

WHAT DO I OWN, IF NOT MYSELF?

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I. INTRODUCTION

New York State has an informed consent procedure for obtaining human tissue for genetic research, which the legislature established to protect donors from discrimination arising out of their genetic information. Moreover, the de-identification and coding requirements set forth by the statute sufficiently insulate a donor's personal identification information from the test results, protecting them from discrimination.

The procedure, however, fails to require disclosure of researchers' personal economic interest in the tissue or research arising out of potential monetary gains. Failing to disclose an economic interest may leave researchers liable to the tissue donor for breach of informed consent.

Providing individuals with a property right in their tissue will allow them to negotiate with a researcher-donee, similar to a sale of goods. The laws of contract will then apply to the transfer of tissue.

Thus, by amending the present informed consent requirements to provide donors with a property interest in their tissues, the statute will protect the donee-researcher from liability due to violation of informed consent requirements outside those expressly enumerated by statute, while simultaneously expanding donors' rights and protections over their tissue to include those enjoyed by having ownership rights in property.

II. CIVIL RIGHTS LAW § 79-L RESEARCH REQUIREMENTS

New York Civil Rights Law § 79-l (hereinafter "NY CRL § 79-l") requires that a researcher-donee seeking tissues or biological samples for genetic testing in New York State must first obtain written informed consent from the donor.¹ There are two types of written informed consent.² The first type of written informed consent is set out in NY CRL § 79-l, subsection two, and must contain at least the following information:

- (1) General description of the test,
- (2) Statement of the purpose of the test,
 - (2-a) Advice to seek professional genetic counseling prior to consenting,
- (3) Statement that a positive result may indicate a predisposition to or affliction with a disease and s/he may want to consult a

¹ N.Y. CIV. RIGHTS LAW § 79-l(2) (McKinney 2002).

² § 79-l(2)(b), (9)(e).

physician or genetic counselor,

(4) General description of each specific disease or condition tested for,

(5) Degree of certainty that a positive result serves as a predictor of such disease, (If there is no level of certainty then disregard this requirement),

(6) Name of the person or categories of persons or organizations to which the test results may be disclosed,

(7) Statement that no other tests shall be conducted, and sample will be destroyed after testing is complete, or at the end of 60 days unless longer has been expressly authorized,

(8) Signature of donor or other authorized person if donor lacks capacity.³

Once a donor has provided the above form of written informed consent, should a researcher wish to conduct tests outside of those specifically listed, or keep the samples for more than sixty days, then he must obtain a second written informed consent from the donor to conduct statutorily and Institutional Review Board (hereinafter "IRB") approved protocols.⁴ The second written informed consent must consist of at least the following information:

(1) A "statement that the sample will be used for future genetic tests;"

(2) Time period that sample will be stored, including if it will be retained for "as long as deemed useful for research purposes;"

(3) Description of how the patient's identity will be protected;

(4) A "statement of the right to withdraw consent";

(5) Option for the individual to consent to future contact for:

(i) Research;

(ii) Findings; and

(iii) Beneficial information regarding preventative or clinical care; and

(6) Explanation of the benefits and risks of future contact under subsection five.⁵

Once both forms of consent have been obtained (under NY CRL § 79-1 (2) and (7)), IRB has approved the protocols of the research, and the samples have either been de-identified or sufficiently coded, then a researcher is free to conduct tests outside of the

³ § 79-1(2). This level of consent was set out in the first codification of NY CRL § 79-1 and has remained since. § 79-1(2) (amended 1997 and 2001).

⁴ Notwithstanding NY CRL § 79-1(7) newborn screening provision; § 79-1(2)(b)(7), (9)(a).

⁵ § 79-1(9)(e)(1)–(6).

scope of the original consent.⁶ However, as part of the second written informed consent, a donor has the right to revoke consent, requiring the donee to destroy all unused, stored samples.⁷

III. A BRIEF HISTORY

A. *DNA Report to the Legislature*

A 1994 report from the New York State Legislative Commission on Science and Technology entitled *DNA-Based Tests: Policy Implications for New York State* (hereinafter “*DNA-Based Tests*”) led to the enactment of New York Civil Rights Law Section 79-1 (hereinafter “NY CRL § 79-1”).⁸ *DNA-Based Tests* provided significant counsel to the New York State Legislature in drafting the original version of NY CRL § 79-1, in three separate ways. First, it provided an explanation of the positive and negative impacts of the technological and scientific advances in the field of genetics.⁹ Next, it reviewed policy measures recommended by the scientific community and described actions already taken by the federal and state governments.¹⁰ Finally, it set out policy options for New York State lawmakers.¹¹

i. Beneficial Impacts of Genetic Testing

DNA-Based Tests indicates several benefits gained from genetic testing, primarily for the purpose of diagnosis.¹² Physicians may diagnose numerous health conditions more accurately and with greater ease through genetic testing.¹³ A

⁶ De-identification is the process of stripping a sample of all information that could link the sample back to the donor. See § 79-1(9)(a)(i); 45 C.F.R. § 164.514(a) (2002). Coding is a system that is set up to protect the identity of an individual while still providing limited social or historical facts about the donor, and in certain circumstances allow for the donor’s identity to be recalled. See § 79-1(9)(a)(ii); see also 45 C.F.R. § 164.514(c).

⁷ N.Y. CIV. RIGHTS LAW § 79-1(9)(b) (McKinney 2002).

⁸ William M. Savino & Stephen J. Smirti, Jr., *Mapping the Law on Genetic Privacy*, N.Y.L.J., Oct. 24, 2000, at 1 [hereinafter *Mapping*]; NY STATE LEGIS. COMM’N ON SCI. & TECH., *DNA-BASED TESTS: POLICY IMPLICATIONS FOR NEW YORK STATE*, LCST Rep. No. 94-1 (1994) [hereinafter *DNA-BASED TESTS*].

⁹ *DNA-BASED TESTS*, *supra* note 8, at 3.

¹⁰ *Id.*

¹¹ *Id.* For the purpose of the present article, only the potential impacts of genetic testing are relevant.

¹² *Id.* at 11–12.

¹³ *Id.* at 11.

compelling example of a benefit of genetic testing provided by the report is the pre-symptomatic diagnosis of retinoblastoma, a hereditary eye cancer that often afflicts children, resulting in blindness or death.¹⁴ Previously, physicians were required to anaesthetize at-risk children and perform invasive retinal examinations every two-to-three months to check their eyes for cancerous tissues; such intrusive and time-consuming tests are unnecessary with genetic testing.¹⁵

Other benefits of genetic testing include: preventative screening, family planning, expediting research, and responding to denials of insurance coverage.¹⁶ Although preventative screening programs have been in place since before the advent of genetic testing, as the technology develops, genetic testing will play a greater role in screening programs.¹⁷ Genetic testing will aid in family planning by assisting prospective parents in determining if they are carriers of hereditary diseases and allowing prospective parents who are carriers to have children successfully without facing the predicament of deciding whether to abort a pregnancy.¹⁸ Finally, denials by insurance companies to underwrite¹⁹ an individual based upon family history may be rebutted through genetic testing by showing that the individual is not afflicted with the genetic makeup necessary for the hereditary disease.²⁰

ii. Adverse Impacts of Genetic Testing

In addition to the potential benefits of genetic testing, *DNA-Based Tests* also discusses potential adverse impacts. The primary concern expressed in the report is discrimination arising out of the non-clinical use of genetic information.²¹ The report

¹⁴ *Id.* (“Another good example of the use of a DNA-based diagnostic test is in the pre-symptomatic diagnosis of retinoblastoma, a hereditary form of eye cancer that strikes in early childhood and leads to blindness and death.”).

¹⁵ DNA-BASED TESTS, *supra* note 8, at 11.

¹⁶ *Id.* at 12.

¹⁷ *Id.* New York State has established a newborn genetic screening program that NY CRL § 9-1 does not affect. N.Y. CIV. RIGHTS LAW § 79-1(7).

¹⁸ DNA-BASED TESTS, *supra* note 8, at 12.

¹⁹ Underwriting is the process of risk-assessment and classification of insured individuals. *Id.* at 56.

²⁰ *Id.* at 12.

²¹ *Id.* at 13. This is aggravated by the often overlooked fact that genetic testing can only make predictions in probabilistic terms and cannot predict if and when a disease will strike with certainty; nor can genetic testing predict the severity of a disease. *Id.*

focuses on the impact that such non-clinical uses of genetic information can have on insurance and employment.²²

a. Insurance Discrimination

Insurers obtain vast amounts of confidential medical information, including genetic test results, which allow underwriters to utilize such information in their efforts to reduce risk. Insurers obtain such information in two ways: first, clinical patients must consent to sharing medical information with insurers to process their claims, and since health insurance coverage has become a necessity, insurers obtain vast amounts of medical information.²³ Second, when insurance applicants are tested, those test results are stored in a centralized database²⁴ to which most insurance companies have access, and may use to prevent adverse selection.²⁵

DNA-Based Tests illustrates the discriminatory exploitation or effects of genetic test results by insurance companies using Office of Technology Assessment studies.²⁶ Fourteen percent of genetic counselors reported that some patients “had difficulties obtaining health insurance after undergoing genetic tests,” particularly when testing positive to carrying the markers for a serious illness.²⁷ More disconcerting was the insurance company’s misunderstanding of genetic test results.²⁸ “Almost half the surveyed insurers believed that carrier status for diseases . . . was a pre-existing condition” despite the fact that genetic testing can only predict a possibility of suffering from the condition in the future.²⁹

²² *Id.* at 13. *DNA-Based Tests* also discusses the potential violations of privacy, and the limited access to genetic testing. *Id.* at 15–17.

²³ *Id.* at 58.

²⁴ See DNA-BASED TESTS, *supra* note 8, at 59. When *DNA-Based Tests* was written, the Medical Information Bureau (“MIB”) held the medical information of about 15 million individuals. *Id.*

²⁵ *Id.* at 59. Adverse selection occurs when individuals personally believe or know that they are at a high risk of becoming ill and fail to share such information with the insurer from whom they seek coverage. *Id.* at 56.

²⁶ *Id.* at 59–60. Those studies include surveys of genetic counselors and insurance company executives. *Id.*

²⁷ *Id.* at 59.

²⁸ *Id.* at 60.

²⁹ *Id.*

b. Employment Discrimination

To reduce costs, employers may choose to use genetic testing to discriminate against the individual employee. While some employers already utilize genetic testing, *DNA-Based Tests* expresses concern that a combination of market pressures, decreased cost and increased availability of testing, and potential loopholes in the Americans with Disabilities Act will create increased genetic testing of employees for improper purposes.³⁰ The impact of employers' increased testing on individuals set forth in the report includes screening for high-risk employees that could cause high health and disability insurance costs, misinterpretation of results that could affect the conditions of employment; and an increased possibility of violation of confidentiality.³¹

DNA-Based Tests further advises the legislature of potential societal effects that may arise out of the discriminatory effects on individual employees by their employers.³² Individuals, unemployable due to a genetic predisposition, might turn to public support for health care.³³ Since those individuals' health care costs for the genetic predisposition would remain largely the same despite unemployment, the employer shifts the burden of bearing that cost to the taxpayer and leaves the individual underproductive.³⁴ Additionally, if an employer limits its workforce to individuals who are resistant to a hazardous work environment, that may lead to relaxed safety standards by employers.³⁵

The report's discussion of the potential benefits and harms associated with genetic testing guided the legislature in establishing the original version of NY DRL § 79-1. The emphasis in the report, given to the potential harms of genetic testing over its potential benefits, has affected the statute's history and language. However, the report failed to advise the legislature that providing a property interest in an individual's tissue or genetic information was an option for protecting an individual from the potential harms discussed above.

³⁰ DNA-BASED TESTS, *supra* note 8, at 63–64.

³¹ *Id.* at 66.

³² *Id.* at 13.

³³ *Id.* at 66.

³⁴ *Id.* at 66–67.

³⁵ *Id.* at 67.

B. Statutory History

Upon review of the statutory history of NY CRL § 79-1, the legislative focus on preventing genetic discrimination becomes obvious. The bill's original sponsor and its supporters outside of the legislature were centrally focused on protecting individuals from the abuse or misuse of genetic information by employers and insurers.³⁶ While chapter 497 of the laws of 1996, which formed the original version of NY CRL § 79-1, expressed an interest in providing individuals a privacy right in controlling the dissemination of their genetic information,³⁷ that right falls short of providing adequate protection of both the donor's and researcher's property interests.

Subsequently, the legislature proposed an amendment in 1997 to address the restrictive language of NY CRL § 79-1. Prior to the amendment, the statute limited testing donated tissues to those tests expressly provided for in the donor's consent, and the researcher could keep the tissues for only sixty days.³⁸ The amendment requires a procedure for renewed informed consent to conduct research outside the scope of the original informed consent required by NY CRL § 79-1(2).³⁹ Upon fulfilling the second informed consent requirements, the researcher may expand the scope of testing and keep the sample indefinitely, or until the donor demands destruction of the sample.⁴⁰ The final amendment to NY CRL § 79-1 was signed into law as chapter 342 of the laws of 2001.⁴¹ At no time throughout the history of NY CRL § 79-1 have the law's amendments established the purpose of the statute to be other than the protection of a donor's genetic information to prevent discrimination.

Since the statute requires de-identification or coding of tissue samples to conduct any significant research,⁴² which effectively protects a donor from discrimination,⁴³ informed consent is

³⁶ *Id.* at 13.

³⁷ 1996 N.Y. Laws 497.

³⁸ 1997 N.Y. Laws 645.

³⁹ N.Y. CIV. RIGHTS LAW § 79-1(2)(b), (7), (8)(f) (McKinney 1997) (amended 1997 and 2002); *see also* § 79-1(9)(a) (2002).

⁴⁰ § 79-1(9) (1998) (amended 2001).

⁴¹ § 79-1.

⁴² That which falls under the scope of N.Y. CIV. RIGHTS LAW § 79-1(9). N.Y. CIV. RIGHTS LAW § 79-1(9)(a).

⁴³ By removing any personally identifiable information from the sample, the donor is anonymous and, therefore, cannot be the subject of discrimination. *See supra* text accompanying notes 7–8 (demonstrating protections for donors who

unnecessary to fulfill that purpose. Researchers, however, following the express requirements of informed consent under NY CRL §§ 79-1(2), (9) are not required to divulge any financial interest, which may leave them liable. Providing individuals with a property interest in their tissue gives them more rights in the “donation” process, while protecting researchers from liability under contract law.

IV. LIABILITY FOR FINANCIAL INTEREST

New York State Civil Rights Law § 79-1 does not require a donee to provide any explanation of a financial interest in the tissue or research, which leaves the researcher-donee vulnerable. Informed consent requires the researcher-donee to divulge any financial interest.⁴⁴ Failing to do so leaves the researcher-donee liable for violation of informed consent. New York State’s present informed consent model under NY CRL § 79-1 does not expressly require researcher-donees to provide donors with an explanation of any financial interest in research conducted on the tissue. Thus, researchers may be liable in tort despite following the procedures set out in NY CRL § 79-1 for lack of informed consent.

A. *Moore v. Regents of University of California*

The California Supreme Court’s decision in *Moore v Regents of the University of California*⁴⁵ illustrates the problem of lack of informed consent.⁴⁶ Moore became a patient at UCLA Medical Center in October of 1976 after being afflicted with hairy-cell leukemia.⁴⁷ Moore was tended to by Dr. Golde, who, after confirming the diagnosis of hairy-cell leukemia, recommended that Moore’s spleen be removed to slow the disease’s progress.⁴⁸ At this time, Moore authorized for Dr. Golde to perform a splenectomy by signing a written consent form.⁴⁹ Dr. Golde and Ms. Quan, a researcher, removed biological samples from Moore’s spleen after the splenectomy without informing Moore of their

cease to be identified).

⁴⁴ Financial interest is defined as “[a]n interest involving money or its equivalent.” BLACK’S LAW DICTIONARY (8th ed. 2004) [hereinafter BLACK’S LAW].

⁴⁵ *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479 (Cal. 1990).

⁴⁶ *Id.* at 483.

⁴⁷ *Id.* at 481.

⁴⁸ *Id.*

⁴⁹ *Id.*

intent to conduct research on the excised spleen.⁵⁰ Following Dr. Golde's instruction, Moore continued to supply biological samples until 1983.⁵¹ During the course of this research, California's Informed Consent requirements governing Dr. Golde and Ms. Quan's research came into effect.⁵²

The Supreme Court of California considered Moore's claim that the disclosure of Dr. Golde's financial interest was required to obtain informed consent and failing to disclose such an interest was a breach of Dr. Golde's fiduciary duty.⁵³ The court stated that the fiduciary duty to disclose facts pertinent to consent is synonymous with obtaining informed consent prior to conducting medical procedures.⁵⁴ When dealing with issues of informed consent, the court concluded: "[A] physician must disclose personal interests unrelated to the patient's health, whether research or economic, that may affect the physician's professional judgment."⁵⁵ Further, the court determined that "a physician's failure to disclose such interests may give rise to a cause of action for performing medical procedures without informed consent or breach of fiduciary duty."⁵⁶

While courts normally apply breach of fiduciary duty to complaints of medical malpractice, breach of fiduciary duty is also clearly applicable to failure to disclose a personal interest.⁵⁷ Additionally, despite the therapeutic nature of the splenectomy, Dr. Golde was still under a duty to reveal his personal interests in the research to Moore.⁵⁸ Thus, Dr. Golde's failure to disclose his personal interests, research or economic, prior to Moore's splenectomy and the postoperative taking of biological samples, leave Dr. Golde, and possibly any employer or sponsor of the research, liable.⁵⁹

The *Moore* court was operating under an informed consent

⁵⁰ *Id.*

⁵¹ *Moore*, 793 P.2d at 481.

⁵² *Id.* at 481–82; Protection of Human Subjects in Medical Experimentation Act, CAL. HEALTH & SAFETY CODE §§ 24170, 24172 (West 1978).

⁵³ Despite thirteen separate causes of action, this analysis is concerned with the complaints for lack of informed consent and breach of a fiduciary duty. *Moore*, 793 P.2d at 483, n.4.

⁵⁴ *Id.* at 483.

⁵⁵ *Id.*

⁵⁶ *Id.*

⁵⁷ *Id.*

⁵⁸ *Id.* at 486. That included any personal interests of an economic nature, which was the primary concern for the *Moore* court. *Id.* at 484–86.

⁵⁹ *Moore*, 793 P.2d at 486–87.

statute pertaining to human research (including genetic testing) codified as California Health & Safety Code (hereinafter “CA H&S”) § 27143.⁶⁰ Despite California’s stringent informed consent requirements under CA H&S § 27143 for genetic testing on human tissue,⁶¹ the *Moore* court determined that a failure to disclose a researcher-donee’s financial interest in the tissue and research constitutes a breach of a researcher’s fiduciary duty.⁶²

California’s informed consent requirements are substantially similar to New York State’s requirements. The CA H&S § 27143 informed consent requirements include, first, that a copy of the “Experimental Subject’s Bill of Rights,” (as set out in CA H&S § 27142),⁶³ be provided to the subject, signed and dated.⁶⁴ The experimental subject’s bill of rights is made up of the same informational disclosure requirements as under NY CRL § 79-1.⁶⁵ Once the donor has signed and dated the “Experimental Subject’s

⁶⁰ CAL. HEALTH & SAFETY CODE § 24173 (West 2004).

⁶¹ *Moore*, 793 P.2d at 484 (reviewing the statute, the court did not discuss any statutory violations, implying that Dr. Golde followed the statute’s guidelines).

⁶² *Id.* at 486.

⁶³ A list of the experimental subjects’ rights are set out, including the rights to:

- (a) Be informed of the nature and purpose of the experiment.
- (b) Be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized.
- (c) Be given a description of any attendant discomforts and risks reasonably to be expected from the experiment.
- (d) Be given an explanation of any benefits to the subject reasonably to be expected from the experiment, if applicable.
- (e) Be given a disclosure of any appropriate alternative procedures, drugs or devices that might be advantageous to the subject, and their relative risks and benefits.
- (f) Be informed of the avenues of medical treatment, if any, available to the subject after the experiment if complications should arise.
- (g) Be given an opportunity to ask any questions concerning the experiment or the procedures involved.
- (h) Be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation in the medical experiment without prejudice.
- (i) Be given a copy of the signed and dated written consent form as provided for by Section 24173 or 24178.
- (j) Be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence on the subject’s decision.

CAL. HEALTH & SAFETY CODE § 24172 (West 2004).

⁶⁴ § 24173.

⁶⁵ *See* N.Y. CIV. RIGHTS LAW § 79-1(2) (McKinney 2002) (including substantially similar disclosure requirements for obtaining informed consent).

Bill of Rights” the donor must then be provided with, and sign, a written consent form that must be verbally explained to the donor in non-technical terminology.⁶⁶ The explanation must contain at least eleven separate aspects of the research that may influence the donor’s decision-making process.⁶⁷ Finally, a witness must sign and date the written consent form⁶⁸ and the donor must consent voluntarily.⁶⁹ It was under these statutory guidelines, similar to those in NY CRL § 79-1, that the researchers in *Moore* operated; the court still found, however, that the researchers violated their fiduciary duty for failure to disclose the researcher-donee’s financial interest in the tissue or research.⁷⁰

⁶⁶ § 24173(a)–(c).

⁶⁷

(1) An explanation of the procedures to be followed in the medical experiment . . .

(2) A description of any attendant discomfort and risks to the subject reasonably to be expected.

(3) An explanation of any benefits to the subject reasonably to be expected, if applicable.

(4) A disclosure of any appropriate alternative procedures, drugs, or devices that might be advantageous to the subject, and their relative risks and benefits.

(5) An estimate of the expected recovery time of the subject after the experiment.

(6) An offer to answer any inquiries concerning the experiment or the procedures involved.

(7) An instruction to the subject that he or she is free to withdraw his or her prior consent to the medical experiment and discontinue participation in the medical experiment at any time, without prejudice to the subject.

(8) The [identification and contact information] of the person or persons actually performing and primarily responsible for the conduct of the experiment.

(9) The name of the sponsor or funding source . . .

(10) The [identification and contact information] of an impartial third party, not associated with the experiment, to whom the subject may address complaints about the experiment.

(11) The material financial stake or interest, if any, that the investigator or research institution has in the outcome of the medical experiment.

§ 24173(c)(1)–(11). Subsection (c)(11), requiring disclosure of economic interest or intent, was added in a 2003 amendment. 2003 Cal. Legis. Serv. 1371 (West).

⁶⁸ § 24173(b).

⁶⁹ See § 24173(e) (discussing consent).

⁷⁰ It is important to point out that the research conducted in *Moore* commenced in 1976 prior to the enactment of § 27143, but the researchers continued to obtain biological samples from Moore into 1983, subsequently working under the statutory informed consent guidelines. *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 481, 483 (Cal. 1990).

Similar to the California statutory informed consent requirements⁷¹ giving rise to *Moore*, New York State's statutory Informed Consent requirements, codified as NY CRL § 79-1, do not expressly require disclosure of any economic interest or intent by the researcher-donee.⁷² Because the purpose of genetic research often is to patent a new discovery and reap the discovery's economic benefits, the lack of a statutory requirement to disclose the economic intent or interests to patients could leave researchers unaware that the common law informed consent requirement may not be satisfied unless all personal interests of the researcher are revealed as well. Therefore, a researcher following the informed consent guidelines set out in NY CRL § 79-1 might still be liable for a claim of lack of informed consent as established in *Moore*.⁷³

V. PROPERTY RIGHTS IN NEW YORK STATE

An alternative approach to New York State's informed consent model, as established by NY CRL § 79-1, is to provide an individual with a property interest in his or her tissues and genetic information. Providing donors with a property interest in their tissues and genetic information instills donors with more rights and protections than is possible through an informed consent model alone. "It has been observed that a privacy right [,

⁷¹ Prior to the 2003 amendment. § 24173.

⁷² See generally N.Y. CIV. RIGHTS LAW § 79-1 (McKinney 2002) (setting forth the informed consent requirements of genetic tests records).

⁷³ The United States District Court for the Southern District of Florida distinguished *Moore* in its *Greenberg v Miami Children's Hospital Research Institute* decision. *Greenberg v Miami Children's Hosp. Research Inst.*, 264 F. Supp. 2d 1064, 1070 (S.D. Fla. 2003). The *Moore* and *Greenburg* courts failed to agree on whether a researcher is duty-bound to disclose any economic interests or intentions to obtain the adequate informed consent of a donor. *Id.*; see also *Moore*, 793 P.2d at 486. The court distinguished *Moore* on the basis that Moore and Dr. Golde shared a therapeutic relationship, while in *Greenberg* the defendants were solely medical researchers, so no therapeutic relationship existed. *Greenberg*, 264 F. Supp. 2d at 1070. However, "Moore admit[ted] in his complaint that defendants disclosed they 'were engaged in strictly academic and purely scientific medical research.'" *Moore*, 793 P.2d at 486. The *Moore* court also found that disclosure of any interest outside the health of a patient motivating a medical procedure, therapeutic or otherwise, is necessary. *Id.* at 486 (discussing why Moore's failure to establish a therapeutic purpose for the splenectomy was inconsequential). Since the *Moore* court did not rely upon the nature of the relationship between Moore and Dr. Golde, but instead relied upon the motivation to perform medical procedures; distinguishing *Moore* based upon the difference between therapeutic and research relationships is not convincing.

such as NY CRL § 79-1,] merely affords an individual a ‘right of non-interference,’ while a property right is a ‘right of positive entitlement.’”⁷⁴ A property right can provide donors discretion over the “control, possession, and transferability” of their tissue.⁷⁵

Therefore, it logically follows that an individual who transfers the title of a tissue sample in its entirety, which includes its genetic information, would thereby protect a physician from liability arising out of a failure to communicate a financial interest in the sample and associated research. This protection arises out of contract law and the rule of consideration.⁷⁶ However, to determine if such a property interest in tissue is possible in New York State, a review of the prima facie elements of property, whether tissue fulfills those prima facie elements of property, and any past treatment of the issue by the state’s courts, is necessary before proceeding.⁷⁷

A. *New York State Common Law Property Requirements*

In a strictly legal sense, property in New York State is a fundamental “aggregate of rights which are guaranteed and protected by the government” and attached to a physical thing.⁷⁸ Property rights attach to any object subject to ownership and legal title.⁷⁹ Traditionally, property is considered to be “the highest right” a person can have in an object.⁸⁰ However, property only attaches to those objects legally owned, and not merely to the subject of an object “to which [a person] only has a moral claim”.⁸¹

Title is the basis for ownership and as title passes, so does

⁷⁴ Mary J. Hildebrand, Jacqueline Klosek & Walter Krzastek, *Toward a Unified Approach to Protection of Genetic Information*, 22 BIOTECHNOLOGY L. REP. 602, 604 (2003).

⁷⁵ *Id.*

⁷⁶ Consideration is “either a benefit to a promisor or a detriment to the promisee” given in exchange for the sought after promise. *Weiner v. McGraw-Hill, Inc.*, 57 N.Y.2d 458, 464 (1982).

⁷⁷ See Hildebrand, *supra* note 74, at 604 (explaining that “it is clear that genetic information has characteristics of property”, but the court should decide its status as a property right).

⁷⁸ *Fulton Light, Heat & Power Co. v. New York*, 65 Misc. 263, 288 (N.Y. Ct. Cl. 1909).

⁷⁹ *Springfield Fire & Marine Ins. Co. v. Allen*, 43 N.Y. 389, 395 (1871).

⁸⁰ *Stief v. Hart*, 1 N.Y. 20, 24 (1847).

⁸¹ *Streever v. Birch*, 17 N.Y.S. 195, 197 (N.Y. Gen. Term 3d Dep’t 1891).

ownership.⁸² Perfect title is established when an individual has “actual possession, the right of possession and the right of property.”⁸³ The New York Court of Appeals has defined the right of possession as “an inherent right to the dominion over, and the beneficial enjoyment of, some valuable right, or interest.”⁸⁴ Six years later, the Court of Appeals defined the right of property as “the right to acquire, possess and enjoy [the property] in any way consistent with the equal rights of others and the just exactions and demands of the State.”⁸⁵ Ownership, arising out of sufficient title provides an individual with complete and exclusive control of an object,⁸⁶ limited only by law or contract.⁸⁷ Thus, to determine if donors may have a property interest in their tissues and genetic information, such objects must comport to the above requirements.

B. Property Characteristics of Tissue and Genetic Information

Tissues are the basic components of the human body.⁸⁸ Organs are formed from either a single type of tissue or a slight combination of varied types of tissues.⁸⁹ Organs work together as systems and the chorus of systems is what makes a physical body.⁹⁰

Cells, containing an individual’s genetic code, are the building blocks of tissues.⁹¹ Each cell contains a nucleus or kernel that appears to control its activities.⁹² Nuclei carry forty-six chromosomes⁹³—the foundation of a body’s individuality.⁹⁴ The body’s genetic code makes up those chromosomes.⁹⁵ That code provides “the detailed specifications for the thousands of

⁸² *Springfield*, 43 N.Y. at 395.

⁸³ *Evans v. Francis*, 101 N.Y.S.2d 716, 718 (N.Y. Sup. Ct. 1951).

⁸⁴ *Metcalfe v. Union Trust Co.*, 181 N.Y. 39, 44 (1905).

⁸⁵ *Ives v. S. Buffalo Ry. Co.*, 201 N.Y. 271, 293 (1911) (citing *Bertholf v. O’Reilly*, 74 N.Y. 509, 515 (1878)).

⁸⁶ Which, ironically, are also requirements of ownership.

⁸⁷ *Newborn v. Peart*, 121 Misc. 221, 224, (N.Y. Sup. Ct. 1923).

⁸⁸ BLACK’S MEDICAL DICTIONARY 714 (Dr. Harvey Marcovitch, ed., The Scarecrow Press, Inc. 41st ed. 2006) [hereinafter BLACK’S MEDICAL].

⁸⁹ *Id.*

⁹⁰ GRAY’S ANATOMY 12 (Peter L. Williams et al. eds., Churchill Livingstone 37th ed. 1989).

⁹¹ See BLACK’S MEDICAL, *supra* note 88, at 122.

⁹² *Id.*

⁹³ *Id.* at 137. One half of a cell’s chromosomes come from each parent. *Id.*

⁹⁴ BLACK’S MEDICAL, *supra* note 88, at 137.

⁹⁵ *Id.*

[different] kinds of protein molecules required by the cell for its existence . . . and for its reproduction.”⁹⁶ Thus, an individual’s tissues, made up of cells and directed by the body’s genetic code, are unique to that person.

For courts to consider tissues and the genetic information contained therein as property, the individual formed from them must have perfect title over those substances. As stated above, perfect title requires “actual possession, the right of possession and the right of property.”⁹⁷ The conscious dominion over one’s physical body gives that individual the sole discretion in directing its use. Thus, while the human body remains intact, that person has actual possession of his or her body and all of its components.

The extensions of a person’s constitutional rights of privacy, as derived in *Roe v. Wade*,⁹⁸ fulfill individuals’ rights of possession and property in their own human bodies, its tissues and the genetic information contained therein.⁹⁹ The right to privacy encompasses the right to control one’s own body.¹⁰⁰ Thus, the right to control one’s body arguably provides exclusive dominion over the use of one’s body, limited by the equal rights of others and the laws of the state. Society has accepted the right to control one’s own body to extend to the right to control their body’s parts.¹⁰¹ Subsequently, the possessor of one’s own human tissue has the rights of possession and property in that tissue, arguably fulfilling all of the requirements for perfect title in property under the common law of New York State.

However, such a common law property right is tenuous. The legislature should firmly establish the right by statute. A review of New York State common law shows that such a property right is obtaining support from the courts.

⁹⁶ *Id.* at 293.

⁹⁷ *Evans v. Francis*, 101 N.Y.S.2d 716, 718 (N.Y. Sup. Ct. 1951).

⁹⁸ *Roe v. Wade*, 410 U.S. 113, 154 (1973) (recognizing that the right of privacy includes making abortion decisions).

⁹⁹ *See Planned Parenthood of S.E. Pa. v. Casey*, 505 U.S. 833, 926–27 (1992) (discussing the holding in *Roe inter alia*, and how the Court has found a privacy right in procreation because of issues regarding bodily integrity and destiny).

¹⁰⁰ *See Roe*, 410 U.S. at 154 (holding that the right of personal privacy includes the right to control whether to procreate).

¹⁰¹ *E. Hartford Educ. Ass’n v. Bd. of Educ. of E. Hartford*, 562 F.2d 838, 841 (2d Cir. 1977).

C. New York Cases Addressing the Issue

The question of whether individuals have property rights in their tissue has not been directly addressed by New York's State or Federal courts. Despite the New York courts' failure to answer the question directly, they have indirectly recognized a property right in tissue. The issue has been discussed in relation to the Right of Sepulcher in a stillborn infant¹⁰² or other close relatives.¹⁰³ The issue was further mentioned in the context of the transfusion of contaminated blood.¹⁰⁴ Finally, in determining whether the use of a criminal's DNA sample in solving uncharged crimes was allowable under statute, the court considered the matter of a property interest in genetic information.¹⁰⁵

i. Dead Bodies

Courts have applied a "quasi-property right" when deciding issues surrounding the surviving kin of a cadaver arising out of the common law Right of Sepulcher. The question of property rights in dead bodies dates back to the 17th century with Lord Coke's determination that there is no property interest in a dead body.¹⁰⁶ However, with advancing medical technology and a changing social outlook, that question has been answered somewhat differently in New York's modern courts.¹⁰⁷ While not completely congruous to the question of whether New York State common law has recognized a property right in one's own tissues, it warrants discussion in that the matter deals with the property rights in the biological substance that is a corpse from which a personal property right in one's own tissues can be extrapolated.

Emeagwali v. Brooklyn Hospital Center is a New York State trial court decision dealing, in part, with the matter of a quasi-property right in a stillborn fetus arising out of the following

¹⁰² *Emeagwali v. Brooklyn Hosp. Ctr.*, No. 29765/98, 2006 WL 435813, at *4 (N.Y. Sup. Ct. Feb. 22, 2006) (discussing the right of sepulcher in a stillborn infant). Sepulcher is the common law right to bury the dead body of one's kin.

¹⁰³ *Colavito v. N.Y. Organ Donor Network, Inc.*, 8 N.Y.3d 43, 53. (2006) (deciding that there is no common law property right in a dead body); *see also Emeagwali*, 2006 WL 435813, at *3 (discussing a cause of action for the common law right to sepulcher).

¹⁰⁴ *Perlmutter v. Beth David Hosp.*, 308 N.Y. 100, 104, 106 (1954).

¹⁰⁵ *People v. Rodriguez*, 196 Misc. 2d 217, 225(N.Y. Sup. Ct. 2003).

¹⁰⁶ *Colavito*, 8 N.Y.3d at 50.

¹⁰⁷ *See id.* at 52-53 (noting that some modern New York courts have approached this question differently from the traditional common law approach).

facts.¹⁰⁸ Complications with Emilian Emeagwali's pregnancy at defendant hospital resulted in a stillbirth.¹⁰⁹ Subsequently, the hospital disposed of the stillborn fetal remains without seeking Mr. and Mrs. Emeagwali's permission, allegedly violating the Emeagwalis' right to bury the stillborn fetus (Right of Sepulcher).¹¹⁰

The court found that the Emeagwalis' claim for violation of their Right to Sepulcher was valid because the court determined that there was a quasi-property interest in the stillborn fetus.¹¹¹ The mother retained a quasi-property right in the fetus due to the fetus's symbolic importance, despite the fact that the stillborn fetus did not have survivors in the normal sense.¹¹² A fetus is different from ordinary tissue in the sense that the potential to become a child makes a fetus the focus of the mother's hopes for the future, thus placing it within the Right of Sepulcher.¹¹³ Despite distinguishing a fetus from "ordinary tissue," the court recognized that a property right may attach to biological matter.

The New York State Court of Appeals decision in *Colavito v. New York Organ Donor Network*¹¹⁴ dealt with the same issue as *Emeagwali* when the court refused to find a property interest in a donor's kidneys. Plaintiff was the directed recipient of donated kidneys.¹¹⁵ The donor's surviving spouse utilized the defendant organization to assist in routing the kidneys to the plaintiff.¹¹⁶ Upon receiving one kidney, the operating physician found it unviable for transplant.¹¹⁷ The physician immediately contacted the defendant for the other kidney, which had already been "allocated to someone else."¹¹⁸ The plaintiff then sued for conversion (the only ground applicable for purposes of this discussion).¹¹⁹

The Court of Appeals found the claim of conversion to be

¹⁰⁸ *Emeagwali v. Brooklyn Hosp. Ctr.*, No. 29765/98, 2006 WL 435813, at *3 (N.Y. Sup. Ct. Feb. 22, 2006).

¹⁰⁹ *Id.* at *1-2.

¹¹⁰ *Id.*

¹¹¹ *Id.* at *5.

¹¹² *Id.*

¹¹³ *Id.*

¹¹⁴ 8 N.Y.3d 43 (2006).

¹¹⁵ *Colavito*, 8 N.Y.3d at 53.

¹¹⁶ *Id.* at 47.

¹¹⁷ *Id.*

¹¹⁸ *Id.*

¹¹⁹ *Id.*

without merit because it did not satisfy the prima facie element that plaintiff had a “possessory right or interest in the property.”¹²⁰ The court based its finding on a review of the common law that “arose out religious and cultural sensibilities involving grave robbery, desecration of corpses and, later on, unauthorized autopsies.”¹²¹ The court ultimately decided that individuals hold a “sacred trust” in a corpse.¹²² The trust includes the right to possess an “unmutilated” corpse and a corresponding duty to bury that corpse, but these cases carefully refused to rely on a property right in a corpse.¹²³ Thus, according to the court, there is no common law property interest in a corpse.¹²⁴

Despite the Court of Appeals’ analysis in *Colavito*, the court does not extinguish a property right in a corpse; and, therefore, the court does not extinguish a property right in one’s own tissues.¹²⁵ The court recognizes that the “no property right”¹²⁶ view developed long before the present state of medical science, and that a conceivable property right in a cadaver or part thereof is possible.¹²⁷ Thus, the court has left the door open for finding a property interest in biological matter. Finally, the court refers to *Johnson v. State of New York*,¹²⁸ which utilizes the same quasi-property approach as the *Emeagwali* court.¹²⁹ While the court implies this decision was an anomaly, in fact it is likely the beginning of a new way to address the matter.

The quasi-property right in a dead body and its biological parts attached to the right of sepulcher provides common law support for establishing a statutory property right in one’s own tissues in two ways. First, both matters are dealing with a property interest in biological substances. Second, the quasi-property right associated with a cadaver requires an origin. Arguably,

¹²⁰ *See id.* at 50.

¹²¹ *Colavito*, 8 N.Y.3d at 50.

¹²² *Id.* at 51–52.

¹²³ *Id.* at 52–53.

¹²⁴ *Id.*

¹²⁵ *See id.* at 53.

¹²⁶ *Id.* at 52–53.

¹²⁷ *Colavito*, 8 N.Y.3d at 53 (commenting on advances in modern science and its possible effect on the common law principle of no property rights in a dead body).

¹²⁸ 37 N.Y.2d 378 (1975).

¹²⁹ *See Colavito*, 8 N.Y.3d at 53 (stating that the court referred to a quasi-property right in *Johnson*); *see also* *Emeagwali v. Brooklyn Hosp. Ctr.*, No. 29765/98, 2006 WL 435813, *passim* (N.Y. Sup. Ct. Feb. 22, 2006).

that quasi-property right arises out of the transfer of rights one has in his or her own body to the decedent's next of kin, or another, for burial, scientific, or medical purposes.

ii. Bad Blood

A review of the New York Court of Appeals' decision in *Perlmutter v. Beth David Hospital* shows an implicit property right in blood transferred to the plaintiff patient from the defendant hospital.¹³⁰ While receiving medical care at defendant hospital, the plaintiff received a blood transfusion and was "sold" the blood.¹³¹ However, the blood was impure.¹³² Subsequently, the plaintiff brought suit based on a theory of breach of the implied warranty for merchantability due to the impure nature of the blood.¹³³

In reviewing the plaintiff's arguments, the majority agreed that there was a transfer of title occurring in the blood, but the transaction was not a contract for the sale of goods; it was one for the sale of services.¹³⁴ Despite the transaction not constituting a sale of goods, the court still recognized a transfer of property interest in the exchange of blood for monetary consideration.¹³⁵ The statement that, "the property or title to certain items of medical material may be . . . transferred from the hospital to the patient" recognized that blood, a reproductive tissue, has a property right attached to it in this setting.¹³⁶ The court further reinforced the transfer of title in the blood via a service contract through analogizing the blood to a canvas to which a party gains title when hiring an artist to paint a portrait.¹³⁷ However, since the main purpose of the contract was for the sale of services and not the sale of blood as a good; the implied warranty of

¹³⁰ *Perlmutter v. Beth David Hosp.*, 308 N.Y. 100, 104 (1954) (stating that the transfer of blood constituted transfer of property).

¹³¹ *Id.* at 103.

¹³² *Id.*

¹³³ *Id.* Implied in each contract for the sale of *goods*, where the seller regularly deals in that type of *good* or otherwise avails himself as such a seller, is a warranty that the *goods* are of a quality, quantity and kind regularly accepted in the industry as fulfilling the terms of the contract. N.Y. GEN. OBLIG. LAW § 2-314(1)–(3) (McKinney 2007) (emphasis added).

¹³⁴ *Perlmutter*, 308 N.Y. at 104.

¹³⁵ *See id.* (stating that while the transfer of blood was not ultimately a sale, it constituted transfer of property).

¹³⁶ *Id.*

¹³⁷ *Id.* at 105.

merchantability did not attach to the contract.¹³⁸ Thus, by considering blood, a regenerative tissue, to be a good with transferable title, the court attached a property interest to blood, further supporting acceptance of tissue as property in New York State.

iii. DNA Evidence

In *People v. Rodriguez*, the New York Supreme Court's Criminal Term in King's County directly recognized a DNA contributor's property right in preventing the genetic information's dissemination in its decision to limit the use of defendant's DNA in solving uncharged crimes.¹³⁹ New York Criminal Procedure Law § 240.40(2)(b)(v) required that defendant, charged with a sex crime, must provide the State with a DNA sample.¹⁴⁰ Upon providing the DNA sample, the defendant moved for an order of protection to limit the dissemination of the DNA evidence.¹⁴¹ The court upheld the protective order on several grounds.

In part, the court relied upon the legislative intent behind enacting NY CRL § 79-1¹⁴² and the language of New York State Executive Law § 995-d.¹⁴³ That intent enumerates "property right in the prevention of dissemination of genetic information."¹⁴⁴ The recognition of a property right in the dissemination of genetic information is powerful evidence that New York State's courts are willing to recognize a property interest in one's own tissue, should the legislature be willing to provide such a right.

New York State courts have not established a property right in one's tissue under common law. While the previously discussed cases each offer support for providing individuals with a property right in their tissue, they fail to explicitly establish such a right. Therefore, it would be prudent for the legislature to establish a

¹³⁸ See *id.* at 104 (noting that the main purpose was a service, and thus, is not a sale under the Sales Act. As such, there is no implied warranty of merchantability).

¹³⁹ *People v. Rodriguez*, 196 Misc. 2d 217, 224–25 (N.Y. Sup. Ct. 2003).

¹⁴⁰ See *id.* at 218 (explaining that the state moved for an order, under CPL 240.02, directing the court to force defendant to provide a blood sample for DNA testing).

¹⁴¹ *Id.*

¹⁴² *Id.* at 225.

¹⁴³ *Id.* at 224–25.

¹⁴⁴ *Id.* at 225.

property interest in one's tissue by amending NY CRL § 79-1 to expressly include that right.

D. Legislative Action and Protection under Contract Law

A statutory property right in one's own tissue allows its titleholder to treat tissues as a transferable good subject to contract law and the de-identification requirements of NY CRL § 79-1. This will subsequently protect the researcher-donee from any of the methods of genetic discrimination. The New York Uniform Commercial Code defines a "good" as "all things . . . which are movable at the time of identification."¹⁴⁵ Such an expansive definition can include one's tissue once the legislature identifies tissue as property since tissue is "movable."¹⁴⁶ Therefore, the titleholder of the tissue can transfer that title to a researcher-donee as a gift or a sale once the researcher-donee or buyer has satisfied the de-identification or coding requirements necessary to protect against genetic discrimination.¹⁴⁷ Absent fraud or unconscionability, a transfer of title removes the donor or seller's interest in the tissue and in any result of the researcher-donee's testing.¹⁴⁸ Furthermore, when a seller exchanges a good for valuable consideration, a court will not question the adequacy of that consideration because the court would be looking to the proportionate value of the promises exchanged, an analysis not appropriate for the judiciary.¹⁴⁹ Because a financial interest is one party's measure of value,¹⁵⁰ to question the validity of a transfer of title in tissue based upon an undisclosed financial interest would be to question the proportionate worth of the benefits or detriments exchange for consideration. Moreover, by providing a patient with a potentially fatal or morbid disease, the ability to contract with a researcher for an interest in any financial benefit research on the transferred tissue may yield, could help in deferring medical costs, and provide a financial incentive to donate. Because courts will not question the validity of consideration based upon the exchanged promises or detriments' relative value, contract law

¹⁴⁵ N.Y. U.C.C. § 2-105(1) (McKinney 2007).

¹⁴⁶ Movable is defined as "[p]roperty that can be moved or displaced." BLACK'S LAW, *supra* note 44, at 1040.

¹⁴⁷ See U.C.C. § 2-106(1) (2002) (defining elements of sales of goods).

¹⁴⁸ See U.C.C. § 2-106(1).

¹⁴⁹ *Apfel v. Prudential-Bache Sec. Inc.*, 81 N.Y.2d 470, 475-76 (1993).

¹⁵⁰ See *supra* Part IV.

protects a researcher from claims for failing to disclose a financial interest in the tissue while providing the donee greater rights to the research conducted on any donated genetic materials while remaining protected by the rigorous de-identification protocols.

VI. CONCLUSION

Amending NY CRL § 79-1 to provide a property right in a donor's tissue expands the rights of the donor while protecting the researcher-donee from liability arising out of a failure to divulge a financial interest in the tissue. The legislature has successfully protected tissue donors from genetic discrimination by insurance companies and employers by requiring de-identification or coding of samples (tissue), but has left researchers unwittingly vulnerable under *Moore* by utilizing an informed consent model that does not include divulgence of a financial interest. Given that tissue fulfills the prima facie elements of property under New York common law, and New York courts have favorably supported providing such a property interest in other contexts, amending NY CRL § 79-1 to provide individuals with a property right in their tissue is a logical and sensible approach. Providing such a right would allow individuals to contract with researchers to obtain consideration for their tissues potentially offsetting insurmountable medical expenses and protect researchers under contract law, thereby fixing the present shortcomings of NY CRL § 79-1.

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