

Genetic Paparazzi: Beyond Genetic Privacy

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The domain of accessible information about celebrities, political leaders, and other public figures is expanding as technology evolves, placing new stresses on already uneasy legal boundaries around their privacy. The availability of cheap, fast, and informative genetic sequencing technologies, combined with growing public interest in genetic information, makes it likely that we will soon witness paparazzi carrying swabs and sterile tubes in search for genetic materials connected in some way to the public figures they pursue. In a world in which genetic paparazzi are not only a possibility, but a probability, courts will inevitably be asked to determine the legal status of genetic materials and information obtained from public figures without consent. The genetics of public figures serves as a useful test case of the legal framework governing genetics and privacy, because public figures are at the same time beneficiaries of more rights than most of us—in the form of rights of publicity—and fewer rights—in the form of diminished expectations of privacy.

When disputes involving genetic paparazzi ultimately reach the courtroom, judges will have to confront scenarios that touch on fundamental questions regarding the nature of genetics and its relationship to concepts of personhood and identity, property, health and disease, intellectual property, and reproductive rights. While the question of what courts will decide is intriguing, this Article moves beyond such predictions to focus on how resulting court decisions in seemingly narrow cases may have broad and potentially harmful

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We are thankful for comments from the participants of the first Bio-Lawlapalooza at Stanford University: Karinne Ludlow, Jordan Paradise, Hank Greely, Nathan Cortez, Teneille Brown, Chris Slobogin, and Sonia Suter; Oskar Livak and participants in the Cornell Legal Faculty Workshop in April 2019; and the participants in the 2019 Petrie-Flom Center Annual Conference on Consuming Genetics at Harvard Law School. We also wish to thank Pam Brannon, Meagan Chinnis, Allison Kim, Alessandra Palazzolo and Brandon Reed for excellent research assistance. This Article builds the analytical framework for ideas introduced in Yaniv Heled & Liza Vertinsky, *Genetic Paparazzi*, in CONSUMING GENETIC TECHNOLOGIES: ETHICAL AND LEGAL CONSIDERATIONS (I. Glenn Cohen, N. Fahrahany, H. Greely & C. Shachar eds., Cambridge University Press) (forthcoming).

impact. Despite the complexity of the legal issues that such suits will implicate, the constraints of existing law make it likely that courts will address such disputes largely through the lens of traditional privacy and publicity rights. In this Article we argue that pursuing genetic paparazzi cases through the narrow lens of existing privacy and publicity law would ignore the multidimensional nature of genetic materials and information, leading to unintended and problematic consequences for how the law approaches genetics. We go on to highlight additional aspects of genetic materials and information that policymakers, courts, and lawyers ought to consider when responding to media excursions into the genetics of public figures so as not to impede other genetic interests that might be implicated.

TABLE OF CONTENTS

I. INTRODUCTION	411
II. PUBLIC FIGURES VERSUS GENETIC PAPARAZZI.....	416
A. <i>Genetic Paparazzi on Their Way</i>	418
B. <i>What Genetic Paparazzi Cases May Look Like</i>	422
III. LEGAL FRAMING OF GENETIC PAPARAZZI CASES	427
A. <i>Rights of Privacy (or Lack Thereof) for Public Figures</i>	429
1. <i>Constitutional Basis for Privacy</i>	429
2. <i>Tort-Based Privacy</i>	430
3. <i>The Newsworthiness Exception to Privacy</i>	431
4. <i>Public Figures and Reduced Expectations of Privacy</i>	434
B. <i>Publicity Rights of Public Figures</i>	436
C. <i>Federal Laws Governing Genetic Privacy</i>	441
D. <i>State Laws Governing Genetic Privacy</i>	443
E. <i>How Genetic Paparazzi Cases Are Likely to Unfold</i>	445
IV. BEYOND PRIVACY AND RIGHT OF PUBLICITY: ALTERNATIVE LEGAL FRAMING OF GENETIC PAPARAZZI SCENARIOS.....	448
A. <i>Genetics as Part of One's Physical Person</i>	449
B. <i>Genetics and Dignity</i>	452
C. <i>Genetics as Individual and Collective Identity</i>	454
D. <i>Genetics as Building Blocks of a Person's Descendants and Reproductive Choice</i>	456
E. <i>Additional Aspects of Genetic Material and Information</i>	458
F. <i>How Should Jurists Account for the Uniqueness of Genetics?</i>	458
V. CONCLUSION.....	462

I. INTRODUCTION

Genetic testing and sequencing technologies are becoming ubiquitous, with improvements in speed, quality, and cost pushing what was once only imaginable into the realm of possible and even plausible.¹ As a result, hypothetical debates about what would happen if the press obtained the genetic material of public figures and published their genetic information may soon become real debates on the floor of a courtroom.² In anticipation of such lawsuits, legal scholars have considered the question of what privacy, if any, celebrities and other public figures may have in their genetic information.³ As is often the case with privacy laws, the answer to this question is protracted and

¹ E.g., Yaniv Erlich, *A Vision for Ubiquitous Sequencing*, 25 GENOME RES. 1411, 1411 (2015) (describing the breathtaking speed of advancements made in reducing cost and increasing speed of genetic sequencing and exploring new frontiers such as DNA sequencing sensors); James D. Watson, Andrew Berry & Kevin Davies, *Nobel Laureate: The Future of DNA Sequencing Will Be in the Palm of Your Hand*, TIME (Oct. 12, 2017), <http://time.com/4971220/future-dna-sequencing/> [<https://perma.cc/EK8P-DCDC>] (discussing the evolution of sequencing technology). See generally *Special Report: Genetic Testing Goes Mainstream*, SCI. NEWS (May 22, 2018), <https://www.sciencenews.org/article/consumer-genetic-testing-ancestry-dna> [<https://perma.cc/5BNG-SKJV>] (exploring the many ways in which consumers can use genetic testing and its implications).

² It seemed like the first such case might be coming when Madonna Ciccone (a.k.a. Madonna) filed a recent complaint in the New York Supreme Court to reclaim personal items including a hairbrush with strands of her hair. See *Ciccone v. Gotta Have It! Collectibles Inc.*, No. 156454/2017, 2018 WL 1911932, at *1, *5, *8 (N.Y. Sup. Ct. Apr. 23, 2018), *aff'd*, 102 N.Y.S.3d 568 (N.Y. App. Div. 2019). Madonna's complaint included a concern that the auction could enable a member of the general public to possess her DNA. *Id.* But the court rejected her claims without ruling on this specific issue. *Id.*; see also Nicolle K. Strand, *Shedding Privacy Along with Our Genetic Material: What Constitutes Adequate Legal Protection Against Surreptitious Genetic Testing?*, 18 AMA J. ETHICS 264, 264–69 (2016) (providing examples of concerns about and perpetration of surreptitious genetic testing of celebrities).

³ See, e.g., Mark A. Rothstein, *Genetic Stalking and Voyeurism: A New Challenge to Privacy*, 57 U. KAN. L. REV. 539, 543 (2009) (considering “whether individuals—celebrity or not—have or should have constitutional, statutory, or common law rights to prevent the seizure, analysis, and publication of genetic information without their consent”). See generally Teneille R. Brown, *Double Helix, Double Standards: Private Matters and Public People*, 11 J. HEALTH CARE L. & POL'Y 295 (2008) (exploring how the legal framework would govern disclosure of a presidential candidate's genetic information); Robert C. Green & George J. Annas, *The Genetic Privacy of Presidential Candidates*, 359 NEW ENG. J. MED. 2192 (2008); Elizabeth E. Joh, *DNA Theft: Recognizing the Crime of Nonconsensual Genetic Collection and Testing*, 91 B.U.L. REV. 665 (2011) [hereinafter Joh, *DNA Theft*] (proposing to make surreptitious gathering and analyzing of genetic information a crime); Elizabeth E. Joh, Essay, *Reclaiming “Abandoned” DNA: The Fourth Amendment and Genetic Privacy*, 100 NW. U. L. REV. 857 (2006) [hereinafter Joh, *Reclaiming*] (exploring limits on surreptitious gathering of DNA); June Mary Z. Makdisi, *Genetic Privacy: New Intrusion a New Tort?*, 34 CREIGHTON L. REV. 965 (2001) (exploring the need for a legal structure to respond to genetic intrusions and examining the tort of intrusion as a way to protect genetic privacy).

fragmented, and amounts to that ageless maxim of legal wisdom: it depends. It depends on the state, on the act(s), on the parties involved, on the setting in which the relevant act(s) take place, and on the shifting social mores and legal norms regarding what is newsworthy and what reasonable expectations of privacy public figures can have.⁴

As the gap between hypothetical and actual genetic paparazzi lawsuits continues to narrow,⁵ the question of what rights public figures may have in their genetic material and information is becoming not only more salient but also more relevant to broader policy debates about how the law does, and should, approach the legal relationship(s) between individuals and their genetics.⁶ The genetics of public figures serves as a useful test case of the legal framework governing genetics and privacy, because public figures are at the same time beneficiaries of more rights and fewer rights than most of us. They are, on the one hand, the object of legitimate public interest and thus subject to lower

⁴ See an overview of the legal framework governing the privacy and publicity rights of public figures and federal and state legislation relevant to genetic privacy in Part II. See also Megan Molteni, *The US Urgently Needs New Genetic Privacy Laws*, WIRED (May 1, 2019), <https://www.wired.com/story/the-us-urgently-needs-new-genetic-privacy-laws/> [<https://perma.cc/G9GT-RKAW>] (discussing the difficulties that arise from the fragmented approach and patchwork of laws governing genetic privacy in the United States, suggesting that the problem with the system arises from the fact that genetic data can have multiple uses beyond its original one).

⁵ One example of this trend is the recent lawsuit brought by Madonna against Gotta Have It! Collectibles, Inc. See *Ciccone*, 2018 WL 1911932, at *1; *infra* Part II.A.

⁶ Legal scholars have proposed a variety of approaches towards securing rights of privacy in genetic information and materials. See, e.g., Lawrence O. Gostin, *Genetic Privacy*, 23 J.L. MED. & ETHICS 320, 327 (1995) (suggesting that respect for personal autonomy is a motivating value for genetic privacy and that individuals should have the right to know about and approve uses of their genetic data); Joh, *DNA Theft*, *supra* note 3, at 670 (advocating for criminalizing the nonconsensual collection of human tissue for the purpose of genetic analysis); Rothstein, *supra* note 3, at 573, 577 (advocating for stronger privacy rights in all health information but suggesting genetic stalking legislation as an intermediate step). See generally Sonia M. Suter, *Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy*, 72 GEO. WASH. L. REV. 737 (2004) (arguing for a relational conception of genetic privacy and the need for remedies “that address dignitary harm and breach of trust,” and arguing against a property rights approach to genetic privacy). Others advocate for a property rights approach to securing genetic privacy. See, e.g., Jessica L. Roberts, *Progressive Genetic Ownership*, 93 NOTRE DAME L. REV. 1105, 1111 (2018) (arguing that the status of genetic ownership is in flux and suggesting progressive property as a theoretical lens for understanding genetic property); Jessica L. Roberts, *Genetic Conversion* 1–2 (Mar. 15, 2019) (unpublished manuscript), https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3357566 [hereinafter Roberts, *Genetic Conversion*] (proposing a right to claims for genetic conversion). See generally Natalie Ram, *DNA by the Entirety*, 115 COLUM. L. REV. 873 (2015) (suggesting tenancy in the entirety as a legal frame for approaching ownership in genetic information). Others argue against a property rights approach based on concerns with the potential impact on research. See generally Jorge L. Contreras, *Genetic Property*, 105 GEO. L.J. 1 (2016) (arguing that the property-like approach to genetic information that a paradigm of informed consent creates in the context of genetic research be replaced with liability rules governing researcher conduct).

expectations of privacy.⁷ On the other hand, they are the beneficiaries of a body of law that protects their business interests in their identity.⁸

Commentators concerned about the potential for nonconsensual gathering and analysis of genetic materials have highlighted the limited control that public figures have over the gathering and use of their genetic information under the current web of privacy and publicity laws.⁹ In response, they have suggested ways of providing additional protections for the genetic privacy of public figures.¹⁰ But in focusing on desirable mechanisms and parameters for securing genetic privacy, we argue that some aspects of genetic materials and the information they contain are inevitably overlooked.¹¹

This Article moves past the question of what may or may not be done with a public figure's genetic information under current law to reveal the insufficiency, and sometimes inadequacy, of relying on genetic privacy or rights of publicity as a governing framework for deciding questions involving genetic materials and information. We argue that the legal framework applicable to genetics and privacy as it now exists is poorly equipped to handle the complexities of genetic materials and information.¹² This is because the current focus on privacy of genetic information fails to capture the complex reality that

⁷ See Jamie E. Nordhaus, Note, *Celebrities' Rights to Privacy: How Far Should the Paparazzi Be Allowed to Go?*, 18 REV. LITIG. 285, 288 (1999).

⁸ *Id.* at 303–05.

⁹ See *supra* note 3 and accompanying text.

¹⁰ See *supra* note 3 and accompanying text.

¹¹ This is part of a larger and older discussion about how the law does, and should, handle competing interests in the human body. See, e.g., Radhika Rao, *Genes and Spleens: Property, Contract, or Privacy Rights in the Human Body*, 35 J.L. MED. & ETHICS 371, 371 (2007) (“Sometimes the body is treated as an object of property, sometimes it is dealt with under the rubric of contract, and sometimes it is not conceived as property at all, but rather as the subject of privacy rights. Which body of law should become the law of the body?”); see also Robin Feldman, *Whose Body Is It Anyway? Human Cells and the Strange Effects of Property and Intellectual Property Law*, 63 STAN. L. REV. 1377, 1378 (2011) (“Through the rambling pathways of property and intellectual property law, we are fast approaching the point at which just about anyone can have property rights in your cells, except you. In addition, with some alteration, anyone can have intellectual property rights in innovations related to the information contained therein, but you do not.”); Samantak Ghosh, Comment, *The Taking of Human Biological Products*, 102 CALIF. L. REV. 511, 515–16 (2014) (emphasizing the implication of patent law, property law, and constitutional law when navigating through the legal analysis of human biological products).

¹² See, e.g., Ram, *supra* note 6, at 873 (“The law fails to accommodate the inconvenient fact that an individual's identifiable genetic information is involuntarily and immutably shared with her close genetic relatives.”); Albert E. Scherr, *Genetic Privacy & the Fourth Amendment: Unregulated Surreptitious DNA Harvesting*, 47 GA. L. REV. 445, 449, 485 (2013) (suggesting that the traditional Fourth Amendment approach to privacy fails to accommodate the multidimensional nature of DNA and that “[t]he kaleidoscope metaphor most fully captures the multi-dimensional nature of the identity that DNA embodies. Identity itself has many components—physical, informational, and dignitary to mention only a few”); Suter, *supra* note 6, at 746 (cautioning that courts must be sensitive to the “expressive role of the law” when dealing with the complex interests people have in their genetics).

genetic information comes from what was once, physically, part of a person; that one's genetic information not only imparts knowledge about that person but is also emblematic of a person's identity—who that person *is*—in the most basic and profound sense;¹³ that one's genetic material and information are also the blueprint for some of one's own unique qualities and constitute the building blocks for one's children;¹⁴ that genetic information may divulge nuggets not just about who a person *is* but also about what they *have* gone through in their lifetime,¹⁵ whom they *could* have been, and even what their *ancestors* may have gone through in their own lifetimes;¹⁶ that genetic information imparts information not just about the individual but also about past, present, and future family members;¹⁷ and that while much is known about our genetics, much more remains unknown, waiting to be uncovered by future research.¹⁸

To make these points, we analyze two timely hypothetical scenarios in which private, nongovernment third parties collect the genetic materials of public figures without permission. These are cases where the collection of the

¹³ See, e.g., Suter, *supra* note 6, at 746 (emphasizing the “dignitary and personhood interests” we have in our genetic information).

¹⁴ See Michael Specter, *The Gene Factory*, NEW YORKER (Dec. 30, 2013), <https://www.newyorker.com/magazine/2014/01/06/the-gene-factory> [<https://perma.cc/YBC3-8M3D>] (discussing the operations of a company that “has bet its future on laying out the genetic codes of as many life-forms as possible” and using these “genetic building blocks of life” for a variety of purposes).

¹⁵ See, e.g., Lucy A. Jewel, *The Biology of Inequality*, 95 DENV. L. REV. 609, 618–19 (2018) (describing ways that DNA can be modified in an epigenetic manner including the quality of maternal care that one gets, childhood trauma and stress, and abuse); Mark A. Rothstein, Yu Cai & Gary E. Merchant, *The Ghost in Our Genes: Legal and Ethical Implications of Epigenetics*, 19 HEALTH MATRIX 1, 3–7 (2009) (stating a “realization that the epigenome is highly sensitive and responsive to environmental influences, including toxic exposures, dietary factors, and behavioral impacts”).

¹⁶ See, e.g., Fazal Khan, *Preserving Human Potential as Freedom: A Framework for Regulating Epigenetic Harms*, 20 HEALTH MATRIX 259, 273 (2010) (explaining several studies performed on rodents showing changes in epigenetics that cross generations); Rothstein et al., *supra* note 15, at 3–4 (“Some epigenetic changes leading to cancers and other diseases have been found to be transgenerational with nearly 100 percent penetrance, in that the altered epigenetic pattern can be transmitted to subsequent generations effectively without physically being exposed to the original trigger of the epigenetic change.”).

¹⁷ See Yaniv Erlich, Tal Shor, Itsik Pe'er & Shai Carmi, *Identity Inference of Genomic Data Using Long-Range Familial Searches*, 362 SCIENCE 690, 690 (2018) (discussing results of testing models of relatedness that show the ability to match family members based only on DNA samples).

¹⁸ See, e.g., Ainsley J. Newson, Samantha J. Leonard, Alison Hall & Clara L. Gaff, *Known Unknowns: Building an Ethics of Uncertainty into Genomic Medicine*, 9 BMC MED. GENOMICS, Sept. 2016, at 4–8 (arguing that uncertainty is an inherent part of current clinical practice in genomics and that clinical processes should adapt to and be responsive to genomic uncertainty); Stephen S. Hall, *Hidden Treasures in Junk DNA*, SCI. AM. (Oct. 1, 2012), <https://www.scientificamerican.com/article/hidden-treasures-in-junk-dna> [<https://perma.cc/P7P4-467T>] (discussing new discoveries that show the many potential functions of what was previously branded as “junk DNA”).

genetic materials is not for the purpose of a government program, law enforcement, or otherwise ordered by a court and where the genetic material and information are obtained without an obvious violation of tort or criminal law. In the first hypothetical, a media outlet claims to have obtained and analyzed the genetic material of a presidential candidate from discarded lunch materials at a political rally. They subsequently publish a list of medical conditions and behavioral tendencies to which the candidate is supposedly predisposed. In the second hypothetical, genetic paparazzi collect and sequence the genetic material obtained from a famous actor known for a unique eye color that he claims is the result of a genetic mutation. They sell their findings, along with the genetic sequencing results, to a tabloid that publishes them, and a stem cell clinic later starts offering injections of stem cells purportedly engineered to contain the genetic mutation, allegedly giving those treated the same special properties.

Objects of paparazzi pursuit such as the presidential candidate and famous actor are likely to sue the paparazzi, their financier-publishers, any implicated technical and medical service providers and personnel, and anyone else who directly utilizes their genetic materials and information. And when such disputes ultimately reach the courtroom, judges will have to confront fundamental questions about the nature of genetics and its relationship to concepts of personhood and identity, property, health and disease, intellectual property, and reproductive rights. Despite the multidimensional nature of genetics, they will most likely do so through the narrow lens of traditional privacy and publicity rights, casting genetic materials and information in a particular light.¹⁹ We argue that the treatment of genetic materials and the information they contain through this constrained lens will prove inadequate to achieve the balance of public and private interests attached to genetic materials and information, with unintended and potentially problematic consequences for how the law approaches genetics.²⁰

The rest of the Article proceeds as follows. Part II discusses the emergence of “genetic paparazzi” and the activities in which they may engage. It describes in fuller detail the hypothetical scenarios referenced above. Part III examines the legal pathways courts will likely select when analyzing legal claims that will inevitably follow genetic paparazzi scenarios. It provides an overview of the

¹⁹ A good example is the lasting impact of the case of *Moore v. Regents of the University of California* on legal claims for conversion of biological samples and the information they contain. See Roberts, *Genetic Conversion*, *supra* note 6, at 4, 14 (emphasizing the lasting impact of the *Moore* case on claims for conversion grounded in biological materials and genetic information); see also *infra* note 207 and accompanying text.

²⁰ For other examples of concerns with broader implications associated with specific ways courts will approach genetic privacy, see Contreras, *supra* note 6, at 1 (arguing that current federal law approaches to the use of genetic data in research create a de facto property regime in genetics that is misguided), and Jorge L. Contreras, *Narratives of Gene Patenting*, 43 FLA. ST. U. L. REV. 1133, 1177 (2016) (discussing how narratives about gene patenting may have influenced court decisions and the importance of narratives more generally for judicial decision-making).

complex patchwork of various federal and state laws that together comprise the current legal framework governing the genetic privacy rights of public figures and suggests how squeezing genetic paparazzi into these alternative pathways might impact the broader legal treatment of genetic materials and the information they contain. Part IV provides alternative perspectives on genetics that fall outside of existing legal pathways and suggests the need for a legal approach that can accommodate these perspectives. We conclude that policymakers, judges, and lawyers need to recognize and be responsive to the multifaceted nature of genetics even in seemingly specialized cases such as our hypothetical genetic paparazzi scenarios to avoid unintended consequences for other genetic interests that might be implicated.

II. PUBLIC FIGURES VERSUS GENETIC PAPARAZZI

We can now extract an immense amount of information about the genetic makeup of any person from the pieces of biology that are unavoidably left behind as each of us moves through our lives—whether it be from pieces of skin, hairs, tissues that we sneeze into, cups and cans we drink from, traces of blood, cigarette butts, or even human waste.²¹ As genetic testing and sequencing technology becomes ever more ubiquitous, rapid, and cheap, our genetic materials and the information they contain become ever more accessible.²² The continued advancement and availability of this technology practically guarantees that the law is going to have to confront the legal status of the genetic materials that we unknowingly, or unthinkingly, discard and such materials' availability for anyone to collect, analyze, publish, use, and profit from.²³ For a few, this question has and will continue to occur in the context of criminal investigations that utilize genetic information acquired from the scene of the crime.²⁴ For most of us, this question will occur in the context of healthcare testing or voluntary use of genetic services to discover our ancestors or learn

²¹ See Green & Annas, *supra* note 3, at 2192–93 (discussing the ease of obtaining DNA samples).

²² See David A. Wheeler et al., Letter, *The Complete Genome of an Individual by Massively Parallel DNA Sequencing*, 452 NATURE 872, 874, 876 (2008) (discussing the speed and reduced cost of a new genetic sequencing technology); Megan Molteni, *Now You Can Sequence Your Whole Genome for Just \$200*, WIRED (Nov. 19, 2018), <https://www.wired.com/story/whole-genome-sequencing-cost-200-dollars> [<https://perma.cc/9FUH-U8ZQ>].

²³ See Joh, *Reclaiming*, *supra* note 3, at 859.

²⁴ See, e.g., Natalie Ram, *Genetic Privacy After Carpenter*, 105 VA. L. REV. 1357, 1366 (2019); Mark A. Rothstein & Meghan K. Talbott, *The Expanding Use of DNA in Law Enforcement: What Role for Privacy?*, 34 J.L. MED. & ETHICS 153, 155–56 (2006); Scherr, *supra* note 12, at 449–50 (arguing that society does recognize a reasonable expectation of privacy in DNA and that this should be reflected in police practices).

more about our genetic makeup.²⁵ For celebrities and other public figures, however, the prospects of third-party use of their genetics are more immediate and potentially more invasive.

The diminished level of legally enforceable expectations of privacy for public figures has already allowed for the emergence of a prosperous tabloid industry fueled by swarms of paparazzi.²⁶ We will likely soon see paparazzi carrying swabs and sterile tubes in search of genetic materials connected in some way to the public figures they pursue.²⁷ Once genetic disclosures about the rich and famous hit the press, courts will inevitably be asked to determine the legal status of the genetic materials and data obtained from public figures without the latter's consent. In ruling on the consequences of intrusive actions taken by genetic paparazzi, courts will seek to fit claims brought against such genetic intrusions into existing modes of legal analysis governing privacy and publicity. Yet, their decisions will implicate fundamental questions about the nature of genetics and the relationship of genetic materials and information to conceptions of personhood and identity, property, intellectual property, and even reproductive rights.

We begin the discussion in this Part with a recent lawsuit filed by the celebrity Madonna Ciccone, better known by her stage name "Madonna," against an online auction house, Gotta Have It! Collectibles, Inc.,²⁸ which illustrates the pertinence of what we call "genetic paparazzi scenarios." We continue the discussion with two hypothetical genetic paparazzi scenarios to further flesh out the kinds of issues judges are likely to confront when disputes between genetic paparazzi and disgruntled public figures reach the courtroom.

²⁵ See Scott Bowen & Muin J. Khoury, *Consumer Genetic Testing Is Booming: But What Are the Benefits and Harms to Individuals and Populations?*, CDC: GENOMICS & PRECISION HEALTH (June 12, 2018), <https://blogs.cdc.gov/genomics/2018/06/12/consumer-genetic-testing> [<https://perma.cc/VTF8-G5CS>] (discussing growth in direct-to-consumer genetic testing for genealogy and health); Antonio Regalado, *2017 Was the Year Consumer DNA Testing Blew Up*, MIT TECH. REV. (Feb. 12, 2018), <https://www.technologyreview.com/s/610233/2017-was-the-year-consumer-dna-testing-blew-up> [<https://perma.cc/PL43-7L68>] (describing significant expansion in direct-to-consumer genealogy testing services).

²⁶ See Nordhaus, *supra* note 7, at 292–95 (exploring tensions between the First Amendment and privacy of public figures); Daniel J. Solove, *Should Celebrities Have Privacy? A Response to Jennifer Lawrence*, TEACHPRIVACY BLOG (Nov. 24, 2014), <https://teachprivacy.com/celebrities-privacy-response-jennifer-lawrence> [<https://perma.cc/UW6A-HGM7>] (discussing law relevant to paparazzi).

²⁷ See generally *supra* note 3.

²⁸ See *Ciccone v. Gotta Have It! Collectibles, Inc.*, No. 156454/2017, 2018 WL 1911932, at *1 (N.Y. Sup. Ct. Apr. 23, 2018), *aff'd*, 102 N.Y.S.3d 568 (N.Y. App. Div. 2019).

A. *Genetic Paparazzi on Their Way*

Madonna has been known as a zealot when it comes to her privacy. According to media reports, among the many measures taken to protect the pop-star's privacy are some that could be viewed as rather peculiar.²⁹ Based on at least one such report, Madonna employs a “sterilisation team” whose job it is “to wipe away any DNA that may have been dropped in her [dressing] room on hairs, skin or saliva.”³⁰ So when an online auction house, Gotta Have It! Collectibles, Inc., put up for auction a used hairbrush belonging to Madonna with some of her hairs still attached,³¹ it was not a surprise that Madonna immediately sought an injunction against the sale.³² She then proceeded to sue the auction house, seeking replevin of the hairbrush.³³

Some may view such measures as excessive, even paranoid.³⁴ Yet Madonna could quite possibly be a visionary, anticipating the emergence of a new kind of paparazzi who are interested not only in candid photos but also in genetic snapshots of the celebrities they follow—what we term here “genetic paparazzi.”³⁵ The rapid rise in the accuracy and detail of genetic sequencing technology, accompanied by a dramatic decrease in its cost, is already responsible for some of the most interesting social developments of our time, and for the legal challenges that have followed. Notable examples are the ubiquity of ancestry analysis services and consequential discovery by many of previously unknown close relatives;³⁶ the identification and arrest of elusive

²⁹ See Clemmie Moodie, *Madonna Appoints a DNA Team to Sterilise Her Dressing Room After She's Used It*, MIRROR, <https://www.mirror.co.uk/3am/weird-celeb-news/madonna-appoints-dna-team-sterilise-907641> [<https://perma.cc/6W2N-BVA9>] (last updated Sept. 25, 2013).

³⁰ *Id.*

³¹ *Ciccone*, 2018 WL 1911932, at *4.

³² *Id.* at *2.

³³ *Id.* at *1.

³⁴ See Ben Locwin, *Madonna May Suffer From 'DNA Paranoia'*, GENETIC LITERACY PROJECT (Feb. 19, 2016), <https://geneticliteracyproject.org/2016/02/19/madonna-may-suffer-dna-paranoia/> [<https://perma.cc/85G8-XUWM>]; Mara Thompson, *Genetic Paparazzi: Could Celebrity DNA Become Public Domain?*, GA. ST. U. NEWS (Apr. 28, 2020), <https://news.gsu.edu/2020/04/28/genetic-paparazzi-could-celebrity-dna-become-public-domain/> [<https://perma.cc/MWW6-9XNT>].

³⁵ *Supra* note 3.

³⁶ See, e.g., Antonio Regalado, *More Than 26 Million People Have Taken an At-Home Ancestry Test*, MIT TECH. REV. (Feb. 11, 2019), <https://www.technologyreview.com/s/612880/more-than-26-million-people-have-taken-an-at-home-ancestry-test/> [<https://perma.cc/2STP-PRL3>] (“By the start of 2019, more than 26 million consumers had added their DNA to four leading commercial ancestry and health databases . . . For consumers, the tests—which cost as little as \$59—offer . . . a chance of discovering family secrets, such as siblings you didn’t know about.”); Tina Hesman Saey, *DNA Testing Can Bring Families Together, but Gives Mixed Answers on Ethnicity*, SCI. NEWS (June 13, 2018), <https://www.sciencenews.org/article/dna-testing-ancestry-family-tree> [<https://perma.cc/PY>].

criminals and daunting questions of access to genetic databases by law enforcement;³⁷ the explosion of genetic tests available for different genetic conditions and questions about how to properly act on such information and with whom to share it;³⁸ and the emergence of noninvasive genetic testing of embryos at very early stages of development.³⁹

6C-DVME] (sharing the story of an adopted man dying of a genetic disease who searched for years for his biological parents and eventually found them after sending his DNA to three DNA companies).

³⁷ The “Golden State Killer” case was one such highly publicized arrest resulting from genetic databases. After over three decades of evading law enforcement, a man suspected of dozens of murders and rapes in the 1970s and 1980s was arrested after law enforcement used DNA from a crime scene and compared it to genetic database websites. See Michael Balsamo, *A Look at DNA Testing That ID'd a Suspected Serial Killer*, WASH. POST (Apr. 27, 2018), https://www.washingtonpost.com/national/health-science/a-look-at-dna-testing-that-idd-a-suspected-serial-killer/2018/04/27/f661b42e-49e6-11e8-8082-105a446d19b8_story.html?noredirect=on&utm_term=.8415b383aa3b [<https://perma.cc/B2ZC-RSYB>]. The crime scene DNA matched with one of the suspect’s relatives and subsequently led to his identification and capture. See *id.*; see also Natalie Ram, *Incidental Informants: Police Can Use Genealogy Databases to Help Identify Criminal Relatives—but Should They?*, MD. B.J., July-Aug. 2018, at 8, 10, 12 (arguing that neither the Fourth Amendment nor Maryland state law protects against the use of DNA by police as was done in the Golden State Killer case and that the legislature should act in order to preserve this type of privacy).

³⁸ A variety of genetic testing is available such as diagnostic testing for cystic fibrosis, carrier testing for sickle cell anemia, and predictive testing for cancer and neurodegenerative diseases, to name just a few. For example, a popular predictive genetic test is one that can alert an individual and relatives of a higher risk of breast cancer by checking if one carries mutated alleles of the breast cancer genes known as BRCA1 or BRCA2. See *Genetic Testing*, MAYO CLINIC, <https://www.mayoclinic.org/tests-procedures/genetic-testing/about/pac-20384827> [<https://perma.cc/3WFF-97KP>]; see also *Pate v. Threlkel*, 661 So. 2d 278, 282 (Fla. 1995) (holding that physicians’ duty to warn a patient’s children of genetically transferable condition is met by warning the patient only); Lee Black, Jacques Simard & Bartha Maria Knoppers, *Genetic Testing, Physicians and the Law: Will the Tortoise Ever Catch Up with the Hare?*, ANNALS HEALTH L. 115, 117 (2010) (“Another area with potential consequences for physicians is disclosure of test results or genetic risk to family members of a patient who refuses to inform family members of the results.”). But see *Safer v. Estate of Pack*, 677 A.2d 1188, 1192 (N.J. Super. Ct. App. Div. 1996) (holding that a physician has a duty to warn those known to be at risk of avoidable harm from a genetically transmissible condition and that this duty extends to members of patient’s immediate family who may be adversely affected by a breach of duty).

³⁹ Noninvasive prenatal testing is currently available to pregnant women typically at week ten and uses the woman’s blood to test fragments of embryonic DNA that come from the placenta. See *What Is Noninvasive Prenatal Testing (NIPT) and What Disorders Can It Screen for?*, U.S. NAT’L LIBR. MED., <https://ghr.nlm.nih.gov/primer/testing/nipt> [<https://perma.cc/QBK7-TPKH>]; see also Alice Klein, *Simple Blood Test Can Detect Genetic Diseases Early in Pregnancy*, NEW SCIENTIST (Jan. 4, 2017), <https://www.newscientist.com/article/mg23331074-100-simple-blood-test-can-detect-genetic-diseases-early-in-pregnancy/> [<https://perma.cc/65KA-WAPK>] (describing a newly developed test, possibly available within five years, that takes DNA from the mother’s blood and has the ability to discover almost any single-gene disorder within the first six to ten weeks of pregnancy).

As a practical matter, technology increasingly enables the non-consensual collection and testing of genetic material dropped by people inadvertently as they move through their day. A hair or eyelash, used tissue, discarded chewing gum, beverage container, or cigarette butt all could provide a gateway into genetic information about us.⁴⁰ The increased availability and lack of technological barriers leave us more reliant on the law as a way of limiting nonconsensual access to and uses of our genetics.

The main concerns for most people involve limits on the use of their genetics by employers, insurers, healthcare providers and researchers.⁴¹ Not surprisingly, it is these concerns that have been the focus of most legislative efforts undertaken thus far to identify and protect interests that individuals may have in their genetics.⁴² As a general rule, only the individual and those authorized by the individual are privy to that individual's genetic information.⁴³

But privacy is not without its limits. Since the emergence of privacy law, there have always been exceptions and limitations to an individual's right of privacy. Notable exceptions exist in the contexts of law enforcement and parentage determinations.⁴⁴ Consent also plays a significant, if contested, role in determining the scope and nature of the uses of genetic information.⁴⁵

⁴⁰ See Strand, *supra* note 2, at 264.

⁴¹ See, e.g., *Genome Statute and Legislation Database*, NAT'L HUM. GENOME RES. INST., <https://www.genome.gov/about-genomics/policy-issues/Genome-Statute-Legislation-Database> [<https://perma.cc/F78L-A8JY>] (last updated Aug. 3, 2020) (listing state genetic privacy laws).

⁴² See *infra* Part III for a summary of the laws governing genetic privacy; see also Leslie E. Wolf et al., *The Web of Legal Protections for Participants in Genomic Research*, 29 HEALTH MATRIX 1, 1 (2019) (providing a comprehensive overview of "federal and state laws offering protections to participants in genomic research"); and *Privacy in Genomics*, NAT'L HUM. GENOME RES. INST., <https://www.genome.gov/27561246/privacy-in-genomics/> [<https://perma.cc/EU68-R6L7>] (last updated Feb. 24, 2020) (discussing numerous federal laws related to genetic privacy concerns).

⁴³ Wolf et al., *supra* note 42, at 34–36, 43–47.

⁴⁴ See, e.g., *Maryland v. King*, 569 U.S. 435, 465–66 (2013) (finding that conducting a DNA swab test as part of an arrest procedure does not violate the Fourth Amendment because the test serves a legitimate state purpose and is not so invasive that it requires a warrant); E. Donald Shapiro, Stewart Reifler & Claudia L. Psome, *The DNA Paternity Test: Legislating the Future Paternity Action*, 7 J.L. & HEALTH 1, 47 (1992); Ruth Padawer, *Who Knew I Was Not the Father?*, N.Y. TIMES MAG. (Nov. 17, 2009), <https://www.nytimes.com/2009/11/22/magazine/22Paternity-t.html> [<https://perma.cc/D3C5-EAKP>] (describing a large increase in paternity testing and raising questions about relevance of genetics for legal obligations to the child).

⁴⁵ See, e.g., Contreras, *supra* note 6, at 1, 28–31 (arguing that current federal law approaches to the use of genetic data in research, including heavy reliance on informed consent, create a de facto property regime in genetics that is misguided); Wolf et al., *supra* note 42, at 10, 21–23 (discussing role of consent in genomics research); see also Editorial, *A Culture of Consent*, 498 NATURE 407, 407 (2013) ("More than 50 years after the WI-38 cell line was derived from a fetus, science and society has still to get to grips with the ethical issues of using human tissue in research.").

The exception that is of most importance to the analysis of genetic paparazzi involves the privacy of public figures, including celebrities, public officeholders, and people who thrust themselves into the public eye.⁴⁶ Courts have long held that the right of such individuals to privacy can sometimes be overridden by the public's right to know and the media's right to report newsworthy information.⁴⁷ Indeed, when it comes to public figures, a long line of cases have defended the right of the press to publish almost anything that can be considered newsworthy or of legitimate public concern.⁴⁸ It seems inevitable that we will soon witness genetic paparazzi in search of genetic materials dropped by the subjects of their pursuit.⁴⁹ Stories of some paparazzi doing just that have already surfaced,⁵⁰ and concerns voiced by public figures⁵¹ suggest

⁴⁶ See discussion *infra* Part III.

⁴⁷ See discussion *infra* Part III.

⁴⁸ See, e.g., Danielle Keats Citron, *Mainstreaming Privacy Torts*, 98 CALIF. L. REV. 1805, 1828–29 (2010) (discussing courts' deference to media in determining what is newsworthy and therefore protected from liability); Shlomit Yanisky-Ravid & Ben Zion Lahav, *Public Interest vs. Private Lives—Affording Public Figures Privacy in the Digital Era: The Three Principle Filtering Model*, 19 U. PA. J. CONST. L. 975, 976 (2017) (“[B]ecause of the widely accepted belief in the ‘right to know’ information of public concern, freedom of speech generally overrides public figures’ right to privacy. As a result, public figures have almost no right to privacy. . . .”).

⁴⁹ The ease in which DNA samples can be collected (particularly by police) without “the targeted person’s knowledge” naturally draws the inference that genetic paparazzi will soon be in pursuit as well. Joh, *Reclaiming*, *supra* note 3, at 860; see, e.g., Brown *supra* note 3, at 299 (exploring how the legal framework would govern disclosure of a presidential candidate’s genetic information); Green & Annas, *supra* note 3, at 2–3 (warning of the shortcomings of relying on genetic information to assess the health risks of a specific person and of inflammatory accusations and exaggeration of genetic risks—which might lead to “genetic McCarthyism”—especially in the context of psychiatric conditions, and also warning that the results of genetic testing, even when presented accurately, would be “emotionally charged”).

⁵⁰ See, e.g., Nicholas Graham, *Obama’s Half-Eaten Breakfast Put Up for Sale on Ebay*, HUFFPOST (May 1, 2008), https://www.huffpost.com/entry/obamas-half-eaten-breakfa_n_98300 [<https://perma.cc/5HVK-EZRJ>] (describing an eBay listing for President Obama’s half-eaten breakfast and silverware with his DNA purportedly on it); see also Catherine Bennion-Pedley, *They Paid What? The 11 Craziest Celeb Items That Sold for £££s*, SUN (June 8, 2016), <https://www.thesun.co.uk/living/1248744/11-crazy-celeb-items-that-sold-for-a-fortune/> [<https://perma.cc/XD29-58HN>] (listing items such as John Lennon’s tooth, Lady Gaga’s fake nail, Jennifer Lawrence’s sports bra, Scarlett Johansson’s tissue, William Shatner’s kidney stone, Britney Spears’s gum and pregnancy test, a jar of Brad Pitt and Angelina Jolie’s breath, Justin Bieber’s hair, Justin Timberlake’s toast, and Queen Elizabeth’s pants); Nicole Bode & Xana O’Neill, *Authentic Britney Hair on Sale for \$1 Million*, SEATTLE TIMES (Feb. 19, 2007), <https://www.seattletimes.com/nation-world/authentic-britney-hair-on-sale-for-1-million/> [<https://perma.cc/N3FB-RKYQ>] (describing an eBay listing of Britney Spears’s hair, a lighter, and drink that she left at the salon the night that she infamously cut all of her hair off).

⁵¹ See, e.g., Joe Coscarelli, *Auction of Intimate Madonna Memorabilia Is Halted by Judge*, N.Y. TIMES (July 19, 2017), <https://www.nytimes.com/2017/07/19/arts/music/>

that it will not be long before genetic paparazzi scenarios like the two described below appear in court.

B. *What Genetic Paparazzi Cases May Look Like*

Paparazzi have long tested the boundaries of privacy and publicity.⁵² They fall at the outskirts of the press, pushing the limits of what is considered newsworthy, capitalizing on what people want to know rather than what they need to know and helping to commoditize the lives of public figures—often not with the public figures' willing consent.⁵³ Public figures also serve as useful test cases of the boundaries of privacy and publicity, pulling into the legal analysis existing debates about what are legitimate objects of public interest on the one hand and what commercial rights should vest in what aspects of personal identity on the other. While there are federal and state law protections against the disclosure and use of genetic test results in specific contexts such as healthcare and paternity determinations,⁵⁴ the ability to engage in nonconsensual testing of dropped genetic material is largely unregulated outside of these specific contexts, seeming to leave the door open for genetic paparazzi in at least some states.⁵⁵

The legal implications of capitalizing on abandoned genetic materials collected from public figures have been explored in the context of thought experiments for at least a decade.⁵⁶ Yet, as far as we can tell, there have been no actual court decisions involving this type of use, leaving us to continue with hypothetical rather than actual cases. In contrast to previous work predicting

Madonna-auction-tupac-letter.html [https://perma.cc/35HT-A766]; Julia Marsh, *Madonna Claims Auction House Is 'Selling Her DNA'*, PAGE SIX (July 18, 2017), https://pagesix.com/2017/07/18/madonna-claims-auction-house-is-selling-her-dna [https://perma.cc/AUN8-3BP9]; see also Paul Krassner, *Excrement in the News*, HUFFPOST (July 6, 2006), http://www.huffingtonpost.com/paul-krassner/excrement-in-the-news_b_24536.html [https://perma.cc/7QDR-36JD] (describing the security measures taken to protect the President's medical information); Michael Y. Park, *The Murky Legal World of the DNA You Leave Behind at Restaurants*, BON APPÉTIT (Jan. 18, 2015), https://www.bonappetit.com/restaurants-travel/article/dna-laws-restaurants [https://perma.cc/52CM-MPPX] (describing legal ramifications of DNA left on restaurant utensils and the protective measures of celebrities and public figures to secure their DNA).

⁵² See Nordhaus, *supra* note 7, at 286.

⁵³ See Patrick J. Alach, Comment, *Paparazzi and Privacy*, 28 LOY. L.A. ENT. L. REV. 205, 205–07 (2007).

⁵⁴ See Shapiro et al., *supra* note 44, at 4–5 nn.13–14; *Genome Statute and Legislation Database*, *supra* note 41.

⁵⁵ See Joh, *DNA Theft*, *supra* note 3, at 669 (“[T]he great majority of American jurisdictions, including the federal government, do not criminalize the nonconsensual collection of human tissue for the purposes of analyzing DNA.”).

⁵⁶ Scholars have been captivated with the idea of nonconsensual collection of genetic materials from celebrities and public figures for more than a decade. See generally *supra* note 3 for some of the work exploring the collection of genetic material and information for media use.

likely outcomes,⁵⁷ we focus on the alternative legal pathways into which courts may funnel genetic paparazzi scenarios and the effects of choosing these narrowing pathways on how we think about and govern genetics more broadly.⁵⁸

We begin our analysis with two hypothetical genetic paparazzi scenarios that have some grounding in real life. In both scenarios, private (namely, nongovernment) third parties collect the genetic materials of public figures without permission, and the collection of the genetic materials is not for the purpose of a government program, law enforcement, or otherwise ordered by a court. In both situations, the genetic material and information are also obtained without an obvious violation of tort or criminal law. And, in both scenarios, the genetic material and information are being used for an overtly commercial purpose, albeit one intertwined with public discourse.

In the first hypothetical, a media outlet claims to have obtained the genetic material of Presidential Candidate from discarded lunch materials at a political rally.⁵⁹ The media outlet publishes a list of medical conditions to which Presidential Candidate is supposedly predisposed, including schizophrenia⁶⁰ and polycystic kidney disease,⁶¹ as well as a confirmation of Presidential Candidate's claims about purported Native American ancestry. The media outlet

⁵⁷ See *supra* note 3.

⁵⁸ The narrowing may occur in light of the way that claims brought by public figures would characterize the harms (and, thus, the legal theories of harm implicated) as well as the aspects of genetics that become the focus of the analysis in such litigation. See, e.g., Scherr, *supra* note 12, at 525 (suggesting that early court decisions using a Fourth Amendment analytical framework mishandled genetic privacy by focusing too “narrowly on property-oriented privacy,” and that modern courts should ask “whether an individual has abandoned the expectation of privacy in the DNA within the nucleus of a cell that is found on an abandoned item, not whether one has abandoned the DNA . . . [t]he physical, informational, and dignitary dimensions of genetic privacy produce an expectation of privacy in the kaleidoscope of identity that is DNA”).

⁵⁹ See Green & Annas, *supra* note 3, at 1, 3 (suggesting there are both strong incentives for and technological capability to engage in nonconsensual sampling of a presidential candidate's genetic materials).

⁶⁰ See Mads Henriksen, Julie Nordgaard & Lennart B. Jansson, *Genetics of Schizophrenia: Overview of Methods, Findings and Limitations*, FRONTIERS HUM. NEUROSCIENCE, June 2017, at 1, 1 (“[T]he genetic architecture of schizophrenia has proven to be highly complex, heterogeneous and polygenic. The disease risk is constituted by numerous common genetic variants of only very small individual effect and by rare, highly penetrant genetic variants of larger effects.”); Osaka Univ., *A New Genetic Marker for Schizophrenia*, SCIENCE DAILY (Sept. 11, 2017), <https://www.sciencedaily.com/releases/2017/09/170911122729.htm> [<https://perma.cc/3X9H-FY95>] (describing the discovery of a genetic variant that may play a role in the disease and that “more than 80% of schizophrenia cases are considered to have a hereditary cause”).

⁶¹ See Stephen T. Reeders et al., *Two Genetic Markers Closely Linked to Adult Polycystic Kidney Disease on Chromosome 16*, 292 BRIT. MED. J. 851, 851 (1986) (discussing the identification of the genetic locus of adult polycystic kidney disease and the implications for diagnosis).

also discloses that Presidential Candidate was found to have the “infidelity gene”⁶² and the “gambling gene.”⁶³

Our second hypothetical scenario involves Famous Actor, who is known for his red eyes. While some gossip columns claim that his eye color is the result of wearing color contact lenses, Famous Actor claims he has a unique genetic mutation that causes the irises of his eyes to be bloodred. Paparazzi, who regularly follow Famous Actor, eventually obtain his genetic material from discarded floss in the trash at his girlfriend’s apartment complex. Upon sequencing the genetic material on the floss, they confirm that Famous Actor indeed has a mutation on a gene associated with eye color, which, according to one commentator, may result in much improved night vision. The paparazzi sell their findings, along with the genetic sequencing results, to a tabloid that publishes them. A few months later, a stem cell clinic starts offering injections of stem cells purportedly engineered to contain Famous Actor’s mutation, allegedly giving those treated the unique eye color and night vision capabilities. The treatment becomes a hit with avid hunters and adherents of the vampire subculture.⁶⁴ A year later, a woman claims to have conceived a child from a

⁶² Namely, certain alleles of genes that have been correlated with a tendency toward marital infidelity. *See, e.g.*, Brendan P. Zietsch, Lars Westberg, Pekka Santtila & Patrick Jern, *Genetic Analysis of Human Extrapair Mating: Heritability, Between-Sex Correlation, and Receptor Genes for Vasopressin and Oxytocin*, 36 *EVOLUTION & HUM. BEHAV.* 130, 130 (2015) (“[F]indings confirm genetic underpinnings of extrapair mating in humans”); Richard A. Friedman, *Infidelity Lurks in Your Genes*, *N.Y. TIMES* (May 22, 2015), <https://www.nytimes.com/2015/05/24/opinion/sunday/infidelity-lurks-in-your-genes.html> [<https://perma.cc/N9PC-GA9C>] (discussing research that he suggests shows the biological basis for infidelity). *But see* John Horgan, “*Infidelity Gene*” *Hyped in the News*, *SCI. AM.: CROSS-CHECK* (May 25, 2015), <https://blogs.scientificamerican.com/cross-check/infidelity-gene-hyped-in-the-news/> [<https://perma.cc/3FH7-X3PW>] (critiquing studies suggesting a genetic propensity to infidelity and resulting media response, emphasizing that “[p]roblems with the replicability of candidate-gene associations for behavioral traits are well documented”) (citation omitted).

⁶³ Namely, certain alleles of genes that have been correlated with a tendency toward addiction, including gambling. *See, e.g.*, A. Ibañez, I. Perez de Castro, J. Fernandez-Piqueras, C. Blanco & J. Saiz-Ruis, *Pathological Gambling and DNA Polymorphic Markers at MAO-A and MAO-B Genes*, 5 *MOLECULAR PSYCHIATRY* 105, 105 (2000) (reporting “[a]n increased incidence of about 20% of pathological gambling in first-degree relatives within clinical samples of pathological gamblers . . . [leading] to consideration of the possible role of a genetic component in the development of this disorder” and “evidence for genetic influence derived from a large twin study performed on 3359 twin pairs in United States . . . [revealing] that inherited factors explained 62% of the diagnosis of pathological gambling disorder”); D.S.S. Lobo, L. Aleksandrova, J. Knight, D.M. Casey, N. el-Guebaly, J.N. Nobrega & J.L. Kennedy, *Addiction-Related Genes in Gambling Disorders: New Insights from Parallel Human and Pre-Clinical Models*, 20 *MOLECULAR PSYCHIATRY* 1002, 1002 (2015) (using human subjects and animal models to explore genetic basis of gambling disorders).

⁶⁴ *See* David Keyworth, *The Socio-Religious Beliefs and Nature of the Contemporary Vampire Subculture*, 17 *J. CONTEMP. RELIGION* 355, 355 (2002) (describing vampire subculture).

gamete made from/with Famous Actor's cells (originating from the floss) via in vitro gametogenesis (IVG).⁶⁵

It is reasonable to assume that Presidential Candidate—in the first scenario—and Famous Actor—in the second scenario—will pursue legal action against the paparazzi, their financier-publishers, any implicated technical service providers and personnel, and—in the case of Famous Actor—medical personnel, as well as the woman who purportedly carries his genetic child. Their claims will include violations of their privacy and publicity rights, along with any other claims they could muster under the laws of whatever states are implicated. Regardless of how creative their legal arguments, in situations where the genetic material is obtained from dropped or shed biological matter collected in public places, the legal claims based on invasion of privacy and violation of publicity rights are likely to predominate.⁶⁶ Thus, once such lawsuits are filed, the litigants will almost inevitably focus their legal battle on privacy and publicity rights and on when and how such rights apply to genetic materials and information collected in the manner described in the hypotheticals.

Looking at nonconsensual collection of genetic material of a public figure, its analysis, and the publication of the results through this dominant lens of privacy and publicity rights, it appears that so long as (i) no other (nonprivacy) tortious or criminal act is committed in the collection, analysis, and publication of the information; (ii) the genetic material is not collected in a setting that lends itself to a reasonable expectation of privacy (e.g., a doctor's office), and the people involved owe no duty of confidentiality to the public figure (e.g., a doctor or nurse); (iii) the information is true and accurate, at least to the extent that is reasonably ascertainable under current scientific knowledge and methods; and (iv) the publication involves a matter "of legitimate concern to the public" that

⁶⁵ See, e.g., Carolyn Y. Johnson, *The 'Game-Changing' Technique to Create Babies from Skin Cells Just Stepped Forward*, WASH. POST (Sept. 20, 2018), https://www.washingtonpost.com/science/2018/09/20/game-changing-technique-create-babies-skin-cells-just-stepped-forward/?utm_term=.1ae9d0db978d [<https://perma.cc/N3V6-KVVD>] (suggesting it is only a matter of time before scientists will be able to generate egg and sperm cells from somatic cells).

⁶⁶ See, e.g., Joh, *Reframing*, *supra* note 3, at 882–83 (rejecting the abandoned property analogy for surreptitious harvesting of genetic materials and arguing that deficiencies in property analogies suggest genetic material is a unique category not capable of abandonment); Rothstein, *Genetic Stalking*, *supra* note 3, at 559–60, 577 (arguing that existing laws are inadequate to address the issue of genetic stalking and that courts are unlikely to recognize biological conversion claims for unauthorized taking of objects for genetic testing; focusing on the need for legislative responses to protect underlying privacy concerns of nonconsensual genetic testing or else "[s]ociety will have succeeded in reaching a level of 'zero' privacy"). Courts have been reluctant to recognize an individual's property interests in biological specimens and the information they contain. Rao, *supra* note 11, at 371. *But see* Roberts, *Genetic Conversion*, *supra* note 6, at 1–2 (suggesting that perhaps claims based on genetic conversion might be recognized in the future as norms governing genetic privacy shift).

amounts to more than “mere curiosity,” the collection, analysis, and publication of a public figure’s genetic information will likely not be considered an illegal invasion of the public figure’s privacy or publicity rights. Commentators analyzing what a court might do when confronted with the surreptitious collection of genetic materials by the media from a public figure have made similar predictions after an exhaustive analysis of alternative claims.⁶⁷

The situation may be different when the genetic material of a public figure is utilized for nonjournalistic purposes that could be regarded as appropriation of the public figure’s likeness in the broad sense. There are also a variety of state genetic privacy statutes that would make genetic paparazzi scenarios legally problematic for the paparazzi, labs involved, publishers of the information, and these and other third parties who would use the information or the genetic material for purposes not explicitly authorized by the individual from whom they were taken or derived. However, these state laws are mostly untested in areas of potential conflict with federal laws and regulations.⁶⁸ Should they ever be asserted against genetic paparazzi or publishers who have published the genetic analysis results of a public figure, these state genetic privacy laws might face a successful First Amendment challenge similar to the ones seen in the

⁶⁷Our analysis is consistent with conclusions drawn by other commentators exploring similar hypotheticals. Joh, *DNA Theft*, *supra* note 3, at 668–69 (“While a number of states and the federal government ban the disclosure of genetic testing results in some circumstances, such as health and employment, the great majority of American jurisdictions, including the federal government, do not criminalize the nonconsensual collection of human tissue for the purposes of analyzing DNA. DNA theft is generally unconstrained by law.”); Makdisi, *supra* note 3, at 1025–26 (exploring the need for a legal structure to respond to genetic intrusions and examining the tort of intrusion as way to protect genetic privacy); Scherr, *supra* note 12, at 454 (“Courts have uniformly rejected Fourth Amendment protection against surreptitious harvesting of out-of-body DNA by the police”—reflecting the view that one abandons their privacy interest when abandoning the material containing one’s DNA); *see also* Rothstein *Genetic Stalking*, *supra* note 3, at 543 (arguing that constitutional law, tort law, and state genetic privacy statutes fail to adequately protect people from genetic stalking and that additional legislation is needed to protect against genetic stalking and voyeurism). We will return to this analysis again after we discuss the legal framework in Part III.

⁶⁸*See, e.g.*, Robert Pear, *States Pass Laws to Regulate Uses of Genetic Testing*, N.Y. TIMES, Oct. 18, 1997, at A1 (discussing areas of potential conflict between state laws and existing practices and legal approaches to the use of genetic information in the late twentieth century). *See generally* *Genome Statute and Legislation Database*, *supra* note 41 (listing state genetic privacy laws). The scope, constitutionality, and fit with federal laws of most of these state privacy statutes have yet to be legally tested. *But see, e.g.*, Jennifer K. Wagner, *A Constitutional Challenge to Alaska’s Genetic Privacy Statute*, PRIVACY REP. (July 18, 2017), <https://theprivacyreport.com/2017/07/18/a-constitutional-challenge-to-alaskas-genetic-privacy-statute/> [<https://perma.cc/PJZ4-GBSD>] (discussing a challenge to the constitutionality of Alaska’s genetic privacy statute asserted as a defense by genealogy company in class action).

context of privacy and defamation lawsuits.⁶⁹ In addition, opportunities might remain for publishers of genetic information who obtain the information lawfully even where the original acquisition runs afoul of the law.⁷⁰ And regardless of the possible legal risks, it is likely that none of the statutes or regulations currently in place would significantly deter a determined genetic paparazzi or preclude a genetic paparazzi scenario altogether, certainly not when the payoff from the publication and the likelihood of a First Amendment defense are both high enough.

While predicting the likely outcomes of these genetic paparazzi scenarios is interesting in itself, we argue that the question of how judges will characterize the legal issues that arise at the intersection of genetics, privacy and publicity will matter as much if not more than the predicted outcomes. Judicial choices about how to characterize the claims, or what we refer to in Part III as choices of legal pathways, will impact the legal treatment of genetic materials and genetic information by influencing our understanding of what interests and whose interests are implicated when genetic materials are gathered and analyzed and genetic information published.

III. LEGAL FRAMING OF GENETIC PAPARAZZI CASES

*The intensity and complexity of life, attendant upon advancing civilization, have rendered necessary some retreat from the world. . . so that solitude and privacy have become more essential to the individual . . .*⁷¹

To consider how the legal issues in genetic paparazzi suits will be characterized, we need to begin with the ways in which courts and legislators currently think about and frame issues of privacy and publicity on the one hand and protections of genetic information on the other hand. When courts confront legal challenges arising from new and transformational technologies, such as genetic sequencing technologies, they start with existing legal categories to see where and whether the new issues fit.⁷² The legal categories selected will impact

⁶⁹For a discussion of the intersection of genetics and the First Amendment, and the idea of genetics as speech, see Barbara J. Evans, *The First Amendment Right to Speak About the Human Genome*, 16 U. PA. J. CONST. L. 549, 551 (2014), and Jorge R. Roig, *Can DNA Be Speech?*, 34 CARDOZO ARTS & ENT. L.J. 163, 165–66 (2016) (arguing that questions about DNA and free speech lead to “the collision and intermingling of [issues of] privacy, patent, and copyright law with freedom of expression”).

⁷⁰*See, e.g.,* *Bartnicki v. Vopper*, 532 U.S. 514, 517–18 (2001) (finding media defendants were not liable for publishing information obtained illegally by a third party where they obtained the information legally).

⁷¹Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 196 (1890).

⁷²In the context of police searches, for example, genetic information is analogized to fingerprints for Fourth Amendment purposes. *See, e.g.,* *Maryland v. King*, 569 U.S. 435, 450–51 (2013). In the context of health records, genetic information is often treated as one

the ways in which the technology and its use are characterized and treated by courts.⁷³ This in turn will influence where jurists, policymakers, and the public focus their attention.⁷⁴

The various state and federal laws discussed in this Part provide the basic legal framework, or web, that courts will rely upon when deciding how to characterize the issues raised by the non-consensual gathering, analysis, and use of genetic materials and information of public figures by the press. This basic legal framework, or web, of state and federal laws that together provide a system of overlapping rights and limitations draws from (i) privacy law, (ii) rights of publicity and related intellectual property laws, (iii) specific federal laws that are limited to particular functions, such as medical privacy and genetic privacy in employment contexts, (iv) state statutes dealing specifically with genetic privacy, and (v) tort law claims grounded in property rights (e.g., trespass, conversion). This Part examines the alternative legal pathways⁷⁵ that courts are

kind of health information. *See, e.g.*, HIPAA Privacy Rule, 45 C.F.R. § 160.103 (2013) (genetic information is health information protected by the Privacy Rule). For cases involving research use of genetic information, informed consent becomes the touchstone. *See, e.g.*, Amy L. McGuire & Laura M. Beskow, *Informed Consent in Genomics and Genetic Research*, ANN. REV. GENOMICS & HUM. GENETICS, 2010, at 361, 362 (describing how for research use of genetic information, informed consent becomes the touchstone).

⁷³This can be seen in part as an application of path dependence in the law. Richard Fallon, *The “Conservative” Paths of the Rehnquist Court’s Federalism Decisions*, 69 U. CHI. L. REV. 429, 434–35 (2002) (“‘[P]ath dependence’ functions as a capsule reference to various ways in which history and surrounding attitudes and expectations influence judicial decisionmaking [including the concept of stare decisis].”); *see also* Gregory N. Mandel, *History Lessons for a General Theory of Law and Technology*, 8 MINN. J.L. SCI. & TECH. 551, 553 (2007) (“Lawyers and judges are trained to work in a system of precedent that depends on categorizing cases according to existing legal rules. The routine response to new issues, not surprisingly, is to try to analogize them to existing legal categorization. Such a response is often rational. But, where the new issue arises as a result of technological change, the old categories may no longer apply.”). *See generally* Oona A. Hathaway, *Path Dependence in the Law: The Course and Pattern of Legal Change in a Common Law System*, 86 IOWA L. REV. 601 (2001) (exploring the path dependence inherent in the common law system and the reliance it creates on earlier court decisions).

⁷⁴Mandel, *supra* note 73, at 553. Many of the most salient examples of how legal approaches to genetics influence policy focus can be found in the context of use by law enforcement, such as the collection of genetic samples by law enforcement from people who are arrested and convicted or the use of consumer genetic databases to track down criminal suspects. *See, e.g.*, Vera Eidelman, Opinion, *The Creepy, Dark Side of DNA Databases*, WASH. POST (May 8, 2018), https://www.washingtonpost.com/opinions/the-creepy-dark-side-of-dna-databases/2018/05/08/279e9c2c-5230-11e8-abd8-265bd07a9859_story.html [<https://perma.cc/7S6C-H9DR>] (“The lines we draw for this case may well provide a road map for investigations of crimes in the future. . . . Now is the time for legislators, the courts and law enforcement to ensure that the benefits of genetic-science technology don’t come at the cost of our privacy rights.”).

⁷⁵By “legal pathways” we are referring to the ways that the legal questions in genetic paparazzi cases will be framed, the legal theories that courts will employ when deciding genetic paparazzi cases, and the choices about which aspects of genetics to focus on in reaching their decisions.

likely to follow when confronting genetic paparazzi scenarios, beginning with an overview of the legal framework and then exploring the implications of alternative pathways.

A. *Rights of Privacy (or Lack Thereof) for Public Figures*

Modern U.S. privacy law is far from a uniform body of law, resembling instead a complex meshwork of state and federal laws and regulations that govern the ways that information can be acquired, accessed, stored, and used.⁷⁶ The concept of privacy underlying the law is itself elusive, shifting with the contexts in which issues of privacy are raised and the technologies that determine what is private as a practical matter and what is not.⁷⁷

1. *Constitutional Basis for Privacy*

At the federal level, different legal frameworks apply to public and private actors. For government actors, discussions of privacy are grounded in a constitutional balancing of public interests in obtaining and using information and private rights to be free from government intrusion.⁷⁸ Although there is no explicit mention of a right to privacy in the U.S. Constitution, the Supreme Court has found support for a right to privacy in the Fourth Amendment⁷⁹ as well as the Fourteenth⁸⁰ and even in the First Amendment⁸¹ and Fifth

⁷⁶ See Neil Richards, Andrew Serwin & Tyler Blake, *Understanding American Privacy*, in RESEARCH HANDBOOK ON PRIVACY AND DATA PROTECTION LAW: VALUES, NORMS AND GLOBAL POLITICS (Gloria González Fuster, Rosamunde van Brakel & Paul De Hert eds.) (forthcoming) (manuscript at 2–3), https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3256918 [<https://perma.cc/Y9JB-ELGE>].

⁷⁷ See Richard A. Posner, *The Right of Privacy*, 12 GA. L. REV. 393, 393 (1978) (“The concept of ‘privacy’ is elusive and ill defined.”); see also Julie E. Cohen, *What Privacy Is For*, 126 HARV. L. REV. 1904, 1906 (2013) (“Privacy is shorthand for breathing room to engage in the processes of boundary management that enable and constitute self-development. So understood, privacy is fundamentally dynamic.”); Ken Gormley, *One Hundred Years of Privacy*, 1992 WIS. L. REV. 1335, 1335 (1992) (arguing that “privacy will remain extremely sensitive to historical triggers, and new permutations of this ‘right to be let alone’ will inevitably develop as American democracy itself evolves”).

⁷⁸ See, e.g., *People v. Saunders*, 531 N.Y.S.2d 987, 989 (N.Y. Sup. Ct. 1988).

⁷⁹ U.S. CONST. amend. IV.

⁸⁰ U.S. CONST. amend. XIV, § 1 (right to privacy inherent in due process); *Griswold v. Connecticut*, 381 U.S. 479, 481–86 (1965) (recognizing a due process right to privacy in connection with finding of married couples’ rights to contraception); see also *Lawrence v. Texas*, 539 U.S. 558, 578–79 (2003) (right to privacy in connection with sexual practices of same-sex couples); *Roe v. Wade*, 410 U.S. 113, 152–55 (1973) (right of privacy invoked in connection with right to abortion) (subsequent history omitted).

⁸¹ U.S. CONST. amend. I (protecting right to free assembly).

Amendment.⁸² Notwithstanding this constitutional support for a right to privacy, the right has, from the outset, been limited by First Amendment concerns with freedom of the press and freedom of speech as well as Fourth Amendment prohibitions on unreasonable searches and seizures.⁸³ Since much of the existing legal debate surrounding nonconsensual gathering of genetic materials has taken place in the context of criminal law, with resulting legal challenges on Fourth Amendment grounds, courts already have some existing cases to draw upon when looking at constitutional arguments for genetic privacy.⁸⁴ The constitutional arguments reinforce the legal focus on limited expectations of privacy and suggest areas where the public interest in access to genetic information might be controlling.⁸⁵

Federal privacy laws governing the private sector are more limited in reach and primarily functional in nature, focusing on specific types of information and sectors of use, such as the gathering and sharing of health data or restrictions on the use of genetic information for employment and insurance purposes.⁸⁶

2. Tort-Based Privacy

Privacy rights have developed much more broadly under state law, emerging as extensions of tort law with varying boundaries of what is protected and what is not.⁸⁷ The legal right to privacy originally emerged as a state-based common law tort grounded on the idea of a “right to be let alone” and free from third party invasions into private life.⁸⁸ The tort-based right to privacy encompasses four different types of harms: (i) intrusion into solitude, (ii) appropriation of an individual’s name or likeness, (iii) public disclosure of

⁸² U.S. CONST. amend. V (protecting against self-incrimination). This in turn protects the privacy of personal information. See Taylor Ichinose, Note, *The Fifth Amendment’s Pressing Issue in the Digital Era: Protecting Your Password but What About Your Prints?*, 57 U. LOUISVILLE L. REV. 353, 375 (2019).

⁸³ See Richards et al., *supra* note 76, at 4 (discussing how U.S. privacy law is “bifurcated” between public and private regimes).

⁸⁴ See generally Holly K. Fernandez, *Genetic Privacy, Abandonment, and DNA Dragnets: Is Fourth Amendment Jurisprudence Adequate?*, HASTINGS CTR. REP., Jan.-Feb. 2005, at 21 (discussing cases involving the use of abandoned genetic property in criminal law).

⁸⁵ See Anya E.R. Prince, *Comprehensive Protection of Genetic Information: One Size Privacy or Property Models May Not Fit All*, 79 BROOK. L. REV. 175, 183–85 (2013).

⁸⁶ See generally Wolf et al., *supra* note 42, at 6 (describing categories of genomic research); *Privacy in Genomics*, *supra* note 42 (describing privacy and research goals in genomics research).

⁸⁷ See, e.g., Nordhaus, *supra* note 7, at 287.

⁸⁸ See *id.* at 287 (exploring the early emergence of the right of privacy); see also *Pavesich v. New England Life Ins. Co.*, 50 S.E. 68, 78 (Ga. 1905) (adopting the conclusion that a person has the “absolute right to be let alone”).

private facts, and (iv) public depiction of the individual in a false light.⁸⁹ Although state laws vary in how they protect privacy, most states recognize some variation of these four torts.⁹⁰ Taken together, these different privacy interests can be understood as providing individuals with some control over the gathering, sharing, and use of information about themselves. These tort-based rights are inalienable rights closely tied to the individual and grounded in the emotional (and other) harms to that individual that might arise from unauthorized gathering, disclosure, or uses of their personal information.⁹¹ Tort-based privacy rights are limited, however, by determinations about what are reasonable (and unreasonable) expectations of privacy, what are subjects of legitimate public interest, and what constitute acceptable and unacceptable intrusions.⁹² In the context of genetic paparazzi scenarios, courts will begin with this idea of genetic materials and information as inherently private and personal to the individual and will then consider where and how the normal limitations on privacy apply once genetic material is abandoned or discarded.

3. *The Newsworthiness Exception to Privacy*

The concept of newsworthiness operates as one of the more important limits on privacy interests, sitting at the intersection of privacy, free speech, and freedom of the press.⁹³ Recognizing the First Amendment (and its reflection in state constitutional and common law) protections of freedom of speech and freedom of the press, federal and state courts alike have long given deference to the newsworthiness defense in cases where the press is accused of violating privacy rights.⁹⁴ Although state rights to privacy vary, they all recognize some

⁸⁹ See William L. Prosser, *Privacy*, 48 CALIF. L. REV. 383, 389 (1960) (describing privacy as consisting of four kinds of invasion of different interests). For a modern iteration, see RESTATEMENT (SECOND) OF TORTS § 652A (AM. LAW INST. 1977). *But see* Neil M. Richards & Daniel J. Solove, *Prosser's Privacy Law: A Mixed Legacy*, 98 CALIF. L. REV. 1887, 1915 (2010) (arguing that Prosser's approach to privacy has failed to evolve to respond to modern challenges).

⁹⁰ Memorandum from Paul M. Schwartz, Univ. Cal. Berkeley Sch. of Law, and Daniel J. Solove, George Washington Univ. Law Sch., *Reworking Information Privacy Law: A Memorandum Regarding Future ALI Projects About Information Privacy Law 8–9* (Aug. 2012) (on file with the *Ohio State Law Journal*).

⁹¹ See Ellen Wright Clayton, Barbara J. Evans, James W. Hazel & Mark A. Rothstein, *The Law of Genetic Privacy: Applications, Implications, and Limitations*, J.L. & BIOSCIENCES, Oct. 2019, at 1, 5–6.

⁹² See Solveig Singleton, *Privacy Versus the First Amendment: A Skeptical Approach*, 11 FORDHAM INTELL. PROP. MEDIA & ENT. L.J. 97, 97 (2000) (exploring tensions between protections of privacy and free speech and, in so doing, examining some of the different limitations on privacy).

⁹³ Erin C. Carroll, *Making News: Balancing Newsworthiness and Privacy in the Age of Algorithms*, 106 GEO. L.J. 69, 75 (2017).

⁹⁴ See, e.g., *Shulman v. Grp. W Prods., Inc.*, 955 P.2d 469, 478–86 (Cal. 1998) (providing a detailed discussion of how different courts have approached the newsworthiness

kind of exception for information regarded as newsworthy.⁹⁵ While the newsworthiness defense to privacy torts is well established, it lacks any precise legal formula for balancing the individual's interest in being free from intrusion against the public interests in allowing the media to publish without fear of liability.⁹⁶ Most courts employ some form of balancing of the status of the individual, the social value of the information, and the depth of the intrusion.⁹⁷ But there is no clear consensus as to how to identify, define and measure the competing interests.⁹⁸ Although the standards for newsworthiness vary, courts share a tendency to defer to the press regarding what is newsworthy.⁹⁹

The contours of privacy torts and the limitations on these torts, including what is considered newsworthy, have changed over time in response to societal and technological developments.¹⁰⁰ The early emergence of legal protections for individuals from invasion of their privacy coincided with the rapid growth in newspaper circulation as well as the introduction of the first mass marketed cameras, advances which allowed for the capture and publication of candid

exception to privacy); *see also Courts Wrestle with Defining Newsworthiness in Privacy Cases*, REPORTERS COMMITTEE FOR FREEDOM PRESS, <https://www.rcfp.org/journals/news-media-and-law-fall-2015/courts-wrestle-defining-news/> [<https://perma.cc/9UVZ-PEYK>] [hereinafter REPORTERS COMMITTEE] (explaining that the standard of newsworthiness varies from state to state).

⁹⁵ *See, e.g.*, J. THOMAS MCCARTHY, *THE RIGHTS OF PUBLICITY AND PRIVACY* § 6:6 (2d ed. 2009) (characterizing state publicity statutes as constituting “a crazy quilt of different responses at different times to different demands on the legislatures”).

⁹⁶ *See* Carroll, *supra* note 93, at 74 (suggesting that there needs to be more explicit balancing between privacy protections and First Amendment protections in the courts).

⁹⁷ *See* REPORTERS COMMITTEE, *supra* note 94 (asserting that courts continue to take an expansive view of newsworthiness; enumerating some of the questions courts may ask when determining newsworthiness, including whether the information relates to anything of political, social or other concern, the social value of publishing the information, the public status of the person, and the degree of intrusion).

⁹⁸ *See generally* Susan M. Gilles, *Public Plaintiffs and Private Facts: Should the “Public Figure” Doctrine Be Transplanted into Privacy Law?*, 83 NEB. L. REV. 1204 (2005) (discussing some of the confusion in determining privacy rights where public figures and subjects of public interest are concerned).

⁹⁹ *See* Citron, *supra* note 48, at 1828–29 (noting that courts “often defer to the media’s judgment” and citing a dated but relevant study that found “from 1974 to 1984, plaintiffs prevailed in 2.8% of cases involving public disclosure claims against the media and in twelve percent of cases involving non-media defendants”); *see also Shulman*, 955 P.2d at 485 (discussing deference given to the press by federal and state courts when considering the newsworthiness exception to privacy; noting that “[i]n general, it is not for a court or jury to say how a particular story is best covered”); *Foster v. Svenson*, 7 N.Y.S.3d 96, 100–01 (N.Y. App. Div. 2015) (describing broad application of newsworthiness and public interest exceptions to privacy and emphasizing that “there is a strong societal interest in facilitating access to information that enables people to discuss and understand contemporary issues”).

¹⁰⁰ *See* Gormley, *supra* note 77, at 1335–36 (arguing that historical changes produce new brands of privacy that balance competing interests, taking the legal concepts of privacy in different directions).

pictures and personal stories accessible to ever larger audiences.¹⁰¹ Public interest in legal rights to privacy was fueled by newsgathering practices and techniques that increasingly intruded into private lives.¹⁰² The concept of newsworthiness and determinations of what subjects are of legitimate public interest are also influenced by changing social mores and conventions.¹⁰³ “News,” for example, is defined in the *Second Restatement of Torts* as information falling within the scope of legitimate public concern, which, in turn, has been defined in accordance with social understandings and community norms about what constitutes news.¹⁰⁴ In a world where social media is increasingly the primary source of “news,” and where Facebook and Twitter are cited by many as an important way of getting the “news,” the realm of what is newsworthy seems to be expanding.¹⁰⁵

Looking at the genetic paparazzi scenarios described earlier, both Presidential Candidate and, perhaps to a lesser extent, Famous Actor, will have to contend with arguments that their genetic information is newsworthy. Courts will therefore need to inquire whether, if at all, the genetic information of public figures should be considered a matter of legitimate public concern. As discussed further below, the fact that both Presidential Candidate and Famous Actor are public figures makes the newsworthiness argument stronger. Thus, claims of newsworthiness by genetic paparazzi will lead to a focus on the expressive content of genetic information and the legitimacy (if any) of personal genetic information as the subject of public interest.

¹⁰¹ DANIEL J. SOLOVE, MARC ROTENBERG & PAUL M. SCHWARTZ, *PRIVACY, INFORMATION, AND TECHNOLOGY* 9–10 (2006).

¹⁰² See, e.g., Diane L. Zimmerman, *Requiem for a Heavyweight: A Farewell to Warren and Brandeis's Privacy Tort*, 68 CORNELL L. REV. 291, 295–96 (1983) (“The circumstances that are said to have inspired the [Warren and Brandeis 1890] article may demonstrate the types of information, and the breadth of the right, that the authors wanted to protect. Proper Bostonians of the 1890s regarded the appearance of their names in the newspapers as a disgrace.”).

¹⁰³ See, e.g., *Shulman*, 955 P.2d at 473 (“[T]he United States has also seen a series of revolutions in mores and conventions that has moved, blurred and, at times, seemingly threatened to erase the line between public and private life.”); see also Amy Gajda, *The Present of Newsworthiness*, 50 NEW ENG. L. REV. 145, 146 (2016) (exploring a court decision focused on news as “a concept that has essentially been defined by traditional publishers and broadcasters, ‘in accordance with the mores of the community’”) (quoting *Judge v. Saltz Plastic Surgery*, 367 P.3d 1006, 1012 (Utah 2016)); Linda N. Woito & Patrick McNulty, *The Privacy Disclosure Tort and the First Amendment: Should the Community Decide Newsworthiness?*, 64 IOWA L. REV. 185, 185–86, 223 (1979).

¹⁰⁴ See RESTATEMENT (SECOND) OF TORTS § 652D (AM. LAW INST. 1977); see also Amy Gajda, *Judging Journalism: The Turn Toward Privacy and Judicial Regulation of the Press*, 97 CALIF. L. REV. 1039, 1065–66 (2009).

¹⁰⁵ See generally Caroll, *supra* note 93 (examining the changing social mores of what constitutes “news” and how it is accessed).

4. *Public Figures and Reduced Expectations of Privacy*

Much has been written about the limited privacy rights of public figures, where the “right to know” and discuss information of public concern and the newsworthiness of so much of their lives often prevails over their “right to be let alone.”¹⁰⁶ Due to their role in public discourse and their close if not always comfortable relationship with the press, public figures occupy a special spot within the web of federal and state privacy laws.¹⁰⁷ Their diminished rights of privacy are the result of a cluster of rationales that depend on their role in public life—whether they occupy positions of power, responsibility, or celebrity.¹⁰⁸ The scope of public figures’ privacy rights are also shaped, and limited, by norms governing what should and should not be the subject of public discourse, and what should and should not be protected from disclosure as private facts.¹⁰⁹

In drawing the parameters around who is a public figure and what this means for privacy rights, the Supreme Court has identified several basic components of the concept of a public figure, defining a public figure in terms of: (i) access to and control over the media, (ii) occupying a public role, such as in politics, sports, or entertainment, and (iii) as a result of this public role, inviting or deserving public scrutiny, (iv) about a matter of public discussion or controversy.¹¹⁰ The reasoning behind public figures’ more limited privacy rights is based on notions of consent—the idea that public figures have voluntarily placed themselves in the public eye and have thus consented to

¹⁰⁶ For a few examples drawn from a vast literature, see Nordhaus, *supra* note 7, at 289–92 (exploring the limits on the right to privacy for celebrities), and Yanisky-Ravid & Lahav, *supra* note 48, at 976 (“In the United States . . . the ‘right to know’ . . . [and] freedom of speech generally overrides public figures’ right to privacy.”). See generally JENNIFER E. ROTHMAN, *THE RIGHT OF PUBLICITY: PRIVACY REIMAGINED FOR A PUBLIC WORLD* (2018) (exploring the limits of privacy and the evolution of rights of publicity and suggesting a reorientation of privacy and publicity rights).

¹⁰⁷ See, e.g., *Lawrence v. Bauer Publ’g. & Printing Ltd.*, 446 A.2d 469, 475 (N.J. 1982) (“Important factors that led the Court to conclude that the *Gertz* plaintiff was not a public figure included plaintiff’s lack of any calculated relationship with the press . . .”) (citing *Gertz v. Robert Welch, Inc.*, 418 U.S. 323, 352 (1974)).

¹⁰⁸ Robert C. Post, *Data Privacy and Dignitary Privacy: Google Spain, the Right to Be Forgotten, and the Construction of the Public Sphere*, 67 *DUKE L.J.* 981, 1013 n.129 (2018).

¹⁰⁹ See, e.g., Daniel J. Solove, *The Virtues of Knowing Less: Justifying Privacy Protections Against Disclosure*, 53 *DUKE L.J.* 967, 1000–01, 1013 (2003) (examining the legal basis for distinguishing between information of public and private concern, suggesting that instead we should focus on the relationships in which information is transferred and the uses to which the information is put); see also Amy Gajda, *Privacy, Press, and the Right to Be Forgotten in the United States*, 93 *WASH. L. REV.* 201, 258–59 (2018) (discussing the balancing considerations between the “public need” and private harm from releasing such information).

¹¹⁰ See, e.g., *Gertz v. Robert Welch, Inc.*, 418 U.S. 323, 345 (1974) (distinguishing between all-purpose public figures, limited-purpose public figures, and private figures); see also Yanisky-Ravid & Lahav, *supra* note 48, at 981 (describing components used in the law to distinguish public figures and arguing that these components are too broad).

limited privacy; their ability to engage in self-defense through access to the media; the inherently public nature of their affairs; and the newsworthy nature of their activities.¹¹¹ Although the determination of whether a person is a public figure under Supreme Court law is by no means clear cut and varies depending on the nature of the privacy right asserted—once a person is found to be a public figure, they can expect limited protection of their privacy interests.¹¹²

In the context of the press, there are few restrictions on the publication of truthful information that has been lawfully obtained, or even unlawfully obtained by a third party but lawfully acquired by the publisher.¹¹³ Indeed, according to some views, “contemporary courts have determined that nearly anyone in whom the public could conceivably be interested is a public figure, and nearly any information regarding a public figure may be by definition ‘newsworthy.’”¹¹⁴ Even where information about a public figure is not accurate, there are high thresholds for assigning liability to the publisher of such information.¹¹⁵

The pervasiveness of technologies available for obtaining and sharing personal information has a particularly significant impact on public figures, with their already diminished expectations of privacy.¹¹⁶ New technologies continue to shift the privacy landscape for public figures by increasing the ease and speed with which information about them can be acquired and shared with potentially large audiences. In so doing, technology further exacerbates existing tensions in the law between privacy rights, on the one hand, and legal protections of freedoms of speech and the press, on the other.¹¹⁷ In addition to technological pressures, First Amendment rights of free speech and freedom of the press have been applied more and more expansively in commercial contexts, treating a variety of commercial activities ranging from campaign finance to the contents

¹¹¹Thomas E. Kadri & Kate Klonick, *Facebook v. Sullivan: Public Figures and Newsworthiness in Online Speech*, 93 S. CAL. L. REV. 37, 80 (2019).

¹¹²For a discussion of the role of public figure status in Supreme Court decisions regarding privacy, see generally Gilles, *supra* note 98.

¹¹³*See, e.g.*, *Bartnicki v. Vopper*, 532 U.S. 514, 516 (2001) (“[A] stranger’s illegal conduct does not suffice to remove the First Amendment shield from speech about a matter of public concern.”); *Smith v. Daily Mail Publ’g Co.*, 443 U.S. 97, 103 (1979) (“[I]f a newspaper lawfully obtains truthful information about a matter of public significance then state officials may not constitutionally punish publication of the information, absent a need to further a state interest of the highest order.”).

¹¹⁴*See, e.g.*, Scott J. Shackelford, *Fragile Merchandise: A Comparative Analysis of the Privacy Rights for Public Figures*, 49 AM. BUS. L.J. 125, 145, 147 (2012) (examining trends of cases dealing with public figures and the newsworthiness exception, arguing that “[i]n the United States the media asserts the public’s right to know, a view to which courts have been sympathetic so as to avoid a chilling effect on public discourse”).

¹¹⁵*See* *N.Y. Times Co. v. Sullivan*, 376 U.S. 254, 287–92 (1964).

¹¹⁶*See, e.g.*, Shackelford, *supra* note 114, at 128–31 (examining the clash between privacy rights of public figures and the public’s right to know over time).

¹¹⁷*See, e.g.*, Yanisky-Ravid & Lahav, *supra* note 48, at 1000 (calling for a new approach to protecting spheres of privacy for public figures in an ever intrusive digital world).

of drug labels as protected speech.¹¹⁸ If these trends were to continue in the context of genetic materials and information, public figures might find themselves having to justify why reports on their genetic information should not be considered as protected speech.

It is against this legal backdrop that courts will be forced to confront the question of how deeply the press can peer into the public figure and whether any aspects of the person will remain off limits. While privacy will be a natural starting point for the courts, following this pathway will frame questions about the legal status of genetic materials and information in particular in potentially limiting ways.¹¹⁹

As previously discussed, the privacy rights of public figures constitute only part of the legal framework—albeit a dominant part—and the privacy cases are likely to capture only limited aspects of the genetic materials and information at stake. As investments in celebrity personas and the commercial value of these personas continue to escalate,¹²⁰ rights of publicity become ever more important for public figures, and courts will have the opportunity to pursue this property-like legal pathway when considering genetic materials and information.

B. Publicity Rights of Public Figures

The limited federal and state law privacy rights of public figures have been complemented by an increasing array of state law rights of publicity that target the commercial aspects of personal traits and information, shifting the legal landscape by adding property-like rights to the picture.¹²¹ The right of publicity has its origins in rights of privacy, particularly in the misappropriation of name or likeness.¹²² While the right of privacy can be broadly understood as the right to control information about oneself—such as name, image, and reputation—

¹¹⁸ See, e.g., Elliot Zaret, *Commercial Speech and the Evolution of the First Amendment*, WASH. LAW., Sept. 2015, at 24, 26; Adam Liptak, *How Conservatives Weaponized the First Amendment*, N.Y. TIMES (June 30, 2018), <https://www.nytimes.com/2018/06/30/us/politics/first-amendment-conservatives-supreme-court.html> [<https://perma.cc/H6LR-RNKF>]. For an interesting analysis of when and how the question of when the First Amendment comes into play, see also Frederick Schauer, *The Boundaries of the First Amendment: A Preliminary Exploration of Constitutional Salience*, 117 HARV. L. REV. 1765, 1765–67 (2004) (“The history of the First Amendment is a history of its boundaries. . . . Once the First Amendment shows up, much of the game is over.”).

¹¹⁹ See discussion *infra* Part IV.F.

¹²⁰ See Anita Elberse & Jeroen Verleun, *The Economic Value of Celebrity Endorsements*, 52 J. ADVERT. RES. 149, 163 (2012) (noting that a celebrity endorsement increases a company’s sales an average of 4% relative to its competition, and also increases a company’s stock value by 0.25%).

¹²¹ See generally Martin H. Redish & Kelsey B. Shust, *The Right of Publicity and the First Amendment in the Modern Age of Commercial Speech*, 56 WM. & MARY L. REV. 1443 (2015) (examining the statutory and common law development of the right of publicity and its intersection with the First Amendment and commercial speech).

¹²² See Kathryn Riley, *Misappropriation of Name or Likeness Versus Invasion of Right of Publicity*, 12 J. CONTEMP. LEGAL ISSUES 587, 587 (2001).

from public disclosure, the right of publicity focuses on control over how that public disclosure takes place, and for whose economic benefit.¹²³ Early claims for violations of publicity rights were based on theories of personal harm arising from a misappropriation of the name, image, or likeness of an individual, but later claims shifted to focus on the economic harm caused by lost opportunities for commercial exploitation and gain.¹²⁴

The right of publicity can be generally understood as “the right to control the commercial use of one’s identity”¹²⁵ as manifested in name, image, and likeness.¹²⁶ The nature and scope of the right varies across states, however, and remains in flux even within states.¹²⁷ Laws creating and protecting rights of publicity are solely a creature of state law, and different states have widely divergent approaches to publicity rights.¹²⁸ About thirty-eight states have some form of common law protection for publicity rights, while thirty states have some form of right of publicity statute.¹²⁹ A separate and distinct “right of publicity” is also recognized in the American Law Institute’s *Third Restatement of Unfair Competition*.¹³⁰

Notwithstanding their variation, most rights of publicity statutes share the following main elements: (i) a determination of who is protected by the right; (ii) a definition of “personality” or the characteristics protected, or not protected, by the right; (iii) a determination of what constitutes violation of the right; (iv) exceptions and limitations to liability; (v) the damages available, and (vi) whether the right can be assigned.¹³¹ Starting from this basic framework, state statutes vary in the degree to which they are willing to attribute property-like features to aspects of one’s identity as well as in the breadth of protection afforded to those features.¹³²

¹²³ *Lugosi v. Universal Pictures*, 603 P.2d 425, 431 (Cal. 1979).

¹²⁴ See, e.g., Stacey L. Dogan & Mark A. Lemley, *What the Right of Publicity Can Learn from Trademark Law*, 58 STAN. L. REV. 1161, 1169–71 (2006).

¹²⁵ Jonathan Faber, *A Brief History of the Right of Publicity*, RIGHT PUBLICITY (July 31, 2015), <https://rightofpublicity.com/brief-history-of-rop> [<https://perma.cc/BNU7-H3LB>].

¹²⁶ For a summary of some of the better-known rights of publicity cases that have helped to define the parameters of the right, see *id.*

¹²⁷ See, e.g., Joshua L. Simmons & Miranda D. Means, *Split Personality: Constructing a Coherent Right of Publicity Statute*, LANDSLIDE, May-June 2018, at 37, 38.

¹²⁸ Uche Ewelukwa Ofodile, *The Frank Broyles Publicity Rights Protection Act of 2016: Potential Minefields*, ARK. LAW., Winter 2017, at 36, 40.

¹²⁹ See Amanda Tate, Note, *Miley Cyrus and the Attack of the Drones: The Right of Publicity and Tabloid Use of Unmanned Aircraft Systems*, 17 TEX. REV. ENT. & SPORTS L. 73, 73–74, 84, 84 n.103 (2015) (describing thirty states with the right of publicity in some capacity, but recognizing that some scholars differ in how they may categorize certain states); Faber, *supra* note 125; see also Tate, *supra*, at 84 n.104 (detailing a non-exhaustive list of states recognizing common law right of publicity).

¹³⁰ See RESTATEMENT (THIRD) OF UNFAIR COMPETITION § 46 cmt. a (AM. LAW INST. 1993).

¹³¹ See generally Simmons & Means, *supra* note 127 (surveying and comparing rights of publicity statutes based on common elements).

¹³² See *id.* at 38.

In at least some of the states, the right of publicity is not limited to public figures, yet, in reality, the vast majority of publicity rights cases involve public figures because the economic stakes are higher.¹³³ Publicity rights cases often involve disputes between a press eager to trade in the details of celebrity and celebrities eager to manage and profit from their carefully cultivated public personas.¹³⁴ The broader the right, the greater the tension between rights holders on the one hand and content creators and service providers (including the media) on the other.¹³⁵

Like privacy rights, publicity rights are limited by the First Amendment and related exceptions based on newsworthiness.¹³⁶ The Restatement of Unfair Competition emphasizes that the right of publicity is “fundamentally constrained by the public and constitutional interest in freedom of expression.”¹³⁷ The newsworthiness limitation on publicity rights is ubiquitous in state common law cases and further recognized as a specific exception to publicity rights in some state statutes.¹³⁸

While First Amendment and newsworthiness limitations play an important role in drawing the boundaries between what publicity rights holders can control and what content providers can use, economic considerations also come into play in balancing their competing interests. The Supreme Court has only once addressed the right of publicity, but in doing so it found that Zacchini, the famous “human cannonball,” had a publicity right in his act that would be

¹³³ *Id.* at 41; see Michael J. Hoisington, *Celebrities Sue over Unauthorized Use of Identity*, HIGGS, FLETCHER & MACK (Aug. 20, 2019), <https://higgslaw.com/celebrities-sue-over-unauthorized-use-of-identity/> [<https://perma.cc/AW42-EV8D>]; see, e.g., Andrew M. Jung, Note, *Twittering Away the Right of Publicity: Personality Rights and Celebrity Impersonation on Social Networking Websites*, 86 CHI.-KENT L. REV. 381, 399 (2011) (characterizing this economic interest within the context of celebrity social networking).

¹³⁴ See Matthew Savare, Comment, *The Price of Celebrity: Valuing the Right of Publicity in Calculating Compensatory Damages*, 11 UCLA ENT. L. REV. 129, 130–31 (2004).

¹³⁵ Simmons & Means, *supra* note 127, at 38; see, e.g., Jonathan Peters, *Media Opposes Right-of-Publicity Bill: ‘An Attack on the First Amendment’*, COLUM. JOURNALISM REV. (June 26, 2017), https://www.cjr.org/united_states_project/right-of-publicity-new-york.php [<https://perma.cc/Q9TK-FEHE>] (describing these tensions for a proposed New York state bill).

¹³⁶ Simmons & Means, *supra* note 127, at 41. For a discussion of the interplay between publicity rights and First Amendment free speech rights, see generally Thomas E. Kadri, *Drawing Trump Naked: Curbing the Right of Publicity to Protect Public Disclosure*, 78 MD. L. REV. 899 (2019) (drawing on a new framework to discuss publicity and First Amendment rights), and Mark A. Lemley, *Privacy, Property, and Publicity*, 117 MICH. L. REV. 1153 (2019) (reviewing JENNIFER E. ROTHMAN, *THE RIGHT OF PUBLICITY: PRIVACY REIMAGINED FOR A PUBLIC WORLD* (2018)).

¹³⁷ RESTATEMENT (THIRD) OF UNFAIR COMPETITION § 47 cmt. c (AM. LAW INST. 1993).

¹³⁸ See, e.g., Kadri, *supra* note 136, at 928–31 (discussing state law exceptions to rights of publicity based on newsworthiness).

harmful by public broadcast on television.¹³⁹ The Court balanced Zacchini's commercial interests in protecting the value of his act against the broadcasting company's First and Fourteenth Amendment defenses, ultimately ruling for Zacchini on the grounds that protection was needed to provide "an economic incentive for him to make the investment required to produce a performance of interest to the public."¹⁴⁰ Since that early case, publicity rights have been asserted with increasing frequency and intensity and have taken on forms that moved away from their roots in the very personal nature of privacy rights, transforming them into powerful intellectual property rights deployed and traded for commercial gain.¹⁴¹

As the right of publicity has evolved, "[h]uman identity itself has become an intellectual property right that can be cultivated and exploited for better or worse and is deemed worthy of protection."¹⁴² The limits of what can be protected have expanded beyond name, image, and likeness to encompass various aspects of identity such as the human voice, certain phrases or distinctive mannerisms, facial expressions, and even digital avatars.¹⁴³ There has been a move in some states, such as celebrity-filled New York and California, to expand the scope of the right of publicity to include almost any kind of speech that even evokes the identity of a celebrity and to vest the right with even stronger property-like characteristics.¹⁴⁴

As the right of publicity has expanded, the tensions between the individual property-like interests and certain First Amendment freedoms have intensified.¹⁴⁵ Some scholars point to the importance of protecting First Amendment free speech rights at the expense of publicity rights to allow for

¹³⁹ *Zacchini v. Scripps-Howard Broad. Co.*, 433 U.S. 562, 563, 575–79 (1977) (finding that the right of publicity is not just to compensate for the performance but also to provide economic incentives for investing in its creation).

¹⁴⁰ *Id.* at 576.

¹⁴¹ *See, e.g.*, ROTHMAN, *supra* note 106, at 7 (arguing "[t]hat the right of publicity got off track when it transformed from a personal right . . . into a powerful intellectual property right" divorced from the identity that gives it value).

¹⁴² William F. Buchsbaum, Note, *Harmonizing the Tension Between the First Amendment and Publicity Rights and Finding the Right Balance: Discerning How Much Freedom Is Warranted and What Needs Protection*, 3 U. CIN. INTELL. PROP. & COMPUTER L.J. 1, 1 (2018).

¹⁴³ *Id.* at 1–2.

¹⁴⁴ *See, e.g.*, Daniel Nazer, *EFF to Court: Don't Let the Right of Publicity Eat the Internet*, ELECTRONIC FRONTIER FOUND.: DEEPLINKS (Jan. 10, 2017), <https://www.eff.org/deeplinks/2017/01/eff-court-dont-let-right-publicity-eat-internet> [<https://perma.cc/B8MZ-TR48>] (discussing the California case of *Cross v. Facebook* in which the court ruled that "any 'use' of a person's identity on a site that also included advertising could support a right of publicity claim"); Daniel Nazer, *New York Rushes to Enact Terrible Right of Publicity Law*, ELECTRONIC FRONTIER FOUND.: DEEPLINKS (June 12, 2017), <https://www.eff.org/deeplinks/2017/06/new-york-rushes-enact-terrible-right-publicity-law> [<https://perma.cc/4PHQ-TTDL>] (discussing a proposed expansion of the right of publicity in New York).

¹⁴⁵ *See, e.g.*, Redish & Shust, *supra* note 121, at 1444 (framing this tension as one whose resolution is well overdue).

robust debate on issues of public importance and self-expression and self-realization, while others argue that allowing for publicity rights supports First Amendment values of self-definition and self-expression.¹⁴⁶ Courts have adopted their own varying approaches to balancing the economic and social interests at play in publicity rights cases, although some commentators argue that the balance has shifted too much towards protecting the commercial interests of publicity rights holders at the expense of public discourse.¹⁴⁷ The overall trend has been towards greater protection of the commercial interests of celebrities in their identities, broadly construed.¹⁴⁸ The laws governing rights of publicity thus create additional directions in which genetic paparazzi cases might push us when thinking about genetic materials and information.

As genetic paparazzi cases emerge, publicity rights may steer the discussion towards whether genetic information should be treated as an intellectual property interest in the same way as other characteristics protected by rights of publicity.¹⁴⁹ The courts have already had to consider the intellectual property aspects of genes in their decisions regarding the patentability of genes, with relatively recent decisions that genes (or at least those that are naturally occurring) are not patentable.¹⁵⁰ Attempts to obtain copyright protection for genetic sequences also appear to have been unsuccessful.¹⁵¹ But the courts have not explored the terrain of publicity rights in one's genetics, and it is possible courts may be willing to expand the protection afforded to one's identity under right of publicity laws to include a person's genetic information.

While privacy and rights of publicity are likely to be the dominant paradigms in genetic paparazzi cases, this is not the end of the story under the current legal framework. In addition to privacy and rights of publicity, courts will also have to navigate a separate set of laws that have emerged in very different contexts to address a different set of concerns surrounding genetic information. Our final sections explore the role of federal and state laws relevant to the non-consensual gathering, analysis, publication, and use of genetic materials and information by private actors.

¹⁴⁶ See Buchsbaum, *supra* note 142, at 4–7 (presenting this academic debate).

¹⁴⁷ See ROTHMAN, *supra* note 106, at 5 (documenting this shift).

¹⁴⁸ See, e.g., Redish & Shust, *supra* note 121, at 1444.

¹⁴⁹ See Lemley, *supra* note 136, at 1154–57 (discussing the history of how the right of publicity came to be viewed as an intellectual property right).

¹⁵⁰ Jacob S. Sherkow & Henry T. Greely, *The History of Patenting Genetic Material*, ANN. REV. GENETICS, 2015, at 161, 173–74 (citing the 2003 Supreme Court decision in *Association for Molecular Pathology v. Myriad Genetics, Inc.*, where the Court held that naturally occurring DNA segments were not patentable).

¹⁵¹ See, e.g., Andrew W. Torrance, *DNA Copyright*, 46 VAL. U. L. REV. 1, 4–6 (2011) (arguing that sequences of DNA should be eligible for copyright).

C. Federal Laws Governing Genetic Privacy

Federal law has adopted a largely functional approach to genetic materials and genetic information.¹⁵² For the most part, federal law governing genetic privacy is designed to govern specific contexts in which genetic materials and information are likely to be collected and used in ways that have potential negative public consequences.¹⁵³ Outside of the research context, federal legislation pertaining to genetics has been motivated primarily by concerns about genetic discrimination in the workplace and in health and insurance markets.¹⁵⁴ Rather than focusing on privacy as a primary goal, federal legislation has focused mainly on ways of limiting discrimination based on genetic information, mostly through the Genetic Information Nondiscrimination Act (GINA).¹⁵⁵

GINA was passed in 2008, after more than a decade of legislative efforts, to address misuse of genetic information by employers and certain health insurance providers.¹⁵⁶ The law restricts the use of genetic information by certain employers in their employment decisions, such as hiring, firing and compensation, and limits their ability to collect genetic information from employees.¹⁵⁷ It also restricts the ability of health plans and insurers to base coverage or premium pricing on a person's genetic information or to require people to undergo genetic testing.¹⁵⁸ Despite its importance, GINA (taken together with a corresponding executive order applying it to the federal government as an employer) is limited in its reach. It focuses on only a limited range of discriminatory uses of genetic information and does nothing to address

¹⁵² For an overview of laws relevant to genetic privacy along with an analysis of some of the limitations of existing legal approaches, see generally Ellen Wright Clayton, Barbara J. Evans, James W. Hazel & Mark A. Rothstein, *The Law of Genetic Privacy: Applications, Implications, and Limitations*, J.L. & BIOSCIENCES, Oct. 2019, at 1.

¹⁵³ See *id.* at 9–26 (providing an overview of laws meant to protect privacy rights because of concerns such as confidentiality breaches in a medical setting or inadvertent third-party disclosures from at-home genetic genealogy testing).

¹⁵⁴ See *id.* at 8–9.

¹⁵⁵ See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (2008) (codified as amended in scattered sections of 29 U.S.C. and 42 U.S.C.).

¹⁵⁶ 42 U.S.C. §§ 1395ss, 2000ff-1 (2012); see, e.g., Jana M. Belflower, Note, *Keeping Pace with Progress: A Proposal for Florida's Genetic Testing Statute*, 42 STETSON L. REV. 249, 252–58 (2012) (discussing historic and current problems with misuse of genetic information as spurring genetic privacy statutes and other protections).

¹⁵⁷ 42 U.S.C. § 2000ff-2; Karen Norrgard, *Protecting Your Genetic Identity: GINA and HIPAA*, SCITABLE (2008), <https://www.nature.com/scitable/topicpage/protecting-your-genetic-identity-gina-and-hipaa-678/#:~:text=Furthermore%2C%20GINA%20prevents%20health%20plans,people%20to%20undergo%20genetic%20testing> [<https://perma.cc/3JGC-Z2N8>].

¹⁵⁸ 42 U.S.C. § 1395ss(s)(2)(F)(ii); Norrgard, *supra* note 157, at 1.

the control of individuals over their own genetic information.¹⁵⁹ The Affordable Care Act (ACA) addressed one glaring limitation of GINA—namely, its lack of protection for people with genetic predispositions for diseases once they show symptoms—by preventing health insurance companies from using pre-existing health conditions to deny coverage.¹⁶⁰ In this way, the ACA is one of the most important legislative responses to concerns about genetic discrimination in healthcare.

Apart from GINA, there are only a few other areas where federal law has paid specific attention to genetic materials and information as such. Concerns about genetic information privacy led to the amendment of HIPAA regulations, in 2013, to specify that genetic information is to be considered protected health information.¹⁶¹ Yet, HIPAA applies only to a rather narrow set of entities in specified medical, healthcare, and health insurance contexts.¹⁶²

A third area where federal laws have developed to address issues relevant to genetic privacy is in the context of research on human subjects.¹⁶³ The Federal Policy for the Protection of Human Subjects (Common Rule),¹⁶⁴ issued in 1991, provides protections for human research subjects through requirements such as obtaining informed consent and the approval of an Institutional Review Board for certain kinds of research.¹⁶⁵ In the context of genomic research involving human participants, individuals must be provided with a description of the research, the ways their genomic information will be used, and the risks and benefits of their participation.¹⁶⁶ The 21st Century Cures Act further provides federal research subjects with a certificate of confidentiality that limits the ability of researchers to release genetic data to government agencies such as law enforcement.¹⁶⁷

¹⁵⁹ See Barbara J. Evans, *The Genetic Information Nondiscrimination Act at Age 10: GINA's Controversial Assertion That Data Transparency Protects Privacy and Civil Rights*, 60 WM. & MARY L. REV. 2017, 2026–27 (2019).

¹⁶⁰ See, e.g., Joshua A. Krisch, *Protecting Patients from Genetic Discrimination*, SCIENTIST (Mar. 1, 2017), <https://www.the-scientist.com/news-opinion/protecting-patients-from-genetic-discrimination-31908> [<https://perma.cc/2DQ5-SDXR>].

¹⁶¹ *Genetic Discrimination*, NAT'L HUM. GENOME RES. INST., <https://www.genome.gov/27568503/genetic-discrimination-and-other-laws/> [<https://perma.cc/7RYZ-YWU2>] [hereinafter *Genetic Discrimination*] (last updated Sept. 16, 2020).

¹⁶² *Who Must Comply with HIPAA Privacy Standards?*, U.S. DEP'T HEALTH & HUM. SERVICES (Dec. 19, 2002), <https://www.hhs.gov/hipaa/for-professionals/faq/190/who-must-comply-with-hipaa-privacy-standards/index.html> [<https://perma.cc/DVD9-2FWC>].

¹⁶³ See generally Wolf et al., *supra* note 42 (providing a comprehensive overview of federal and state laws offering protections to participants in genomic research).

¹⁶⁴ 45 C.F.R. § 46.101 (2018).

¹⁶⁵ See 45 C.F.R. §§ 46.103–.120 (2018).

¹⁶⁶ 45 C.F.R. § 46.116.

¹⁶⁷ Leslie E. Wolf & Laura M. Beskow, *New and Improved? 21st Century Cures Act Revisions to Certificates of Confidentiality*, 44 AM. J.L. & MED. 343, 344–46, 346 n.15 (2018).

GINA and the additional protections provided by the ACA, along with HIPAA and the Common Rule, appear to be the only enacted pieces of federal legislation that specifically address genetic information and materials where government action is not involved.¹⁶⁸ While these federal laws can play an important role in the contexts of employment and research uses of genetic information, they do not pertain to matters directly related to the media and its gathering and use of genetic materials and information.¹⁶⁹ For better or for worse, states have played a far more active role in fashioning genetic privacy legislation, and as we discuss in the next section, many state statutes do address the types of gathering and use of genetic information by private, non-governmental actors that genetic paparazzi scenarios entail.

D. State Laws Governing Genetic Privacy

Since the 1990s there have been numerous bills put before Congress addressing genetics, with many advocating for special protections for genetic information.¹⁷⁰ One of the earliest proposals called for a comprehensive and restrictive federal genetic privacy act, arguing that the only way to effectively protect genetic privacy would be to prohibit the unauthorized collection and analysis of individually identifiable DNA.¹⁷¹ This form of genetic exceptionalism has not been embraced at the federal level, and alternative proposals for addressing genetic privacy as part of a broader federal privacy legislation have yet to be adopted,¹⁷² leaving states to decide whether and how to regulate the gathering and use of genetic materials and information at the state level.

The first wave of state legislation dealing with the use of genetic information began as the Human Genome Project was nearing completion and, for the first time, the possibility of mapping a human genome became a reality.¹⁷³ In the wake of the Human Genome Project, nearly all states have enacted legislation that specifically addresses at least some of the most worrisome aspects of genetic information, mostly genetic discrimination in

¹⁶⁸ See *Genetic Discrimination*, *supra* note 161.

¹⁶⁹ See *id.*

¹⁷⁰ The debate over whether we need to address genetic information separately and with special concern continues to this day. See, e.g., Sonia M. Suter, *The Allure and Peril of Genetic Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L.Q. 669, 670–71 (2001).

¹⁷¹ See Patricia (Winnie) Roche, Leonard H. Glantz & George J. Annas, *The Genetic Privacy Act: A Proposal for National Legislation*, 37 JURIMETRICS 1, 4 (1996) (describing the provisions of an early proposal, the Genetic Privacy Act of 1995).

¹⁷² See generally Megan Molteni, *The U.S. Urgently Needs New Genetic Privacy Laws*, WIRED (May 1, 2019), <https://www.wired.com/story/the-us-urgently-needs-new-genetic-privacy-laws/> [<https://perma.cc/XV6M-44QP>] (summarizing different views about how to respond to the limits of the current federal approach to genetics and privacy).

¹⁷³ Alissa Johnson, *Plunging into the Gene Pool*, ST. LEGISLATURES, Mar. 2007, at 22, 22.

insurance and employment.¹⁷⁴ Some states have further extended protections to genetic information more broadly, including genetic testing results, parenthood determinations, and more.¹⁷⁵ These laws are complex and multifarious, their scope depending on variables such as the nature of the information acquired, the type of genetic test conducted, the entities obtaining the information, and the types of use.¹⁷⁶ States continue to enact new laws or modify existing laws to respond to concerns about genetic privacy.¹⁷⁷ Although many of these state genetic privacy statutes are not new, they vary greatly across states and remain a relatively uncharted territory for the courts.

In reviewing existing surveys of state genetic privacy laws, it appears that almost every state has embraced some form of genetic exceptionalism in the sense that the states have identified genetic information as deserving of special treatment under the law.¹⁷⁸ About half the states have laws that would make it illegal (and in seven states even a crime¹⁷⁹) to carry out any or all of the kinds of non-consensual collection, analysis, publication, and use of genetic material and information included in the genetic paparazzi scenarios described in Part I.¹⁸⁰ These laws do so in one of four main ways: (i) most prominently, by defining genetic information as confidential information that may not be published by anyone without informed consent (e.g., in Arizona, South Carolina, and Virginia¹⁸¹); (ii) by defining genetic information as the property of the person from whom they are derived (e.g., in Alaska, Colorado, Florida,

¹⁷⁴ *Id.* at 23.

¹⁷⁵ See Mark A. Rothstein, *Genetic Exceptionalism and Legislative Pragmatism*, 35 J.L. MED. & ETHICS 59, 59 (Supp. 2007) (discussing the general broadening of protections throughout the states); *Genetics and Health Insurance State Anti-Discrimination Laws*, NAT'L CONF. ST. LEGISLATURES, <https://www.ncsl.org/research/health/genetic-nondiscrimination-in-health-insurance-laws.aspx> [<https://perma.cc/6KSL-CHTY>] (summarizing state laws regarding the use of genetic information in health insurance); *Genetic Employment Laws*, NAT'L CONF. ST. LEGISLATURES, <https://www.ncsl.org/research/health/genetic-employment-laws.aspx> [<https://perma.cc/P3QX-YDD9>] (last updated Jan. 2008) (likewise for employment laws); *State Genetic Privacy Laws*, NAT'L CONF. ST. LEGISLATURES, <http://pierce.wesleyancollege.edu/faculty/hboettger-tong/docs/hbt%20public%20folder/FYS/State%20Genetic%20Summary%20Table%20on%20Privacy%20Laws.htm> [<https://perma.cc/89Q2-LW38>] [hereinafter NCSL *State Privacy Laws*] (likewise for privacy laws).

¹⁷⁶ See *Genome Statute and Legislation Database*, *supra* note 41.

¹⁷⁷ See *id.*

¹⁷⁸ See, e.g., Rothstein, *supra* note 175, at 59–62 (providing a description of how genetic exceptionalism has been adopted by policymakers). Washington State is the only state to explicitly treat genetic information in the same way as other types of health information, defining healthcare information to encompass genetic information in its state health privacy law. See NCSL *State Privacy Laws*, *supra* note 175.

¹⁷⁹ These states are Alaska, Delaware, Florida, Nevada, New Jersey, New York, and Oregon. See NCSL *State Privacy Laws*, *supra* note 175.

¹⁸⁰ See *id.* (twenty-six states require consent to disclose genetic information).

¹⁸¹ See ARIZ. REV. STAT. § 1-602(A)(8) (LexisNexis 2020); S.C. CODE ANN. § 38-93-40(A) (2020); VA. CODE ANN. § 38.2-508.4(C) (2020).

Georgia, and Louisiana¹⁸²); (iii) by imposing personal duties on lab personnel regarding the use and disclosure of genetic material and/or information (e.g., in Illinois¹⁸³); and/or (iv) by prohibiting genetic testing for purposes other than “to obtain information for therapeutic or diagnostic purposes” (uniquely, in Georgia¹⁸⁴).

While at least some of these state genetic privacy laws would seem to prohibit the actions of genetic paparazzi, the scope and limitations of these state genetic privacy statutes have been largely untested by the courts. Where there have been challenges to state privacy statutes or their application, the cases appear to have revolved primarily around government data practices that conflict with state genetic privacy statutes; the government practices have often been allowed to continue.¹⁸⁵ In addition, while the protections afforded by at least some of the states may seem to accord strong protections to genetic information, in most cases individuals have the ability to authorize the collection and use of their genetic information, placing a heavy burden on consent as the guardian of privacy interests.¹⁸⁶ Courts will inevitably have to confront questions that lie at the intersection of state genetic privacy laws and genetic paparazzi actions as they pertain to the privacy and publicity rights of public figures. While traditional privacy and publicity pathways may prevail, these state genetic privacy statutes nonetheless leave us with additional state-law pathways grounded in different views of genetic privacy to consider.

E. How Genetic Paparazzi Cases Are Likely to Unfold

The above sections describe the legal pathways that courts are likely to follow when faced with genetic paparazzi cases, each with a different way of characterizing the interests and rights involved. Tort-based approaches to privacy are aimed at protecting reasonable expectations of privacy and guarding against privacy invasions offensive to a reasonable person, focusing on torts of intrusion, publication of private facts, false light and misappropriation, and the personal harms that these invasions of privacy may entail.¹⁸⁷ Publicity rights aim at controlling the uses of, and benefits from, personal identity, particularly

¹⁸² See ALASKA STAT. § 18.13.010(a)(2) (2019); COLO. REV. STAT. § 10-3-1104.6(1)(a) (2020); FLA. STAT. ANN. § 760.40(2)(a) (West 2020); GA. CODE ANN. § 33-54-1(1) (2020); LA. STAT. ANN. § 22:1023(E) (2020). These states employ a property-based approach to genetic privacy. See also NCSL *State Privacy Laws*, *supra* note 175.

¹⁸³ 225 ILL. COMP. STAT. 135 / 90 (2020).

¹⁸⁴ GA. CODE ANN. § 33-54-3(a) (2020).

¹⁸⁵ See, e.g., *Bearder v. State*, 806 N.W.2d 766, 776 (Minn. 2011) (discussing whether Minnesota’s newborn screening program violated the State’s genetic privacy statute).

¹⁸⁶ See NCSL *State Privacy Laws*, *supra* note 175 (“Laws in 16 states require informed consent for a third party either to perform or require a genetic test or to obtain genetic information. Twenty-four states require informed consent to disclose genetic information. In addition, Rhode Island and Washington require written authorization to disclose genetic information.”).

¹⁸⁷ See *supra* text accompanying notes 87–92 (Part III.A.2: Tort-Based Privacy).

commercial uses and economic benefits.¹⁸⁸ Where the press is involved, the First Amendment and considerations of newsworthiness will carve their own path, limiting both privacy and publicity rights.¹⁸⁹ Property-based claims, such as claims of conversion of genetic materials and information, have in the past been largely rejected by courts, at least where it comes to individual claims of ownership over one's own biological samples, although this could change in the future.¹⁹⁰ State-law based versions of genetic privacy offer additional conceptions of genetic privacy to consider, with many grounded in concepts of genetic information as personal property.

Courts will begin with this choice of legal pathways when confronting the first genetic paparazzi scenario in Part II involving the collection, analysis, and publication of facts about Presidential Candidate.¹⁹¹ Looking to how similar claims have been handled, a court's analysis in this type of case is likely to include: (i) questions of intrusion—was the collection and sequencing of the genetic material an invasion of privacy even when the materials were available in a public space?—and whether the intrusion is unreasonable where the information uncovered is genetic information; (ii) whether publishing genetic information constitutes publication of something highly offensive to a reasonable person and, if so, whether genetic information is nevertheless newsworthy or of legitimate public interest; and (iii) false light claims and potential defamation claims based on imputing characteristics on the person possessing certain genetic markers, e.g., proclivity to gambling and infidelity on a person possessing the “gambling” and “infidelity” genes.¹⁹² Where the analysis focuses on the newsworthiness of the genetic information, courts will think about the “social value” of genetic information and the extent to which the publication intruded into areas considered truly private even for a presidential candidate.¹⁹³

¹⁸⁸ See *supra* text accompanying notes 121–151 (Part III.B: Publicity Rights of Public Figures).

¹⁸⁹ See *supra* text accompanying notes 93–105 (Part III.A.3: The Newsworthiness Exception to Privacy).

¹⁹⁰ *But see, e.g.*, Roberts, *supra* note 6, at 1125–26 (proposing a right to claims for genetic conversion, and suggesting courts may in the future be more receptive to such claims).

¹⁹¹ For analysis of privacy and publicity claims that have or can arise in the context of presidential candidates and presidents, see generally Green & Annas, *supra* note 3; Kadri, *supra* note 136 (examining tensions between rights of free speech and publicity rights in context of restricting portrayals of real people); and Noah Feldman, *Elizabeth Warren and the Death of Genetic Privacy*, BLOOMBERG: OPINION (Oct. 15, 2018), <https://www.bloomberg.com/opinion/articles/2018-10-15/elizabeth-warren-dna-tests-and-the-death-of-genetic-privacy> [<https://perma.cc/E47V-YURW>] (arguing that cheap DNA testing is having an impact on cultural expectations about accessibility, and that the effects of cultural change will be magnified in a world of big data).

¹⁹² See *supra* text accompanying notes 71–148 (Part III: Legal Framing of Genetic Paparazzi Cases).

¹⁹³ See *supra* text accompanying notes 93–104 (Part III.A.3: The Newsworthiness Exception to Privacy).

The second genetic paparazzi scenario in Part I raises similar claims, although the emphasis is likely to shift more towards commercial, non-speech-related uses of genetic information. Again based on how similar cases involving the exploitation of the name, image, and likeness of public figures have been handled in the past, the court's analysis will go beyond questions of intrusion, false light, and publication of private facts to also consider: (i) whether either or both the publishing and, later, the use of the genetic materials and information has been a misappropriation of Famous Actor's name or likeness for commercial purposes without consent, and (ii) whether this use for either or both publishing and subsequent commercial applications is a violation of Famous Actor's rights of publicity, raising questions about the nature and scope of property rights in one's genetics.¹⁹⁴

As a result of thinking about genetics in this manner and in this light, courts will likely end up channeling questions about the genetics of public figures into one or more of the following legal pathways: (i) genetics as falling within the domain of privacy, including considerations of what reasonable expectations of privacy are and what types of disclosures would be highly offensive to reasonable people; (ii) genetics as speech, or even as "news," in line with First Amendment and newsworthiness limitations on privacy; (iii) genetics as property and intellectual property, following a rights of publicity analysis and specific state statutes; and (iv) genetics as health information, subject to the same protections and limitations as other kinds of health information and reserving a large role for consent.¹⁹⁵

Anchoring the genetic paparazzi claims in a traditional tort-based privacy analysis—the first pathway—leads to a focus on an individual's genetic information as unique to that person and emphasizes the role of public expectations and social norms about the privacy of genetics as a central part of determining the scope and nature of individual rights.¹⁹⁶

When shifting to focus on the newsworthiness of genetic information about public figures, courts will focus on the various meanings attached to genetic information and the significance of these meanings in the public discourse, as well as shifting ideas about what are legitimate matters of public concern.¹⁹⁷

Publicity rights as well as state laws that deem genetic information personal property will lead to a commodification of genetic materials and the information

¹⁹⁴ Jonathan L. Faber, *Indiana: A Celebrity-Friendly Jurisdiction*, RES GESTAE, Mar. 2000, at 24, 25–26.

¹⁹⁵ See *supra* notes 1–19 and accompanying text.

¹⁹⁶ See generally Makdisi, *supra* note 3.

¹⁹⁷ See, e.g., Lew McCreary, *What Was Privacy?*, HARV. BUS. REV., Oct. 2008, at 123, 123–25 (exploring the social and technological construction of privacy); Feldman, *supra* note 191 (arguing that "[g]enetic privacy is well on its way to becoming obsolete, thanks to the voluntary use of cheap DNA testing technology and the astonishing power of statistics"); Josephine Wolff, *Losing Our Fourth Amendment Data Protection*, N.Y. TIMES (Apr. 28, 2019), <https://www.nytimes.com/2019/04/28/opinion/fourth-amendment-privacy.html> [<https://perma.cc/87AN-Q9GL>] ("The courts have shielded information when we have a 'reasonable expectation' it will stay private. What happens when we stop believing?").

they contain. This pathway will involve considerations of the commercial value of genetic information and materials and focus on rights to control and benefit from these assets.

The fourth pathway is closest to the federal and specific genetic state laws' focus on protecting against genetic discrimination in certain contexts and relying on informed consent in others. Both Presidential Candidate and Famous Actor scenarios raise questions about implied consent: do public figures such as Presidential Candidate and Famous Actor impliedly consent to this depth of interrogation into their genetics simply by stepping into the public spotlight?

The above discussion has identified how alternative legal pathways will characterize the legal interests that attach to genetic materials and information in the context of the press and public figures. Part IV goes one step further to explore how these existing legal frames leave out important aspects of genetic materials and information, and in doing so, create potential inadequacies in how the law handles genetic materials and information.

IV. BEYOND PRIVACY AND RIGHT OF PUBLICITY: ALTERNATIVE LEGAL FRAMING OF GENETIC PAPARAZZI SCENARIOS

The genetic paparazzi scenarios explored in Part II will force courts to confront the legal status of genetic materials and information in the context of laws governing the privacy and publicity rights of public figures and legal protections afforded to the press. In response, courts will channel questions about genetic materials and information into the privacy and publicity pathways discussed above. But, as further explained in this concluding Part, viewing genetics through the constrained lens of privacy and publicity rights could have unintended and potentially negative consequences. This is because the privacy and publicity rights perspectives reduce a person's genetics to a mere assemblage of personal information and regulate genetics with only these aspects of genetics in mind. Yet, a person's genetics are much more than that.

First, a person's genetics are a physical-chemical object or assortment of objects—nucleotides, short DNA and RNA strands, chromosomes, whole nuclei, etc.—that are or were once part of a person's body.¹⁹⁸ As such, genetic materials may be the subject of property interests and, perhaps, property or quasi-property rights.¹⁹⁹

Second, these physical-chemical objects determine how a person's body functions: namely, how it builds its proteins and regulates these proteins' transcription.²⁰⁰

Third, a person's genetic makeup constitutes the building blocks and serves as the physical scaffold for one's biological descendants.²⁰¹

¹⁹⁸ See generally Richard R. Sinden, *DNA*, in 1 GENETICS 292 (2d ed. 2018) (ebook).

¹⁹⁹ See, e.g., Roberts, *Genetic Conversion*, *supra* note 6, at 1–2.

²⁰⁰ See generally Sinden, *supra* note 198.

²⁰¹ Ram, *supra* note 6, at 876.

Fourth, having the unique property of being at the same time individual and shared, one's genetic makeup holds the key to that person's biological, ethnic, and familial identity—one's direct biological lineal connection with ancestors and offspring.²⁰²

Fifth, since one's genome is shared by *no other human*—and epigenetically, not even an identical twin—the uniqueness of one's genetics is emblematic of a person's individual identity that is theirs alone.²⁰³

Finally, and importantly, a person's genetics may well have further meanings that are yet to be discovered and elucidated.²⁰⁴

These, and other, dimensions of genetic material and information do not fit easily into existing legal pathways, and they are often overlooked as a result. This Part characterizes some of the additional types of genetic interests that need to be considered by jurists when confronted with legal paparazzi scenarios and explores some of the harms that can result when these interests are ignored. Once a richer view of genetics is adopted, alternative legal pathways suggest themselves, but invariably fail to accommodate the variety of interests that are implicated. This Part concludes with some ideas for making the law more responsive to the multiple dimensions of genetics and emphasizes the potential negative consequences of refusing to go beyond the narrowing legal pathways of genetic privacy and publicity.

A. *Genetics as Part of One's Physical Person*

By focusing on the privacy and publicity interests in genetic information, it is easy to sidestep the fact that this information was, invariably, derived from physical objects which were once part of a person's body and which were dropped or shed, often involuntarily, by that person. Focusing instead on the connection between the information and the body from which it was derived, we could argue that genetic paparazzi and those who publish the information they generate inevitably invade, at least at some level, their target's physical person, parts of which they have procured and used without that person's knowledge and consent.

Genetic paparazzi may argue that genetic materials shed and dropped by the subjects of their pursuit were in fact *abandoned* by the public figures from whom they originated. Similar claims have been made in cases involving the

²⁰² *Id.* at 876.

²⁰³ *See id.* at 876, 899 (noting however that “[i]dential twins, of course, are very nearly genetically identical”).

²⁰⁴ *See, e.g.,* Shelley L. Berger, Tony Kouzarides, Ramin Shiekhattar & Ali Shilatifard, Perspective, *An Operational Definition of Epigenetics*, 23 GENES & DEV. 781, 782 (2009) (discussing the emerging field of epigenetics); Simon A. Cole, *Is the “Junk” DNA Designation Bunk?*, 102 NW. U. L. REV. COLLOQUY 54, 56 (2007) (explaining how scientists are “discovering functions” in DNA previously thought to have no purpose); Henriksen, Nordgaard & Jansson, *supra* note 60, at 1 (discussing advances in geneticists' understanding of schizophrenia).

procurement of genetic material for purposes of criminal investigations.²⁰⁵ Abandonment, however, is not an appropriate label for an involuntary act. Indeed, no one would make the similar argument that the involuntary dropping of a wallet constitutes an abandonment of that wallet and its contents. Arguably, even such acts of disposing of bodily materials that do involve some level of awareness and voluntariness on the part of the disposer—brushing one’s hair, scratching one’s skin, spitting, etc.—do not encompass the levels of volition that would constitute the intent necessary for legal abandonment.

Genetic paparazzi may further argue that since we all now know that our bodies involuntarily shed genetic material, then—like Madonna²⁰⁶—public figures who do not wish to have their genetic materials procured by others ought to take appropriate measures to make such materials unavailable to third parties. The merits of such arguments, we believe, are and will continue to be the subject of evolving social norms. There are good reasons to think that protection of one’s genetic materials from procurement by third parties outside of the context of criminal investigations²⁰⁷ is not and ought not to be viewed as the norm. Recognizing such a “norm” might force public figures to take unusual measures to prevent the dropping and collection of their involuntarily shed genetic material. It might also give the genetic material of public figures a status akin to trade secrets, which would only be legally protectable from disclosure if and so long as a public figure were to take reasonable measures to protect such material from falling into the hands of third parties.²⁰⁸ This, in turn, would make the lives of public figures—at least those who wish to maintain their genetics to themselves—even more difficult and isolated than they already are.

The law has been inconsistent in its attitude toward a person’s interests in their body and the genetic materials it contains. On the one hand, there are a few

²⁰⁵ See, e.g., *United States v. Davis*, 657 F. Supp. 2d 630, 635, 645 (D. Md. 2009) (exhibiting how the government argued that the defendant did not have a reasonable expectation to privacy in regard to bloodstains on his clothing because these items were lawfully in police custody and/or abandoned); *Raynor v. State*, 99 A.3d 753, 754–55, 765, 767 (Md. 2014) (holding defendant did not possess a reasonable expectation of privacy in his genetic material found on the arm rests of a chair in a police station because he abandoned any expectation of privacy and, thus, police did not violate the Fourth Amendment); *Williamson v. State*, 993 A.2d 626, 628–30, 634 (Md. 2010) (holding the same for an discarded cup left in a jail cell).

²⁰⁶ See *supra* notes 29–34 and accompanying text.

²⁰⁷ Although sophisticated criminals may take great pains to avoid having their genetic materials discovered in crime scenes or otherwise fall into the hands of law enforcement, we reserve judgment as to whether such behavior should be considered a “norm” among criminals as well as what effect such a norm, if it were to exist and be legally recognized, might have on legal analyses outside of the criminal context.

²⁰⁸ Cf. *Tyson Foods, Inc. v. ConAgra, Inc.*, 79 S.W.3d 326, 330, 334 (Ark. 2002) (“Absent clear corporate action . . . a subjective belief of an individual employee that the information is confidential or even had value seems largely irrelevant [to a trade secret claim.]”); *Valco Cincinnati, Inc. v. N & D Machining Serv., Inc.*, 492 N.E.2d 814, 819 (Ohio 1986) (requiring a manufacturer to initiate “measures designed to insure the security of those things considered trade secrets”).

notable court cases that declined to recognize a person's property interests in voluntarily discarded tissue.²⁰⁹ Similarly, most states do not recognize property rights in one's genetics, and even fewer recognize such rights in a person's own genetic materials.²¹⁰ On the other hand, the law does recognize the existence of at least quasi-property interests in dead corpses²¹¹ and in certain body tissues²¹²—mostly reproductive cells and blood²¹³—while explicitly excepting such rights in non-renewable tissue for public policy reasons.²¹⁴ In drawing these lines, the law seems to respond to deep rooted intuitions that our bodies, including things that originate from them, are “ours,” and remain such even after they are no longer part of our person. The same intuitions, we believe, exist with respect to our genetic materials, which, in turn, ought to pave the way to a legal recognition in a person's ongoing legal interests (perhaps even rising to the level of property or quasi-property rights) in a person's discarded and shed genetic materials. We further maintain that such interests and rights in one's genetic materials ought to receive even stronger recognition where one's special or unique genetics have functional implications, namely where their genome contains mutations or other features whose functional implications may be

²⁰⁹ *Greenberg v. Miami Children's Hosp. Research Inst., Inc.*, 264 F. Supp. 2d 1064, 1074 (S.D. Fla. 2003) (holding that plaintiff did not have a property interest in body tissue and genetic matter that was donated for research); *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 480–81, 487–93 (Cal. 1990) (holding that plaintiff did not retain ownership interest in his cells following a voluntary excision procedure to support a cause of action for conversion).

²¹⁰ *See, e.g.*, ALASKA STAT. § 18.13.010(a)(2) (2019) (“[A] DNA sample and the results of a DNA analysis performed on the sample are the exclusive property of the person sampled or analyzed.”); COLO. REV. STAT. § 10-3-1104.6(1)(a) (2020) (“Genetic information is the unique property of the individual to whom the information pertains.”); FLA. STAT. ANN. § 760.40(2)(a) (West 2020) (“Except for purposes of criminal prosecution, except for purposes of determining paternity . . . and except for purposes of acquiring specimens . . . the results of such DNA analysis, whether held by a public or private entity, are the exclusive property of the person tested.”); GA. CODE ANN. § 33-54-1(1) (2020) (“Genetic information is the unique property of the individual tested.”).

²¹¹ *See, e.g.*, *Siver v. Rockingham Mem'l Hosp.*, 48 F. Supp. 2d 608, 610 (W.D. Va. 1999) (noting that Virginia recognizes a quasi-property right to preserve and bury the remains of a human body as well as a right to bring an action in tort for unlawful invasion of a near-relative's rights with respect to a dead body); WILLIAM L. PROSSER, HANDBOOK OF THE LAW OF TORTS 58–59 (4th ed. 1971) (referring to a “property right” to a corpse, which does not exist while the decedent is living and is used for the purpose of burial).

²¹² *See, e.g.*, *Wash. Univ. v. Catalona*, 490 F.3d 667, 674 (8th Cir. 2007) (holding that under Missouri law, research participants made a gift of their removed prostate cancer tissue and that the gift was accepted by the university as donee, as required to find valid inter vivos gift).

²¹³ *See* 42 U.S.C. § 274e(c)(1) (2010). The National Organ Transplant Act narrowly defines human organ so as to exclude human gametes, thereby allowing for the sale of such cells. *See also* GA. CODE ANN. § 16-12-160(b)(1) (2020) (“The purchase or sale of whole blood, blood plasma, blood products, blood derivatives, other self-replicating body fluids, or hair” is exempted from the prohibition on the sale of the human body or any part thereof.).

²¹⁴ *See, e.g.*, 42 U.S.C. § 274e(c)(1); GA. CODE ANN. § 16-12-160(b)(1).

deemed useful, helpful, or otherwise desirable. An example is the unique genetic mutation of Famous Actor in the second scenario we describe in Part II, which results in the red eyes phenotype.²¹⁵

Jurists, particularly judges, should take these deeply held intuitions of ownership individuals often have with respect to their bodies in general and their genetic materials in particular into account in genetic paparazzi contexts. Procuring a person's genetic material without consent may well give rise to sentiments of invasion of one's person, which are akin to those suffered by victims of such offenses as battery and assault, sans bruises and lacerations. In other words, some people will probably experience the nonconsensual appropriation of their discarded or shed cells as an invasion of their person in ways that go beyond the core protectable interests under invasion of privacy torts.

Resolving a case that involves the nonconsensual appropriation and use of a person's unique genetic mutations and other features (e.g., the use of Famous Actor's eye-color allele by the stem cell clinics) as a mere violation of privacy or right of publicity laws, would thus fail to fully address their interests in their body and in the physical aspects of their genetic makeup. Such failure, in turn, could deprive a public figure of their interests in the physical aspects of their genetic materials and, potentially, their ability to profit from their genetic uniqueness. It might also unfairly enrich the procuring third parties whom—apart from their potential liability under privacy and right of publicity laws—may be allowed to “bank on” that uniqueness, like they have in the cases of John Moore, Daniel Greenberg, and Henrietta Lacks.²¹⁶

B. *Genetics and Dignity*

Once we recognize that a person's discarded genetic material was—and at some level remains—part of that person, we must also recognize that procurement, possession, and analysis of such material without the person's knowledge and consent constitutes a violation of that person's dignity. Although the concept of dignity is mostly absent from U.S. constitutional law,²¹⁷ privacy

²¹⁵ Cf. *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 482 n.2 (Cal. 1990) (“Because T-lymphocytes produce many different lymphokines, the relevant gene is often like a needle in a haystack. . . . Moore's T-lymphocytes were interesting . . . because they overproduced certain lymphokines, thus making the corresponding genetic material easier to identify.”); REBECCA SKLOOT, *THE IMMORTAL LIFE OF HENRIETTA LACKS* 1 (2010) (describing the enormous value of HeLa cells, which were created from the unique cancerous tumor of Henrietta Lacks).

²¹⁶ See *Greenberg v. Miami Children's Hosp. Research Inst., Inc.*, 264 F. Supp. 2d 1064, 1067 (S.D. Fla. 2003); *Moore*, 793 P.2d at 481; SKLOOT, *supra* note 215, at 1.

²¹⁷ See, e.g., *From Griswold to Lawrence and Beyond: The Battle over Personal Privacy and the New Supreme Court*, PEW RES. CTR. (Mar. 2, 2006), <http://www.pewforum.org/2006/03/02/from-griswold-to-lawrence-and-beyond-the-battle-over-personal-privacy-and-the-new-supreme-court> [<https://perma.cc/JTL2-8J62>] (sharing discussions at a symposium on the nature of and justifications for privacy protections).

law is rife with allusions and references to dignity.²¹⁸ State law torts protecting rights of privacy emerged, for example, as a reaction to intrusions into spheres regarded as inherently personal, reflecting the idea of a “right to be let alone” as an essential human freedom.²¹⁹ The notion of privacy as an essential part of human dignity has also led to protections of privacy as a human right in international instruments such as the Universal Declaration of Human Rights.²²⁰ The recognition of a person’s genetics as more than the aggregate of their genetic data—their “informational body”—is further reflected in international instruments such as the Universal Declaration on the Human Genome and Human Rights, The International Declaration on Human Genetic Data, and the Universal Declaration on Bioethics and Human Rights.²²¹

Giving recognition to the notion that a person’s genetics are more than just information thus requires legal acknowledgment of interests that go beyond the scope of current legal protections. Such recognition could include providing strong(er) rights of privacy designed specifically to protect human dignity, with significant limits on the collection, testing, sharing, and use of genetic information without a person’s consent.²²² Such an approach might well come into conflict with, or at least raise significant questions with respect to, a number of current practices involving the nonconsensual collection, testing, and use of genetic material and information, including in law enforcement and parenthood determinations. Yet, reconciling existing legal tenets with new (or newly found) ethical, societal, and legal mores is not foreign to the law, and there is no reason

²¹⁸ See, e.g., Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881, 882–83 (2008); COLO. REV. STAT. 10-3-1104.6 (2020); GA. CODE ANN. § 33-54-1 (2020).

²¹⁹ See, e.g., *Pavesich v. New Eng. Life Ins. Co.*, 50 S.E. 68, 78 (Ga. 1905); cf. Nordhaus, *supra* note 7, at 287 (exploring the early emergence of the right of privacy).

²²⁰ See G.A. Res. 217 (III) A, Universal Declaration of Human Rights, art. 12 (Dec. 10, 1948) (“No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.”).

²²¹ G.A. Res. 33/36, annex, Universal Declaration on Bioethics and Human Rights, at 74 (Oct. 19, 2005); G.A. Res. 32/22, International Declaration on Human Genetic Data, at 39 (Oct. 16, 2003); G.A. Res. 29/16, Universal Declaration on the Human Genome and Human Rights, at 42 (Nov. 11, 1997).

²²² A good example for the insufficiency of current privacy law to address injuries to dignity is *Havasupai Tribe v. Arizona Board of Regents*, 204 P.3d 1063 (Ariz. Ct. App. 2008). The legal case—which eventually settled—focused on the issue of consent but was prompted by underlying offenses against Havasupai’s notions of heritage and identity that have little if any recourse under current privacy law. *Id.* at 1066–67; see also Michelle M. Mello & Leslie E. Wolf, Perspective, *The Havasupai Indian Tribe Case—Lessons for Research Involving Stored Biologic Samples*, 363 NEW ENG. J. MED. 204, 206 (2010) (“The Havasupai case illustrates the problems of considering new uses of stored biospecimens only through the lens of potential risks to individual contributors. The desire of participants to control the use of their biospecimens also has moral significance, as does a community’s stake in research that may affect its collective interests.”).

to view the need to reshape existing practices in light of such new norms as a critical impediment to the acceptance of these norms.

Hence, we maintain that genetic paparazzi procurement of a public figure's genetic material, possessing it, analyzing it, and observing the results of the analysis without consent, would constitute a harm to the public figure's dignity. Jurists should recognize that such harm exists. And while it is not fully addressed by tort causes of action under existing privacy, right of publicity, and defamation laws, it may well require addressing under other, existing, or new causes of action.²²³

C. *Genetics as Individual and Collective Identity*

The main object of privacy law in the context of genetics is the informational content of one's genetic materials. The information itself may reveal many things about the person to whom it relates and impart information about that person's ancestors as well as descendants.²²⁴ Furthermore, in the advent of the science of epigenetics, information about a person's genetic transcription patterns has the potential to reveal specific events that shaped these patterns including, possibly, ones that took place even before that person's lifetime.²²⁵

Yet genetic information has another facet that does not seem to be fully recognized in privacy law. A person's genetics are also the foundation for their identity as a member of a certain biological species (*Homo sapiens*) and subspecies (*Homo sapiens sapiens*), geographic origins (e.g., Eastern European, South Asian, North African), cultural and ethnic group (e.g., Han Chinese, Quebecois French, Native American, Scottish, Sephardic Jew),²²⁶ ancestry and extended family, and their own nuclear family.²²⁷ Furthermore, while the vast majority of a person's genetic code is shared with other people—indeed, to a

²²³ This approach may also resonate with views of privacy as an essential part of human dignity. See, e.g., Edward J. Bloustein, *Privacy as an Aspect of Human Dignity: An Answer to Dean Prosser*, 39 N.Y.U. L. REV. 962, 973–74 (1964) (arguing that protections for privacy should rest on a protection of human dignity); cf. Luciano Floridi, *Four Challenges for a Theory of Informational Privacy*, 8 ETHICS & INFO. TECH. 109, 111 (2006) (describing privacy as protection of personal identity).

²²⁴ See, e.g., Ram, *supra* note 6, at 876.

²²⁵ See, e.g., A.K. Short et al., *Elevated Paternal Glucocorticoid Exposure Alters the Small Noncoding RNA Profile in Sperm and Modifies Anxiety and Depressive Phenotypes in the Offspring*, TRANSLATIONAL PSYCHIATRY 1, 10 (2016) (showing that elevated levels of glucocorticoids in male mice is involved in the transmission of stress-induced traits across generations in a process involving small noncoding RNA signals).

²²⁶ But see JONATHAN KAHN, RACE IN A BOTTLE 7–8, 10–14 (2013) (warning of the negative consequences of characterizing race as a genomic trait); Troy Duster, Policy Forum, *Race and Reification in Science*, 307 SCIENCE 1050, 1050–51 (2005) (arguing it is “crucial to resist actively the temptation to deploy racial categories as if immutable in nature and society”).

²²⁷ See, e.g., Ram, *supra* note 6, at 876.

large extent with all living things—there is a small but meaningful amount of our genome that sets each of us apart from everyone else and which makes each of us unique in our genetic and epigenetic makeup.²²⁸

Recognizing that a person's genetics are entwined with their identity would mean that in procuring a public figure's genetic material and the information it contains, genetic paparazzi will be holding more than just the physical object and information. They will be holding the key to that person's identity in the most profound, basic, and intimate way—their “genetic identity card.” Hence, uncovering and disclosing information pertaining to a public figure's identity without consent could give rise to harms that might not be fully addressed by the tort causes of action that are available to plaintiffs under existing privacy, right of publicity, and defamation laws.

To illustrate, take the first genetic paparazzi scenario discussed in Part I and the purported “confirmation” of an alleged Native American ancestry of Presidential Candidate. The procurement and testing of Presidential Candidate's genetic material constitute harms that may negatively affect her in ways that go beyond the harms resulting from the publication of the results of genetic analysis.²²⁹ First, attempting to determine Presidential Candidate's “Native American ancestry” through her genetics may well be opposed to what it means to belong to the specific Native American group or to what that group views as ancestry.²³⁰ Second, the uninvited testing itself would be a violation of Presidential Candidate's dignity and an encroachment on her freedom from having her genetic materials procured and analyzed without her consent. And third, the results of the testing might cause harm to Presidential Candidate's dignity and identity in ways that may go even beyond the invasion of her privacy. Suppose the genetic testing revealed that Presidential Candidate has no discernable genetic connection to any known Native American population. Such “discovery” would not only fail to resolve the issue of her belonging to the group, but it would also interfere with Presidential Candidate's identity by disrupting her self-perception and sense of belonging in ways that go beyond a mere invasion of privacy or even slander.

²²⁸ Adam Auton et al., *A Global Reference for Human Genetic Variation*, 526 NATURE 68, 68 (2015) (finding that a typical human genome varies from a reference human genome at 4.1–5.0 million sites out of a total of 3.2 billion base pairs in the human genome).

²²⁹ To clarify, in referring to such “confirmation” of alleged Native American ancestry, we do not mean to imply that Native American identity is a matter of or could be determined by genetics or to condone an interpretation of genetic information making such extrapolation.

²³⁰ See, e.g., Will Chavez, *Cherokee Nation Responds to Senator Warren's DNA Test*, CHEROKEE PHOENIX (Oct. 16, 2018), <https://www.cherokeephoenix.org/Article/index/62699> [<https://perma.cc/AF3W-TVG4>] (“Using a DNA test to lay claim to any connection to the Cherokee Nation or any tribal nation, even vaguely, is inappropriate and wrong. ‘It makes a mockery out of DNA tests and its legitimate uses while also dishonoring legitimate tribal governments and their citizens.’”); Linda Geddes, *There Is No DNA Test to Prove You're Native American*, NEW SCIENTIST (Feb. 5, 2014), <https://www.newscientist.com/article/mg22129554-400-there-is-no-dna-test-to-prove-youre-native-american/> [<https://perma.cc/3SMN-4KZ6>].

Take, for example, the possibility that one of Presidential Candidate's ancestors, who was not himself/herself of Native American origin, was adopted and, thus, had no genetic relation to the tribe, but still has grown up in a tribe or was otherwise raised by a Native American parent, step-parent or co-parent, and then married outside the tribe. In such a case, putting consent and privacy issues aside, the genetic analysis determination of lack of Native American ancestry would give a false result and disrupt Presidential Candidate's (who might not even know the full details of her own lineage and adoption of that ancestor) perception of identity and sense of self. Moreover, reducing the issue of identity to genetics is potentially harmful to the specific Native American group with which Presidential Candidate associates herself.²³¹

Other examples may entail the linking of a public figure to a notorious criminal, connecting the figure to a controversial cultural or ethnic group (e.g., the Spanish Conquistadors), or revealing that the public figure or one of their ancestors was not sired by their purported father. Again, jurists and policymakers ought to recognize that one's genetics are entwined with and often have bearing on their identity; and we ought to acknowledge that the law, as it currently stands, provides little or no recourse for harms to one's identity resulting from the nonconsensual testing and disclosure of one's genetic information.

D. Genetics as Building Blocks of a Person's Descendants and Reproductive Choice

A uniquely important characteristic of a person's genetics is that it constitutes, statistically speaking, about half²³² of the genome of the person's descendants.²³³ As such, a person's genome—half of which is present in that person's reproductive cells—is the early building blocks of and physical scaffold for that person's biological descendants.²³⁴ Thus, disclosure of a person's genetic information is also, inevitably, disclosure of at least some of the genetics of that person's past, present, and future descendants. At the very basic level, beyond the informational aspect and from a functional perspective, a person's genetic material is *the same material* that is present in that person's gametes and, ultimately, *from which that person's descendants are created*,

²³¹ See Chavez, *supra* note 230.

²³² The Y chromosome is shorter than the X chromosome. Hence, the amount of genetic material passed down to males by their father is smaller than the amount of genetic material passed down from their mother. Girls, who inherit an X chromosome from both parents presumably receive about the same amount of genetic material from each parent (not accounting for deleterious and additive genetic variants in specific genetic loci). See Elof Carlsson, *Chromosomal Theory of Inheritance*, in 1 GENETICS 181, 182–85 (2d ed. 2018) (ebook).

²³³ *Id.* at 184.

²³⁴ *Id.* at 182.

once such gamete(s) meet those of that person's partner in reproduction.²³⁵ Hence, holding a person's genetic material (let alone the person's gametes) is holding the building blocks of that person's descendants and half of the genetic scaffolding from which these descendants will (or have) come to be.

Continuing progress in the emerging science and technology of IVG²³⁶ means that in the not-so-distant future a person's somatic genetic material, as opposed to his/her gametes, may be used to create artificial gametes that could then be used in reproduction.²³⁷ Such technological advancement could have far-reaching consequences for those public figures who are the subject of adoration. As we hypothesize in the second paparazzi scenario in Part II, IVG would make it possible to use a public figure's genetic material to create gametes to conceive or otherwise bring about his/her genetic descendants without the public figure's knowledge and consent.²³⁸

The creation of gametes and ultimate reproduction using IVG will no doubt require significant amounts of scientific knowledge, technical expertise, and medical assistance, and so one may dare to hope that at least some of those involved would require the consent of the public figure involved and refuse to partake in non-consensual IVG. Indeed, ethical conduct on the part of professionals involved would hamper the creation of gametes and conception of descendants such as Famous Actor's child in the second genetic paparazzi scenario. Such refusal would be consistent with numerous court opinions that have recognized the existence of a right *not* to procreate and gave it precedence over another person's alleged right to bring about mutual descendants.²³⁹ And yet, in the absence of specific laws prohibiting any or all of the acts necessary for such a scenario to become a reality, and with celebrity culture being what it is, we must assume that such scenarios cannot be dismissed as mere fantasies. Accordingly, jurists considering a real-life genetic paparazzi scenario would do well to keep in mind that its consequences, whatever they might be—especially as they pertain to third parties' ability to obtain and keep public figures genetic material—may well also have reproductive implications.

²³⁵ *Cf. id.*

²³⁶ See Sonia M. Suter, *In Vitro Gametogenesis: Just Another Way to Have a Baby?*, J.L. & BIOSCIENCES, Apr. 2016, at 87, 88; Johnson, *supra* note 65.

²³⁷ Suter, *supra* note 236, at 89–92.

²³⁸ See *supra* Part II.B.

²³⁹ See, e.g., J.B. v. M.B., 783 A.2d 707, 717 (N.J. 2001) (“[Former wife’s] fundamental right not to procreate is irrevocably extinguished if a surrogate mother bears J.B.’s child. We will not force J.B. to become a biological parent against her will.”); Davis v. Davis, 842 S.W.2d 588, 604 (Tenn. 1992) (“Ordinarily, the party wishing to avoid procreation should prevail, assuming that the other party has a reasonable possibility of achieving parenthood by means other than use of the preembryos in question.”). To be sure, though, the right not to procreate does not extend to forcing a pregnant woman to end a pregnancy. I. Glenn Cohen, *The Constitution and the Rights Not to Procreate*, 60 STAN. L. REV. 1135, 1140–41, 1143–44 (2008).

E. *Additional Aspects of Genetic Material and Information*

As our knowledge and understanding of genetics in general and human genetics in particular grows, it is quite possible that we will find new meanings and, thus, additional pertinent aspects of genetic materials and information. Take, for example, the relatively recent emergence of the field of epigenetics and what it tells us about the underlying mechanisms that regulate the transcription of genes.²⁴⁰ As these and other aspects and meanings of genetics emerge, they will be impacted by a legal framework that has been developed in response to narrower issues and understandings of genetics, such as the genetic paparazzi scenarios we describe in Part II.

F. *How Should Jurists Account for the Uniqueness of Genetics?*

While courts will inevitably approach genetic paparazzi scenarios through the pathways of privacy and right of publicity laws, we have argued that limiting the lens through which genetic paparazzi scenarios are evaluated to these bodies of law will ignore important aspects of genetic materials and information, resulting in deficient case law and, potentially, injustice. In particular, by focusing only on privacy and right of publicity, courts deciding genetic paparazzi cases will fail to address ownership, identity, dignity, reproductive, and possibly other interests inherent to genetics. Channeling genetic paparazzi scenarios into narrow legal pathways might also influence how the law, more generally, addresses issues relating to genetic materials and information in other contexts. In this concluding section we return to our hypotheticals to illustrate how these concerns may play out in court decision-making, and to suggest some ways of mitigating such harm.

First, the concept of privacy interests in genetic materials and information is amorphous and difficult to define, leaving courts to rely heavily on analogies with existing types of intrusions into privacy when responding to such new privacy questions.²⁴¹ Thus, pursuing privacy as a legal pathway for resolving genetic paparazzi scenarios will involve a comparison of non-consensual gathering and processing of genetic information with other forms of intrusion such as acquiring fingerprints from discarded coffee cups or using different surveillance technologies to take photographs within the home.²⁴² In the case of

²⁴⁰ The field of epigenetics as we currently understand it emerged in the 1990s and received its current form in the early 2000s. See generally Berger et al., *supra* note 204; Virginia Hughes, *The Sins of the Father*, 507 NATURE 22 (2014).

²⁴¹ See, e.g., Black et al., *supra* note 38, at 118–19 (arguing HIPAA is insufficient to address the privacy risk in genetic testing); Cohen, *supra* note 239, at 1148–65 (discussing courts analyzing the right to genetic parenthood through the lens of abortion and contraception cases).

²⁴² Cf. *United States v. Dionisio*, 410 U.S. 1, 14 (1973) (“[T]he Fourth Amendment provides no protection for what ‘a person knowingly exposes to the public . . . facial

Presidential Candidate, for example, analogies might be drawn between disclosure of genetic information and disclosure of tax returns or health conditions. Such comparisons, however, are unlikely to give sufficient recognition to any property and dignity interests of Presidential Candidate in her genetic materials. Similarly, in the case of Famous Actor, a court may draw on distinctions made in criminal cases that are based on how much genetic information is obtained and what that information reveals about the person beyond just identity.²⁴³ But in so doing, the court might lose sight of the fact that the information about the genetics of Famous Actor's red eyes, while small in relative quantity, is intimately personal. Thus, the use of analogies to fit genetics into existing privacy categories will inevitably leave out some important aspects of genetics.

Second, thinking of the genetic paparazzi scenarios in privacy terms tends to emphasize the importance of an individual's control over their genetic information and the individualized, personal harm that may result from a loss of control as the defining legal issue. Yet, as discussed earlier, genetics is by its nature something that encompasses more than just individual rights and interests.²⁴⁴ Thus, viewing genetic paparazzi scenarios exclusively through the lens of privacy would sidestep implications for numerous other individuals and groups.

Third, the fact that both Presidential Candidate and Famous Actor are public figures places claims for genetic privacy squarely against claims by the press that such materials and information are newsworthy and part of legitimate public discourse.²⁴⁵ Amidst the expansive application of the First Amendment to deregulate what can be accessed and published, we might worry about the willingness to characterize genetics as speech that cannot be restricted.²⁴⁶ Viewing genetic paparazzi cases through the lens of privacy law, courts will focus on questions of whether and what kinds of genetic information might be newsworthy while ignoring pretty much any incidental issue thereof. Presidential Candidate will have a hard time arguing that genetic propensity for disease—especially one with potential cognitive impact like schizophrenia—is not newsworthy, given the public interest in the health of presidential candidates, thus deciding the matter in favor of publication while ignoring virtually any other genetic interest Presidential Candidate may have (e.g., in not

characteristics . . . handwriting, [and] his voice [are] repeatedly produced for others . . .”) (citations omitted); *Williamson v. State*, 993 A.2d 626, 628–30, 634 (Md. 2010) (finding that an empty coffee cup left in a jail cell does not warrant the reasonable expectation of privacy).

²⁴³ See, e.g., *Cole*, *supra* note 204, at 56–60 (discussing “non-coding” DNA otherwise known as “Junk DNA” which is “popularly characterized as lacking any particular biological function”).

²⁴⁴ See, e.g., *Ram*, *supra* note 24, at 1424; see also *supra* Part III.B.

²⁴⁵ See *supra* Part II.

²⁴⁶ See, e.g., *Roig*, *supra* note 69, at 165–66 (arguing that questions about DNA and free speech lead to “the collision and intermingling of privacy, patent, and copyright law with freedom of expression”).

knowing this information). Famous Actor will likely face the same battle over the genetic information about his unique genetic mutation with the same result.

Fourth, should courts accept the premise that one's genetics are yet another tenet of one's identity—the subject of publicity rights—they will construe the individual interest as a commercial interest rather than an inalienable personal interest. In so doing, courts might shift the focus of the discussion to the commercial value of one's genetics, to the potential exclusion of non-economic aspects of genetic information and its use. The second genetic paparazzi scenario in particular is likely to lead a court to focus on publicity rights. Famous Actor would argue that his red eyes, and the unique genetics behind them, are a part of his identity—indeed, they have become his defining feature. He will thus seek protection of his publicity rights in the genetic materials and the information they contain. The subsequent use of his genetic information by stem cell clinics could push the court further down this intellectual property pathway, as it confronts claims of misappropriation of likeness as manifest in genetics, for commercial use. In so doing, the court might give insufficient recognition to the harm caused to Famous Actor's reproductive and identity interests.

These are but few examples of how focusing on privacy and right of publicity in genetic paparazzi cases could lead to the exclusion of some genetic interests from consideration and thus lead to injustice. Such outcomes are further compounded by the fact that different states vary greatly in the protections afforded under their privacy, right of publicity, and specific genetic privacy laws. As a result, genetic paparazzi suits might be unable to claim injuries even to those interests that are typically covered by privacy and right of publicity laws.²⁴⁷ As of the time of writing, twelve states do not recognize any right of publicity, only five states recognize the existence of property interests in genetic information, and no state seems to recognize a property interest in a person's genetic material.²⁴⁸ In short: even under the most favorable circumstances, plaintiffs in genetic paparazzi cases will be limited in their ability to obtain recourse that would recognize the full range of their interests in their non-consensually obtained genetic materials and the information these materials contain.

Given the inadequacies of current law to accommodate the issues raised by genetic paparazzi, it would be natural to look to legislators for a solution. Yet, with the exception of reproductive technologies, legislatures are reluctant to

²⁴⁷ See *supra* Part III.

²⁴⁸ See Simmons & Means, *supra* note 127, at 40 tbl.2; see also COLO. REV. STAT. § 10-3-1104.6(1)(a) (2020) (“Genetic information is the unique property of the individual to whom the information pertains.”); FLA. STAT. ANN. § 760.40(2)(a) (West 2020) (declaring results of genetic testing “exclusive property of the person tested”); GA. CODE ANN. § 33-54-1 (2020) (“Genetic information is the unique property of the individual tested.”); LA. STAT. ANN. § 22:1023(E) (2020) (describing genetic information as “property” of the person tested); OR. REV. STAT. § 192.537(1) (2020) (“[A]n individual's genetic information and DNA sample are private and must be protected, and an individual has a right to the protection of that privacy.”). With some alterations, this list of statutes and the accompanying descriptions were first compiled in Joh, *Reclaiming*, *supra* note 3, at 868 n.61.

intervene in matters involving new technology and are highly unlikely to tackle head on the inadequacy of current legislation for addressing the full range of interests that individuals—not just public figures—have in their genetic materials and information.²⁴⁹ Courts, on the other hand, do not usually have the luxury of shirking away from cases that come before them and are unlikely to be able to do so once a genetic paparazzi case presents itself.

Given that courts will be tasked with confronting the issues that genetic paparazzi cases raise within the limits of existing law, we conclude with a few thoughts to guide their decisions. First, judges tackling such scenarios would do well to keep in mind the limited and evolving nature of our understanding of genetics. This is not to say that we advocate for the application of an approach akin to the precautionary principle²⁵⁰ in how the law should approach genetics, which might lead to overbroad prohibitions on the disclosure of any genetic information of any public figure under any circumstance due to some unknown future implications. Rather, when jurists approach a person's genetics, including in cases involving public figures, we ought to do so with the realization that the science of genetics is still—at least as compared to other, more “established” sciences—in its infancy; and we ought to keep reminding ourselves that there is much that is yet unknown and awaits discovery.

But, second, we also warn against excessive judicial formalism. Courts deciding cases similar to the genetic paparazzi scenarios we describe would do well to avoid a formalistic approach that constrains their thinking about such cases to existing legal constructs. Rather, such courts should be open to new ways of thinking about or applying the law to scenarios that might not yet be well established. Consider, for example, the idea of genetic speech. Such a concept may entail access to one's own genetic information and self-knowledge, but might also implicate allowing the use of genetic materials of public figures and the publication of the information such materials contain as part of a freedom of the press to access such materials and publish such information under the First Amendment.²⁵¹ Another example is the idea of genetics as the subject of personal property, which is increasingly at odds with the view of genetics as a goldmine for technology developers, including in the area of therapeutics.²⁵²

²⁴⁹ See Suter, *supra* note 170, at 670–71, 690–91, 695–99; cf. Wagner, *supra* note 68 (discussing a constitutional challenge to Alaska's genetic privacy statute).

²⁵⁰ Press Release, Wingspread, Wingspread Statement on the Precautionary Principle (Jan. 20, 1998), www.who.int/ifcs/documents/forums/forum5/wingspread.doc (on file with the *Ohio State Law Journal*) (defining the precautionary principle as follows: “When an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically. In this context the proponent of an activity, rather than the public, should bear the burden of proof”).

²⁵¹ Cf. Solove, *supra* note 109, at 1013–14 (arguing that the black and white analysis of whether speech is public or private is flawed and that contextual analysis is critical).

²⁵² This tension has led to the emergence of such concepts as “bioprospecting” and “biopiracy” and to a view of genetics as a natural resource. See, e.g., Convention on

Third, we hope courts will choose to recognize the uniqueness of genetics and give adequate consideration and—to the extent possible—legal recognition to the full range of interests implicated in the genetic paparazzi cases before them. Such recognition may take many forms and be brought into court opinions in many ways, e.g., judicial notice, court discretion under the law or in equity, and specifically crafted and possibly novel forms of equitable relief.

Finally, it is our hope that courts deciding genetic paparazzi cases play an active role in directing the evolution of the law as it pertains to genetics, thereby lighting the way to legislative efforts that might eventually follow.

V. CONCLUSION

Genetic paparazzi cases are coming, and the legal system will inevitably be called upon to determine where and how the genetic materials and information of public figures fit into the existing web of privacy and publicity rights. When it does, jurists will establish norms and precedents in the context of public figures that will influence how we think about and protect, or do not protect, various interests that individuals—not just public figures—have in their genetics.

The ways that jurists approach genetic paparazzi scenarios will likely inform not only cases involving the press and publication of genetic information, but also the broader legal framework that is emerging, largely in haphazard fashion, to govern a world in which genetic materials and genetic information play more prominent roles in many aspects of everyday life. We have argued that genetics is best understood not as a mere source of data but as a unique multi-faceted entity embodying different meanings, functions, and values. As our knowledge and understanding of genetics in general and human genetics in particular grows, so will the list of potential uses of genetic materials and information and so too will the meanings, functions, and values of such materials and information. The law must be able to accommodate and respond to this multi-dimensional nature of genetics even in narrower contexts which lend themselves to traditional legal pathways.

It is important to recognize that decisions involving the genetics of public figures, in what seems like a narrow case today, may well have far reaching future consequences in other areas for many more people. We should therefore pursue legal approaches that can accommodate the multi-dimensional nature of genetics, moving beyond genetic privacy and right of publicity. Acknowledging this reality will help attorneys, judges, and, in other contexts, legislators, meet the challenges that twenty-first century genetics pose to the law.

Biological Diversity, June 5, 1992, 1760 U.N.T.S. 79 (treating biological diversity as a resource); Anupam Chander & Madhavi Sunder, *The Romance of the Public Domain*, 92 CALIF. L. REV. 1331, 1364–67 (2004) (discussing “bioprospecting” and “biopiracy”); Cynthia M. Ho, *Biopiracy and Beyond: A Consideration of Socio-Cultural Conflicts with Global Patent Policies*, 39 U. MICH. J.L. REFORM 433, 436–40 (2006).