Preventing the Discovery of Plaintiff Genetic Profiles by Defendants Seeking to Limit Damages in Personal Injury Litigation

Mark A. Rothstein

University of Houston

Follow this and additional works at: https://www.repository.law.indiana.edu/ilj

Part of the Evidence Commons, and the Torts Commons

Recommended Citation
Available at: https://www.repository.law.indiana.edu/ilj/vol71/iss4/4

This Article is brought to you for free and open access by the Law School Journals at Digital Repository @ Maurer Law. It has been accepted for inclusion in Indiana Law Journal by an authorized editor of Digital Repository @ Maurer Law. For more information, please contact rvaughan@indiana.edu.
Preventing the Discovery of Plaintiff Genetic Profiles by Defendants Seeking to Limit Damages in Personal Injury Litigation

MARK A. ROTHSTEIN

INTRODUCTION .................................................... 878
I. THE GROWTH OF GENETIC PREDICTION .......................... 879
II. DAMAGES FOR LOST FUTURE EARNINGS .................................. 884
III. DISCOVERY OF MEDICAL RECORDS ........................................ 887
IV. COMPULSED MEDICAL EXAMINATIONS .................................. 889
V. PUBLIC POLICY ISSUES .............................................. 892
   A. Medical vs. Nonmedical Uses of Genetic Information ............. 892
   B. Genetic vs. Other Medical Information .................................. 893
   C. Ethical Issues in Discovery of Genetic Information .............. 894
      1. Privacy/Autonomy ............................................ 894
      2. Confidentiality ............................................. 896
      3. Nonmaleficence ............................................. 897
VI. ALTERNATIVES TO PREVENT DISCOVERY OF GENETIC RECORDS AND COMPULSED GENETIC TESTING ................................... 899
   A. Drawing Lines and Weighing Costs and Benefits ................. 899
   B. Protective Orders Under Rule 26(c) of the Federal Rules of Civil Procedure and State Law Analogs ............. 901
   C. Enacting a Genetic Privacy and Confidentiality Law ............ 902
      1. Specific Confidentiality Laws .................................. 902
         a. HIV Records .............................................. 903
         b. Substance Abuse Treatment Records ........................ 904
         c. Records of Medical Research .............................. 904
      2. Key Elements of a Genetic Privacy and Confidentiality Law ... 905
         a. All Genetic Records Must Be Kept Separate from
            Other Medical Records .................................... 905
         b. All Genetic Information Disclosures, Not to Health Care
            Providers, Are Limited to the Individual Whose
            Records Are Involved ....................................... 906
         c. Genetic Records Are Not Subject to Subpoena ............. 906
         d. Prohibiting Disclosure of Genetic Records to Establish
            Plaintiff's Future Lost Income in a Civil Action .......... 906
         e. Prohibition of Compulsed Genetic Testing .................. 907
   D. Variable Periodic Payment of Damages ............................ 907
CONCLUSION ........................................................ 908

* Hugh Roy and Lillie Cranz Cullen Distinguished Professor of Law and Director, Health Law and Policy Institute, University of Houston. J.D., Georgetown University; B.A., University of Pittsburgh. The Author is indebted to the following individuals who read an earlier draft and made a number of very helpful suggestions: Lori B. Andrews, Ellen Wright Clayton, David Crump, Sandra Honda, Bob Ragazzo, and Bill Winslade. The research assistance of Lena Basilie, Steve Loden, and Glen Shu also is greatly appreciated.
INTRODUCTION

Imagine the following situation: Dr. Jane Smith is a thirty-five year-old neurosurgeon who entered private practice three years ago upon completion of her training. She has an annual income of $200,000. One day, while crossing the street from the doctors' parking lot to the hospital, she is run over by a Zippy Express delivery truck, whose unlicensed, intoxicated driver was speeding to a delivery and failed to stop for a red light. As a result of the accident, Dr. Smith has become quadriplegic and will be unable to perform surgery again.

In a negligence action against Zippy Express, a key component of Dr. Smith's economic damages is her lost income. Assuming she would have been able to work for thirty more years, with an income of $200,000 per year, this would amount to six million in current dollars, exclusive of projected earnings increases, merely for lost income.

Suppose, however, that Dr. Smith is in the unaffected, presymptomatic stage of Huntington's disease, amyotrophic lateral sclerosis, or some other late-onset genetic disorder. Further suppose that experts will testify that, in all likelihood, irrespective of the accident, she would not have been able to practice medicine beyond age forty-five and that her life expectancy is fifty years. Applying traditional damages principles, this information would reduce her recovery for economic injury by at least four million dollars.

Zippy Express and its insurers therefore would have a great economic incentive to discover information about Dr. Smith's genetic profile and to introduce this information at trial. Should the defendants be able to discover this information by obtaining access to Dr. Smith's medical records? Should they be able to obtain a court order directing Dr. Smith to submit to genetic testing? Should it matter whether genetic testing previously had been performed on Dr. Smith or whether there was something in her family or medical history to suspect a genetic disorder? Should it matter whether Dr. Smith was suspected of having a genetic risk of a monogenic disorder, such as Huntington's disease, or a multifactorial disorder, such as cancer? What effect, if any, should be given to the penetrance, variable expressivity, and treatability of the disorder? Should it matter if Dr. Smith objects to genetic testing?

The preceding scenario and the resulting questions have the potential to become commonplace. Without thoughtful judicial or legislative intervention, the combination of exponential increases in genetic information generated by the Human Genome Project and overwhelming economic incentives of defendants to limit their liability in personal injury cases will give rise to irresistible pressures to include genetic information in civil litigation. Conceivably, in every case in which the plaintiff seeks to recover for permanent or long-term disability or lost future earnings, regardless of the legal theory of the case, the defendant could seek to discover the plaintiff's risk of premature incapacity or mortality by obtaining genetic records or performing genetic testing.¹

This Article considers the scientific, legal, and policy issues underlying the use of genetic information to determine damages in personal injury litigation. A related and important set of issues surrounds the admissibility of genetic information at trial. Because

¹. The life expectancy of the injured party is also relevant when the plaintiff seeks damages for medical expenses and pain and suffering, as well as in wrongful death actions.
the legal standards for discovery of evidence are generally broader than for its admissibility, and because of a desire to keep this complicated subject within manageable proportions, this Article is limited to the issue of discovery of genetic information.

Part I discusses the Human Genome Project and the growing ability of medical science to predict the risk of an individual's future health. It describes several serious, late-onset genetic conditions that could be relevant in personal injury litigation. It also discusses the scientific limitations on our ability to predict future health status based on genetic information. Part II contains a discussion of the general law of damages for lost future earnings in personal injury. It includes a discussion of how evidence of the plaintiff's preinjury medical condition may affect these damages. Part III considers the circumstances under which a defendant may obtain discovery of a plaintiff's medical records pursuant to Rule 26 of the Federal Rules of Civil Procedure and its state analogs. Part IV continues with a discussion of when a defendant may compel the physical examination of a plaintiff pursuant to Rule 35 of the Federal Rules of Civil Procedure and its state analogs. Part V considers the public policy implications of using a personal injury plaintiff's genetic profile to assess damages. The public policy concerns not only implicate privacy and confidentiality issues, but also the possible effects on clinical genetics and the willingness of at-risk individuals to undergo genetic testing when the records are discoverable. It contrasts the public health and public policy interests in the primary (i.e., health care) and secondary (i.e., litigation) uses of genetic information.

Part VI proposes three alternatives designed to promote the plaintiff's interests in privacy and confidentiality, the defendant's interest in avoiding overcompensation, the judiciary's interest in avoiding complexity in litigation, and the public's interest in the public health and the conservation of health resources. The three suggested alternatives involve, from most modest to most drastic: (1) the use of protective orders pursuant to Rule 26(c) of the Federal Rules of Civil Procedure to limit discovery of genetic information and bar physical examinations; (2) a new statute protecting the confidentiality of genetic information; and (3) a total restructuring of the payment of damages by enacting a variable periodic payment of damages statute. This Article concludes by noting the imminence and potential magnitude of the issue. It urges a prompt and thorough discussion of the proposed alternatives, as well as others, to avoid the misuse of genetic information in litigation.

I. THE GROWTH OF GENETIC PREDICTION

The rapid expansion of genetic understanding and technology during the 1980's made it realistic to consider the ambitious undertaking of mapping and sequencing the entire human genome. In 1990, the Human Genome Project officially began. Although not a

2. Gene mapping involves determining the relative locations of different genes on chromosomes. CONGRESS OF THE UNITED STATES, OFFICE OF TECHNOLOGY ASSESSMENT, CYSTIC FIBROSIS AND DNA TESTS: IMPLICATIONS OF CARRIER SCREENING 280 (1992) [hereinafter CYSTIC FIBROSIS AND DNA TESTS].


4. A genome is all the genetic material in the chromosomes of a particular organism; its size is generally given as its total number of base pairs. WEBSTER'S THIRD NEW INTERNATIONAL DICTIONARY 947 (1981). See generally Victor A. McKusick, Mapping and Sequencing the Human Genome, 320 NEW ENG. J. MED. 910 (1989); James D. Watson, The Human Genome Project: Past, Present, and Future, 248 SCIENCE 44 (1990).
When the effort began, there was great concern over whether the goals and timetable of the project were feasible. By the end of 1993, however, the first “rough” comprehensive map of the human genome was announced, well ahead of schedule. By the spring of 1995, the first large-scale sequencing effort had begun. It is now reasonable to assume that the mapping and sequencing of the human genome envisioned by the project will be completed by or before the year 2005.

The first breakthroughs came in locating the genes responsible for many of the most common monogenic disorders. By July, 1995, scientists had localized 14,244 polymorphisms on specific regions of chromosomes and had identified 1116 disease-related genes at 909 loci. Some of the disease genes identified include genes for cystic fibrosis, Duchenne muscular dystrophy, fragile X syndrome, hemochromatosis, Leish-M-Nyhan syndrome, neurofibromatosis-type 1, and retinoblastoma.


8. Elliot Marshall, Emphasis Turns from Mapping to Large-Scale Sequencing, 268 SCIENCE 1270 (1995); see also Nicholas Wade, Rare that sequencing may be 99% completed by 2002. See generally Rachel Nowak, Bacterial Genome Sequence Bagged, 269 SCIENCE 468 (1995) (discussing completion of first genome of living organism and suggesting that techniques used on microorganisms may be used for human genome).

9. Genome Data Base, Johns Hopkins University (on-line) (July 26, 1995).


11. Cystic fibrosis is an autosomal recessive disorder that usually begins in infancy and is characterized by chronic respiratory infection, pancreatic insufficiency, abnormally viscid mucous secretions, and susceptibility to thermal stress. The MERCK MANUAL OF DIAGNOSIS AND THERAPY 2206 (16th ed. 1992) [hereinafter MERCK MANUAL]; see Bat-Sheva Kerem et al., Identification of the Cystic Fibrosis Gene: Genetic Analysis, 245 SCIENCE 1073 (1989).

12. Duchenne muscular dystrophy is an X-linked disorder resulting from a mutation in the gene that encodes dystrophin, which causes progressive weakness and degeneration of muscle fibers. VICTOR A. MCKUSICK, MENDELIAN INHERITANCE IN MAN: CATALOGS OF AUTOSOMAL DOMINANT, AUTOSOMAL RECESSIVE, AND X-LINKED PHENOTYPES 1922 (10th ed. 1992); see M. Koening et al., Complete Cloning of the Duchenne Muscular Dystrophy (DMD) cDNA and Preliminary Genetic Organization of the DMD Gene in Normal and Affected Individuals, 50 CELL 509 (1987).

13. Fragile X syndrome, an X-linked disorder, is the most common form of inherited mental retardation. MCKUSICK, supra note 12, at 1904; see E.J. Kremer et al., Mapping of DNA Instability at the Fragile X to a Trinucleotide Repeat Sequence p(CCG)n, 252 SCIENCE 1711 (1991).

14. Hemochromatosis is an autosomal recessive disorder in which an increasing overload of iron in the liver leads to cirrhosis of the liver, diabetes, hypermelanomic pigmentation of the skin, and heart failure. It is rare before middle age. MCKUSICK, supra note 12, at 1453; see E.C. Fajwinska et al., Localization of the Hemochromatosis Gene Close to D6S105, 53 AM. J. HUM. GENETICS 347 (1993).

15. Hemophilia A is an X-linked disorder that results in a hereditary defect in antihemophiliac globulin (factor VIII). The deficiency in coagulation factors leads to bleeding disorders that begin in early childhood. MCKUSICK, supra note 12, at 1848; see Jane Gitschier et al., Characterization of the Human Factor VIII Gene, 312 NATURE 326 (1984).

16. Lesch-Nyhan syndrome is an X-linked disorder characterized by mental retardation, spastic cerebral palsy, hyperactivity, self-mutilating behavior, and self-destructive biting of fingers and lips. MCKUSICK, supra note 12, at 1873; see Al Edwards et al., Automated DNA Sequencing of the Human HPRT Locus, 6 GENOMICS 593 (1990).

17. Neurofibromatosis type 1 is an autosomal dominant disorder. Patients may exhibit a variety of symptoms, but the only consistent ones are cafe-au-lait spots and fibromatous skin tumors. It is associated with a tendency to malignant degeneration of the neurofibromas. MCKUSICK, supra note 12, at 759; see Richard M. Cawthon et al., A Major Segment of the Neurofibromatosis Type 1 Gene: cDNA Sequence, Genomic Structure, and Point Mutations, 62 CELL 193 (1990).

18. Retinoblastoma, an autosomal recessive disorder, is a malignant tumor that arises from the nuclear layers of the retina. It is usually diagnosed before age two and, if diagnosed early, has a cure rate exceeding 80%; however, treatment usually requires removal of much of the optic nerve. MERCK MANUAL, supra note 11, at 2035; see Stephen H. Friend et al., A Human DNA Segment with Properties of the Gene That Predisposes to Retinoblastoma and Osteosarcoma, 323
During 1994 and 1995, major new advances were announced in the search for cancer-causing genes. Genes responsible for a portion of breast,\textsuperscript{19} colon,\textsuperscript{20} ovarian,\textsuperscript{21} prostate,\textsuperscript{22} and other cancers were discovered. In addition to the previously discovered p53\textsuperscript{23} tumor suppressor gene, the ATM (ataxia telangiectasia mutated) gene\textsuperscript{24} was discovered in 1995. Both of these genes have been associated with numerous forms of cancer. Work also has been proceeding on the identification of genes associated with other multifactorial disorders, such as heart disease,\textsuperscript{25} diabetes,\textsuperscript{26} asthma,\textsuperscript{27} and rheumatoid arthritis,\textsuperscript{28} as well as various neuropsychiatric conditions\textsuperscript{29} and behaviors.\textsuperscript{30}

A number of the genes already discovered and others under investigation are associated with adult-onset disorders. Thus, these disorders are of particular relevance to the issue of damages in personal injury litigation. Genetic testing of an asymptomatic plaintiff might indicate that the individual is at an increased risk of or is expected to develop a certain disorder that would mean premature disability (and decreased earning capacity) or death. Among the monogenic adult-onset disorders that could result in severe disability or death are the following: acute intermittent porphyria,\textsuperscript{31} adult polycystic

\begin{thebibliography}{30}
\bibitem{19} Yoshio Miki et al., \emph{A Strong Candidate for the Breast and Ovarian Cancer Susceptibility Gene BRCA1}, 266 SCIENCE 66 (1994).
\bibitem{20} Richard Fishel et al., \emph{The Human Mutator Gene Homolog MSH2 and Its Association with Hereditary Nonpolyposis Colon Cancer}, 75 CELL 1027 (1993).
\bibitem{21} Miki et al., supra note 19; David C. Schultz et al., \emph{Characterization of Chromosome 9 in Human Ovarian Neoplasia Involving 9p, Including CDKN2}, 55 CANCER RES. 2150 (1995).
\bibitem{22} Jin-Tang Dong et al., \emph{KAI1, A Metastasis Suppressor Gene for Prostate Cancer on Human Chromosome 11p11.2}, 268 SCIENCE 884 (1995).
\bibitem{23} See Frederick P. Li et al., \emph{Recommendations on Predictive Testing for Germ Line p53 Mutations Among Cancer-Prone Individuals}, 84 J. NAT'L CANCER INST. 1156 (1992).
\bibitem{24} See Kinney S. Savitsky et al., \emph{A Single Ataxia Telangiectasia Gene with a Product Similar to PI-3 Kinase}, 268 SCIENCE 1749 (1995).
\bibitem{25} See Amo G. Motulsky \& John D. Brunzell, \emph{Genetics of Coronary Atherosclerosis}, in \emph{THE GENETIC BASIS OF COMMON DISEASES} 150 (Richard A. King et al. eds., 1992).
\bibitem{26} See Jack L. Leathy \& Aubrey E. Boyd III, \emph{Diabetes Genes in Non-insulin-dependent Diabetes Mellitus}, 328 NEW ENG. J. MED. 56 (1993).
\bibitem{27} See Diikje S. Postma et al., \emph{Genetic Susceptibility to Asthma—Bronchial Hyperresponsiveness Coinherited with a Major Gene for Atopy}, 333 NEW ENG. J. MED. 894 (1995).
\bibitem{28} See Richard A. King, \emph{Rheumatoid Arthritis}, in \emph{THE GENETIC BASIS OF COMMON DISEASES}, supra note 25, at 596.
\bibitem{29} See Ying-Hui Fu et al., \emph{Variation in the CCG Repeat at the Fragile X Site Results in Genetic Instability: Resolution of the Sherman Paradox}, 67 CELL 1047 (1991) (explaining the fragile X syndrome); Peter McGuffin et al., \emph{Genetic Basis of Schizophrenia}, 346 LANCET 678 (1995) (discussing schizophrenia).
\bibitem{30} See, e.g., Joseph Biederman et al., \emph{Further Evidence for Family-Genetic Risk Factors in Attention Deficit Hyperactivity Disorder: Patterns of Comorbidity in Probands and Relatives in Psychiatrically and Pediatrically Referred Samples}, 49 ARCHIVES GEN. PSYCHIATRY 728 (1992) (discussing attention deficit hyperactivity disorder); Dean H. Hamer et al., \emph{A Linkage Between DNA Markers on the X Chromosome and Male Sexual Orientation}, 261 SCIENCE 321 (1993) (discussing sexual orientation); Daniel Goleman, \emph{A Genetic Clue to Bed-Wetting Is Located}, N.Y. TIMES, July 1, 1995, at A1, A8 (presenting research that bed-wetting is not emotional).
\bibitem{31} Acute intermittent porphyria is an autosomal dominant, adult-onset disorder characterized by a variety of neuropathic symptoms resulting from reduced levels of the heme synthesizing enzyme hydroxymethylbilane. Activation of the disease is related to ectogenic factors such as drugs, diet, and steroid hormones. \textsc{Harrison’s Principles of Internal Medicine} 2015-76, 2208 (Kurt J. Isselbacher et al. eds., 13th ed. 1994) [hereinafter \textsc{Harrison’s}]; \textsc{McKusick}, supra note 12, at 904-05.
\end{thebibliography}
kidney disease type-1,23 amyotrophic lateral sclerosis,24 early-onset Alzheimer's disease,25 familial nephritis,26 Huntington's disease,27 Kennedy's disease,28 Marfan syndrome,29 myotonic dystrophy,30 hereditary hemorrhagic telangiectasia,31 and Wilson's disease.32 Many of these disorders are relatively uncommon, but the ability to perform multiplex testing33 will make it feasible and cost-effective for defendants to test for them.

Although new genetic discoveries will greatly aid in the prediction of an individual's future health, genetics is not a crystal ball. The information derived from genetic testing is frequently ambiguous or not well understood. For virtually all disorders, the results must be expressed as a likelihood that the individual will develop the disorder. Even then, the severity or the nature of symptoms or the effect on the individual may not be known.

The imprecision surrounding genetic prognostication is related to several important genetic concepts. These include the mode of inheritance,34 whether it is a single gene or
multifactorial (complex) disorder, the degree of penetrance of the disorder, the variable expressivity of the disorder, allelic heterogeneity, allelic expansion, and genomic imprinting.

To begin, there is a fundamental difference between single gene (monogenic or Mendelian) and multifactorial (polygenic) disorders. In the former, the disorder is caused by the mutation of a single gene. Individuals who are homozygous for recessive disorders, as well as those with mutations for autosomal dominant and X-linked disorders, are deemed affected, although the consequences of being affected may vary among individuals. For example, due to the high penetrance of the genetic disorder, males with an unusual constriction of the X chromosome are said to have fragile X syndrome, although the severity of the manifestation of the condition (mental retardation) may vary considerably. With other monogenic disorders, because of "incomplete penetrance," even having the gene does not mean that the individual will ever be affected.

"Problems of penetrance and expressivity become even greater in testing for complex disorders in which multiple factors, of which the gene being tested is only one, contribute to the causation of the disease." This may involve polygenic disorders, in which two or more genes are responsible for the condition, as well as multifactorial disorders, in which a combination of genetic and environmental factors are responsible.

Cystic fibrosis ("CF") illustrates the principle of allelic heterogeneity. This gene was first identified in 1989, and the first mutation discovered, known as delta F508, accounted for about seventy percent of CF mutations in individuals of European ancestry. Within a year, over 160 mutations were discovered, and by 1993, over 200 mutations had been discovered. Until all of the major mutations of a gene are discovered, it will be difficult to assess the weight of any test result.

It is important to resist the temptation to put too much emphasis on the results of any single genetic test. Genetic testing is an emerging technology. It is particularly useful in the clinical setting to assess whether individuals who are known to be at risk of of the gene. If a person with a dominant disorder mates with a person without the disorder, their children will each have a 50% chance of inheriting the disorder. Id. at 78.

In autosomal recessive inheritance, a deleterious gene produces its disease only in the homozygote. Affected individuals must receive one mutant gene from each parent. Because recessively inherited disorders are usually rare, almost all homozygous affected individuals result from the mating of two heterozygous, unaffected individuals. The offspring of two heterozygous parents have a 25% chance of being homozygous unaffected, a 50% chance of being heterozygous unaffected, and a 25% chance of being homozygous affected. Id. at 79.

In X-linked recessive inheritance, the aberrant gene is carried on the X chromosome. The disease appears almost always in males, whose mothers are unaffected but heterozygous carriers of the mutant gene. When a carrier female mates with an unaffected male, 50% of daughters will be unaffected and 50% will be unaffected carriers; 50% of males will be affected and 50% of males will be unaffected. Id. at 82.

44. See infra text accompanying notes 50-53.
45. See infra text accompanying notes 50-53.
46. See infra text accompanying notes 50-53.
47. See infra text accompanying notes 50-53.
48. Allelic expansion occurs when a gene segment increases in size when it is transmitted from parent to child. The severity of the disease is often related to the size of the allele and therefore the severity of the disorder may increase in each generation, a phenomenon known as anticipation. ASSESSING GENETIC RISKS, supra note 42, at 63.
49. In recent years, it has been observed that for some rare disorders, the severity and nature of the disorder may depend on which parent provided the faulty gene. This phenomenon is called genomic imprinting. Id. at 62.
50. Id. at 38.
monogenic disorders are unaffected, heterozygous carriers of recessive disorders, or presymptomatic for late-onset disorders. Genetic testing is less valid scientifically when used to predict the future health (phenotypic expression) of asymptomatic individuals. It is even more speculative to try to predict the risk of an individual developing a multifactorial disorder. Current genetic technology can, at best, assign a broad range of risk. The only true test is the test of time.

II. DAMAGES FOR LOST FUTURE EARNINGS

In personal injury litigation, special damages for quantifiable losses are based on the increased expenses and lost income caused by the injury. The latter component, lost future earnings, is a function of income level and work life expectancy. A claim for lost future earnings or lost earning capacity is “an estimate of lost present ability to work in appropriate occupations, now and in the future.” By contrast, a claim for lost earnings refers to the loss of income from the time of injury until the date of the trial. Ordinarily, damages for lost future earnings are only relevant after the plaintiff proves that he or she has suffered a permanent injury. Thereafter, the evidence focuses on two issues: (1) the plaintiff’s expected rate of earnings, and (2) the plaintiff’s expected number of lost years of earning capacity.

Under the prevailing American rule, a tort victim suing for damages for permanent injuries is permitted to base his recovery “on his prospective earnings for the balance of his life expectancy at the time of his injury undiminished by any shortening of that expectancy as a result of the injury.”

The first part, rate of earnings, is relatively easy to compute. It is based on the plaintiff’s abilities, training, experience, and preinjury earnings. Prospects for wage increases and loss of fringe benefits also are considered. Loss of future earnings is not all-or-nothing; thus, reduction of future earnings as well as inability to generate any earnings at all are recoverable.

The second part, determining life expectancy, is already more difficult, and it is likely to become increasingly complicated in the new era of genetics and predictive medicine.

Currently, life expectancy is based initially on standard mortality tables. These tables, however, are merely the starting point for making a determination of life expectancy or

56. See Exxon Corp. v. Fulgham, 294 S.E.2d 894, 898 (Va. 1982).
60. Id. at 361.
work expectancy. "[S]uch evidence is not conclusive but merely an aid to assist [the jury] in determining the present value of any future damages determined to be due . . . ."  

Perhaps the earliest American case on this issue is Denman v. Johnston. The defendant negligently drove a team of horses, which struck the plaintiff and caused serious injury. Prior to the accident, however, the plaintiff was suffering from a hernia and unspecified internal injuries. The Supreme Court of Michigan held that mortality tables alone could not be used to determine the plaintiff's life expectancy. "[O]ther testimony of experts would be required to show what the plaintiff's expectancy of life would be, taking into consideration his ailments, and the effect they would probably have to shorten his expectancy."

The courts have permitted a wide range of information to be introduced by either party in attempting to ascertain the plaintiff's life expectancy and work expectancy with more precision than mortality tables. These additional factors include the plaintiff's work history, as well as past and current health, constitution, and habits. In a minority of jurisdictions, mortality tables proffered by the plaintiff are deemed inadmissible if the plaintiff had a preexisting condition, the theory being that mortality tables are based on the lives of "healthy people."

Under both the majority and minority approaches, evidence of the plaintiff's medical condition before the injury is relevant to the issue of damages. By permitting the introduction of evidence of the plaintiff's shorter life expectancy, the plaintiff is prevented from obtaining a windfall.

It is Plaintiff's choice to pursue claims that necessitate the introduction of life expectancy information and basic fairness dictates that Plaintiff should not be allowed to make a potentially large recovery against [Defendant] based on an average life span when, in reality, Plaintiff may well have a shorter than average life expectancy.

There are two types of evidence that could indicate that the plaintiff has a shorter life expectancy than the standard mortality tables. The first type of evidence involves previously diagnosed diseases. If the plaintiff already had been diagnosed with cancer, heart disease, or some other life-threatening illness at the time of the injury, this evidence would be admissible to show a reduced life expectancy. The second type of evidence involves factors that predict the likelihood of disease which would cause

64. 48 N.W. 565 (Mich. 1891).
65. Id. at 568. See generally CHARLES T. MCCORMICK, HANDBOOK ON THE LAW OF DAMAGES § 86 (1935).
66. See, e.g., Bums v. Shields, 261 A.2d 161, 163 (Md. 1970) (holding that prior dismissal from employment for making a false statement in job application was admissible to show diminished earning capacity).
69. This Article does not deal with the issue of computing damages resulting from the defendant's aggravation of the plaintiff's preexisting condition—the "thin skull" rule. Rather, it deals with the discovery of medical information indicating that, notwithstanding the defendant's conduct, the plaintiff's work expectancy or life expectancy was less than the actuarial norm. Thus, by application of traditional apportionment principles, the defendant is responsible only for the additional diminution in life expectancy attributable to its wrongful conduct.
72. Simon, 470 So. 2d at 945; Sampson v. Missouri Pac. R.R., 360 S.W.2d 573, 586 (Mo. 1978).
premature mortality. The courts have admitted a wide range of evidence of behavioral factors in attempting to prove that the plaintiff had a diminished life expectancy at the time of the injury. These factors include the plaintiff’s use of drugs, alcohol, or cigarettes. If evidence of cigarette smoking is admissible to show that the plaintiff’s life expectancy is lessened because of the possibility of lung cancer, emphysema, or heart disease, then evidence that the plaintiff was genetically predisposed to such a disorder also would seem to be admissible. From the defendant’s standpoint, the only issue is how to obtain access to such genetic information. The main ways include discovery of existing medical records, questioning the plaintiff at deposition, compelling a medical examination of the plaintiff, and questioning the plaintiff’s physicians by interrogatories or depositions.

Although virtually all of the cases involve the defendant’s attempt to introduce evidence of the plaintiff’s shorter life expectancy, it is also possible for the plaintiff to introduce evidence of longevity. For example, in Escobar v. Seatrain Lines, Inc., a wrongful death action was brought by the widow of a longshore worker who was killed while unloading containers on the defendant’s ship. In determining lost future earnings, the jury awarded damages above the work expectancy of the average worker. The court upheld the verdict. The jury’s calculations obviously were predicated on their finding that at the time of the accident decedent was in excellent health and had extraordinary prospects for longevity. An autopsy disclosed that his arteries were free of atherosclerosis and that his cardiovascular condition was comparable to that of a 20 year old. His subcutaneous fat was one fifth of normal, another factor contributing to longevity. Dr. Michael Baden . . . testified that decedent would be grouped within the top 5% of persons his age in terms of life expectancy. His father died at age 89 and his mother was still alive at age 86. Dr. Lawrence Bress . . . testified that based on genetic inheritance, decedent’s cardiovascular condition, heart, liver and organs in excellent condition, he could be expected to outlive his parents.

With genetic prediction becoming increasingly sophisticated, it may be possible to estimate increased longevity. Nevertheless, for the foreseeable future, it is likely that decreased life expectancy will be the primary focus in personal injury litigation.

---


78. Escobar, 566 N.Y.S.2d 813 (Sup. Ct. 1990), rev’d and remanded, 573 N.Y.S.2d 498 (App. Div. 1991) (Escobar II). The case was reversed because the jury award was too high. The plaintiff had equated his earning potential with that of a more qualified employee. The court did not address the issue of life expectancy evidence. Escobar II, 573 N.Y.S.2d at 500-01.

Predicting life expectancy and work expectancy are relevant to the issue of estimating damages. The method by which damages are paid is a separate but related issue. The single recovery or lump sum payment rule provides that the plaintiff’s judgment is for all harms—past and future—caused by the defendant’s conduct related to the cause of action. The plaintiff receives a single award, reduced to present value, that cannot be decreased or increased even if the plaintiff’s situation changes.

One aspect of the lump sum rule involves awarding damages for future losses. Obviously, it is speculative to estimate lost life expectancy or lost work expectancy. In any individual case, the plaintiff’s actual life span may be longer or shorter than that predicted in mortality tables.

No finder of fact can predict whether any specific [individual] will live to the exact time of the actuarial expectancy, or less, or longer. For if there were such omniscience, insurance companies would use the omniscient individual to set insurance premiums on specific individuals rather than relying on actuarial tables.

Thus, in any individual case, the plaintiff or the defendant may receive a windfall or a shortfall.

Despite this drawback, there are two main reasons why the lump sum rule has endured for centuries. First, even though it may result in unfairness in individual cases, it is fair in the aggregate. Over time, using mortality tables will result in all plaintiffs recovering the total amount reasonably to be paid by all defendants. Second, it is efficient because a single recovery is determined in a single proceeding.

### III. DISCOVERY OF MEDICAL RECORDS

The easiest way for a personal injury defendant to learn a plaintiff’s prior medical history is to discover the plaintiff’s medical records. Requests for the medical records of personal injury plaintiffs are considered routine and are rarely challenged. Courts considering the issue of discovering a plaintiff’s medical records have applied the general principle that discovery requests are liberally granted.

If evidence of a plaintiff’s preinjury health status is admissible on the issue of

79. The doctrines of res judicata and merger also deserve mention. Res judicata is deeply ingrained in Anglo-American tradition. It traces its origins to Roman law. Essentially, “every person is entitled to his or her day in court... but when a final decision has been reached, that should be the end of it.” MILTON D. GREEN, BASIC CIVIL PROCEDURE 227 (2d ed. 1979). The two primary purposes of the doctrine are to promote the defendant’s interest in not being vexed twice by the same claim and the public interest of resolving litigation. JACK H. FRIEDENTHAL ET AL., CIVIL PROCEDURE § 14.3 (2d ed. 1993).


82. While the terms “windfall” and “shortfall” may be appropriate in describing the effect on defendants, the plaintiff receives a windfall only by dying sooner than expected and a shortfall by living longer than expected.

83. For a discussion of the concept of periodic payment of damages, see infra part VI.D.


85. Rule 26(b)(1) of the Federal Rules of Civil Procedure provides in pertinent part: Parties may obtain discovery regarding any matter, not privileged, which is relevant to the subject matter involved in the pending action, whether it relates to the claim or defense of the party seeking discovery or to the claim or defense of any other party... The information sought need not be admissible at the trial if the information sought
damages, then medical records indicating health status are presumptively discoverable. Thus, courts routinely order the discovery of medical records, including records relevant to the issue of damages for lost future earnings. Even sensitive information, such as psychiatric records, have been ordered disclosed.

_Agosto v. Trusswal Systems Corp._ is a particularly illustrative case. In a products liability action, the defendant sought to discover the plaintiff's medical records and to depose the plaintiff about his medical history. The defendant apparently had learned that the plaintiff had tested positive for HIV. After applying a balancing test, the court ordered discovery.

If [the Defendant] is held liable, damages for these claims will be awarded in part based on evidence of Plaintiff's life expectancy. It is not certain how many of those who test positive for the HIV virus contract AIDS, however, AIDS results from HIV infection and those who contract AIDS have a significantly diminished life expectancy. Therefore, HIV-related evidence of Plaintiff's health is necessary if [the Defendant] is to adequately prepare defenses to Plaintiff's claims.

The court did not address the issue of whether the plaintiff's medical records would have been discoverable in the absence of some well-founded belief on the defendant's part that the plaintiff was HIV-positive.

Another important issue in the _Agosto_ case involved the effect, if any, of a Pennsylvania law providing for the confidentiality of HIV-related information. The court held that by filing the lawsuit the plaintiff had waived his rights under the statute, and even if he did not waive his rights, the defendant established a "compelling need" for disclosure under the statute. The plaintiff's only option to resist discovery of his medical records was to abandon his claim for future damages. "[The Defendant] is entitled to access to the HIV-related information in this case if Plaintiff decides to continue pressing his future pain and suffering and lost earning capacity claims."

Although _Agosto_ involved a specific HIV confidentiality statute, most waiver cases involve waiver of the physician-patient privilege. The issue of waiver is also important in light of the existence of various other privilege or confidentiality statutes and the possibility that other such laws may be enacted. For example, some physician-patient

---

86. See _supra_ part II.
91. Id. at 120.
92. For a discussion of when a medical examination, including HIV or genetic testing, may be ordered, see _infra_ part IV.
94. _Agosto_, 142 F.R.D. at 120.
95. Id.
96. Id. See generally Ugo Colella, _HIV-Related Information and the Tension Between Confidentiality and Liberal Discovery_, 16 J. LEGAL MED. 33 (1995) (suggesting specific criteria for determining whether HIV-related information should be discoverable in civil disputes).
97. For a further discussion, see _infra_ part VI C.
privilege statutes specifically provide that the filing of a lawsuit for personal injury constitutes a waiver of the statutory privilege.\textsuperscript{98}

There are also three judicial theories applied by the courts in waiver cases. The simplest is the "automatic waiver rule," which provides that merely by filing the lawsuit the plaintiff waives all privileges regarding medical record privacy.\textsuperscript{99} The second test balances the compelling need for discovery against the right of privacy.\textsuperscript{100} The third approach uses a three-part test, which focuses on: (a) whether the party asserting the privilege has initiated the legal action, (b) whether the asserting party has placed the issue "in controversy," and (c) whether the information is "vital" to the opposing party.\textsuperscript{101} All three approaches have been subject to criticism, but the effect of these rules—that is, finding a waiver—is virtually the same under any of the approaches.\textsuperscript{102}

### IV. Compelled Medical Examinations

The most intrusive form of medical discovery is the compelled medical examination. Rule 35 of the Federal Rules of Civil Procedure provides that a mental or physical examination may be ordered by the court in an action in which the mental or physical condition of a party is "in controversy," upon a showing of "good cause."\textsuperscript{103} The rules of civil procedure of every state,\textsuperscript{104} except Mississippi,\textsuperscript{105} contain similar provisions.

In *Schlagenhauf v. Holder*,\textsuperscript{106} the Supreme Court considered the meaning of the terms "in controversy" and "good cause."

---


100. The California courts have applied the following balancing test: "Even when discovery of private information is found directly relevant to the issues of ongoing litigation, it will not be automatically allowed; there must be a careful balancing of the compelling public need for discovery against the fundamental right of privacy." Estate of Gallo v. Corpiglio, 39 Cal. Rptr. 2d 470, 473 (Ct. App. 1995). The "fundamental right of privacy" in California is based on the state constitution. See Lantz v. Superior Court, 34 Cal. Rptr. 2d 358, 367 (Ct. App. 1994); Davis v. Superior Court, 9 Cal. Rptr. 2d 331, 335 (Ct. App. 1992). For a different formulation of a balancing test, see Black Panther Party v. Smith, 661 F.2d 1243, 1266-67 (D.C. Cir. 1981), vacated without opinion, 458 U.S. 1118 (1982).


If (i) assertion of the privilege is the result of some affirmative act, such as filing suit, by the asserting party; (ii) through the affirmative action, the asserting party has placed the protected information at issue by making it relevant to the case; and (iii) application of the privilege would deny the opposing party access to information vital to its defense, the court should find that the asserting party has impliedly waived the privilege through its own affirmative conduct.


103. FED. R. CIV. P. 35(a).

104. State provisions for medical examinations actually preceded the adoption of the Federal Rules of Civil Procedure in 1938. 8A CHARLES A. WRIGHT & ARTHUR R. MILLER, FEDERAL PRACTICE AND PROCEDURE § 2231 (1994). Subsequent to the adoption of the Federal Rules, most states have amended their requirements to conform to the Federal Rules. There are a few notable exceptions. South Carolina only permits examinations when the amount in controversy is over $100,000. S.C. R. CIV. P. 35. Florida and Illinois no longer require a showing of good cause. Fla. R. Civ. P. 1.360; Ill. SUP. CT. R. 215. In California, any defendant may demand one physical examination of the plaintiff at any time without a showing of "in controversy" or "good cause," so long as the examination is within 75 miles of the plaintiff's residence and the examination does not include any diagnostic test that is painful, protracted, or intrusive. CAL. CIV. PROC. CODE § 2032 (West 1996).


Supp. (1991 & LAW N.H. (West & CODE Supp. 663(a) (Supp. ordered testing pursuant to a discovery order. Pettyjohn. 35 testing or forgo any claims for future damages.' Likewise, in other cases, good cause to
the plaintiff s HIV status was in controversy and required the plaintiff to undergo HIV
sought an order requiring that plaintiff submit to a blood test. The district court held that
liability action in which he sought to recover damages for personal injuries caused
court-ordered medical examination that includes genetic testing.

cause the defendant to suspect an underlying genetic condition, and then seek to have a

information in the plaintiff's medical record may

any time a plaintiff seeks to recover for physical injuries, his or her physical condition
is "in controversy." Although this may establish the discoverability of plaintiff's medical
records pursuant to Rule 26, it does not necessarily establish the existence of good
cause for a medical examination. An important question is whether information in the
plaintiff's medical records can establish good cause for a medical examination. This is

available to obtain the desired information by other means is also

Schlagenhauf has been interpreted by both federal and state courts to mean that any
time a plaintiff seeks to recover for physical injuries, his or her physical condition is
"in controversy." Although this may establish the discoverability of plaintiff's medical
records pursuant to Rule 26, it does not necessarily establish the existence of good
cause for a medical examination. An important question is whether information in the
plaintiff's medical records can establish good cause for a medical examination. This is
crucial to the issue of genetics, because information in the plaintiff's medical record may
cause the defendant to suspect an underlying genetic condition, and then seek to have a

court-ordered medical examination that includes genetic testing.

In Pettyjohn v. Goodyear Tire & Rubber Co., the plaintiff brought a products

liability action in which he sought to recover damages for personal injuries caused by the
explosion of a tire. In the course of reviewing the plaintiff's medical records, the
defendant observed a notation in the margin of one report indicating that the plaintiff was
HIV-positive. The defendant, in attempting to limit its damages for future earnings, then

sought an order requiring that plaintiff submit to a blood test. The district court held that
the plaintiff's HIV status was in controversy and required the plaintiff to undergo HIV
testing or forgo any claims for future damages. Likewise, in other cases, good cause to

107. Id. at 118.
110. See supra part III.
112. For a discussion of the case, see Peter H. Berge, Setting Limits on Involuntary HIV Antibody Testing Under Rule
Pettyjohn.

Forty-three states have statutes that deal with compelled HIV testing, although most of these laws would permit court-ordered testing pursuant to a discovery order. See ALA. CODE § 22-11A-51 (Supp. 1995); ARIZ. REV. STAT. ANN. § 36-663(a) (Supp. 1995); ARK. CODE ANN. § 20-15-905 (Michie 1991); COLO. REV. STAT. ANN. § 25-4-1401 (West 1990 & Supp. 1995); CONN. GEN. STAT. ANN. § 19a-582 (West Supp. 1995); DEL. CODE ANN. tit. 16, § 1202 (Supp. 1995); FLA. STAT. ANN. § 381.004(3)(a) (West 1993); GA. CODE ANN. §§ 31-17A-2 to -3 (1991); HAW. REV. STAT. § 325-16 (1993); IDAHO CODE § 39-610 (1993); ILL. ANN. STAT. ch. 410, para. 305/4 to 305/9 (Smith-Hurd 1993 & Supp. 1995); IND. CODE § 16-41-6-1 (1993); IOWA CODE ANN. § 141.22 (West 1989 & Supp. 1995); KAN. STAT. ANN. § 22-2913(c) (1988
order a mental examination was established by the ambiguity of the plaintiff's medical records\textsuperscript{123} and statements of the plaintiff's physician.\textsuperscript{114}

Even when the "in controversy" and "good cause" requirements of Rule 35 are satisfied, the court has discretion in deciding whether to compel an examination.\textsuperscript{115} In general, the cases in which courts order a physical or mental examination fall into three categories.

First, the information must not be available elsewhere. The movant must show that other discovery procedures, such as the production of medical records, have been exhausted.\textsuperscript{116} Second, it must be established that useful information is likely to be gained from the examination. For example, repetitive examinations will not be permitted\textsuperscript{117} unless special circumstances justify an additional examination.\textsuperscript{118} Third, the examination must not create health risks to the examinee. Although most of the cases involving health risks are concerned with physical risks,\textsuperscript{119} there is some support for the view that the feelings, reputation, and psychological impact on the examinee also should be considered.\textsuperscript{120} For example, in Doe v. Roe, maternal grandparents attempted to gain custody of their grandchild from the allegedly unfit father. They sought an order requiring the child's father to have an HIV test. In rejecting the motion, the court noted that "the psychological impact of learning that one is [HIV-positive] has been compared to receiving a death sentence."\textsuperscript{121}

The potential psychological and social harm to the examinee is merely one factor to consider in the context of genetics. Public policy concerns about confidentiality and conservation of resources, discussed in the next section, also need to be weighed against the need for the information revealed by the testing. These issues are likely to arise in motions to compel genetic testing under Rule 35.\textsuperscript{122} The few cases that have been decided under this rule, however, have not developed the issues sufficiently to provide needed guidance to courts dealing with a genetics case of first impression.

\textsuperscript{114} Hodges v. Keane, 145 F.R.D. 332, 335 (S.D.N.Y. 1993). The evidence from the examination was later excluded from trial because it was too prejudicial. Hodges v. Keane, 886 F. Supp. 352 (S.D.N.Y. 1995).
\textsuperscript{120} Hardy v. Riser, 309 F. Supp. 1234, 1241 (N.D. Miss. 1970) (dictum).
\textsuperscript{121} Id. at 718 (Sup. Ct. 1988).
\textsuperscript{122} Ed at 722. Where the potential harm to the party seeking discovery is physical, the courts are more likely to order discovery despite claims of confidentiality. See Syring v. Tucker, 498 N.W.2d 370, 377-78 (Wis.) (ordering HIV testing in case in which defendant, who intentionally bit the plaintiff, claimed to be HIV-positive), reconsideration denied, 505 N.W.2d 142 (Wis. 1993).
\textsuperscript{123} For a further discussion, see infra part V.C.
V. PUBLIC POLICY ISSUES

Parts I through IV of this Article have discussed the new developments in genetics and how, under the current law of damages and civil procedure, genetic information might be relevant and discoverable. The key question is whether permitting personal injury defendants to gain access to individual genetic profiles through medical records or compelled genetic testing is good public policy.

This Part begins by drawing two important distinctions: (1) the difference between medical and nonmedical uses of genetic information, and (2) the difference between genetic and other forms of medical information. After concluding that the nonmedical use of genetic information raises special concerns and that genetic information is a special form of information, the ethical principles of privacy, autonomy, confidentiality, and nonmaleficence are applied to the use of genetic information in personal injury litigation.

A. Medical vs. Nonmedical Uses of Genetic Information

A variety of extremely important and complex policy issues revolve around the broad issue of using genetic information for medical purposes. These include informed consent, the duty to warn, public health screening, and medical malpractice. The seeming immediacy of these concerns sometimes has obscured the equally important, and in some ways more troublesome, potential for nonmedical or secondary use of genetic information. The power of genetic information gives rise to the likelihood that individuals and entities with a financial, personal, or similar interest in identifying an individual or predicting an individual's future health or behavior will seek to obtain and use this information.

The broad range of potential uses of genetic information makes it extremely venturesome to formulate ethical, legal, or social principles of universal applicability. Certain themes, however, recur. They involve resolving the conflicts between individuals and third parties over control of individual genetic information; balancing the potential benefits of certain genetic information against the costs and consequences of obtaining it; and placing into proper perspective the enormous evolutionary, psychological, and social power of genetic information.

In its 1994 report entitled Assessing Genetic Risks: Implications for Health and Social Policy, a committee of the Institute of Medicine of the National Academy of Sciences
reaffirmed the principle that genetic tests "should be of benefit to the individual being tested."\textsuperscript{126} The committee expressed concern about the nonmedical use of genetic information, and said it was "concerned that some uses of genetic test information may represent harmful and unwarranted intrusions on individual privacy."\textsuperscript{127}

The previous statement suggests that genetic information may be different from other types of medical information and that compelled disclosure of genetic information may constitute an invasion of privacy. These two themes are addressed below. In a more general sense, however, the statement raises the issue of nonmaleficence, the bioethics principle that harm ought not be inflicted intentionally in the provision of medical services.\textsuperscript{128} This principle is not absolute, especially when the harms are not physical but are social or psychological. Yet the magnitude of the potential negative consequences of genetic testing is great.\textsuperscript{129} Therefore, when a social good, such as getting a job or recovering in tort for personal injury, is conditioned on disclosing genetic records or submitting to genetic testing, there should be a compelling need for the information derived from the test. As described more fully below, the use of genetic testing for discovery of future damages would not meet this test.\textsuperscript{130}

### B. Genetic vs. Other Medical Information

An initial focus of the Human Genome Project has been to identify the genes responsible for many of the most widespread or lethal single-gene disorders. Even with this group of disorders, but especially after the focus expanded to include multifactorial disorders, it became increasingly clear that environmental factors are extremely important to the course of "genetic" diseases. At the same time, new studies have demonstrated that many common, seemingly "nongenetic" disorders, from familial hypercholesterolemia\textsuperscript{131} and hypertension\textsuperscript{132} to osteoporosis,\textsuperscript{133} have demonstrable genetic components. It is indisputable that the lines are blurred between genetic and nongenetic disorders and, indeed, it may become more widely recognized in the scientific world that it is inadvisable to perpetuate the distinction.\textsuperscript{134}

Given the current scientific thinking, is there any reason why genetic information should be subject to greater protection than other kinds of medical information? There are three reasons, all of which are more social than medical.

First, there is a seeming inevitability to genetic disorders, even at the presymptomatic stage, that is rare for "nongenetic disorders."\textsuperscript{135} Notwithstanding variable penetrance,

\textsuperscript{126} ASSESSING GENETIC RISKS, supra note 42, at 47.
\textsuperscript{127} Id.
\textsuperscript{128} See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 189 (4th ed. 1994).
\textsuperscript{129} For a further discussion of nonmaleficence, see infra part V.C.3.
\textsuperscript{130} In other instances in which there is a compelling need to test, all appropriate steps should be taken to minimize the psychological and social harm caused by the genetic information. This would include confidentiality protections and, where individual diagnostic information is revealed, appropriate genetic counseling.
\textsuperscript{132} See Wylie Burke & Arno G. Motulsky, Hypertension, in THE GENETIC BASIS OF COMMON DISEASES, supra note 25, at 170.
\textsuperscript{133} Nigel A. Morrison et al., Prediction of Bone Density from Vitamin D Receptor Alleles, 367 NATURE 284 (1994).
\textsuperscript{134} See Philip J. Boyle, Shaping Priorities in Genetic Medicine, HASTINGS CTR. REP., May-June 1995, at S2, S4.
\textsuperscript{135} A notable exception is HIV infection. The inevitability of symptoms of HIV disease in the future (along with the lethality of the condition and the stigma associated with the mode of transmission and the makeup of the affected groups) contribute to the psychological and social burdens of asymptomatic HIV infection.
variable expressivity, and other scientific principles discussed earlier, at least as to late-onset monogenic disorders, being presymptomatic means there is a high likelihood of being affected in the future. Moreover, individuals are often regarded as helpless to prevent genetic disorders.

Second, a great stigma attaches to genetic disorders, and that stigma directly relates to the fact of heritability. Genetic disorders run in families; parents, siblings, and other relatives may be affected or at risk. The risk of transmission to offspring also may create a barrier to reproduction. The transgenerational aspect of genetic disease makes it especially odious, because it may be viewed as a flaw in one’s ancestors and a cloud hanging over future progeny for generations to come.

Third, some genetic traits naturally fall along racial and ethnic lines. The abominable misuse of genetic information for eugenic purposes in the 20th century in the United States, not to mention Nazi Germany, is alone enough to give great pause to any unrestrained discovery of genetic information or compelled genetic testing.

All three of these reasons reinforce the notion that it is not the genetic etiology of the disorders, but the reaction of other people, including family members and third parties, that causes the deleterious social consequences. Nevertheless, in light of the factors just mentioned, the reluctance of individuals to divulge genetic information is not irrational and cannot be overlooked in developing policies to prevent individuals from suffering the stigma and discrimination associated with genetic disorders.

C. Ethical Issues in Discovery of Genetic Information

1. Privacy/Autonomy

Privacy involves a condition of limited access to a person. As a legal concept, the right to privacy is the right of a person to be left alone, to have some element of his or her person free from intrusion by others. According to one view, privacy has three major usages: physical privacy (“freedom from contact with other people”); informational privacy (freedom from “accessibility of personal information”); and decisional privacy (freedom to make “autonomous choices about the personal and intimate matters that constitute private lives”).

136. See supra notes 43-53 and accompanying text.
140. Patricia A. King, The Past as Prologue: Race, Class & Gene Discrimination, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES, supra note 138, at 94; see ANTHONY P. POLEDNACK, RACIAL AND ETHNIC DIFFERENCES IN DISEASE (1989); see also TROY DUSTER, BACKDOOR TO EUGENICS (1990).
All three usages of privacy could be implicated in the discovery of a personal injury plaintiff's genetic profile. If genetic testing were ordered by a court, there would be an incursion on physical privacy. The information revealed by the test or through discovery of extant genetic medical records would be an intrusion on informational privacy. The compelled submission to testing, which would reveal this information, would constrain decisional privacy.

All three usages, but especially decisional privacy, relate closely to the concept of autonomy. “Rights of privacy are valid claims against unauthorized access that have their basis in the right to authorize or decline access. These rights are justified by rights of autonomous choice that are correlative to the obligations expressed in the principle of respect for autonomy.” One aspect of autonomy is self-determination. It may be viewed as a negative right which “imposes on everyone the obligation not to coerce or otherwise interfere with the action of another.” Furthermore, “[i]n the context of genetic testing and screening, respect for autonomy refers to the right of persons to make an informed, independent judgment about whether they wish to be tested and then whether they wish to know the details of the outcome of the testing.”

Autonomy and informed consent are the cornerstones of nondirective genetic counseling. “Concern about early abuses in the eugenics movement helped to make the principle of nondirectiveness, and the corollary of respect for client autonomy, key concepts of genetic counseling today.” This is especially important in respecting the wishes of clients about whether to undergo genetic testing to learn their risk of late-onset genetic disorders.

Huntington's disease ("HD") is an example of a disorder that often places at-risk individuals in a quandary. Before the discovery of the HD gene, most at-risk individuals (56% to 77%) said they would take a test if one were available. But when a test actually was developed, a much lower percentage wanted to be tested. In one study, only 9.5% wanted to be tested. The five most important reasons for refusal cited by the investigators included: “(1) if the results were adverse, the risk of developing HD for existing children would increase, (2) the absence of an effective cure, (3) potential loss of health insurance, (4) financial costs of testing, and (5) inability to ‘undo’ the knowledge.”

The decision whether to undergo genetic testing for a serious late-onset genetic disorder is extremely difficult. Even with informed consent and nondirective counseling, the effect of the test result on an individual and the individual's family can be devastating. In the absence of a compelling reason, one must conclude that a court order directing an individual to submit to genetic testing to detect late-onset genetic

145. BEAUCHAMP & CHILDRESS, supra note 128, at 410.
146. Bruce Miller, Autonomy, in 1 ENCYCLOPEDIA OF BIOETHICS, supra note 144, at 215, 217; see also Bruce Miller, Types of Autonomy and Their Significance, in BIOETHICS: READINGS AND CASES 105-09 (Baruch A. Brody & H. Tristram Engelhardt, Jr. eds., 1987).
147. ASSESSING GENETIC RISKS, supra note 42, at 248.
148. Id. at 152.
150. Id.; see also Sandi Wiggins et al., The Psychological Consequences of Predictive Testing for Huntington's Disease, 327 NEW ENG. J. MED. 1401 (1992); Charles Siebert, The DNA We've Been Dealt, N.Y. TIMES, Sept. 17, 1995, § 6 (Magazine), at 50.
disorders violates the ethical principle of nonmaleficence. The genetic testing is not rendered ethically acceptable merely because it is nominally "voluntary," when refusing to comply with the testing surrenders a possibly substantial legal claim for compensation resulting from the wrongful conduct of the defendant. Public policy, therefore, must be to prohibit such coerced testing.

2. Confidentiality

Although sometimes used interchangeably with privacy, confidentiality refers to an individual's reasonable expectation that certain sensitive information revealed within a confidential relationship will not be redisclosed to a third party without the individual's consent.152 Ever since the Oath of Hippocrates in the fifth century B.C., confidentiality has been "one of the cardinal obligations of physicians."153 Unless patients are assured that their communications will not be revealed, they will not be forthcoming with sensitive information, thereby impeding the effectiveness of medical interventions.

In general, medical information is regarded as confidential.154 With the exception of statutory obligations (e.g., reporting gunshot wounds, child abuse, communicable diseases)155 or common law obligations (e.g., reporting threats to kill identifiable victims),156 medical information will not be disclosed without the consent of the patient. Confidentiality is an instrumental value; its significance depends on the importance of the underlying values it promotes. In the context of genetic information, the underlying values, including preventing psychological and social harm to the individual, are substantial.

Confidentiality has not been accorded great weight in lawsuits. In personal injury litigation, however, the theory has developed that the plaintiff, by placing his or her medical condition in issue, has impliedly consented to the disclosure of relevant medical information to the defendant.157 Failure of the plaintiff to produce the medical records or to submit to a court-ordered medical examination is grounds for dismissal.158 The defendant's interest in determining the validity of the plaintiff's claim is deemed to outweigh the plaintiff's interest in confidentiality.

Two public policy issues stem from the disclosure (including disclosure in the course of litigation) of confidential genetic information. First, as with all sensitive medical information, compelled disclosure creates a risk of embarrassment and stigma.159 Genetic information may be considered to touch the essence of humanity. It also reveals information about the individual's relatives—past, present, and future. In an estimated

152. See William J. Winslade, Confidentiality, in 1 ENCYCLOPEDIA OF BIOETHICS, supra note 144, at 451, 452.
153. BIOETHICS: READINGS AND CASES, supra note 146, at 291.
156. See Tarasoff v. Regents of the Univ. of Cal., 551 P.2d 334 (Cal. 1976) (holding that psychotherapist has common law duty to warn identifiable, intended victim of patient's death threats).
157. See supra notes 99-102 and accompanying text.
159. This assumes that there will not be further redisclosure or use of this information, in which case there would be secondary risks of discrimination or further embarrassment.
one to ten percent of births, paternity is misattributed.\textsuperscript{160} This information could be divulged in the course of performing genetic testing of a plaintiff.\textsuperscript{161} Confidentiality demands that sensitive information of this nature not be revealed without a compelling reason.

Second, rules on the confidentiality of medical information have a marked effect on the willingness of individuals to disclose sensitive information in the clinical setting. In the context of genetic testing, public policy should encourage at-risk individuals who are so inclined to undergo genetic testing without fear that their genetic records will be disclosed without their truly voluntary consent. It is unlikely that individuals would decline genetic testing because they feared that if they were involved in an accident, their genetics test results could be discovered in a personal injury case. Nevertheless, the discovery of medical records in litigation must be considered in the context of other secondary uses of genetic information. Many individuals who decline testing are concerned that employers, insurers, or other third parties might gain access to the information. As with these other third party users, in the absence of a compelling reason, genetic medical records should be beyond the reach of discovery in personal injury litigation.

3. Nonmaleficence

The bioethics expression of the principle of nonmaleficence—\textit{primum non nocere}, or "above all do no harm"—is well known, although "its origins are obscure and its implications unclear."\textsuperscript{162} The harms to be avoided under nonmaleficence include not only physical injuries, but also personal, psychological, familial, and social injuries. Thus, the harms may be intangible as well as tangible, and they may be the consequence of actions which are not, in themselves, inherently maleficent.

Several potential harms already have been discussed in this section. These include invasions of privacy and overriding individual autonomy where genetic testing is ordered over the objection of the individual. Plaintiffs in personal injury actions, it was noted, could be given the choice of acquiescing in genetic testing, and possibly being confronted with information that they preferred not to know, or relinquishing their claims to recover for substantial harms that were inflicted on them by allegedly responsible third parties.\textsuperscript{163} If genetic records developed in the clinical setting were discoverable, clients could face a possible breach of confidentiality in the redisclosure of personal information, and concerns about later disclosures might dissuade those at-risk individuals who wanted to be tested.
Besides coercion and discouragement, there are three other harms to be avoided. Avoiding these harms supports the public policy of prohibiting the discovery of genetic information and not permitting compelled genetic testing.

First, we ought not permit genetic testing when it is not being used primarily for the benefit of the person being tested. Overriding considerations of public health and safety must be met before using such a powerful technology beyond the clinical setting. The genetics literature contains numerous reports of psychological harms, including suicide, involving individuals who were unable to adjust to genetic information.

Second, substandard genetic testing and counseling ought to be avoided. An increasingly costly component of the overall genetic testing process is genetic counseling. When a court compels genetic testing of a personal injury plaintiff paid for by the defendant, it is unlikely that time-consuming, nondirective genetic counseling also will be included. Thus, a possibility exists that individuals will not only be confronted with potentially devastating information that they did not want to know, but they will receive little or no counseling before or after the test to prepare them to deal with the information. Indeed, in genetic counseling it is often suggested that individuals deemed unprepared to receive possibly difficult information should defer their testing until a more propitious time. That alternative would not be available in the course of litigation.

Third, genetic resources, human and financial, ought not be wasted. As of 1995, there were only 792 board-certified clinical geneticists and 814 board-certified genetic counselors in the United States. With the expense of genetic testing and counseling, and with a finite number of trained professionals, there already is great concern that access to appropriate genetic services will not be available to all individuals who want them.

By contrast, each year there are nearly one million tort cases brought in the United States. If genetic information about the plaintiff became an issue in even a small percentage of these cases, genetic services providers would be overwhelmed. Wealthy, institutional defendants would syphon off a substantial amount of genetic resources to perform genetic testing and testify about the results. This is a troubling prospect because

---

164. For a discussion of laws protecting the confidentiality of substance abuse treatment records and HIV test results, see infra parts VI.C.1.a and VI.C.1.b.

165. Some examples of possible justifications for genetic testing would be establishing filial relations and conducting DNA forensics associated with a criminal investigation. The specifics of these exceptions are beyond the scope of this Article.

166. See, e.g., Lindsay A. Farrer, Suicide and Attempted Suicide in Huntington Disease: Implications for Preclinical Testing of Persons at Risk, 24 AM. J. MED. GENETICS 305, 305 (1986) (reporting that 5.7% of HD patients died of suicide and 27.6% attempted suicide at least once).

167. The American Board of Medical Genetics administers an examination every three years. The most recent examination was in 1993. The figure of 792 clinical geneticists does not include Ph.D. medical geneticists, clinical cytogenticists, clinical biochemical geneticists, and molecular geneticists. The total number of board certifications in all of these categories is 1686, although some individuals are certified in more than one category. Telephone Interview with Sharon Robinson, Administrator, American Board of Medical Genetics (Aug. 29, 1995).


169. This estimate was derived in the following manner. According to the most recent study by the National Center for State Courts, in 1993 there were 532,391 tort cases filed in the 27 states studied. BRIAN J. OSTROM & NEAL B. KAUNDER, STATE JUSTICE INSTITUTE, EXAMINING THE WORK OF STATE COURTS 22 (1993). These states had a total population in 1993 of 172,723,000, approximately 67% of the 1993 population of the United States of 257,783,000. Therefore, in 1993, all state court filings may be estimated at 798,000. Including the tort cases filed in the federal courts and projecting population data to 1995 leads to the estimate of nearly one million tort cases filed.
genetic tests performed for purposes of litigation provide little or no medical benefit either to the individuals tested or to society.

VI. ALTERNATIVES TO PREVENT DISCOVERY OF GENETIC RECORDS AND COMPelled GENETIC TESTING

A. Drawing Lines and Weighing Costs and Benefits

The policy interests discussed in Part V do not mesh well with the current legal rules on discovery and damages. Indeed, it is a daunting task to devise feasible modifications to civil procedure and the law of damages to accommodate the substantial policy interests in protecting genetic information. The outer extremes are easy to describe. It would violate public policy to permit unfettered access to genetic information and genetic examinations of personal injury plaintiffs at the whim of defendants. It also would be unfair to defendants to award compensatory damages for lost future earnings while the court excludes all evidence of the plaintiffs’ preinjury or future health. Thus, it is necessary to find a middle ground, and this process involves drawing lines, making distinctions, and balancing interests. This Subpart outlines the appropriate places to begin drawing these lines.

One starting point is to focus on the reason genetic information is sought. Here, there is a vital distinction between genetic evidence relevant to the issue of causation and genetic evidence relevant to the issue of damages. With adequate protective orders prohibiting redisclosure of the information, evidence of the plaintiff’s genetic profile should be discoverable when it is relevant to the issue of causation.

For example, in a products liability lawsuit filed in 1990, a juvenile plaintiff alleged that his severe birth defects, including microcephaly and mental retardation (including an I.Q. of forty), were caused by his in utero exposure to the solvent methyl ethyl ketone as his mother worked assembling electronics components.70 The defendant’s experts claimed that the plaintiff’s physical and behavioral characteristics suggested the cause of his injuries was not solvent exposure, but fragile X syndrome, a genetic disorder.71 The court ordered that medical personnel be allowed to draw two, ten cubic centimeter blood samples for genetic testing, rejecting the argument that this was an invasive procedure which would cause severe distress.72

Before genetic testing is ordered to help establish the cause of plaintiffs’ injuries, courts should require a clear showing of a basis in fact to suspect that the testing is necessary. Furthermore, a protective order should be issued to limit the disclosure of the results. As discussed below, because genetic testing should not be ordered merely as a

---


71. For a more detailed explanation of fragile X syndrome, see supra note 13.

72. The teenage plaintiff was terrified of needles and had to be held down by his mother, which caused the child great emotional trauma. Lehrman, supra note 170, at A1; see also Dodd-Anderson v. Stevens, Nos. 92-1015-MLB, 92-1016-MLB, 1993 WL 273373 (D. Kan. May 4, 1993) (ordering genetic testing in medical malpractice action brought by child with brain injury, but not expressly mentioning whether testing was for purpose of proving causation).
possible way of limiting damages, testing intended to address damages should not become permissible simply by alleging that it is to determine causation.

The next thing to consider is whether the plaintiff’s current health status is discoverable. Under established principles, if the plaintiff has a shortened life expectancy because of an already manifested illness, such as heart disease, cancer, or some genetic disorder, this fact is relevant and should be discoverable and admissible. A plaintiff with a life expectancy of one year would reap a windfall if the defendant were forced to pay lump sum damages based on a life expectancy of thirty years.

What about the discovery of predictive health information, genetic or otherwise? There are two possibilities. The first involves the asymptomatic plaintiff who is unaware of any genetic predisposition to a serious late-onset disorder. Medical records would be uninformative, and ordering discovery through compelled genetic testing would be tantamount to judicial sanctioning of a genetic fishing expedition. This testing would be extremely difficult to justify, because it would require the plaintiff to confront information he or she did not know previously and that he or she may not want to know.173 Furthermore, as discussed below, defendants, collectively, are in no worse a position than they would be by using standard mortality tables.

Does the analysis change if the plaintiff previously underwent genetic testing in the clinical setting or otherwise knew (such as through family health history) of his or her genetic risks? In this situation, no problem exists with the plaintiff being involuntarily confronted with new, possibly devastating information. Nevertheless, two other strong policies demand that the information not be discoverable. First, the plaintiff should be able to maintain the confidentiality of the information without disclosing such intimate medical information to litigants and counsel, as well as other individuals, such as family members, who may not have known of the original testing. Second, by permitting discovery, individuals may be deterred from undergoing genetic testing because of fear of the secondary consequences of having the information accessible. They also may be deterred from bringing meritorious tort claims to avoid the disclosure of sensitive genetic information.

The case for preventing discovery of already known genetic information is certainly less compelling than that of discovering information that was previously unknown. Nevertheless, practical problems link these two scenarios. Because plaintiffs have a great economic incentive to withhold information about genetic predisposition, defendants would have to assume that such information existed and consequently seek discovery of genetic information on their own.174

In summary, genetic testing to establish causation, narrowly defined and with a protective order, should be permissible. As to damages, discovery of medical conditions, including genetic disorders that already have manifested themselves, should also be permissible. This includes gathering medical records, questioning the plaintiff and the plaintiff’s physicians at deposition, and, upon an appropriate showing of good cause, compelling a medical examination. Discovery of general medical records should be

---

173. It is true that learning of genetic predisposition to a late-onset disorder may, in some instances and to some people, be regarded as beneficial. Inasmuch as the individual chose not to avail himself or herself of the information, however, any possible salutary effect cannot justify the intrusion.

174. This is analogous to the insurance principle of adverse selection, in which those at the greatest risk are most likely to seek insurance. It is specifically to avoid adverse selection that insurance companies assert that they need to be able to perform genetic testing. See generally Mark A. Rothstein, Genetics, Insurance, and the Ethics of Genetic Counseling, in 3 MOLECULAR GENETIC MEDICINE 159 (Theodore Friedmann ed., 1993).
permitted even in the absence of any reason to suspect a serious disorder. Otherwise, plaintiffs with extant but nonobvious disorders would receive a windfall. Without new legislation, however, genetic information in general medical records could be revealed, with the attendant negative implications for public policy previously discussed. Finally, a compelled genetic test should not be permitted when the individual is asymptomatic, regardless of whether the plaintiff has knowledge of a significant genetic risk. To be fair, however, plaintiffs should be precluded from introducing evidence of genetic predictors of longevity.

What are the costs and benefits of permitting or prohibiting this type of discovery? Part II showed that the lump sum payment rule is outcome-neutral in the aggregate because, theoretically over time, all plaintiffs will receive the same total amount of money from all defendants that they would have been paid if all payments were made retroactively instead of prospectively. The analysis does not change with the advent of new genetic information. In fact, if one adds the costs of genetic testing and litigating the issue of life expectancy, defendants in the aggregate will be worse off if discovery of genetic information and genetic testing were permitted. On the other hand, some defendants will be much better off and, without restrictions on their ability to obtain genetic information, many plaintiffs, regardless of their financial recoveries, will be in a much worse position.

The following three subsections present three alternatives to deal with the problem of discovery of genetic information. The first alternative is a judicial solution, through an expansive reading and liberal use of protective orders pursuant to Rule 26(c) of the Federal Rules of Civil Procedure. The second option would enact a specific genetic confidentiality statute. After discussing some existing confidentiality laws, the key elements of a genetic confidentiality statute are presented in subsection VI.C.2. The third option would enact legislation for the variable periodic payment of damages. The theory is simple: If defendants paid plaintiffs for lost income for their working lives and terminated payments if the plaintiff died prematurely because of a preinjury medical condition, then there would be no need to discover the plaintiff's medical records and discovery requests for genetic information could be denied as irrelevant.

B. Protective Orders Under Rule 26(c) of the Federal Rules of Civil Procedure and State Law Analogs

Rule 26(c) of the Federal Rules of Civil Procedure authorizes the trial court to issue a wide range of discovery orders for the protection of parties during the discovery process. Similar provisions are found in the rules of civil procedure of virtually every state. The movant must show that good cause exists to prevent the opposing party from engaging in any form of discovery which would be an "annoyance, embarrassment, oppression, or undue burden or expense" to the movant. Rule 26(c) prohibits or limits the disclosure of relevant information, and so acts as a "necessary safeguard" in a system which permits virtually unlimited discovery.
The movant bears the burden of proving the necessity of the protective order. This burden must be met by showing specific examples of the harms to be avoided and the high likelihood that harm will occur. In some cases, the courts will require an in camera examination of the evidence before issuing a protective order.

A finding of "good cause" to issue a protective order depends on the facts of the case, but the term "good cause" "generally signifies a sound basis or legitimate need to take judicial action." Frequently, the courts will consider whether alternative means for discovery are available. If so, then a protective order is more likely to be issued.

Although no cases have yet addressed the specific issue of discovery of genetic information, it is clear that a trial court may issue a protective order to safeguard privacy. In Seattle Times Co. v. Rhinehart, the Supreme Court observed that abuse of pretrial discovery "is not limited to matters of delay and expense; discovery also may seriously implicate privacy interests of litigants and third parties." The Court further noted: "Although the Rule [26(c)] contains no specific reference to privacy or to other rights or interests that may be implicated, such matters are implicit in the broad purpose and language of the Rule."

Rule 26(c) empowers the court to issue "any order which justice requires," including "that the discovery not be had." When presented with a motion to limit discovery through issuance of a protective order, the court should weigh the relative interests of the parties seeking and opposing discovery, as well as the public interest. As demonstrated in Part V, both the personal injury plaintiff's and the public's interests in preserving privacy and preventing the discovery of confidential genetic information are substantial. They outweigh the defendant's interest in discovering a genetic basis for limiting damages. Thus, there are ample legal and equitable grounds for issuing a protective order.

C. Enacting a Genetic Privacy and Confidentiality Law

1. Specific Confidentiality Laws

Legislation affording statutory protection for a particular class of medical records is not novel. Numerous states have enacted laws protecting the confidentiality of HIV records. At the federal level, legislation protects the confidentiality of substance abuse records and records of genetic research.

180. See Swift v. Swift, 64 F.R.D. 440, 443 (E.D.N.Y. 1974). Although there is no time requirement in Rule 26(c), the motion should be filed in a timely manner. Prior to 1970, Rule 30 of the Federal Rules of Civil Procedure required that a motion for a protective order be "seasonably" made. The 1970 revision deleted any reference to time, but motions have been denied on the basis of inexcusable delay in filing. See Nestle Foods, 129 F.R.D. at 487 (denying protective order filed two months after discovery due); United States v. Panhandle E. Corp., 118 F.R.D. 346, 350-51 (D. Del. 1988) (denying protective order filed three weeks after discovery due).
184. Id. at 34-35.
185. Id. at 35 n.21.
a. HIV Records

Nineteen states have laws that protect the confidentiality of HIV records. As explained by one court, "the purpose of [these laws] is to control the spread of the HIV virus by encouraging the public to submit to voluntary testing through an assurance of confidentiality." Most of the states permit disclosure of the information pursuant to court order upon a showing of "compelling need." Only the laws in Colorado and Idaho have no "compelling need" exception. In most states with a compelling need exception, by statute, the need for the information in civil litigation is sufficient. In other states, such as Pennsylvania, compelling need must be determined by the court on an individual basis.

Even in those states with confidentiality laws, some courts have recognized the admissibility (and therefore the discoverability) of the plaintiff's HIV status for the purpose of assessing damages in a personal injury action. For example, in Dwight B. v. Board of Education of the City of Newburgh, the court noted:

In bringing this action plaintiff has placed into issue not only his past and present medical condition, but seeks also to argue the permanency of his injuries. That anyone, let alone a young boy, has tested HIV positive, is a cause for great sadness. However, suppressing this information from a jury which is charged with judging his medical condition and, if appropriate, placing an award based on life expectancy, would not serve the interests of justice, and would certainly violate defendant's right to a fair trial.

HIV confidentiality laws seek to prevent the spread of infection. If confidentiality is assured, at-risk individuals will be more likely to undergo testing. Those who test positive will also be more likely to take precautions against transmission of the infection. Because the primary purpose of these laws is to promote public health, the courts have easily subordinated the laws' secondary interest in confidentiality to the search for truth in litigation.


188. "[T]he court shall weigh the need for disclosure against the privacy interest of the individual and the public interest which may be harmed by disclosure." Pa. Stat. Ann. tit. 35, § 7608(c).


b. Substance Abuse Treatment Records

To encourage individuals to participate in substance abuse treatment programs, federal law provides that any federally directed or federally funded program must ensure the confidentiality of patient records. Disclosure is permitted without the consent of the individual in three situations: (1) to medical personnel in a bona fide medical emergency; (2) to qualified personnel for conducting scientific research or program audits, as long as the records are not in a personally identifiable form; and (3) upon a court order if good cause is shown, which includes "the need to avert a substantial risk of death or serious bodily harm." Of the three exceptions, the good cause provision is the most vague. There is no evidence, however, that this exception has been used to justify any wide-scale release of confidential information. For example, courts have found good cause to release records where a psychotherapist was being investigated for billing fraud; where a defendant convicted of heroin distribution was required to participate in a drug treatment program as a condition of probation; and where an administratrix sought to recover for an arrestee's death while in custody and defendants requested medical records to determine whether drug use caused the death. Conversely, a court did not find good cause when a putative father in a paternity proceeding sought to obtain the natural mother's drug treatment records to attack her credibility.

c. Records of Medical Research

The Public Health Service Act, as amended in 1988, contains a provision protecting the privacy of individuals who are research subjects. The Secretary of Health and Human Services is authorized to issue a certificate of confidentiality to researchers engaged in "biomedical, behavioral, clinical, or other research . . . to protect the privacy of individuals who are the subject of such research." Significantly, the ability to assert the confidentiality protection rests exclusively with the researchers, who must seek the certificate from the Secretary and resist disclosure of the research records. "Persons so authorized to protect the privacy of such individuals may not be compelled in any Federal, State, or local, civil, criminal, administrative, legislative, or other proceedings to identify such individuals."

191. The statute provides, in relevant part:
Records of the identity, diagnosis, prognosis, or treatment of any patient which are maintained in connection with the performance of any program or activity relating to substance abuse education, prevention, training, treatment, rehabilitation, or research, which is conducted, regulated, or directly or indirectly assisted by any department or agency of the United States shall, except as provided in subsection (e), be confidential and be disclosed only for the purposes and under the circumstances expressly authorized under subsection (b).
192. Id. § 290dd-2(b)(2).
198. Id.
199. Id.
The rationale for this legislation is easy to understand, and it parallels the need for protection of genetic records in the clinical setting. Without this protection, individuals may be reluctant to participate in medical research due to possible adverse personal consequences. Moreover, the statute does not merely prohibit researchers from disclosing the information; it also bars court-ordered disclosure in legal proceedings. This is precisely the type of protection needed for genetic records.

2. Key Elements of a Genetic Privacy and Confidentiality Law

a. All Genetic Records Must Be Kept Separate from Other Medical Records

This provision requires that all health care providers who generate or maintain genetic records store them apart from other medical records. Such a provision promotes confidentiality and prevents the disclosure of genetic records when other health records are released. The idea of storing sensitive medical records in separate files has been used successfully in other contexts.

Defining the term "genetic" in any genetic confidentiality statute would be a conceptually difficult, although unavoidable, task. As a scientific matter, any attempt to distinguish genetic medical records from nongenetic medical records is admittedly imprecise. Nevertheless, it is clear that certain predictive genetic information which, if disseminated, is likely to cause stigma, embarrassment, discrimination, and loss of esteem should be protected from disclosure.

One may choose from several models in formulating a definition of the term "genetic." A number of state legislatures have already enacted laws to prevent discrimination in employment and insurance on the basis of genetic information or genetic testing. The most comprehensive definition is found in California:

"Genetic characteristics" as used in this section means any scientifically or medically identifiable gene or chromosome, or alteration thereof, that is known to be a cause of a disease or disorder, or determined to be associated with a statistically increased risk of development of a disease or disorder, that is presently not associated with any symptoms of any disease or disorder.

200. The original version of the statute applied only to research involving the use of illicit substances, but it was difficult to find research subjects who were willing to admit that they had engaged in unlawful conduct. The 1988 amendment broadened the protection to all forms of biomedical research, thereby recognizing that negative consequences could attach to research subjects' lawful activities as well. See generally Charles L. Earley & Louise C. Strong, Certificates of Confidentiality: A Valuable Tool for Protecting Genetic Data, 57 AM. J. HUM. GENETICS 727 (1995).

201. For example, psychiatric records are often stored separately from other medical records. Also, § 12112(d)(3) of the Americans with Disabilities Act, 42 U.S.C. § 12101-12213 (1994 & Supp. 1995), provides that covered employers must store all employee medical records in separate files (not with personnel files), which must be kept confidential. Similar provisions are contained in state disability discrimination laws.


204. CAL. HEALTH & SAFETY CODE § 1374.7(e) (West Supp. 1996).
The significance of this definition is that it is not linked to "genetic testing" or any specific genetic diseases or traits. A broad definition of "genetic" better protects against a wide range of possible forms of discrimination, including that based on family histories.

b. All Genetic Information Disclosures, Not to Health Care Providers, Are Limited to the Individual Whose Records Are Involved

No release authorizing disclosure of these records to any party other than the person whose genetic records are involved should be permitted except under the following circumstances: First, where testing is appropriately authorized on children or incompetent patients, parents or guardians may be notified of genetic information. Second, the personal representative of the individual may be provided with the records in the event the individual is deceased. Third, genetic information may be provided to law enforcement authorities and other designated agencies for purposes of identification, provided that the release is pursuant to legal process and the individual is unavailable for testing.

Such a provision, with only narrow exceptions, limits disclosure of genetic information to anyone other than the individual. The individual cannot sign a release authorizing disclosure of the records to a third party.

c. Genetic Records Are Not Subject to Subpoena

The statute must expressly provide that genetic records are not subject to subpoena. Without such a provision, the statute would have little value. This provision also permits the health care provider or other custodian of genetic records to resist disclosure.

In 1995, Oregon enacted the first comprehensive genetic privacy legislation. Among other provisions, "a person may not disclose or be compelled, by subpoena or any other means, to disclose . . . genetic information about the individual in a manner that permits identification of the individual." An exception is made, however, for disclosures pursuant to a specific court order in civil litigation, and, as such, this provision does not satisfy the concerns set forth in this Article.

d. Prohibiting Disclosure of Genetic Records to Establish Plaintiff's Future Lost Income in a Civil Action

This provision would prohibit conditioning any civil action on discovery of plaintiff's genetic records. It is designed to prevent plaintiffs from being ordered to produce their own genetic records. Although the above provision is limited to civil litigation, similar language could be used to prohibit the conditioning of employment or insurance on the disclosure of genetic information. Significantly, the provision is specifically limited to the issue of damages; it allows defendants to discover genetic information necessary to

206. Id. § 659.720(1).
207. Id. § 659.720(1)(b).
demonstrate that the plaintiff’s injuries were caused by genetic factors rather than by any action of the defendant.

To obtain causation-related genetic discovery, the defendant would have to demonstrate a reasonable basis for believing that the plaintiff’s alleged injuries could be the result of genetic factors. When discovery is ordered, the plaintiff would have a right to require that defendant’s experts and counsel be subject to a protective order, that the information be reviewed in camera, and that the record be sealed.

e. Prohibition of Compelled Genetic Testing

The statute should expressly prohibit the compelled genetic testing of any individual in civil litigation.

D. Variable Periodic Payment of Damages

If payment to the plaintiff were made in installments for the duration of the plaintiff’s life, as opposed to a lump sum payment, it would be unnecessary to estimate the life expectancy or work life expectancy of the plaintiff. Payments would simply terminate on the plaintiff’s death. Under such a payment system, therefore, predictions of the plaintiff’s future health status and life expectancy, including those based on the plaintiff’s genotype, would be irrelevant. Such a system would differ markedly from the current lump sum payment system and the current statutory enactments providing for periodic payments of damages.

As mentioned earlier, lump sum payments have been used at common law for centuries. Nevertheless, periodic payments have been used successfully in other countries. There are three main arguments supporting periodic payments: (1) they more accurately reflect the plaintiff’s actual loss; (2) they avoid the dissipation of resources by the plaintiff; and (3) they have more advantageous tax consequences for the plaintiff. There are also three main arguments in favor of the continued use of the lump sum payment rule: (1) simplicity; (2) efficiency; and (3) finality.

Most states have enacted statutes providing for the optional use of periodic payments of damages. In general, opposition from both plaintiffs (who tend to want immediate payment in full) and insurance companies (who dislike the uncertainty of carrying forward obligations for an unknown period of years) has curbed the use of these laws. As currently drafted, however, the statutes are inadequate to relieve the pressure to discover genetic records.

The Uniform Periodic Payment of Judgments Act ("UPPJA"), provides that, in a claim for future economic loss over $100,000, either party may elect a periodic payment

---


211. See Henderson, supra note 80.


award rather than a lump sum judgment. If a party elects to receive a periodic payment award, the court will ask the jury to specify any past damages in a lump sum, any future noneconomic loss in a lump sum, and future damages for medical expenses and other economic loss. The jury must then determine the annual periods over which the claims for medical expenses and other economic loss will accrue. More importantly, the jury must determine how long the claimant would have lived but for the injury. Virtually all of the current periodic payment statutes still require litigation over the plaintiff's preinjury life expectancy.

The problem with current periodic payment statutes is that they establish a lump sum calculation of damages using a periodic payment mechanism. Only a system of variable payments would eliminate the need for an estimate of life expectancy. Although plaintiffs tend to view periodic payment statutes as pro-defendant, plaintiffs may be willing to elect periodic payments in exchange for a ban on discovery of genetic information. Defendants would be able to avoid the problem of overcompensation and the cost of proving life expectancy if a feasible, efficient system for variable periodic payments were developed.

CONCLUSION

Professor John G. Fleming began a 1962 law review article on damages with the following sentence:

Significant and continuing advances by contemporary medicine in diagnostic and clinical skills have made it increasingly more possible and common to venture a prognosis of diminished life expectancy for victims of disease and accident, sufficiently reliable to meet the conventional legal standard of proof on a balance of probabilities.

Undoubtedly, Professor Fleming was referring to predictions of life expectancy based on currently manifested medical conditions. He probably could not have imagined that by the end of the century, the DNA in a single drop of blood could be used to predict the future health status of an asymptomatic individual.

In personal injury litigation, blindly permitting the discovery of unlimited amounts of medical information for determining damages does not serve justice. The incantation of the "search for truth" in discovery cannot be used to override all other interests. It is true that a wide range of personal information, including facts about income and relationships, is routinely discovered in civil litigation. Yet, substantial and unique public policy interests weigh in favor of protecting the privacy and confidentiality of sensitive genetic information. Individuals should not be deterred from asserting valid legal claims due to concerns about the needlessly intrusive discovery of genetic information.

No cases have yet been reported in which defendants have sought to discover genetic information or to perform genetic testing on a personal injury plaintiff solely for use in assessing damages. Nevertheless, such an action will inevitably occur. Indeed, it is surprising that it has not occurred already. The financial stakes for individual defendants

214. Id. § 2.
215. Id. § 4.
216. Id.
217. Any statute would need to include provisions to protect the plaintiff in the event of the defendant's bankruptcy or insolvency.
are too high, and the adversarial culture of personal injury litigation too ingrained, to assume that genetic information will not mutate from the criminal to the civil courts. Motions to compel production of genetic records or to compel genetic testing are not a matter of "whether," but of "when." Therefore, time is of the essence in addressing these concerns.

This Article has presented three ways to prevent the use of a personal injury plaintiff's genetic profile in assessing damages. One of the alternatives is judicial, while two are legislative. The judicial solution is the easiest to implement. Judges in the federal and state courts already have the power to prevent burdensome and embarrassing discovery by issuing protective orders. The problem is that, even in the most favorable scenario, it will take years to achieve any degree of consensus in the courts that discovery of a personal injury plaintiff's genetic profile solely for the purposes of assessing damages is impermissible. It is more likely that there will be a split of authority and many jurisdictions will have no authoritative position.

The second alternative involves enacting legislation to protect the confidentiality of genetic information. This approach has the virtue of providing protections to individuals beyond the narrow realm of civil litigation. However, there are several problems with this alternative. First, without a federal law, there will be gaps in the protections afforded by the states. Second, legislatures will face difficulties in agreeing on a definition of "genetic" to be used in the statute. Third, drafters must reconsider the issue of whether genetic confidentiality legislation should provide an exception to court-ordered discovery.

The third alternative is to modify the system of damages in personal injury litigation to adopt variable periodic payment of damages. This approach has the virtue of being a more comprehensive response to the problem, as well as obviating the need to define "genetic." On the other hand, merely changing the system of damages in personal injury litigation will not prohibit disclosures beyond litigation. Moreover, this alternative is unlikely to be adopted, because its sweep is so broad and because it is certain to engender intense opposition from both plaintiffs' and defendants' counsel.

These three alternatives are neither mutually exclusive nor exhaustive of the possible approaches to prevent excessive genetic probing in civil litigation. Nevertheless, various measures need to be carefully considered and expeditiously implemented before human geneticists become regular consultants and witnesses in tort litigation.

And what would happen to Dr. Jane Smith, the hypothetical plaintiff of this Article's Introduction, under today's law? Undoubtedly, the defendant may obtain Smith's medical records, because her physical condition is relevant to past and future medical expenses. The court compelling production of her medical records could exclude, on public policy grounds, all predictive genetic information. However, it is an open question how many courts are prepared to exclude such information.

If health care providers stored all of Dr. Smith's genetic records separately, and if a statute limiting their discoverability existed, this would permit discovery of her medical records without discovery of her genetic records. Assuming her existing genetic records are discoverable, genetic testing of Dr. Smith could be barred on public policy grounds, regardless of whether there is genetic test information in her medical records. A protective order under Rule 26(c) of the Federal Rules of Civil Procedure could be sought to prevent the "burdensome" and "embarrassing" production of her genetic records, depositions of Dr. Smith or her treating physicians regarding genetic information, or
compelled genetic testing. Again, it is not clear whether courts would adopt this approach.

Finally, if the damages awarded to Dr. Smith were payable on a variable, periodic basis, they would be paid when due, without regard for her predicted life expectancy or work life expectancy. The defendant would pay and Dr. Smith would receive exactly the amount of money which reflects her work life and life span.

Although Dr. Smith will no longer be able to practice neurosurgery, perhaps she could take additional training in medical genetics. A need exists for trained medical geneticists in providing health care, where the goal is solely to improve the health of the patient.