights*, 8 Forum for Applied Research and Public Policy, Fall 1993.

greater a privacy interest than in their fingerprints. “The DNA profile in [the federal databank] uniquely identifies an individual but does not contain any other information about the person, such as physical or medical characteristics.” Gov’t Supp. En Banc Brief, p. 10.⁵ Defendant/Appellant Kincade (“Kincade”) argues that greater privacy interests attach to DNA sampling because it is obtained through a intrusive blood draw, but does not dispute the Government’s underlying claim that DNA profiles reveal only identity.

As discussed in detail below, DNA databases have developed on both State and Federal levels to store and maintain DNA profiles. The biological DNA evidence in the form of blood and tissue used to produce DNA profiles is kept and stored in state DNA databases indefinitely. Amicus will demonstrate that DNA profiles and the biological samples implicate far more than mere identity, and that even the limited DNA profiles in the federal database can reveal medical history, propensity for disease, race and ethnic origin. Third parties such as insurers, employers, and governmental agencies have an interest in these samples, which can be used for non-forensic purposes to produce information in relation to health and other personal issues. As new technologies develop, the sharing of this

⁵ *See also*, Govt. Supp. En Banc Brief, p. 8 n.5 (arguing that unlike blood tests, DNA test does not “reveal a host of private medical facts” about an individual”); p. 9 n.6 (DNA test is only “for the purpose of adding to a record of identity”); p. 11 (arguing DNA testing should be permitted because probationers like Kincade have “no legitimate expectation of privacy in [their] identity”); p. 20-21 (“The search at issue here is designed to obtain only reliable indicia of the probationer’s identity).

information, whether or not purposeful or contemplated today, poses a grave risk of genetic discrimination in the areas of health care, employment, and governmental services, and has far reaching and profound implications for individuals' protected privacy interests.

In addition, although the collection and banking of DNA samples and the creation of DNA data banks may have legitimate medical, scientific and forensic purposes, the current trend is to move away from limited-purpose forensic data banks and to expand the groups subjected to involuntary DNA sampling. As technology advances, some researchers believe that DNA profiles, such as those at issue in this case, will be used by law enforcement authorities to identify a propensity for traits associated with criminal behavior, such as alcoholism.

To prevent such misuse, there is a clear need for protections, such as the requirement for individualized suspicion urged by the Defendant-Appellant Kincade (hereinafter "Kincade") in this case. Because the Government has failed to appreciate the significance of the DNA information at issue here, the balancing test that it proposes is improperly weighed. The privacy interests at stake are far greater than mere identification, and command far greater protections than those proposed by the Government. Because the purposes and target populations of involuntary DNA testing are changing rapidly, the weight this Court accords the privacy interests associated with DNA profiles will impact the civil rights of many

groups of individuals, not merely probationers such as Mr. Kincade. Accordingly, the decision of this Court must be affirmed.

II. FACTUAL BACKGROUND

A. As Technology has Improved, DNA Reveals Far More than An Individual's Identity.

DNA began being used as an identification record after its discovery by German biochemist Friedrich Miescher. Decades later American biochemist James D. Watson described the molecular structure of DNA.⁶ Genetic research scientists in the United States and England later developed DNA typing, the process by which DNA is cut to reveal identifiable patterns. These patterns can be used for identification purposes because they show the great variability between different people.⁷ By the mid 1990's, DNA evidence was viewed as a well-established forensic technique.⁸ The creation of DNA databases quickly followed. To create the database, DNA information is extracted from actual bodily samples of genetic material: blood, skin, hair, semen, etc. The “profiles” stored in DNA databases are based on genetic testing which examines 13 genetic loci.⁹ These loci are sometimes referred to as "junk DNA."¹⁰

⁶ Jost, *supra* note 1, at 457, 458.

⁷ *Id.*

⁸ *Id.* at 458-60.

⁹ Nancy Beatty Gregoire, *Federal Probation Joins the World of DNA Collection*,

DNA testing of a biological sample has the potential to reveal much about the individual tested. One legal commentator observes that “[t]he DNA print may ultimately contain vastly more information than a fingerprint, including the presence of genetic defects, predisposition to diseases, and perhaps even sexual orientation.” Krent, *supra* note 2, 74 Tex. L. Rev. at 95-96. Bioethicist George Annas, a national expert in the field of law and medicine, has described DNA as an individual’s “future diary.”¹¹

Genetic research has identified more than 4,000 genetic diseases and conditions which can be detected through DNA analysis, including Fragile X Syndrome, Marfan Syndrome, Hemophilia, Cystic Fibrosis, Duchenne/Becker Muscular Dystrophy, Huntington’s Disease, Sickle Cell Disease, Tay Sachs, Alzheimer Disease and common forms of cancer and heart disease.¹² Some of these include genetic markers for conditions which have not yet become manifest,

66 Fed. Probation 30 (2002).

¹⁰ Jost, *supra* note 1, at 451.

¹¹ Annas, *supra* note 3, 270 JAMA at 2346. George Annas, J.D., M.P.H., is the Edward R. Utey Professor of Health Law, Chairman of Health Law Department at the Boston University School of Public Health. He holds a degree in law from Harvard Law School and an M.P.H. from the Harvard School of Public Health.

¹² *Your Genes Your Health*, Dolan DNA Learning Center, (visited Feb. 25, 2004), <<http://www.ygyh.org>>. The Dolan DNA Learning Center (DNALC) is the world’s first science center devoted entirely to public genetics education and is an operating unit of Cold Spring Harbor Laboratory, an important center for molecular genetics research in New York State. *See also*, Mari Hudson, *Genetics: DNA Tests for Which Diseases*, (Oct. 29, 2003)

<<http://www.health24.co.za/news/Genetics/1-916,25205.asp>>.

but which the individual may develop in the future, such as carpal tunnel syndrome or Huntington's Disease.

DNA profiles can already be sorted by racial and ethnic characteristics. Juengst, *supra* note 2, 75 Chi-Kent L.Rev. at 71. “[I]t is possible to identify a collection of genetic markers that are distinctive enough to allow confident genetic [ethnic affiliation estimations].” *Id.*, n. 69. Consequently, DNA profiles “are more threatening to privacy than photographs,” since “passing for one race or another is still possible in mug shots.” *Id.* Thus, use of racial and ethnic markers in DNA samples may reveal “genuine secrets [which] . . . could cause psychological and social harm to the individual and her families by upsetting her social identity.” *Id.* *Accord*, Elkins, *supra* note 2, 17 Notre Dame J.L. Ethics & Pub. Pol'y at 285-86.

As technology develops, researchers are investigating whether there are also genetic markers for behavior traits. Rothstein & Carnahan, *supra* note 2, 67 Brook. L. Rev. at 158; Hibbert, *supra* note 2, 34 Wake Forest L. Rev. at 817-21. According to one commentator, “the information contained in DNA databanks could be used for purposes other than criminal identification, such as trying to determine whether an individual is genetically disposed to certain kinds of behavior.” Hansen, *supra* note 2, A.B.A. Journal at 42. Other commentators agree that “the possibility that DNA samples stored by law enforcement agencies might be exploited for correlative studies attempting to show genetic predisposition to

social deviance is a legitimate concern.” Burk & Hess, *supra* note 2, 5 Geo. Mason U. Civ. Rts. L.J. at 14.

B. State and Federal DNA Databases.

In 1990, the Federal Bureau of Investigation (“FBI”) created a national DNA database, which exists in addition to individual state databases.¹³ In 1994, Congress passed the DNA Identification Act, which authorized the FBI to create the Combined DNA Index System (“CODIS”).¹⁴ CODIS is a three-tiered system of information.¹⁵ Level one, the Local DNA Index System (“LDIS”), contains information entered by local police and sheriff’s department laboratories.¹⁶ The second level, the State DNA Index System (“SDIS”), permits local laboratories to trade information within a state.¹⁷ The third tier, the National DNA Index System (“NDIS”), gives states the option to exchange data with other states.¹⁸

All fifty states now require some or all of their convicted offenders to provide DNA samples to the state, and state participation in the National DNA

¹³ Gregoire, *supra* note 8 at 31.

¹⁴ *Id. see also* 42 U.S.C. §§ 3751, 3753, 3793, 3797 (1994).

¹⁵ Stevens, *supra* note 2, 79 Texas L. Rev. at 928.

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ *Id.*

Index System level of CODIS has grown dramatically.¹⁹ In fact, as of January 2004 there were 1,593,866 profiles of known state offenders on file.²⁰

C. The DNA Analysis Backlog Elimination Act of 2000.

Because the DNA Identification Act did not provide for the national banking of samples from persons who had been convicted of Federal crimes, Congress enacted the DNA Analysis Backlog Elimination Act of 2000 (“DNA Act”). 42 U.S.C. §14135. This Act requires, among other things, that United States probation officers collect a DNA sample from an individual being supervised while on probation, parole, or supervised release who has been convicted of a qualifying federal offense.²¹ 42 U.S.C. 14135a(a)(2). It is this provision which is at issue in the pending case.

D. The Patchwork of Laws Governing DNA Collection by States.

¹⁹ *Participating States*, (visited Feb. 24, 2004), <<http://www.fbi.gov/hq/lab/codis/partstates.htm>>. All states, with the exception of Missouri and Rhode Island, participate in the NDIS.

²⁰ *NDIS Statistics*, (visited Feb. 24, 2004), <<http://www.fbi.gov/hq/lab/codis/clickmap.htm>>.

²¹ 42 U.S.C. § 14135a(a)(1) The Act also mandates that the Director of the Bureau of Prisons collect a DNA sample from each individual in the custody of the Bureau of Prisons who is or has been convicted of a qualifying federal offense.

Today, all fifty states have legislation requiring DNA testing for specific classes of convicted offenders.²² Every state collects DNA samples from convicted sex offenders; beyond this, however, the states differ significantly.²³

Most states require DNA samples from only a narrow group of felons, such as those convicted of homicide and sexual assault.²⁴ Four states — including Alabama, New Mexico, Virginia, and Wyoming — require DNA samples from all convicted felons.²⁵ A few states require the collection of DNA samples for some classes of misdemeanors.²⁶

Idaho requires collection of DNA samples for offenses such as robbery, aggravated arson, and racketeering in addition to sexual abuse, rape, and murder.²⁷ North Carolina lists, among others, the burning of a mobile home and the malicious throwing of corrosive acid or alkali in its list of crimes included in the state DNA database law.²⁸

²² Lawson, *supra* note 2, 9 Wm. & Mary Bill Rts. J. at 650.

²³ Hibbert, *supra* note 2, 34 Wake Forest L. Rev. at 775-778.

²⁴ Peter Donnelly & Richard D. Friedman, *DNA Database Searches and the Legal Consumption of Scientific Evidence*, 97 Mich L. Rev. 931, 939 (1999).

²⁵ See Ala. Code § 36-18-24 (2001); N.M. Stat. Ann. §§ 29-16-1 - 29-16-13 (Michie 2003); Va. Code Ann. § 19.2-310.2 (Cum. Supp. 2002); Wyo. Stat. Ann. §§ 7-19-401 – 7-19-405 (Michie 2003).

²⁶ See Ariz. Rev. Stat. Ann. § 31-281 (A) (West 2002); Ark. Code Ann. § 12-12-1109 (Supp. 2003); Del. Code Ann. Tit. 29 § 4713 (1997).

²⁷ See Idaho Code § 19-5506 (Michie Cum. Supp. 2003).

²⁸ See N.C. Gen Stat. § 15A-266.4 (1997).

Louisiana has the most inclusive database and mandates the collection of DNA samples from any person arrested for felony sex offenses and other enumerated offenses.²⁹

Arizona, Kansas, and Oregon require juveniles to submit DNA samples if found delinquent for certain sex crimes, and these DNA samples then can be used in investigations once these juveniles reach the age of majority.³⁰

Of particular relevance to Amicus and the Court, there is a current ballot initiative in California that would require the “collection of DNA samples from all felons, and from adults and juveniles *arrested* for or charged with specific crimes, and submission to [the] State database; and, in five years, from adults *arrested* for or charged with *any* felony.” (Emphasis added.)³¹ If passed, California may soon have the broadest program of involuntary DNA testing in the nation.

E. DNA Profiles, “Junk” DNA and the Retention of Biological Samples.

The Government’s position that DNA profiles involve only minor privacy interests is based on the legislative history of the DNA Act:

²⁹ See La. Rev. Stat. Ann. § 15: 609 (West Cum. Supp. 2003).

³⁰ See Ariz. Rev. Stat. Ann. §§ 13-4438, 31-282 (West 2002); Kan. Stat. Ann. § 21-2511(a) (Cum. Supp. 2002); Or. Rev. Stat. § 419C.473(1) (1999). These statutes are an expansion of the standard statutes authorizing samples from convicted offenders because a juvenile is technically not convicted, but rather adjudicated.

³¹ *California 2004 Initiative Update*, (visited Feb. 25, 2004), <http://www.ss.ca.gov/elections/elections_j.htm#1029>.

[T]he genetic markers used for forensic DNA testing were purposely selected because they are not associated with any known physical or medical characteristics, providing further assurance against the use of convicted offender DNA profiles for purposes other than law enforcement identification. In common parlance, they show only the configuration of DNA at selected "junk sites" which do not control or influence the expression of any trait.

H.R. Rep. No. 106-900(I), 106th Cong., 2d Sess. (Sept. 26, 2000), 2000 WL 1420163, at *27, cited in Gov't Supp. En Banc Br. at p. 3.

However, a report by the Office of Technology Assessment of the United States Congress offers a different view. *Genetic Witness: Forensic Uses of DNA Tests*, Government Printing Office, July 1990. The report warned:

[S]ome of the probes used in forensic science locate alleles that lie near a disease locus, thus there may be some association between the "junk" DNA and the disease locus. The possibility exists to test DNA acquired specifically for identification purposes for disease information in a database. This option may become more attractive over time, especially as the number and types of probes for genetic orders increase.

Id. at 10.

The scientific community has also challenged the assumption that so-called "junk" DNA contains only meaningless information.³² As technology has continued to advance, scientific researchers are finding that, "the huge stretches of

³² Wayt Gibbs, *The Gems of "Junk" DNA*, Scientific American, November 2003, at 29-37; *Parasite or Partner? Study Suggests New Role for Junk DNA*, (May 12, 2002) <http://www.eurekalert.org/pub_releases/2002-05/uomh-pop051002.php>; Edie Lau, *Much DNA Just "Junk" – Or Is It? Human Genome Project Spurs New Look at Mystery Material*, Sacramento Bee, (March 19, 2001) <<http://www.arn.org/docs2/news/junkdna031901.htm>>.

genetic material known in biology classrooms for generations as ‘junk DNA’ actually contain instructions essential for the growth and survival of people and other organisms, and may hold keys to understanding complex diseases like cancer, strokes, and heart attacks.”³³

A second issue being debated is that state DNA databases store and maintain not only profiles composed of “junk DNA” but also the biological evidence used to produce the profiles. McEwen, *supra* note 3, at 237. Dr. Jean E. McEwen, who is a lawyer and Director of the Ethics program at the National Human Genome Research Institute, has stated that “the major privacy issues in DNA data banking arise not from the maintenance of the DNA data but from the retention of the samples themselves.” *Id.*³⁴ *Accord*, Jost, *supra* note 1, at 451; Stevens, *supra* note 2, at 79 Tex. L. Rev. at 935.

³³ Justin Gillis, “*Junk DNA*” *Contains Essential Information*, Washington Post, (December 4, 2002), <http://www.washingtonpost.com/ac2/wp-dyn?pagename=article&node=&contentId=A9055-2002Dec4¬Found=true>. *Accord*, Juengst, *supra* note 2 at 75 (rare genetic marker for indian populations in South America and Eskimo groups is part of “junk” DNA).

³⁴ The Human Genome Project is a coordinated, international research effort, jointly managed by the U.S. Department of Energy and the National Institutes of Health, to analyze the structure of human DNA and to map and sequence the estimated 50,000-100,000 human genes. *See* National Human Genome Research Inst., *The Human Genome Project* (visited Feb. 29, 2000) <<http://www.nhgri.nih.gov/HGP/>>.

Neither the DNA Act nor any of the fifty states that participate in CODIS require that the biological samples be destroyed after the DNA profile is created.³⁵ DNA samples are banked and stored on the grounds that the samples may need to be re-tested as new markers or testing technologies become standard.³⁶ Consequently, storage of the biological evidence can continue indefinitely, even after the sample has served its initial purpose (i.e. producing a DNA profile of a criminal suspect).

Efforts to reform procedures for storage of DNA samples have been unsuccessful. “The National Academy of Sciences advises that DNA samples be destroyed promptly after analysis; the issue had been considered by the National Commission on the Future of DNA Evidence, but no comprehensive policy has been formulated.” Stevens, *supra* note 2, 79 Tex. L.Rev. at 934. *Accord*, Juengst, *supra* note 2 at 66. *See also*, *Genetic Witnesses*, *supra* note 3, at 37, 133 (Congressional office proposes legislation to prohibit the storage of DNA samples “as a step to ensure that personal genetic information beyond DNA profiles does not find its way into centralized computer data files that could have adverse effects on an individual’s future”).

³⁵ *DNA Forensics*, (visited Feb. 23, 2004), <http://www.ornl.gov/sci/techresources/Human_Genome/elsi/forensics.shtml>.

³⁶ Jean E. McEwen, *Forensic DNA Data Banking by State Crime Laboratories*, 56 *Am J. Hum. Genetics* 1487, 1490-91 (1995); Juengst, *supra* note 2, 75 *Chi. Kent. L. Rev.* at 66.

III.ARGUMENT

A. Constant Advances in Technology will Invite the Expansion of Involuntary DNA Testing to Non-Forensic Purposes.

While a DNA bank for criminal identification purposes has legitimate forensic uses, constant advances in technology will invite its expansion to non-forensic purposes. An expansion of purpose beyond that which was originally intended is common to identification systems, and is referred to as “function creep.”³⁷

The evolving use of Social Security numbers in the United States is cited as a classic example of “function creep.” *Id.* When Social Security numbers were first issued in 1936, the federal government assured the public that use of the numbers would be limited to Social Security programs. Today, however, the Social Security number (SSN) is the most frequently used recordkeeping number in the United States. In “the name of efficiency and rationality, huge computer banks match our social security numbers to almost every phase of our life, giving the government a permanent and complete warehouse of data on all our activities.” *Id.* The use of SSNs has expanded over time from governmental to non-

³⁷ The term “function creep” refers to the process by which data collected for one purpose is then applied “to additional purposes not announced, or perhaps even intended, at the commencement of the scheme.” Simon G. Davies, *Touching Big Brother: How Biometric Technology Will Fuse Flesh and Machine*, 7 Information Technology & People, (1994) <<http://www.privacy.org/pi/reports/biometric.html>>.

governmental purposes and is regularly used for employee files, medical records, health insurance accounts, credit and banking accounts, university ID cards, and many other purposes.³⁸ One result is the emerging crime of “identity theft,” based on the easy access to SSNs by unauthorized individuals.

Census data offers another example of “function creep.” *Id.* Census records were originally created for general statistical purposes. Census records were then used during World War II to round up innocent Japanese Americans and place them in internment camps. *Id.*³⁹ More recently, census data has been used to develop anti-terrorism air passenger profiling systems, a purpose that goes well beyond its original, limited purposes.⁴⁰

“Function creep” is a natural occurrence in identification systems. It is a neutral process, secondary to technological advances. Whether the outcome of “function creep” is benevolent or malevolent depends on the amount of protection

³⁸ *Fact Sheet 10: Your Social Security Number: How Secure Is It?* (Utility Consumers’ Action Network / Privacy Rights Clearinghouse) June 1993 / Revised June 2002.

³⁹ Stevens, *supra* note 2, 79 Tex. L. Rev. at n. 90. *See also* Steven A. Holmes, *Census Blamed in Internment of Japanese*, New York Times, *reprinted in* Seattle Post-Intelligencer, (March 17, 2000) <<http://seattlepi.nwsourc.com/national/cens17.shtml>>.

⁴⁰ Audrey Hudson, *Study Used Census Information for Terror Profile*, Washington Times, (January 19, 2004) <<http://www.washingtontimes.com/national/20040118-114335-2930r.htm>>; Audrey Hudson, *Nasa “Deidentified” Passengers*, Washington Times, (January 22, 2004) <<http://www.washingtontimes.com/national/20040122-104701-2120r.htm>>.

built into the identification system itself. In the case of DNA testing for law enforcement purposes, such protections do not exist, on either a federal or state level. *See* Section B, *infra*.

The many legal commentators discussed throughout concur that DNA databases have the potential for far more than mere identification purposes, contrary to the Government's claim. The resulting infringement on an individual's civil rights and liberties is, and will continue to be, far-reaching and profound. The Court should weigh this impact when balancing the interests in a case such as this, and render its decision accordingly.

B. State Law Offers Little, if Any Protection from the Expanded Use of Collected Genetic Information for Non-Forensic Purposes.

A number of state statutes currently contain exceptions that would allow the FBI's CODIS data base to be used and expanded for non-forensic purposes. Massachusetts's law, for example, contains an open-ended authorization for any disclosure that is, or may be, required as a condition of federal funding and allows for the disclosure of information, including personally identifiable information for "advancing other humanitarian purposes."⁴¹

⁴¹ Mass. Gen. Laws Ann. ch. 22E, §§ 12, 13 (West 1999).

North Dakota law requires DNA records to be made available to "any public official who requires that information in connection with discharge of the official's official duties."⁴²

The State of Mississippi has no statutory restrictions on the use of forensic DNA and leaves it to the Mississippi State Crime Lab to determine any restrictions.⁴³

Nevada's law simply provides "that samples be used for an analysis to determine the genetic markers of the blood." There is no definition of the term "genetic markers", which on its face could include any information that could be derived from DNA and no restrictions on the use or availability of the DNA sample or test results.⁴⁴

A host of states generally make the data available to law enforcement agencies without further restriction, thus implicitly allowing genetic tests for physical and mental traits or for predisposition to disease.⁴⁵

While all of these non-forensic purposes appear innocuous, they reflect the availability of forensic databases and stored genetic samples for other purposes.

42 N.D. Cent. Code §§ 31-13-06 (1999).

43 Miss. Code Ann. § 45-33-15(2)(a) (1999).

44 Nev. Rev. Stat. § 176.0913 (1998).

45 *See, e.g.*, Arizona Stat. § 31-281, Arkansas Code Ann. §§ 12-12-1105-1113, California Penal Code § 299.5, Colorado St, § 17-2-201, Delaware Code Ann. Tit. 29 § 4713, et. seq.

Over time the pressure to use stored genetic information and DNA for "the common good" may prove irresistible. The few statutory restrictions that exist today can easily be reduced or eliminated in the future - the result of legislatures influenced by special interest groups and constituencies - thereby opening these samples up to new uses, never before contemplated.

The risk of expanded use is heightened by the fact that federal and state laws authorizing DNA testing make no provisions to destroy biological DNA samples. *See Factual Background, Section II.E. supra.* While the FBI would like to represent that these biological DNA samples will never be used for anything besides catching criminals, it is inevitable that as technology advances, at some point, they will be used for other purposes without the consent or knowledge of the individual tested.

The Government claims that "federal privacy law" is adequate protection against the dissemination and misuse of information in a DNA sample. Gov't Supp. En Banc Brief at 9. It is not. State statutory provisions, as noted above, authorize the sharing and use of DNA information beyond that provided in federal law, making the federal provisions inconsequential. These authorized uses, as also noted above, will only broaden over time.

Federal privacy protections in the past have failed to prevent instances "in which the government has abused supposedly confidential information. For

example, in the 1940s, J. Edgar Hoover obtained the military's confidential 'fingerprint files'." Stevens, *supra* note 2, 79 Texas L.Rev. at n. 90.

C. The Classes of People Subjected to Involuntary DNA Testing are Expanding Rapidly and Without Sufficient Justification, So that this Court's Characterization of the Privacy Issues at Stake Will Affect Far More Than Probationers.

More than a decade ago, a seminal article on DNA profiling warned that the expansion of the classes of people subjected to involuntary DNA testing was inevitable:

Once a technological program like DNA identification gets established for a pariah group such as sex offenders, it is inevitable that there will be pressure to extend it to yet other groups and also to allow access to increasing numbers of individuals and institutions who claim "that they need the information."

Shapiro & Weinberg, *supra* note 2, 38 Clev. St. L. Rev. at 477.

This prediction was correct. In the 14 years since the 1990 article, states have gone from collecting DNA from convicted sex offenders – the original target group for DNA profiling (on the theory that they are likely to be recidivists and that they frequently leave biological evidence) - to data banks of all violent offenders collecting DNA profiles of, to juvenile offenders in 29 states. Moreover, there are rapid-fire proposals to expand DNA profiling even further, to new and

ever greater numbers of persons.⁴⁶ As noted earlier in this brief, California is poised to enact a law which would result in the collection of DNA material on an involuntary basis from all persons who have merely been arrested for a crime.

One commentator critiques the expansion of DNA databases to arrestees who have not been convicted of any crime. “To expand the statutes to cover more and more individuals without any suspicion or probable cause would be to leave privacy issues up to law enforcement officials. This is clearly a violation of every person’s constitutional right. . . . [S]oon the statutes will encompass every individual regardless of any arrest or conviction,” if the court accepts “general interest in crime control” as constitutional justification. Herlica, *supra* note 2, 52 Syracuse L. Rev. at 975-76 (arguing that DNA databanks do not fall within the special needs exceptions in *City of Indianapolis v. Edmond*, 531 U.S. 32 (2000) and recommending other limitations and protections to minimize the intrusion on privacy). Echoing this “slippery slope” concern, another commenter queried:

If we are going to take DNA from prisoners because they are at-risk [of committing crimes in the future], why shouldn’t we take DNA from teenagers, from homeless people, from Catholic priests, from any subgroup of society that someone is able to make a statistical argument of being at-risk?⁴⁷

⁴⁶ National Conference of State Legislatures, DNA 2003, (visited Feb. 23, 2004), <<http://www.ncsl.org/programs/health/genetics/dna2003.htm>>. (In 2003, 40 states had bills pending in the legislature regarding DNA testing in the law enforcement context).

⁴⁷ *Strands of Justice: Do DNA Databanks Infringe on Defendants’ Rights?*, (July 17, 1998) <http://www.pbs.org/newshour/forum/july98/dna_databanks03.html>.

Although the issue before the Court is involuntary DNA testing of probationers, whatever balance this Court strikes will obviously affect other groups. As noted above, more states are conducting involuntary DNA testing of arrestees who have been convicted of no crime. In addition, some localities are conducting “DNA dragnets” of people with no criminal history, simply because they live or work near a crime scene.⁴⁸ There are reports that these supposedly voluntary tests are carried out in a coercive fashion, leaving the subjects little choice to refuse.⁴⁹ Several commentators have called for even broader, involuntary “dragnets” based on the racial and ethnic characteristics revealed by DNA samples left at a crime scene.⁵⁰

D. The Dual Expansion of Involuntary DNA Testing will Result in Genetic Discrimination Against Large Numbers of People, and Will Have Far Reaching and Profound Implications for Protected Privacy Interests.

⁴⁸ Yeshulas, *supra* note 2, 8 Suffolk J. Trial & App. Advoc. at 134; Grand, *supra* note 2, 23 Cardozo L. Rev. at 2295-2298.

⁴⁹ Juengst, *supra* note 2, 75 Chi. Kent L. Rev. at 78; Stevens, *supra* note 2, 69 Tex. L. Rev. 921 n. 241; Grand, *supra* note 2, 23 Cardozo L. Rev. at 2305.

⁵⁰ Elkins, *supra* note 2, 17 Notre Dame J. L. Ethics and Pub. Pol’y at 269; David Kaye, *Two Fallacies About DNA DataBanks for Law Enforcement*, 67 Brook. L. Rev. 179, 205 (2001).

The process of “function creep” discussed above demonstrates the risk that genetic information obtained for forensic purposes may one day bar applicants from employment, insurance or medical care.

Some critics of DNA databases fear that as the databases expand, the information may be used for discriminatory purposes outside of law enforcement, such as denying insurance, employment, or even the right to have children – all based on an individual’s genetic makeup. Indeed, statistics like the recent admission by twenty-five percent of Fortune 500 companies that they have used DNA testing to weed out job applicants with a certain disposition for genetic diseases prove that these concerns are legitimate.

Stevens, *supra* note 2, 79 Tex. L.Rev. at 933.

There are few laws, and certainly none at the federal level, which expressly and comprehensively prohibit genetic discrimination by employers, insurers or medical care providers. *See* Paul Steven Miller, *Is There a Pink Slip in My Genes?: Discrimination in the Workplace*, 3 J. Health Care L & Pol’y 225, 237 (2001). For the last several years, Congress has considered legislation to ban genetic discrimination in health insurance and employment, but no bill has yet been enacted. *Id.* Although 41 states have enacted legislation on genetic discrimination in health insurance and 31 states have enacted legislation on genetic discrimination in the workplace,⁵¹ the result is a patchwork of differing protections.

⁵¹ *The Genetic Information and Nondiscrimination Act: A Summary*, National Human Genome Research Institute: Policy and Ethics, (February 2004) <http://www.genome.gov/10002347>>; *Genetic Information and Health Insurance: Enacted State Legislation*, (May 2003) <<http://www.genome.gov/10002338>>.

Without comprehensive federal legislation, many in the United States will remain vulnerable to genetic discrimination.

The Council for Responsible Genetics⁵² has warned of the creation of a "genetic underclass" in the U.S., a hierarchy in which only people with "acceptable" genetic profiles will have access to health care, financial security, home ownership, employment, the freedom to change jobs, etc.⁵³ Given the history of the eugenics movement this warning should be taken seriously. The eugenics movement was a major force in the U.S. from the early 1900's through the 1930's, and it had substantial influence on public policy. For example, the involuntary sterilization of "social inadequates" was widespread and was upheld by the U.S. Supreme Court in 1927 in the infamous decision in *Buck v. Bell*, 274 U.S. 200 (1927). Then Justice Oliver Wendell Holmes, writing for the majority,

Genetic Information and the Workplace: Enacted State Legislation, (May 2003) <<http://www.genome.gov/10002339>>.

⁵² The Council for Responsible Genetics is a national nonprofit bioethics organization that was founded in 1983 and is based in Cambridge, Massachusetts. Its membership includes scientists, public health advocates, and others interested in the use of new genetic technologies in a socially responsible manner. The Council's main mission is to educate and raise the public's awareness about the ethical implications of emerging genetic issues and to document cases of genetic discrimination. See, *Position Statement on Genetic Information* (visited Feb. 29, 2000) <<http://www.gene-watch.org/org.html>>.

⁵³ Council for Responsible Genetics, *Laws Regarding Genetic Discrimination*, Cambridge, Mass. (1996); See also, Carol Lee, *Creating a Genetic Underclass: The Potential for Genetic Discrimination by the Health Insurance Industry*, 13 Pace L. Rev. 189 (1993).

approved the involuntary sterilization of Carrie Buck, "a feeble-minded white woman," on the grounds that "three generations of imbeciles are enough." *Id.* at 274.

Much more recently, the U.S. Air Force required African-American applicants to undergo genetic testing for Sickle Cell Disease after the mutation responsible for Sickle Cell disease was discovered in 1979. The Air Force dismissed 143 applicants because they were carriers, even though none of them had the condition. Only after a trainee filed a lawsuit did the Air Force eventually withdraw the requirement.⁵⁴

Reports and surveys confirm that the use of genetic testing in the workplace is on the rise. In 1982, a federal government survey found that only 1.6% of companies who responded were using genetic testing for employment purposes.⁵⁵ Surveys conducted by the American Management Association found that the percentage of employees conducting genetic testing grew from 6% to 10% (6000 employees) in 1997 to 30% in 1999 and was expected to "skyrocket" further.⁵⁶

⁵⁴ D. Nelkin, *Genetic Screening in the Workplace*, in Organizations, Uncertainties and Risks, 119-130 (J.F. Short Jr. ed., Westview Press, 1992).

⁵⁵ *The Role of Genetic Testing in the Prevention of Occupational Disease*, Office of Technology Assessment, April 1983.

⁵⁶ *Pink Slip in Your Genes*, Scientific American, (January 2001) <<http://www.sciam.com/2001/0101scicit2.html>>.

The existence of legal protections have not prevented abuses and invasions of worker privacy as genetic testing in the workplace has expanded. In February 2001, the Equal Employment Opportunity Commission (“EEOC”) sued Burlington Northern Santa Fe Railroad, claiming that the company had conducted secret genetic tests on its workers to defend against workers compensation claims for carpal tunnel syndrome.⁵⁷ Eventually, the company settled the EEOC action (as well as a similar union lawsuit), halted the non-consensual testing program and agreed to destroy the DNA samples and records.⁵⁸

Prohibitions against genetic discrimination have also failed to protect against discrimination.⁵⁹ In a 1996 survey of nearly 1,000 individuals who were at risk for genetic conditions, over 22% reported that they had experienced some form of discrimination based on their risk status.⁶⁰ The Council for Responsible Genetics has documented hundreds of cases in which healthy people have been denied

⁵⁷ *EEOC Petitions Court to Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing Under Americans with Disabilities Act*, U.S. Equal Employment Opportunity Commission, (Feb. 9, 2001).

⁵⁸ *Id.* See also Rip Watson, *Burlington Northern Settles Suit Over Genetic Tests*, Bloomberg News (Apr. 11, 2001).

⁵⁹ P. Billings, et al., *Discrimination as a Consequence of Genetic Testing*, 50 *American Journal of Human Genetics*, 476-482 (1992).

⁶⁰ Lisa N. Geller, et al., *Individual Family, and Social Dimensions of Genetic Discrimination: A Case Study Analysis*, 2 *Science and Engineering Ethics* (1996).

insurance or a job based on genetic "predictions."⁶¹ The U.S. Department of Labor has concluded that the inappropriate and discriminatory use of genetic information is a very serious workplace issue.⁶²

Concerns regarding the unauthorized and discriminatory use of involuntarily collected DNA samples are not limited to the areas of employment, insurance, and health care. The release of personal information from DNA samples may result in the "[d]isclosure of painful facts about family relationships (such as non-paternity); stigmatization associated with having a genetic abnormality; and intra-familial discord." Green *et al.*, *supra* note 2, 11 Harv. J.L. & Tech. at 572-73.⁶³ The vast amount of information to be obtained from DNA is such that discriminatory uses are likely in other areas as well. See, Factual Background, *supra*.

DNA data banking statutes have been expanded in recent years to include provisions that many regard as excessively broad. Yee, *supra* note 2, 22 Amer. J. of Crim. Law at 479. The expansion has also generated concerns that collected information could be used for research regarding, among other things, purported

⁶¹ Council for Responsible Genetics, *Position Paper on Genetic Discrimination*, *supra* note 49.

⁶² *Genetic Information and the Workplace*, U.S. Department of Labor Report, (January 20, 1998)
<<http://www.dol.gov/asp/programs/history/herman/reports/genetics.htm>>.

⁶³ See also Grand, *supra* note 2, 23 Cardozo L. Rev. at 2288 (disclosure may result in embarrassment, humiliation, public hostility, and even financial harm).

links to criminality. Rothstein *et al*, *supra* note 2, 67 Brooklyn L.Rev. at 158.64 Another concern is whether government agencies could obtain DNA information for purposes of child support collection or immigration proceedings. *Id*.

IV. CONCLUSION

The discriminatory uses currently made of the genetic information contained in DNA underscore the fact that the involuntary collection and banking of DNA samples *already* implicates far more than a mere “record of identity”, as the Government claims. With the mapping of the human genome now well underway, future DNA analysis may soon reveal even more about an individual, including his or her medical history; proclivities towards certain diseases; and hereditary information such as race, physical, and behavioral traits.

The Government is absolutely incorrect in arguing that DNA profiles are solely a record of identity, in which the individual has no privacy interest. Because DNA profiles and the samples from which they are drawn reveal far more than mere identity, the unregulated atmosphere in which DNA data bases are maintained raises substantial concerns about the constitutionality of involuntary DNA collection. Legal protections such as the “individualized suspicion” requirement sought in this case are required to guard our protected privacy

64 *See also* Hansen, *supra* note 2, at 42; Burk *et al.*, *supra* note 2, 5 Geo. Mason U. Civ. Rts. L.J. 1 at 14; Juengst, *supra* note 2, n. 69; Krent, *supra* note 2, 74 Tex. L. Rev. 95-96.

interests against future abuse. If the interests at stake here are properly weighed, the Governments interests do not prevail. The decision of this Court must be affirmed.

Dated: March 3, 2004.

Respectfully Submitted

PROTECTION & ADVOCACY, INC.

By: _____
Michelle Uzeta, Esq.
Amicus and Attorneys for Amicus Curiae