Book Review: Abraham Lincoln's DNA and Other Adventures in Genetics by Philip R. Reilly

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Introduction

*Abraham Lincoln's DNA and Other Adventures in Genetics* by Dr. Philip R. Reilly is a collection of twenty-four essays about genetics as well as a “mini-textbook” of genetic concepts and technologies. The stories illustrate how advances in genetics impact society in many areas including: history, justice, human behavior, plants and animals, diseases, and ethical dilemmas. Through Reilly’s stories, the reader is exposed not only to the fundamentals of genetics, but also to the multitude of legal and ethical issues in a variety of areas such as privacy, agriculture, crime, property, health care, insurance, estate planning, and domestic relations.

Dr. Philip R. Reilly is the CEO of Interleukin Genetics, Inc., located in Waltham, Massachusetts. From 1990 to 2000, he served as the Executive Director of the Shriver Center for Mental Retardation, Inc. Reilly has held faculty appointments at Harvard Medical School and Brandeis University, and is currently an Assistant Professor at Tufts University School of Medicine. He is the President of American Society of Law, Medicine, and Ethics, a not-for-profit organization headquartered in Boston, Massachusetts and has served on many national committees chartered to explore public policy issues raised by advances in genetics. Reilly is the author of four books, has published more than 100 articles in scholarly journals, and is frequently asked to comment on topics relating to genetics by the national media. Dr. Reilly holds a B.A. from Cornell University, a J.D. from Columbia University, and an M.D. from Yale University.

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A Brief Look at the Genome

Cells are the fundamental working units that compose every living system. The "genome" is an organism's complete set of DNA (deoxyribonucleic acid). Genomes vary greatly in size depending on the organism; for example, the human genome is estimated to contain 30,000 genes. All the instructions needed to direct cellular activity are contained within the chemical DNA; every cell, except mature red blood cells, contains a complete set of DNA. In humans, DNA is arranged on twenty-three chromosomes. Each chromosome contains many genes, which are the basic physical and functional units of heredity. However, genes comprise only about 2% of the human genome with the remainder comprised of "noncoding" regions responsible for providing chromosomal structural integrity and regulating where, when and in what quantity proteins are made.

It is important to note that while much of the focus is on the study of genes, it is proteins that perform most life functions and make up the majority of cellular structures. Proteins are large, complex molecules made up of smaller subunits called amino acids and the constellation of all proteins in a cell is called the proteome. Unlike the relatively unchanging genome, the dynamic proteome is constantly changing in response to environmental signals both in and outside the cell. A protein's chemistry and behavior are specified by both the gene sequence and the number and identities of other proteins made in the same cell at the same time and with which it associates and reacts. Proteomics, the study of exploring protein structure and activities, will be the focus of much future research as it attempts to explain the molecular basis of health and disease.

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3 Id.
5 Id.
6 Id.
7 Id.
8 Id.
9 See, HGP, supra note 4.
10 Id.
11 Id.
12 Id.
In 1990, the Human Genome Project began as an international effort to sequence the three-billion DNA letters in the human genome. In April 2003, the Human Genome Project announced the remarkable achievement in the history of science that the final base pair in the human DNA sequence had been identified. The mapping of the human genome does not mark the conclusion, but rather the beginning of the genetic revolution for the human race.

Science, especially the study of genetics, is often considered an overwhelming topic for many people, especially for individuals with a non-science background. Reilly's book is specially tailored for the most “non-science” audience. Clearly, his purpose in writing this book is to allow the reader to develop a greater awareness of how the genetic revolution is impacting our public and private lives. His stories effectively illustrate genetic concepts while entertaining and absorbing the reader in each compelling true story. The book's bibliography is a particularly helpful resource should the reader desire additional information on any of the topics presented.

A Synopsis of the “Adventures in Genetics”

*Abraham Lincoln’s DNA and Other Adventures in Genetics* focuses on a broad range of topics relating to the study of genetics and addresses many of the critical policy and ethical issues that have emerged as a result. Issues include: Who should have access to your genetic information and how will it be used? Who owns and controls genetic information? What are the psychological impacts and stigmatization that may result from an individual’s genetic differences? Are parents properly counseled concerning reproductive issues and how reliable is fetal genetic testing? How are healthcare professionals prepared concerning genetic advances and how is the public being educated? And how safe are genetically modified foods?

The author uses a similar pattern in each chapter to effectively address genetic concepts and emerging issues. The book moves from the basic concepts of genetics, for example addressing heredity and Mendel’s study of dominant and recessive genes in garden peas, to more complex topics including discussions about genetic disorders, such as XYY Syndrome and Monoamine Oxidase A Deficiency.

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14 *Id.*
Reilly utilizes real life events to illustrate genetic lessons and weaves in the myriad of issues that society must consider. For example, in Chapter 5, Reilly begins with a story about the first cat that provided evidence leading to the conviction of second-degree murderer. The story illustrates the genetic concept of polymerase chain reaction ("PCR"), a technology first used to analyze bone samples. Today, PCR has completely transformed the method of collecting DNA evidence at crime scenes. We now know that people leave a sufficient amount of DNA on virtually whatever they touch to permit a lab to develop an identification profile. This development has had immense consequences for society in the areas of crime prevention, criminal identification and privacy. As the author suggests, universal DNA banking is a reality; however, the issue of whether mandatory DNA sampling for identification purposes violates the constitutional right to privacy has yet to be resolved.

The third section discusses how genetics relates to mental illness, personality, and talent. Reilly explores the genetic study of manic-depressive illness through an examination of the Old Order Amish population. Other topics of discussion include the symptoms and the development in the search to find the culprit gene for schizophrenia, why the study of the dog genome is important in comparison to the study of the human genome, and the possible connection between genes and behavior for bed-wetting, happiness, novelty-seeking, and sociability.

In the fourth section, Reilly focuses his attention on how advances in genetic engineering have impacted plant and animal growth. For example, Chapter 13 begins with a story about the first genetically engineered cocktail party, where virtually all the hors d'oeuvres were prepared from genetically modified organisms (GMOs). Food that has been "genetically engineered or modified" means that its genetic makeup has been altered through a process of technological manipulation.

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15 Reilly, supra note 13, at 53.
16 Id. at 58.
17 Id. at 63.
18 Id.
19 Reilly, supra note 13, at 121-129.
20 Id. at 157. Specifically, the author cites the 1996 convention of the Biotechnology Industrial Organizations (BIO) in Houston, Texas, where these hors d'oeuvres were served.
to the concerns surrounding advances in human genetics, these genetic technologies affecting plants and animals are surrounded by controversies that focus on human and environmental safety, labeling and consumer choice, intellectual property rights, ethics, food security, poverty reduction, and environmental conservation. Reilly explores many of the issues relating to transgenic crops and how genetic engineering has immensely transformed American agriculture, including the debate over genetically modified organisms and the major arguments in the United States over GMOs. The author further explores the topics of transgenic animals, hormones as drugs, animal factories to produce drugs, how the study of mice has contributed to the study of genetics, and options for saving endangered species through genetics.

Finally, the fifth section focuses on genetically linked diseases and the sixth section addresses many of the important issues that are fueling the public debate over the uses of genetic information. Despite the author’s accomplishment of providing the reader with a numerous issues relating to the relevant topics throughout the book, Reilly uses the last section of the book to delve into many of the controversial issues that affect individuals, including issues that concern our fundamental rights. For example, the reader learns about the types of genetic screening tests used today, how newborn genetic screening has progressed, and why prenatal testing and “carrier screening” used to identify individuals who carry genes for recessive disorders raise so many ethical issues. Additionally, Reilly’s stories illustrate the dilemmas individuals face when deciding whether to take a DNA tests for mutations that cause untreatable disorders such as Alzheimer’s and Huntington’s Disease.

A Glimpse Into Abraham Lincoln’s DNA

It should come as no surprise that scientists have proposed genetic testing on one of the most studied and admired figures in American history. Reilly addresses the issue of whether scientists should be allowed to test Abraham Lincoln’s tissue in Chapter 1. Although Lincoln appeared healthy, he could have been born with a mutation in the fibrillin gene resulting in a relatively mild form of Marfan’s Syndrome.

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22 Id.
24 REILLY, supra note 13, at 264. Tandem mass spectrometry analyzes a tiny volume of blood to detect unusual molecules which are then compared to a database of metabolites associated with rare genetic disorders.
a disease characterized by weaknesses in connective tissue, especially that of bones, joints, eyes and the heart.25

Individuals who suffer from Marfan's Syndrome are often tall and long limbed; this fueled speculations that Lincoln had the condition.26 Researchers proposed genetic testing for Marfan’s Syndrome on samples of Abraham Lincoln’s hair, bone chips and blood stains stored at the National Museum of Health and Medicine, a division of the Armed Forces Institute of Pathology.27 However, due to the finite supply of Lincoln’s DNA, administrators at the National Museum of History and Medicine decided to delay the study, pending improvements in DNA test techniques and more knowledge about the genetic cause of Marfan’s Syndrome.28

From the beginning, heated debates have surrounded the issue of whether to clone Lincoln’s DNA in order to test his genetic makeup.29 For example, on one side of the debate Jeremy Rifkin, a prominent critic of genetic experimentation, has argued that the genetic testing should not be allowed to move forward.30 According to Rifkin, the technology advances in genetics are “running way ahead of the ability of society to put in place the appropriate social mechanisms to make sure it’s not abused and misused and to ensure that this is the direction we want to go.”31 Reilly provides ample consideration on the issue of the technical feasibility of testing through a discussion on how the panel chosen to determine whether or not to allow access to Lincoln’s DNA focused on this important question. As it turned out, the panel was unanimous in its recommendation that testing would not occur until the fibrillin gene has been thoroughly studied.32

29 Id.
30 Id.
31 REILLY, supra note 13, at 10. Fibrillin is a connective tissue protein; it is a component of both the lens of the eye and the wall of the aorta.
32 Dunham, supra note 27, at id.
In contrast, some scholars argue that the genetic testing on Lincoln's DNA should never be permitted due to not only existing ethical concerns, but also issues of an individual’s right to privacy and the doctrine of informed consent. For example, Arthur Caplan, director of the University of Minnesota’s Center for Biomedical Ethics, stated that because “Lincoln spent his entire life trying to convince his fellow Americans that biology wasn’t important in defining who people are (in his opposition to slavery)...it is bitterly ironic to subject him to a [genetic] test that tries to understand him in terms of his biology.” Moreover, according to Caplan, we should not allow genetic testing regardless of whether the individual is alive or deceased, without explicit consent from the subject or descendants, “even if it means that the DNA from a historical figure becomes off-limits.” However, these very issues have been considered by the panel, in which Reilly was a member, that determined that the arguments in favor of testing were more compelling than those opposed to to testing Lincoln’s DNA.

Reilly suggests that if Lincoln, one of the most revered figures in our nation's history, did have Marfan’s Syndrome then it would perhaps improve the understanding and diminish much of the social stigma of the disease that people face today. A similar argument could be made if it is determined that Lincoln suffered from depression, which would have likely impacted his day-to-day activities much more than having Marfan’s Syndrome alone. Although it seems likely that someday the public will know whether Lincoln had Marfan’s Syndrome or if he suffered from depression, scientists still have yet to test Lincoln’s DNA. According to the Museum, “the DNA test to determine whether or not the chromosomal marker for Marfan’s Syndrome can be detected would require the full destruction of the Lincoln biological materials.” Multiple panels have determined that the greater public good is served by not destroying this non-renewable national historic treasure,” thus, confirming testing has not been permitted to date.

33 Dunham, supra note 29, at id.
34 Id.
35 Id.
36 REILLY, supra note 13, at 8.
37 Id. at 3. Marfan syndrome affects about 1 in 20,000 persons; the defective gene causes weakness in the connective tissue. A person with Marfan syndrome could die suddenly due to rupture of the main blood vessel to the heart.
38 Id. at 10.
40 Id.
Changing the World One Baby at a Time

The purpose of newborn screening for genetic disorders is to limit the morbidity and mortality attributable to selected inherited diseases.\(^{41}\) In 1960, a low-cost method was introduced to screen newborns for a single gene disorder called phenylketonuria (PKU), which affects an estimated one in ten-thousand white individuals and, if not promptly diagnosed and treated, leads to severe mental retardation or death.\(^{42}\) In Chapter 21, Reilly discusses the fact that newborn genetic screening has expanded to test millions of children for three to ten severe but treatable metabolic disorders.\(^{43}\) Little controversy has erupted because the tests are highly accurate and there is a great deal physicians can do for children born with these rare disorders.\(^{44}\) However, as Reilly suggests, the number and type of genetic tests available to parents is dramatically increasing due to the rapid advances in genetics.

One persistent ethical issue in newborn screening is whether screening should be voluntary or mandatory.\(^{45}\) Newborn screening varies from state to state, however every state has enacted statutes requiring mandatory testing of newborns for at least three genetic disorders.\(^{46}\) For example, under Massachusetts law, the Newborn Screening Program was created to test all newborns within 48 to 72 hours after birth for ten treatable diseases.\(^{47}\) The genetic information is stored according to the name on the birth certificate in a central data bank and the state uses the information to link identified "at-risk" families with needed services.\(^{48}\) According to the state, despite the easily identifiable personal information, the names


\(^{43}\) Reilly, supra note 13, at 264.

\(^{44}\) Id.

\(^{45}\) Pediatrics, supra note 38, at 1451.


are never released to third parties.\textsuperscript{49} Even though the data that is released is non-identifiable, one could argue it is not truly anonymous and the stored genetic samples could potentially be used for further genetic testing in the future. For example, the government may wish to access the data bank to determine future needs of special education or other similar issues that may affect a particular community.

As Reilly suggests, genetic screening raises a whole host of new and difficult questions about the nature of the data that is rapidly becoming available. Two important emerging issues are informed consent and a parent's right to choose whether to have their newborn tested. As a result of these advances in genetic research, we are quickly approaching a time where parents may choose whether to test their newborn for a wide variety of disorders, some of which may be treatable. However, states may take the right to choose away from parents by enacting mandatory testing as new genetic tests become available. For example, all states except South Dakota permit parental refusal of newborn screening for religious or personal reasons.\textsuperscript{50} Reilly addresses the issue concerning "any test that merely produces information about a degree of risk for an adult-onset disorder or for a non-life threatening condition falls far short of justifying mandatory testing."\textsuperscript{51}

One concern surrounding the mandatory testing laws is the invasion of the mother's right to privacy especially where the constitutionality of laws that require newborns to be tested for these rare disorders has yet to be challenged.\textsuperscript{52} One ethical justification offered for mandatory screening is the claim that society's obligation to promote child welfare through early detection and treatment of selected conditions supersedes parental prerogatives to refuse this simple medical intervention.\textsuperscript{53} However, parents traditionally have broad discretion for making health care decisions for their children. Although parents generally do not want to give up effective treatments for life-threatening conditions, they should be allowed to pursue a variety of options in less threatening circumstances, including options that their physician might otherwise not advise.\textsuperscript{54}

\textsuperscript{49} Id.
\textsuperscript{50} Pediatrics, supra note 38, at 1451.
\textsuperscript{51} Reilly, supra note 13, at 265.
\textsuperscript{52} Id.
\textsuperscript{54} Pediatrics, supra note 38, at 1451.
Furthermore, it is argued that the great majority of parents will continue to be supportive of newborn screening when they are informed adequately of the risks and benefits. With continued broad public support, approaches involving informed consent or parental permission may fulfill the important goals of the programs and enhance program quality while respecting traditional parental rights to be informed participants in health care decisions for their children. For example, Wyoming and Maryland are the only two states that require informed consent for newborn screening, although 13 other states require that parents be informed about newborn screening before testing. As Reilly points out, 99% of new mothers participate in the pilot program launched in Massachusetts when invited to do so, which may be an indication of the high degree of willingness where the parents understand the benefits of genetic testing.

Is Sexual Orientation Determined By What's In Your Genes?

As Reilly suggests, few scientists had studied the potential genetic contribution to homosexuality until the explosion of the HIV/AIDS epidemic. Reilly devotes Chapter 12 to address the question of how much evidence exists to support the notion that homosexuality is genetically determined through the research of geneticist Dean Hamer. In the early 1990s, Hamer announced that he had found a gene on the X chromosome that had a powerful correlation to sexual orientation. The study evoked some criticism because gay men conducted some of the initial research. However, regardless of the researchers’ initial motive or desire for a particular outcome, some geneticists have found this work objective and sound. However, Reilly suggests that these findings cannot completely discount the role that the environment has on gene expression; however they do suggest signs of heritability.
It is important to note that this research is in its early stages. Hamer's gene has not yet been found and decoded, and the "gay gene" connection could be misleading, causing even Hamer to caution people to refrain from misrepresenting his research. At this time we can only be certain that there is a strong, albeit inconclusive, indication that a gene somewhere on the X chromosome may have an influence on homosexuality.

Other studies have provided different explanations for homosexuality. For example, some research has established a correlation between birth order and homosexuality in men. A male with older brothers is more likely to be gay compared to one with no siblings, younger siblings, or only older sisters. Similar results have been documented in studies from the United States, Great Britain, the Netherlands, and Canada.

Relying on the genetic research suggesting that there is a biological cause of homosexuality, many gay men and lesbians have attempted to use the results to advance the cause for full and equal civil rights. Despite the fact that science offers no conclusive proof of a genetic cause for homosexuality, some gay rights activists continue to say that sexual activity between members of the same sex is a characteristic on par with race or gender. Using the reasoning that biology is the underlying cause for the "trait" of homosexuality, activists have pushed for equal rights in areas such adoption and the right to marry. Without scientific evidence to support such claims, some argue it is wrong and dangerously misleading to say that sexual preferences is innate and determined at birth.

However, as the study of the human genome moves forward, a definite genetic link to homosexuality may become a reality. As Reilly points out, if

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64 Ridley, supra note 61, at 116.
65 Id. at 118.
66 Id. at 116-21.
68 Id., supra note 61, at 118.
69 Id.
71 Id.
72 Id.
73 Id.
researchers locate the gene variations that predispose men to homosexuality, there will certainly be a way to test for it. As a result, affected individuals will have a persuasive constitutional argument for equal treatment based upon an immutable trait. Rather than exploring in depth the issue of civil rights, Reilly instead focuses on the issue of genetic testing, specifically prenatal genetic testing and abortion. Reilly states that because prenatal genetic testing "is so closely linked to abortion, our society is already bitterly split over whether prenatal testing is morally permissible." His contention hinges upon a presumption that should a gay gene be identified then parents might choose to abort fetuses with that gene to avoid having a child genetically predisposed to homosexuality. In typical fashion, Reilly raises more questions than answers, but he gives each side a fair examination throughout.

**Conclusion**

Reilly's stories are written to allow the reader to learn effortlessly many of the basic genetic concepts through real-life stories. The author poses numerous questions for the reader to ponder based the subject matter of that chapter. He is careful to point out the proponents and opponents for many of the larger issues including his own opinion where appropriate.

*Abraham Lincoln's DNA and other Adventures in Genetics* is exceptionally well-suited for both a general audience and practitioners in a wide variety of legal fields. The book will be particularly useful to those who have even the slightest interest in genetics and how this science is impacting society. Those interested in right to individual privacy should consider reading it as well. The book provides the reader with a deeper sense of the study of genetics and how the science will impact the human race. Clearly, the law is evolving far more slowly than the advances in genetic research and technology. In the not so distant future, scientist will more than likely have the opportunity to test Abraham Lincoln's DNA. As a society, we must continue to increase our awareness and understanding of the issues and implications resulting from these advances, which as Reilly explains, will significantly impact humanity.

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74 Reilly, supra note 13, at 152.
76 Reilly, supra note 13, at 154.
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