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MANIPULATING FATE:

MEDICAL INNOVATIONS, ETHICAL IMPLICATIONS, THEATRICAL ILLUMINATIONS

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PROLOGUE

> *As the unity of the modern world becomes increasingly a technological rather than a social affair, the techniques of the arts provide the most valuable means of insight into the real direction of our own collective purposes.*[1]

Transformative innovations in medicine and their ethical complexities create frequent confusion and misinterpretation that color our imagination. Placed in historical context, theatre provides a framework to reflect upon how the ethical, legal, and social implications of emerging technologies evolve over time and how attempts to control fate through medical science have shaped—and been shaped by—personal and professional relationships.[2] The

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[1] MARSHALL MCLUHAN, THE MECHANICAL BRIDE: FOLKLORE OF INDUSTRIAL MAN 87 (The Vanguard Press 1951).

[2] This article is part of a broader bioethical and legal research project to stimulate interdisciplinary discourse on the implications of emerging medical technologies and to enhance the health policy process. By creating an analytical framework using theatre chronologically, it deepens our understanding of the ethical complexities raised by medical innovations in the context of society. To illuminate these issues, excerpts from a sample of established and lesser known theatrical productions were selected after reading and analyzing hundreds of plays, attending live performances, and listening to audio recordings from the LA Theatre Works Relativity series. *See generally* Karen Rothenberg, *From Eugenics to the "New" Genetics: "The Play's The Thing,"* 79 FORDHAM L. REV. 407 (2010); Karen

drama of these human interactions is powerful and has the potential to generate fear, create hope, transform identity, and inspire empathy—a vivid source to observe the complex implications of translating research into clinical practice through the lens of other individuals. Such images bring to life the tension and depth of emotions depicted in a broad spectrum of plays encompassing numerous medical subspecialties, including infectious disease, psychiatry, assisted reproduction, genetics/genomics, oncology, neuroscience, and regenerative medicine. They also reflect the role that legal and bioethical principles can play to mediate these tensions in society.

Narratives from theatrical productions spanning three centuries[3]—from Richard Peake's 1823 *Presumption; or, The Fate of Frankenstein*[4] to Sharr White's 2011 *The Other Place*[5]—illuminate reactions to advancing medical technologies and interventions that have the potential to alter our destiny. From a scientist's presumption that he will have the power to bring to life new creations, to a neuroscientist's belief that clinical drug trials will allow her to avoid entering the "other place" of her dementia, the dramatic arts offer a rich vehicle for exploring transformative innovations in medicine and their ethical and legal implications.[6] "Theatre, given its cast of characters, is the social art form par excellence. . . . it grants life to the whole consort, and asks us to see

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Rothenberg & Lynn Bush, *Genes and Plays: Bringing ELSI Issues to Life*, 14 GENETICS IN MED. 274 (2012).

[3] The specific date accorded to each play is not absolute. Generally, several years elapse from revisions in manuscript to publication and, from small regional venues to prominent national theatres. In addition, revivals often occur decades or centuries later, sometimes with significant changes to the characters and dialogue. Although most of the plays are placed in their relative chronological order, a few contemporary plays are situated a few years before or after to better analyze the evolution of an ethical theme. Furthermore, placement of the plays is based upon the era in which the playwright created the theatrical drama, rather than the decade in which the actual event occurred.

[4] RICHARD BRINSLEY PEAKE, PRESUMPTION; OR, THE FATE OF FRANKENSTEIN (Stephen C. Behrendt ed., Romantic Circles) (1823), *available at* http://www.rc.umd.edu/editions/peake/toc.html (last visited Jan. 25, 2012).

[5] *See* SHARR WHITE, THE OTHER PLACE (Dramatists Play Service 2011).

[6] PEAKE, *supra* note 4; WHITE, *supra* note 5, at 41-42.

just how porous, how interdependent, how infected, our private 'agenda' really is."[7]

As the scientific landscape shifts at an ever increasing pace, it becomes even more essential to search for creative approaches to better understand the issues and to place them in historical and societal context. With these goals in mind, this article is structured in the format of a play with six Acts representing the evolution of societal issues raised by attempts to manipulate fate by advances in medical science. Excerpts from forty-six plays are integrated chronologically to reflect the ethical and legal context of their era—and the analysis of the themes that reoccur over the centuries.

The first Act, "Creatures Large & Small," sets the stage beginning in the early nineteenth century and takes us to the beginning of the twentieth, exploring both the promises and perils of experimentation with emerging medical technologies. From the debut of the creation of a monster in *Frankenstein*[8] to the control of microbes in *An Enemy of the People*[9] to the choice of who gets medical resources in the *Doctor's Dilemma*,[10] these and other early plays dramatize complex issues for our society that we continue to grapple with today. We build on these ethical challenges in Act II, "Mendel, Docs & Rabbits," within the context of inheritance theory in *To-morrow*[11] and *Strange Interlude*,[12] to infection control historically represented in *Spirochete*,[13] to insanity, capacity and consent in *Harvey*.[14] The third Act, "Genes,

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[7] ARNOLD WEINSTEIN, A SCREAM GOES THROUGH THE HOUSE: WHAT LITERATURE TEACHES US ABOUT LIFE 33 (2003).

[8] PEAKE, *supra* note 4.

[9] HENRIK IBSEN, AN ENEMY OF THE PEOPLE (1882), *reprinted in* FOUR MAJOR PLAYS, VOLUME II: GHOSTS; AN ENEMY OF THE PEOPLE; THE LADY FROM THE SEA; JOHN GABRIEL BORKHAM 83 (Rolf Fjelde trans., Signet Classics 2d ed. 1970).

[10] GEORGE BERNARD SHAW, THE DOCTOR'S DILEMMA (1906) (Digireads 1911).

[11] PERCY MACKAYE, TO-MORROW: A PLAY IN THREE ACTS (Frederick A. Stokes, 1912).

[12] EUGENE O'NEILL, STRANGE INTERLUDE (1927) (1928), *reprinted in* THREE PLAYS: DESIRE UNDER THE ELMS; STRANGE INTERLUDE; MORNING BECOMES ELECTRA 65 (Vintage Books 1995).

[13] ARNOLD SUNDGAARD, SPIROCHETE (1938), *available at* http://dspace.wrlc.org/doc/bitstream/2041/60699/Spirochetedisplay.pdf.

[14] MARY CHASE, HARVEY (1944) (Dramatists Play Service 1970).

Dreams & Screams" evolves from the discovery of the Double Helix in 1953 to the formalization of the discipline of bioethics and a heightened interest in end-of-life and neuropsychiatric disorders. Excerpts from such plays as *Who's Afraid of Virginia Woolf*,[15] *Whose Life is It Anyway?*,[16] *Children of A Lesser God*,[17] and *Agnes of God*[18] illuminate a diverse range of ethical and legal dilemmas from imagining our future with DNA to death with dignity, disability and deafness, and the determination of truth, respectively.

Beginning in the 1980s, Act IV, "AIDS & Evers," links two major public health epidemics that disproportionally impacted large numbers of vulnerable and marginalized populations. From *The Normal Heart*,[19] to *Angels in America*[20] to *Miss Evers' Boys*,[21] we witness how society and science respond to threats of infectious diseases, including the AIDS epidemic and the legacy of Tuskegee where treatment for syphilis was withheld. Act V, "Hi Tech, Lo Tech & No Tech," explores fifteen years beginning with the initiation of mapping the human genome and the acceleration of emerging medical technologies with their ethical, legal, and social implications. From chromosomes to codes to clones to no codes, a wide variety of plays including *Twilight of the Golds*,[22] *Wit*,[23] *A Number*[24] and *33 Variations*[25] bring to life the debate over the use and misuse of medical technology. The final Act, "Genomes & Unknowns," includes a

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[15] EDWARD ALBEE, WHO'S AFRAID OF VIRGINIA WOOLF? (Dramatists Play Service 2004) (1962).

[16] BRIAN CLARK, WHOSE LIFE IS IT ANYWAY? (1972) (Dramatic Publishing 1974).

[17] MARK MEDOFF, CHILDREN OF A LESSER GOD (1979) (Dramatists Play Service 1980).

[18] JOHN PIELMEIER, AGNES OF GOD (Samuel French 1982).

[19] LARRY KRAMER, *The Normal Heart* (1985), *in* THE NORMAL HEART AND THE DESTINY OF ME : TWO PLAYS BY LARRY KRAMER 1 (Grove Press 2000).

[20] TONY KUSHNER, ANGELS IN AMERICA: A GAY FANTASIA ON NATIONAL THEMES (Theatre Communications Group 1995).

[21] DAVID FELDSHUH, MISS EVERS' BOYS (Dramatists Play Service 1995).

[22] JONATHAN TOLINS, TWILIGHT OF THE GOLDS (1992) (Samuel French 1994).

[23] MARGARET EDSON, WIT (Dramatists Play Service 1999).

[24] CARYL CHURCHILL, A NUMBER (Theatre Communications Group 2002).

[25] MOISÉS KAUFMAN, 33 VARIATIONS (Dramatists Play Service 2011).

number of less-known plays, such as *Lucy*,[26] *Distracted*,[27] *The Good Egg*,[28] and *The Other Place*,[29] illuminating, in part, how the genomic revolution is expanding expectations for explanations and interventions for Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, assisted reproduction, and Alzheimer's disease. Even though the power of technology continues to increase dramatically, raising more ethical implications, the urge to use medical innovations to manipulate our fate and those of others remains constant.

ACT I: CREATURES LARGE & SMALL

Richard Peake's *Presumption; or, The Fate of Frankenstein*, is an illustrative starting point—the first theatrical adaptation of Mary Shelley's prescient novel.[30] The tension between the initial presumption that innovation in medical science is largely beneficial with the reality that the potential for inherent risks always exists in experimentation[31] is articulated by Peake's character, the physician-scientist Frank:

> Aye, I am engaged heart and soul in the pursuit of discovery—a grand, unheard wonder. None but those who have experienced can conceive the enticement of Science; he who looks into the book of nature, finds

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[26] DAMIEN ATKINS, LUCY (2009) (Playwrights Can. Press 2010).

[27] LISA LOOMER, DISTRACTED (Dramatists Play Service 2009).

[28] DOROTHY FORTENBERRY, THE GOOD EGG (2010) (Broadway Play Publishing 2011).

[29] WHITE, *supra* note 5.

[30] MARY SHELLEY, FRANKENSTEIN; OR, THE MODERN PROMETHEUS (Maurice Hindle ed., Penguin 2003) (1818). Shelley's character, Dr. Victor Frankenstein, reflects: "Did any one indeed exist, except I, the creator, who would believe, unless his senses convinced him, in the existence of the living monument of presumption and rash ignorance which I had let loose upon the world?" *Id.* at 81. Interestingly, although Shelley only used the word "presumption" once, the British playwright Peake seized upon the link between presumption and fate to dramatize the ethical and societal implications of creating and manipulating nature, including for the title of his play.

[31] *See* TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS (6th ed. 2009); RUTH R. FADEN ET AL., A HISTORY AND THEORY OF INFORMED CONSENT (1986); Norman Howard-Jones, *Human Experimentation in Historical and Ethical Perspectives*, 16 SOC. SCI. & MED. 1429 (1982).

> an inexhaustible source of novelty, of wonder, and delight. What hidden treasures are contained in her mighty volume—what strange, undreamed-of mysteries![32]

Yet as scientists and others have witnessed at various times throughout history, this excitement over the promise of innovation has the potential to turn into disaster for individuals and society.[33] Reflecting on the monster he created, Frank questions:

> What have I accomplished? The beauty of my dream has vanished! . . . a flash breaks in upon my darkened soul, and tells me my attempt was impious . . . The dreadful spectre of a human form . . . so hideous as the wrench I have endowed with life![34]

Whereas the Hippocratic Oath[35] espoused the paradigm "to do good or to do no harm" and Percival's 1803 *Medical Ethics*[36] expanded on professional virtues to gain public trust, theatre often dramatizes the potential of the disequilibrium in the power relationship between physician-scientists and patient-participants.[37] An examination of this unequal and controlling relationship sets the stage for further drama illuminating the consequences—at times tragic—that extend beyond individuals to impact families, friends, professional colleagues and society.

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[32] PEAKE, *supra* note 4, at act 1, sc. 1.

[33] *See* MARTIN S. PERNICK, A CALCULUS OF SUFFERING: PAIN, PROFESSIONALISM, AND ANESTHESIA IN NINETEENTH-CENTURY AMERICA 58-62 (1985); DAVID J. ROTHMAN, STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING 1-2 (1991); CLAUDE BERNARD, AN INTRODUCTION TO THE STUDY OF EXPERIMENTAL MEDICINE (Henry C. Greene trans., 1927).

[34] PEAKE, *supra* note 4, at act 1, sc. 3.

[35] HIPPOCRATES, THE CORPUS 1-2 (Conrad Fischer ed., 2008).

[36] THOMAS PERCIVAL, MEDICAL ETHICS; OR A CODE OF INSTITUTES AND PRECEPTS, ADAPTED TO THE PROFESSIONAL INTERESTS OF PHYSICIANS AND SURGEONS (1803). *See also* Michael Davis, *What Can We Learn by Looking at the First Code of Professional Ethics*? 24 THEORETICAL MED. & BIOETHICS 433, 445 (2003).

[37] *See* OSLER'S BEDSIDE LIBRARY: GREAT WRITERS WHO INSPIRED A GREAT PHYSICIAN (Michael A. LaCombe & David J. Elpern eds., 2010).

In the 1837 play *Woyzeck*,[38] Georg Büchner, the German author and professor of comparative anatomy, explores through caricature the abuses that may result from crossing the boundaries of a professional relationship in order to assert a dangerous degree of power and control over the fate of others. The ethical and societal implications of human experimentation[39] are magnified by the impoverished character Woyzeck being placed on an untenable three month protocol—a restricted diet of solely peas, as well as the daily return of a twenty-four hour urine collection.[40] Büchner highlights the caution that must be taken if the main goal of research appears to focus largely on the benefits to the scientist when the Doctor tells Woyzeck, his deteriorating research subject, "I'm going to revolutionize science, I'm going to blow it all sky-high. Uric acid 0.1, ammonium hydrochlorate, hyperoxide."[41]

While on this experimental protocol, Woyzeck naively asks: "Doctor, have you ever caught sight of the other side of nature? Sometimes, when the sun's up high in the middle of the day and it seems like the world is bursting into flames, this terrible voice starts talking to me."[42] The Doctor delights in the fact that Woyzeck has "the most beautiful *aberratio mentalis partialis*, category two, such a beautiful example" and questions him "Still doing everything as usual? . . . Eating your peas? . . . You're an interesting case, Woyzeck, an interesting case. You'll be getting a bonus. Keep at it."[43]

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[38] GEORG BÜCHNER, WOYZECK (1837) (1879), *reprinted in* COMPLETE PLAYS, LENZ AND OTHER WRITINGS 109 (John Reddick trans., Penguin Books 1993).

[39] *See* BERNARD, *supra* note 33.

[40] *See* William Henry, *Experiments on the Urine Discharged in Diabetes Mellitus, with Remarks on That Disease*, 2 MEDICO-CHIRURGICAL TRANSACTIONS 119, 119-22 (1811); William Henry, *History of Discoveries Respecting the Uric Acid*, *in* 2 MEMOIRS AND PROCEEDINGS - MANCHESTER LITERARY AND PHILOSOPHICAL SOCIETY 391 (1813); William Henry, *Inaugural Dissertation on the Uric Acid*, 4 EDINBURGH MED. & SURGICAL J. 114, 114-16 (1808); *see generally* Henry B. Jones, *On the State in Which the Uric Acid Exists in the Urine*, 27 MEDICO-CHIRURGICAL TRANSACTIONS 102 (1844).

[41] BÜCHNER, *supra* note 38, at 121.

[42] *Id.* at 122.

[43] *Id.*

Displaying the progress of his experiment with his colleagues in an amphitheatre, the Doctor proudly declares "this human specimen here, d'you see, for three months it has eaten nothing but peas, observe the effects, just feel how irregular the pulse is, here, and notice the eyes."[44] When Woyzeck remarks that "everything's going dark," the Doctor flippantly replies: "Cheer up, Woyzeck, just a few more days and it'll all be over; examine him, gentlemen, examine him."[45]

With these short excerpts, Buchner exposes us to the unethical design and implementation of unscientific methods and concerns about the medical risks to a vulnerable individual—some of the issues that were addressed in the AMA Code of Ethics in 1847[46] and in subsequent codes and professional regulations that would continue to evolve.[47] By the end of the play, we witness how an unethical human experiment destroys both Woyzeck's physical and mental capacity, causing him to murder his wife and resulting in the tragic twist of their fates.[48]

Norwegian playwright Henrik Ibsen's *Ghosts*[49] also explores the dynamics of controlling destiny within the family, albeit this time dramatizing a hereditable etiology. In this context, the doctors crudely explain that congenital syphilis is inherited: "the sins of the fathers are visited upon the children."[50] The play depicts the son, Osvald, as having no control over his fate from the disease, since

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[44] *Id.* at 126.

[45] *Id.*

[46] AM. MED. ASS'N, CODE OF ETHICS (1847). Over 125 years later, as a result of the Tuskegee syphilis study, Congress created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *See infra* note 289 and accompanying text.

[47] ROBERT BAKER, THE AMERICAN MEDICAL ETHICS REVOLUTION: HOW THE AMA'S CODE OF ETHICS HAS TRANSFORMED PHYSICIANS' RELATIONSHIPS TO PATIENTS, PROFESSIONALS, AND SOCIETY 199-200 (1999); *see also* AM. MED. ASS'N, STATE MEDICAL LICENSURE REQUIREMENTS AND STATISTICS (2012).

[48] BÜCHNER, *supra* note 38, at 134.

[49] HENRIK IBSEN, GHOSTS (1881), *reprinted in* FOUR MAJOR PLAYS: GHOSTS; AND AN ENEMY OF THE PEOPLE; THE LADY FROM THE SEA 1 (Rolf Fjelde trans., Signet Classics 2d. 1970).

[50] IBSEN, GHOSTS, *supra* note 49 , at 55; *see* ALLAN M. BRANDT, NO MAGIC BULLET: A SOCIAL HISTORY OF VENEREAL DISEASE IN THE UNITED STATES SINCE 1880 (1985).

science had not yet discovered a cure. Even "one of the foremost doctors" gave him little hope as Osvald reports to his mother: "Right from your birth, your whole system has been more or less worm-eaten. The actual expression he used was *vermoulu*."[51]

Osvald, however, finds a means to control his pain—and his ultimate fate—with the reluctant aid of his mother, Mrs. Alving, with whom he pleads to "give me that help."[52] When she viscerally responds, "I, who gave you life!" he quickly replies, "I never asked you for life. And what is this life you gave me? I don't want it! . . . Have you no mother-love for me at all—to see me suffer this unbearable fear!"[53] She reluctantly agrees, "if it becomes necessary,"[54] to give him enough morphine to end his life—echoing the continuing ethical debate on assisted suicide.[55]

Our inability to control fate to improve public health was at the center of the controversy in another Ibsen play, *An Enemy of the People*.[56] By 1882, when the play was authored, innovation in science enabled us to detect bacteria, yet we did not have the chemical mechanisms to control this threat to society.[57] Given the invisible nature of these microbes and no quick fix, it posed a great challenge

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[51] IBSEN, GHOSTS, *supra* note 49, at 55 (emphasis in original).

[52] *Id*. at 80.

[53] *Id.*

[54] *Id.*

[55] *See infra* notes 320-33, 397-411, and accompanying text; KATHLEEN M. FOLEY & HERBERT HENDIN, THE CASE AGAINST ASSISTED SUICIDE: FOR THE RIGHT TO END-OF-LIFE CARE (2002); ARTHUR KLEINMAN, THE ILLNESS NARRATIVES: SUFFERING, HEALING, AND THE HUMAN CONDITION (1988); John Rawls et al., *Assisted Suicide: The Philospher's Brief*, *in* PHILOSOPHY AND DEATH: INTRODUCTORY READINGS (Samantha Brennan & Robert J. Stainton eds., 2010); Timothy E. Quill, *Physician-Assisted Death in the United States: Are the Existing "Last Resorts" Enough?*, HASTINGS CENTER REP., Sept.-Oct. 2008, at 17.

[56] IBSEN, *supra* note 9.

[57] *See* H. Charlton Bastian, *The Germ-Theory of Disease: Being a Discussion of the Relation of Bacteria and Allied Organisms to Virulent Inflammations and Specific Contagious Fevers*, 1 BRIT. MED. J. 469 (1875); K. Codell Carter, *Koch's Postulates in Relation to the Work of Jacob Henle and Edwin Klebs*, 29 MED. HIST. 353 (1985); Germain Sée, *The Tubercle Bacillus: Its Morphology, Mode of Detection; Its Life History; Its Results in the Human Organism; The Culture of the Tubercle Bacillus*, 112 BOSTON MED. & SURGICAL J. 265 (1885); *The History of the Germ Theory*, 1 BRIT. MED. J. 312 (1888); *The Germ-Theory a Century Ago*, 1 BRIT. MED. J. 306 (1888).

for the town's doctor to convince the politicians to take action to control the water supply and close the public baths, much like occurred a century later during the beginning of the AIDS epidemic.[58]

Representing the views of his constituents, the town's mayor doubts the seriousness of the problem that "no one can see" and believes that Dr. Stockmann is "exaggerating considerably."[59] The mayor further rebukes him: "A capable doctor must know the right steps to take—he should be able to control toxic elements, and to treat them if they make their presence too obvious."[60] Later on, Dr. Stockmann reflects upon his increasing frustration: "Damn it, science should be able to provide some counteragent, some kind of germicide. . . . But—everyone says this is all just imagination. . . . didn't they brand me enemy of the people?"[61]

In spite of scientific gains in physiology, pathology and organic chemistry during this time, many in the medical profession were frustrated by the lack of progress in having the tools to treat disease and alleviate suffering. Without medications or other therapies yet to be developed, the inability to effectively ameliorate mental illness challenged physicians who felt they had little control to modify this fate.[62] As dramatized in Chekhov's 1895 play *The Seagull*,[63] the caring physician Dorn was helpless at that time, just like his depressed

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[58] *See infra* notes 242-73 and accompanying text; Scott Burris, *Legal Aspects of Regulating Bathhouses: Cases from 1984-1995*, *in* GAY BATHHOUSES AND PUBLIC POLICY 131 (William J. Woods & Diane Binson eds., 2003). *See also* LAWRENCE O. GOSTIN, PUBLIC HEALTH LAW: POWER, DUTY, RESTRAINT (2010).

[59] IBSEN, *supra* note 9, at 109, 121. *See also* H. Donkin, *Thoughts on Ignorance and Quackery*, 2 BRIT. MED. J. 577, 577-79 (1880); Editorial, *Quackery in the Past*, 1 BRIT. MED. J. 1250 (1911).

[60] IBSEN, *supra* note 9, at 121.

[61] *Id*. at 189-90.

[62] *See* G.E. Berrios, *Melancholia and Depression During the 19th Century: A Conceptual History*, 153 BRIT. J. PSYCHIATRY 298 (1988); DEMOCRITUS JUNIOR, THE ANATOMY OF MELANCHOLY: WHAT IT IS WITH ALL THE KINDS, CAUSES, SYMPTOMES, PROGNOSTICKES & SEVERALL CURES OF IT 722 (4th ed. Oxford: Henry Cripps, 1632); W.F. Farquharson, *On Melancholia: An Analysis of 730 Consecutive Cases*, 40 BRIT. J. PSYCHIATRY 11 (1894); Theodore W. Fisher, *Recent Progress in the Treatment of Mental Diseases*, 101 BOSTON MED. & SURGICAL J. 655 (1879).

[63] ANTON CHEKHOV, THE SEAGULL (1895), *reprinted in* FIVE PLAYS: IVANOV, THE SEAGULL, UNCLE VANYA, THREE SISTERS, THE CHERRY ORCHARD 65 (Ronald Hingley trans., Oxford 2008).

patient, Constantine Treplev, in not being able to prevent Constantine's suicide.

Early on in the play, Constantine Treplev shares his anguish with his friend Nina: "I meanly killed that seagull this morning. I lay it at your feet."[64] Nina quickly responds in horror, "What's wrong with you?" and after a pause he bluntly states, "I shall soon kill myself the same way."[65] Towards the end of the play, a shot is heard offstage and Irina, Constantine Treplev's mother, is terrified.[66] The doctor tries to conceal the truth: "Don't worry. A bottle must have gone off inside my medical bag, don't worry."[67] Relieved, Irina remarks, "Oh dear, I was frightened. . . . It made me feel quite ill."[68] Dorn then whispers to another friend in the room, "Get Irina out of here somehow. The fact is, Constantine has shot himself."[69]

Even with many innovations in psychopharmacology and other technologies, we still do not have effective methods to adequately treat everyone with depression. In fact, regardless of the subspecialty, physician-scientists continue to be pushed to develop approaches that create new hopes—along with new failures and new ethical dilemmas.[70]

George Bernard Shaw's 1906 play, *The Doctor's Dilemma*,[71] dramatizes this reality. Early in the twentieth century, there was a growing understanding of germ theory, its implications for attacking

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[64] *Id.* at 87.

[65] *Id.*

[66] *Id.* at 115.

[67] *Id.*

[68] *Id.*

[69] *Id.*

[70] *See* Henry K. Beecher, *Ethics and Clinical Research*, 274 NEW ENG. J. MED. 1354 (1966); Charles W. Lidz et al., *Therapeutic Misconception and the Appreciation of Risks in Clinical Trials*, 58 SOC. SCI. & MED. 1689 (2004); George Rosen, *Patterns of Health Research in the United States, 1900-1960*, 39 BULL. HIST. MED. 201 (1965); *see generally* ALBERT R. JONSEN, THE BIRTH OF BIOETHICS (1998).

[71] SHAW, *supra* note 10.

infection and its promise for controlling diseases[72]—yet there were also limits on who would be selected for experimental treatment. A century later we continue to debate the ethics of allocating scarce resources.[73]

As Shaw's character, Dr. Ridgeon, reflects, "My laboratory, my staff, and myself are working at full pressure. We are doing our utmost. The treatment is a new one. It takes time, means, and skill; and there is not enough for another case. Our ten cases are already chosen cases."[74] He further laments, "I have had to consider, not only whether the man could be saved, but whether he was worth saving. There were fifty cases to choose from; and forty had to be condemned to death."[75] When a woman begs him to include her sick husband for Ridgeon's "experimental test," the doctor replies, "You are asking me to kill another man for his sake; for as surely as I undertake another case, I shall have to hand back one of the old ones to the ordinary treatment . . . It's a dilemma."[76]

ACT II: MENDEL, DOCS & RABBITS

The attempt to control the fate of others and the quest for a better human species, further played out through a growing fascination with the re-emergence of Gregor Mendel's inheritance theory.[77]

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[72] *See generally* NANCY TOMES, THE GOSPEL OF GERMS: MEN, WOMEN, AND THE MICROBE IN AMERICAN LIFE (1998).

[73] *See* RENÉE C. FOX & JUDITH P. SWAZEY, THE COURAGE TO FAIL: A SOCIAL VIEW OF ORGAN TRANSPLANTS AND DIALYSIS (new ed. 2002); Dyce Duckworth, *Observations on Rational Empiricism and Scientific Medicine: The Boundaries Dividing Them*, 1 BRIT. MED. J. 1217 (1911); K. Rakszawski & J.E. Bekelman, *Allocation of High Demand, Scarce Medical Technology: Lessons for Proton Radiotherapy*, 27 J. CLINICAL ONCOLOGY (SUPPLEMENT) e17570 (2009); Philip M. Rosoff, *Unpredictable Drug Shortages: An Ethical Framework for Short-Term Rationing in Hospitals*, 12 AM. J. BIOETHICS 1 (2012); Emily A. Largent & Steven D. Pearson, *Which Orphans Will Find a Home? The Rule of Rescue in Resource Allocation for Rare Diseases*, HASTINGS CENTER REP., Jan.-Feb. 2012, at 27.

[74] SHAW, *supra* note 10, at 28.

[75] *Id.*

[76] *Id.* at 30, 44.

[77] *See* Rothenberg, *supra* note 2, at 409. *See also* DANIEL J. KEVLES, IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY (1985); WENDY KLINE, BUILDING A BETTER RACE

Seized upon by American playwrights, Percy MacKaye in his 1912 play *To-morrow*[78] promotes eugenics as unquestionable science and creates the character Professor Raeburn who authoritatively declares, "[W]e have the key which may unlock a vast kingdom of human happiness, the law of Mendel."[79] Based on this theory, the father in the play encourages his daughter to marry a "eugenically superior" individual rather than the man she loved whose bloodline they deemed tainted by congenital blindness.[80] As Raeburn exclaims, "Sound Americans" should be bred "as carefully . . . as their sheep and cattle . . . forbidding the production of the worse stock, and by encouraging the production of the best."[81] In fact, over the next decade, forced sterilization laws and restrictive U.S. immigration quotas were justified as social policy in part based on Mendel's theory and the scientific belief in the "genetic inferiority" of marginalized populations.[82]

Whereas Professor Raeburn believes that selective breeding is key to promoting strong citizens and weeding out the ill and less able, Dr. Knock, the titular character in Jules Romains' 1923 French satire,[83] is able to use propaganda to convince the townspeople that they are all sick—with the presumption that their fate could be altered by the "miracle of science."[84] In response to the rich hypochondriac "Lady in Purple" complaining of headaches, Dr. Knock inquires, "Can you picture a crab or a squid or a giant spider nibbling or sucking or pecking away at your brain?"[85] "I suppose it's

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(2001).

[78] MACKAYE, *supra* note 11. *See* TAMSEN WOLFF, MENDEL'S THEATRE: HEREDITY, EUGENICS, AND EARLY TWENTIETH-CENTURY AMERICAN DRAMA (2009) (exploring link between American theatre and the eugenics movement; specifically 60, 124-25 for discussion of *To-Morrow*).

[79] MACKAYE, *supra* note 11, at 23.

[80] *Id*. at 22.

[81] *Id*. at 22-23.

[82] *See* Buck v. Bell, 274 U.S. 200 (1927). *See also* Rothenberg, *supra* note 2, at 413-14, 416-18.

[83] JULES ROMAINS, KNOCK (1923) (James Gidney trans., Baron's Educational Series 1962).

[84] Jack Godin, *Introduction* to JULES ROMAINS, KNOCK *i*, *vi* (James Gidney trans., Baron's Educational Series 1962).

[85] ROMAINS, *supra* note 83, at 44.

fatal and absolutely incurable?" she queries, then adds in puzzlement, "the pipe-stem thing or the spider?"[86] Dr. Knock responds, "You can be cured of either. I might not dare offer any hope to an ordinary patient who wouldn't have either the time or the means for the most up-to-date methods. . . . to stick to it for two or three years. . . . It involves minute calculations of the dosage of radioactivity—and almost daily visits."[87] Like the physician in *Woyzeck*, Dr. Knock illuminates the risks that quackery presents to harm the health of individuals,[88] as well as the potential to tarnish the reputation and public trust of the medical profession.[89]

The unethical behavior of the physician-scientist continued to be examined a few years later in *Strange Interlude*,[90] the 1928 Pulitzer award winning play. Eugene O'Neill uses a friendship between Darrell, a physician, and a married couple, Nina and Sam, to explore various ways the doctor could help to control the genetic fate of mental illness in the family.[91] Darrell learns from Nina that "Sam's mother told me I couldn't have my baby. You see, Doctor, Sam's great-grandfather was insane, and Sam's grandmother died in an asylum, and Sam's father had lost his mind for years before he died, and an aunt who is still alive is crazy."[92] Nina then pleads for help: "I need your advice—your *scientific* advice this time. . . . I need the courage of someone who could stand outside and reason it out as if Sam and I were no more than guinea pigs."[93]

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[86] *Id*. at 44-45.

[87] *Id*. at 45.

[88] *See* RICHARD CABOT, ADVENTURES ON THE BORDERLANDS OF ETHICS (1926); John Byers, *Quackery -- with Special Reference to Female Complaints*, 1 BRIT. MED. J. 1239 (1911); A.J. Clark, *The Historical Aspect of Quackery*, 2 BRIT. MED. J. 589 (1927); Editorial, *The Borderland of Quackery* (pts. 1 & 2), 1 BRIT. MED. J. 1548 (1902), 1 BRIT. MED. J. 1608 (1902); *The New Quackery*, 4 CAN. MED. ASS'N J. 128 (1914).

[89] *See* Bayard Holmes, *The Regulation of Quacks by Local Legislation*, 20 JAMA, no. 2, 1893 at 52. *See also* Terri A. Winnick, *From Quackery to "Complementary" Medicine: The American Medical Profession Confronts Alternative Therapies*, 52 SOC. PROBS. 38, 40 (2005).

[90] O'NEILL, *supra* note 12.

[91] *See* Wolff, *supra* note 78, at 141-67.

[92] O'NEILL, *supra* note 12, at 144.

[93] *Id*. at 145.

Darrell ponders:

> Let me see. . . . I am in the laboratory and they are guinea pigs . . . in fact, in the interest of science, I can be for the purpose of this experiment, a healthy guinea pig myself and still remain an observer. . . .Happiness hates the timid! So does Science! . . . and my duty as an experimental searcher after truth . . . to observe these three guinea pigs, of which I am one. . . .[94]

Rationalizing his role in having sex with Nina unbeknownst to Sam, to help create her child, Doctor Darrell states "the man should have a mind that can truly understand—a scientific mind superior to the moral scruples that cause so much human blundering and unhappiness."[95]

As the play evolves, the physician friend Darrell attempts to justify his unethical action of agreeing to father Nina and Sam's child to avoid the "ghost" of mental illness invading future generations.[96] Mirroring the concerns of the day as played out in theatre, that same year, Chauncey Leake, a well-respected physician, repudiated Percival's 1803 *Code of Ethics* as being more about etiquette and not enough about moral, professional behavior.[97] One can only imagine what Leake and his colleagues would have thought of Darrell's experiment and its implications on human relationships and society.

In 1933, another Pulitzer winner, *Men in White*,[98] by Sidney Kingsley, portrays the role of doctors in tempting fate, including the exploration of boundaries surrounding professional conduct.[99] In this play, Dr. George Ferguson, a young resident, impregnates a nurse who later requires emergency surgery at the hospital where they both work, following a botched abortion elsewhere. The senior

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[94] *Id*. at 146-47.

[95] *Id*. at 149.

[96] *See* Ted R. Ellis, *The Materialization of Ghosts in Strange Interlude*, AM. NOTES & QUERIES, Mar. 1981, at 110.

[97] Percival, *supra* note 36; Baker, *supra* note 47; ALBERT R. JONSEN, A SHORT HISTORY OF MEDICAL ETHICS 90 (2000).

[98] SIDNEY KINGSLEY, MEN IN WHITE (1933) (Covici Friede 4th prtg. 1934).

[99] *Id*.

physician, Dr. Hochberg, reflects with Ferguson on the current limitations and future hopes of introducing medical innovations to improve patient outcomes: "I tried . . . everything. Caffeine intravenously. Adrenalin directly into the heart. Useless! That little blood-clot in the lung . . . and we're helpless. Forty years I've spent in medicine . . . and I couldn't help her."[100]

Frustrated, Ferguson questions the futility of their profession: "Then what's the use? What good is it all? Why go on? It takes everything from you and when you need it most it leaves you helpless. We don't know anything. . . . We're only guessing."[101] In trying to persuade Ferguson not to give up, Hochberg tries to be positive: "But, at least our guesses today are closer than they were twenty years ago. And twenty years from now, they'll be still closer. That's what we're here for. . . . there's so much to be done."[102]

Attempting to create medical innovations in the wake of scientific uncertainty[103] is also the theme explored in the 1938 Federal Theatre Project propaganda play *Spirochete* by Arnold Sundgaard.[104] In using this historical perspective to trace the evolution of syphilis and the quest for a cure from 1493 to 1937,[105] *Spirochete* presents medical researchers and doctors as working to modify the fate of the disease, struggling with moralists over time who wanted to punish those they deemed not worthy of a cure. The character Dr. Hoffman notes that in 1905 it is "increasingly apparent that the virus isolated by Dr. Siegel in 1898 is not the cause of syphilis," leading another physician, "First Doctor," to react, "There are as many causes found for syphilis as there are scientists to look for them. Every time a man peers into his microscope these days he comes up shouting, 'Ah, at

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[100] *Id*. at 135.

[101] *Id*. at 135-36.

[102] *Id*. at 136.

[103] *See* RENÉE C. FOX, EXPERIMENT PERILOUS: PHYSICIANS AND PATIENTS FACING THE UNKNOWN 237-39 (1959); J.P. Bull, *The Historical Development of Clinical Therapeutic Trials*, 10 J. CHRONIC DISEASES 218 (1959).

[104] SUNDGAARD, *supra* note 13, at 11.

[105] The infamous Tuskegee experiments, the legacy of which still haunts medical research, started over a half decade before the play was written. *See infra* notes 276-95 and accompanying text.

last I have found it!' It's ridiculous," and further state "medicine is making a spectacle of itself with all these wild guesses."[106]

The play concludes by highlighting the travails of John, his pregnant wife Martha, and their child Tony blinded by John's infection, in order to illustrate the moral imperative for passage of legislation to mandate prenatal and premarital testing for syphilis.[107] This type of public health initiative was made possible by innovations in medicine that created the tools for society to control the destiny of future generations.[108] In contrast to the frustration expressed by "First Doctor" decades earlier, the current Doctor exclaims his excitement that public health interventions could indeed change fate:

> Even the unborn are not beyond our reach. . . . We can begin treatment as late as the fifth month and in ten cases out of eleven the child will be normal. The main thing is to test by the Kahn or the Wassermann and find out where this disease is lurking. . . . If he had been tested at the time of marriage it could have been prevented.[109]

Innovation in the diagnosis and treatment of syphilis was just one example of the many advances in medical research during the late 1930s and early 1940s presumed to benefit society. Through the discovery of the genetics of blood groups and phenylketonuria (PKU), researchers were able to better understand the mechanisms underlying a number of disorders, including hemophilia and thalassemia.[110] With this newfound knowledge, the enthusiasm for testing began to fuel an interest in expanding public health screening measures across the country.[111]

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[106] SUNDGAARD, *supra* note 13, at 57.

[107] *See Id.* at scene 4.

[108] *See* Abel Wolman, *A Statement of the Position of the American Public Health Association with Reference to the National Health Bill of 1939 (S. 1620)*, 29 AM. J. PUB. HEALTH & NATION'S HEALTH 686 (1939); *see also* ALLAN M. BRANDT, NO MAGIC BULLET: A SOCIAL HISTORY OF VENEREAL DISEASE IN THE UNITED STATES SINCE 1880, at 149-50 (1985).

[109] SUNDGAARD, *supra* note 13, at 110.

[110] *See* SUSAN LINDEE, MOMENTS OF TRUTH IN GENETIC MEDICINE 30, 195, 198 (2005).

[111] *Id.* at 29, 195.

At the same time, some members of the public were becoming disenchanted with the medical profession, especially the AMA, and socialized medicine was being discussed as a viable option.[112] The Federal Theatre Project explores these themes and their ethical implications—which are still being debated today[113]—in Oscar Saul and H.R. Hayes's 1940 "Living Newspaper" propaganda play *The Medicine Show*.[114] The reality that without access to care, innovations in medicine will be of little value and not be available to change the fate from disease of those in need is described by the Statistician character:

> You are listening to the beating of the human heart amplified five thousand times. Every year in the United States that heart will stop in two hundred and fifty thousand bodies that need not die. Now you must share the struggles of those who fight for life. . . . you are in the medical maze every day of your lives. You can't escape the figures.[115]

In a later scene, Mackenzie, a pediatrician, expresses his frustration that although there is an effective medical intervention, a vaccine, there are "not enough doctors, no hospitals . . ." and with anger emphasizes "this boy has diphtheria. He's not been inoculated."[116] In this public health context, the principle of social

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[112] *See, e.g.*, John A. Kenney, *The National Health Act of 1939*, 31 J. NAT'L MED. ASS'N 154 (1939); Beatrix Hoffman, *Health Care Reform and Social Movements in the United States*, 93 AM. J. PUB. HEALTH 75 (2003); Nicole Lurie, *Health Disparities—Less Talk, More Action*, 353 NEW ENG. J. MED. 727 (2005); Harold Maslow, *The Background of the Wagner National Health Bill*, 6 LAW & CONTEMP. PROBS. 606 (1939); Jeremy Rabkin, *American Exceptionalism and the Healthcare Reform Debate*, 35 HARV. J.L. & PUB. POL'Y 153 (2012); Saul S. Radovsky, *U.S. Medical Practice before Medicare and Now—Differences and Consequences*, 322 NEW ENG. J. MED. 263 (1990).

[113] *See* Ezekiel J. Emanuel & Steven D. Pearson, *Physician Autonomy and Health Care Reform*, 307 JAMA 367 (2012); Charlotte Tucker, *Health Reform Law to Have Its Day in Nation's Highest Court Next Month*, 42 NATION'S HEALTH 1 (2012); Arthur A. Daemmrich, *U.S. Healthcare Reform: Reaction to the Patient Protection and Affordable Care Act of 2010* (Harvard Bus. Sch. BGIE Unit Case No. 711-103, 2011).

[114] OSCAR SAUL & H.R. HAYES, THE MEDICINE SHOW (1940) (1986) (photo. reprint 1988).

[115] *Id*. at 1-4, 1-8.

[116] *Id*. at 1-39. *See also* JAMES COLGROVE, STATE OF IMMUNITY : THE POLITICS OF VACCINATION IN TWENTIETH-CENTURY AMERICA 149-50 (2006); James Colgrove et al., *HPV Vaccination Mandates—Lawmaking Amid Political and Scientific Controversy*, 363 NEW ENG. J. MED. 785 (2010).

justice, as dramatized in theatre, provides one of the rationales for expanding access to health care.[117]

Even when patients have access to every innovation in medicine that money can buy, there is no guarantee that they will be cured. Moreover, technologies presumed to benefit individuals can raise their own set of vexing ethical dilemmas—particularly for those with neuropsychiatric disorders.[118] In the 1944 classic *Harvey*, Mary Chase explores Elwood Dowd's hallucinations with Harvey, his imaginary rabbit-friend, and his wealthy family's conflict whether to legally commit him to a sanitarium where many therapeutic modalities are offered.[119] Dr. Sanderson recommends "shock formula number 977," opining that "Mr. Dowd will not see this rabbit any more after this injection. We've used it in hundreds of psychopathic cases."[120] However, Dr. Chumley cautions, "This injection carries a violent reaction. We can't give it to him without his consent. Will he give it?" Veta, Elwood's sister, replies, "Of course he will, if I ask him," to which Dr. Chumley questions, " To give up this rabbit—I doubt it." Myrtle, Veta's daughter, quickly responds, "Don't ask him. Just give it to him."[121]

The ethical implications of administering innovative treatments are complex, especially with interventions that can alter the essence of personality in patients who might be deemed to lack capacity to make their own decisions.[122] This is illustrated following Veta's taxi ride en route to the sanitarium, when the cab driver observes:

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[117] *See* MADISON POWERS & RUTH FADEN, SOCIAL JUSTICE: THE MORAL FOUNDATIONS OF PUBLIC HEALTH AND HEALTH POLICY 80 (2006); Norman Daniels et al., *Why Justice Is Good for Our Health: The Social Determinants of Health Inequalities*, DAEDALUS, Fall 1999, at 215.

[118] *See* Victor E. Gonda, *Treatment of Mental Disorders with Electrically Induced Convulsions*, 2 DISEASES NERVOUS SYS. 84 (1941); R.E. Hemphill & W. Grey Walter, *The Treatment of Mental Disorders by Electrically Induced Convulsions*, 87 BRIT. J. PSYCHIATRY 256 (1941); Harold D. Palmer et al., *Therapy in Involutional Melancholia*, 97 AM. J. PSYCHIATRY 1086 (1941); J.H. Quastel, *Biochemistry and Mental Disorder*, 220 LANCET 1417 (1932).

[119] *See* CHASE, *supra* note 14.

[120] *Id*. at 60.

[121] *Id*. at 65.

[122] *See* Paul S. Appelbaum & Thomas Grisso, *Assessing Patients' Capacities to Consent to Treatment*, 319 NEW ENG. J. MED. 1635 (1988).

> I've been drivin' this route fifteen years. I've brought 'em out here to get that stuff and drove 'em back after they had it. It changes 'em. . . . On the way out here they sit back and enjoy the ride. . . . Sometimes we stop and watch the birds when there ain't no birds and look at the sunsets when it's rainin'. . . . But afterward—oh—oh.[123]

Veta is now forced to consider all the risks of the injection on her brother and shouts: "Stop it—stop it—don't give it to him! . . . I don't want Elwood that way."[124] In this dramatic scene, Mary Chase illuminates the individual and societal implications of allowing others to manipulate[125] the fate of vulnerable individuals.[126]

ACT III: GENES, DREAMS & SCREAMS

Following the Second World War, scientific advancement to modify disease was so rapid and expansive that the period is referred to as the "Golden Age" of medicine.[127] Lithium and chlorpromazine provided for some pharmacological control of psychiatric disorders; infectious disease gained greater control when streptomycin, penicillin and polio vaccines were made available to the public.[128] There was a further surge in scientific innovations with a notable increase in federal funding for biomedical research.[129] Cardiac pacemakers, electric defibrillators and cardiac catheterization altered the destiny of many families confronting heart disease;[130]

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[123] CHASE, *supra* note 14, at 69.

[124] *Id.* at 69-70. *See generally* PAUL S. APPELBAUM ET AL., INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE (1987); Jessica Wilen Berg et al., *Constructing Competence: Formulating Standards of Legal Competence to Make Medical Decisions*, 48 RUTGERS L. REV. 345, 353-54 (1996).

[125] THOMAS GRISSO & PAUL S. APPELBAUM, ASSESSING COMPETENCE TO CONSENT TO TREATMENT: A GUIDE FOR PHYSICIANS AND OTHER HEALTH PROFESSIONALS (1998).

[126] *See* APPELBAUM ET AL., *supra* note 124, at 23.

[127] *See* John C. Burnham, *American Medicine's Golden Age: What Happened to It?*, 215 SCIENCE 1474, 1474 (1982).

[128] See JONSEN, *supra* note 70.

[129] *See* Donald C. Swain, *The Rise of a Research Empire: NIH, 1930 to 1950*, 138 SCIENCE 1233, 1234 (1962).

[130] *See* Richard Sutton et al., *History of Electrical Therapy for the Heart*, 9 EUR. HEART J. I3 (Supp. I, Dec. 2007.

Methotrexate, invented to modify the dismal fate from leukemia, opened the door for chemotherapy;[131] and the birth control pill revolutionized family planning.[132]

After the discovery of the Double Helix in 1953, [133] a whole new scientific field emerged—the "new genetics"— and was followed by prenatal genetic testing, assisted reproduction technologies and experimentation with gene therapy.[134] With the promise of new genetic discoveries and technologies came the growing recognition of the potential perils for our future.[135]

Although celebrated as a play about dysfunctional marital relationships, Edward Albee's 1962 play *Who's Afraid of Virginia Woolf?*[136] also directly addresses society's concerns about the threat of genetic manipulation and its implications for future generations. Set on a college campus, George, the senior history professor, verbally attacks Nick, the young science professor:

> You're the one! You're the one's going to make all that trouble . . . I'm very mistrustful. . . . I read somewhere that science fiction is really not fiction at all . . . that you people are rearranging my genes, so that everyone will be like everyone else. Now, I won't have that! It would be a . . . shame.[137]

Albee dramatizes the disharmony of their disciplines and generations—the historian who reflects on the past as prologue and the biologist who creates and manipulates the future—similar to tensions explored during the same time by C.P. Snow's *The Two*

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[131] *See* Vincent T. DeVita, Jr. & Edward Chu, *A History of Cancer Chemotherapy*, 68 CANCER RESEARCH 8643 (2008).

[132] *See* John A. McCracken, *Reflections on the 50th Anniversary of the Birth Control Pill*, 83 BIOLOGY REPRODUCTION 684 (2010). *See also* JONSEN, *supra* note 70, at 12 (summarizing the rapid advances in medical therapies throughout the course of the twentieth century).

[133] *See* J.D. Watson & F.H.C. Crick, *Molecular Structure of Nucleic Acids: A Structure for Deoxyribose Nucleic Acid*, 171 NATURE 737 (1953).

[134] *See* JAMES SCHWARTZ, IN PURSUIT OF THE GENE: FROM DARWIN TO DNA (2009).

[135] *See* JONSEN, *supra* note 70, at 177-82; LINDEE, *supra* note 110, at 57.

[136] ALBEE, *supra* note 15, at 33.

[137] *Id*. at 20.

Cultures and the Scientific Revolution.[138] The dichotomy of their professional world views shapes their presumptions about the inherent benefits and risks of genetic manipulation. George accuses Nick of trying to create "a race of scientists and mathematicians, each dedicated to and working for the greater glory of the super-civilization. . . . There will be a certain . . . loss of liberty, I imagine, as a result of this experiment. . . . Cultures and races will eventually vanish. . ."[139] Exasperated, Nick asks: "Are you finished?"[140]

Albee brings to life many of the ethical and societal concerns we still face today: who controls the fate of science; to what extent will we tolerate the threat of scientific innovations altering relationships; what impact will genetic manipulation have on our individual, familial and cultural identities; and what presumptions do we share about the power of emerging technologies to control our fate?

Kurt Vonnegut's *Fortitude*,[141] a 1960s satirical adaptation of *Frankenstein*, also explores the societal implications of experimenting with new technologies—creating vivid images that set up the tension between the fortitude to achieve scientific advances presumed to positively manipulate our destiny and the risks that threaten to take over our humanity.[142] Dr. Frankenstein is a brilliant physician-scientist who creates Sylvia, depicted as a head on a tripod hooked up to machines controlling her bodily functions with a master panel that he manipulates to keep her alive.[143] Also in the basement

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[138] C.P. SNOW, THE TWO CULTURES AND A SECOND LOOK: AN EXPANDED VERSION OF THE TWO CULTURES AND THE SCIENTIFIC REVOLUTION (1969). *See also* Joseph J. Fins & Inmaculada de Melo-Martin, *C.P. Snow's "Two Cultures" Fifty Years Later: An Enduring Problem with an Elusive Solution*, 32 TECH. IN SOC'Y 1 (2010); Bruce Jennings, *Enlightenment and Enchantment: Technology and Moral Limits*, 32 TECH. IN SOC'Y 25 (2010); Stephen R. Latham, *Law Between the Cultures: C.P. Snow's* The Two Cultures *and the Problem of Scientific Illiteracy in Law*, 32 TECH. IN SOC'Y 31 (2010); David J. Skorton, *Bridging the "Two Cultures" Divide in Medicine and the Academy*, 32 TECH. IN SOC'Y 49 (2010).

[139] ALBEE, *supra* note 15, at 33

[140] *Id.*

[141] KURT VONNEGUT, *Fortitude*, *in* WAMPETERS, FOMA & GRANFALLOONS (OPINIONS) 43 (Dial Press 1999) (1965).

[142] *See* FOX, *supra* note 103.

[143] VONNEGUT, *supra* note 141, at 43.

laboratory is Dr. Swift, his assistant, and young Dr. Little, who is called in to help Sylvia with her request to terminate this experiment and let her die.[144] Frankenstein points out: "Those are her kidneys over there. That's her liver, of course. There you got her pancreas. . . . Believe me, those are some expensive sweetbreads."[145]

Frankenstein proudly comments: "You don't live like this on Blue Cross. . . . I gave her her first major operation thirty-six years ago. She's had seventy-eight operations since then."[146] In addition to the financial implications of such *fortitude*, Vonnegut exposes us to the nascent debate over being kept alive by extraordinary means and having others take control of your fate. Sylvia expresses concern: "I do wish I had somebody to talk to about death . . . ,"[147] and then states: "I asked him yesterday what would happen if my brain started to go. He was serene. He said I wasn't to worry my pretty little head about that. 'We'll cross that bridge when we come to it,' he told me. . . . Oh, God, the bridges I've crossed!"[148] Vonnegut's imagery mirrors with exaggeration many of the major technological advances in medicine making headlines around that time: human heart transplantation experiments and chronic hemodialysis technologies created the potential to extend life in unimaginable ways,[149] and, as a result, complex bioethical issues began to emerge, challenging our presumptions about the benefits and risks of controlling fate.[150]

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[144] *Id*.

[145] *Id*. at 43-44

[146] *Id*. at 44.

[147] *Id*. at 54.

[148] *Id*. at 55.

[149] *See* Renée C. Fox, *The Medical Profession's Changing Outlook on Hemodialysis (1950-1976)*, *in* ESSAYS IN MEDICAL SOCIOLOGY: JOURNEYS INTO THE FIELD 120, 122-23 (Transaction Books ed., 1988); *A Plea for a Transplant Moratorium*, SCI. NEWS, Mar. 16, 1968, at 256, 256; Bd. on Med. of the Nat'l Acad. of Scis., *Cardiac Transplantation in Man*, 204 JAMA 805 (1968); Irving H. Page, *The Ethics of Heart Transplantation: A Personal View*, 207 JAMA 109, 110-12 (1969); Delford L. Stickel, *Ethical and Moral Aspects of Transplantation*, 3 MONOGRAPHS IN SURGICAL SCIS. 267, 269 (1966); J. Russell Elkington, *Moral Problems in the Use of Borrowed Organs, Artificial and Transplanted*, 60 ANNALS INTERNAL MED. 309, 310 (1964).

[150] *See* JAY KATZ ET AL., EXPERIMENTATION WITH HUMAN BEINGS: THE AUTHORITY OF THE

Much like we witness in *Fortitude*, the opening scene of Dale Wasserman's 1964 play *One Flew Over the Cuckoo's Nest*[151] has health professionals at a master control panel monitoring patients, machines, transformers, and relays with "godlike" power.[152] In this adaptation of Ken Kesey's novel,[153] the play brings to life how technology can be abused when under the control of an individual obsessed with manipulating power.[154] After some provocative dialogue between inpatients at a state mental hospital and the infamous Nurse Ratched, she repeatedly taunts them with threats of ordering dangerous amounts of promising technologies as well as numerous types of questionable interventions.[155] When one patient says he is going "down to the Shock Shop," another explains: "Electro-Shock Therapy . . . [a] device which combines the best features of the sleeping pill, the electric chair and the torture rack. . . . Zap! Punishment and therapy in one shocking package. Chief Broom, there. He's had two hundred treatments."[156]

Later on, when Nurse Ratched wants to further control their behavior, she threatens them with a "surgical procedure. . . . Quite simple, really."[157] When a naïve patient questions what the operation entails, a more seasoned patient responds, "I guess she means lobotomy. . . . [Y]ou might call it a sort of . . . castration of the

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INVESTIGATOR, SUBJECT, PROFESSIONS, AND STATE IN THE HUMAN EXPERIMENTATION PROCESS 1-2 (1972); Renée C. Fox., *A Sociological Perspective on Organ Transplantation and Hemodialysis*, 169 ANNALS N. Y. ACAD. SCIS. 416-17 (1970), *reprinted in* KATZ, *supra* note 150, at 708-09; Leon R. Kass, *Caveat on Transplants*, WASH. POST, Jan. 14, 1968, at B-1 col. 5, *reprinted in* KATZ, *supra* note 150, at 1070-71; *What and When Is Death?*, Editorial, 204 JAMA 539 (1968); Mita Giacomini, *A Change of Heart and a Change of Mind? Technology and the Redefinition of Death in 1968*, 44 SOC. SCI. & MED. 1465, 1471-74 (1997); Shana Alexander, *They Decide Who Lives, Who Dies*: *Medical Miracle Puts a Moral Burden on a Small Committee*, LIFE, Nov. 9, 1962, at 102, 104-06.

[151] DALE WASSERMAN, ONE FLEW OVER THE CUCKOO'S NEST: A PLAY IN TWO ACTS (1964) (Samuel French 1970).

[152] *Id.* at 5.

[153] KEN KESEY, ONE FLEW OVER THE CUCKOO'S NEST (17th prtg., New Am. Library 1962).

[154] *See* WASSERMAN, *supra* note 151.

[155] *Id.* at 59-66.

[156] *Id.* at 27.

[157] *Id.* at 65.

brain."[158] With the growing debate on psychosurgery[159] and other advances in technology, informed consent and research ethics became more of an imperative.[160] During this period the public's perception of the benefits and risks of medical innovation was evolving—whether in a psychiatric context or over life and death issues—reflecting in part moral ambiguities for individuals, families, health professionals, and society.[161]

The formalization of bioethics as a discipline intensified scrutiny of the interplay among science, policy, and the public.[162] As medical interventions became technologically more complex, this new field of bioethics was framing a number of fundamental questions for society to consider: is the extension of life beneficial if the individual experiences diminished consciousness or pain? What is the benefit? What is the harm? Who should live and who should die when considering the allocation of scarce resources?[163] Additional questions were raised over the next few decades, and the legal and ethical foundations of the "right to die" were established for both those patients who have capacity and those who may need others to decide on their behalf. [164]

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[158] *Id*. at 66.

[159] *See* NAT'L COMM'N FOR THE PROT. OF HUMAN SUBJECTS OF BIOMEDICAL & BEHAVIORAL RESEARCH, PSYCHOSURGERY: REP. AND RECOMMENDATIONS, at xv (1977); Walter Freeman & James W. Watts, *Prefrontal Lobotomy in the Treatment of Mental Disorders*, 30 S. MED. J. 23, 23, 30 (1937).

[160] *See* Appelbaum & Grisso, *supra* note 122, at 1635, 1637; Nicholas D. Schiff et al., *Deep Brain Stimulation, Neuroethics, and the Minimally Conscious State: Moving Beyond Proof of Principle*, 66 ARCHIVES OF NEUROLOGY 697, 700-01 (2009).

[161] *See* Alexander, *supra* note 150, at 104-27; Schiff, *supra* note 160, at 703; NAT'L COMM'N FOR THE PROT. OF HUMAN SUBJECTS OF BIOMEDICAL & BEHAVIORAL RESEARCH, *supra* note 159, at 7-10.

[162] *See* TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 8-9 (6th ed. 2009); RUTH R. FADEN ET AL., A HISTORY AND THEORY OF INFORMED CONSENT 92, 96 (1986); JONSEN, *supra* note 70; DAVID J. ROTHMAN, STRANGERS AT THE BEDSIDE : A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING 247-62 (2d paperback ed., Walter de Gruyter 2003) (1991).

[163] *See generally* BEAUCHAMP & CHILDRESS, *supra* note 162.

[164] *See* ALAN MEISEL & KATHY CERMINARA, THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING, §§ 2.01, 4.01-4.01[c] (3d ed. 2004 & Supp. 2005, Supp. 2006, Supp. 2009, Supp. 2011).

Brian Clark's *Whose Life is it Anyway?*[165] had a significant role in heightening public awareness on who decides how and when a patient may die, given the realities of the power dichotomy and innovations in medicine.[166] The 1972 play illustrates the ethical conflict between Dr. Scott and Ken, his young patient, who is initially kept alive by technology and is now questioning the quality of his life.[167] Unable to physically control his own fate, Ken is at the mercy of others to enable him to die with dignity: "Go and convince Dr. Frankenstein that he has successfully made his monster and he can now let it go."[168] Shortly afterward, Ken emphasizes his position:

> I really have absolutely no desire at all to be the object of scientific virtuosity. I have thought things over very carefully. I do have plenty of time for thinking and I have decided that I do not want to go on living with so much effort for so little result . . . . I might even learn to do wonderful things, like turn the pages of a book with some miracle of modern science. . . . But I don't want to become happy by becoming the computer section of a complex machine. And morally, you must accept my decision.[169]

To which Dr. Scott firmly replies: "Not according to my morals."[170]

Ken questions, "And why are yours better than mine?," then answers for himself, "They're better because you're more powerful. I am in your power. To hell with a morality that is based on the proposition that might is right."[171] Later on, Ken reasons:

> [E]ach man must make his own decision. And mine is to die quietly and with as much dignity as I can muster and I need your help. . . . It is

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[165] CLARK, *supra* note 16.

[166] Alexander M. Capron, *Foreword* to JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT, at xxii-xxiii (Johns Hopkins Press ed., Johns Hopkins Univ. Press 2002) (1984). *See also* FADEN ET AL., *supra* note 31, at 17; PETER G. FILENE, IN THE ARMS OF OTHERS: A CULTURAL HISTORY OF THE RIGHT-TO-DIE IN AMERICA xiv-xv, 8-9, 219 (1998); Charles Fried, *Terminating Life Support: Out of the Closet!*, 295 NEW ENG. J. MED. 390, 390-91 (1976).

[167] *See* CLARK, *supra* note 16.

[168] *Id*. at 30.

[169] *Id*. at 32, 39.

[170] *Id*. at 39.

[171] *Id*.

> not undignified if the man wants to stay alive, but I must restate that the dignity starts with his choice. Without it, it is degrading because technology has taken over from human will. My Lord, if I cannot be a man, I do not wish to be a medical achievement.[172]

In response to society's growing concern with loss of control over how we live and how we die, the hospice movement[173] was embraced as an alternative to counter the de-humanization of more and more technology on individuals and their relationships.[174] Contrary to the medical community's presumption at the time that everyone would welcome the availability of new technology, the public in fact began to question its value to extend life at all costs.[175]

As highlighted a few years later in Michael Cristofer's *The Shadow Box*,[176] patients near the end of life and their families share their experiences living as part of a hospice community, including having support for the control of pain.[177] Brian, one of the patients, reflects:

> Our dreams are beautiful, our fate is sad. . . . You always think . . . no matter what they tell you . . . you always think you have more time.

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[172] *Id.* at 43, 80.

[173] *See* SANDOL STODDARD, THE HOSPICE MOVEMENT: A BETTER WAY OF CARING FOR THE DYING (4th prtg. Stein & Day 1978); W. NOEL KEYES, BIOETHICAL AND EVOLUTIONARY APPROACHES TO MEDICINE AND THE LAW 873-74 (2007); Lainie Rutkow, *Optional or Optimal? The Medicaid Hospice Benefit at Twenty*, 22 J. CONTEMP. HEALTH L. & POL'Y 107, 109-10 (2005). *See also* 42 U.S.C. § 1396r(b)(1)(B)(2) (2012); Medicare & Medicaid Programs: Reapproval of the Community Health Accreditation Program (CHAP) for Deeming Authority for Hospices, 68 Fed. Reg. 55,616 (Sept. 26, 2003); 42 U.S.C. § 1395c (2012).

[174] *See* Anita J. Tarzian & Diane E. Hoffmann, *A Statewide Survey Identifying Perceived Barriers to Hospice Use in Nursing Homes*, 8 J. HOSPICE & PALLIATIVE NURSING 328, 335 (2006).

[175] *See* JOSEPH J. FINS, A PALLIATIVE ETHIC OF CARE: CLINICAL WISDOM AT LIFE'S END 18-19 (2006); PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS 15-18 (1983).

[176] MICHAEL CRISTOFER, THE SHADOW BOX (Samuel French 1977).

[177] *See id. See also* Diane E. Hoffmann, *Pain Management and Palliative Care in the Era of Managed Care: Issues for Health Insurers*, 26 J.L. MED. & ETHICS 267, 267-68 (1998) (explaining the problem of inadequate pain management for terminally ill patients).

> And you don't. But I appreciate what you're trying to do here, and I do enjoy being a guinea pig.[178]

With resignation, his friend later acknowledges "he is terminal—officially. . . . [T]here's nothing they can do for him in the hospital . . . . There's some pain. But it's tolerable. At least he makes it seem tolerable. They keep shooting him full of cortisone."[179]

Another form of pain that is a challenge to control emanates from psychiatric illness, as explored in *Equus*.[180] Peter Shaffer's 1974 play centers on Alan, a child with severe reactive depression, and his psychiatrist, Dysart, who feels inadequate at not having the tools to change the fate of many of his young patients: "The thing is, I'm desperate. . . . All reined up in old language and old assumptions. . . ."[181] Dysart is determined to help this boy by experimenting with any number of treatment modalities that might control his psychic pain and make him feel "normal" again.[182] These ethical and medical challenges of treating children remain today, in part because there is not sufficient data to substantiate the most effective medical interventions.[183]

Alan horrifically blinded six horses with a metal spike, and magistrate Hesther brings him to Dysart with the hope that the doctor could control the boy's abnormal behavior and his future.[184] Alan suggests, "It'll be the drug next. . . . Shove needles in people, pump them full of truth drug, so they can't help saying things.

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[178] CRISTOFER, *supra* note 176, at 22.

[179] *Id.* at 25.

[180] PETER SHAFFER, EQUUS (1974) (Scribner 2005).

[181] *Id.* at 10.

[182] *See* SHAFFER, *supra* note 180.

[183] *See* Michael G. Aman & Cristan A. Farmer, *Psychotropic Medication Research in Children and Adolescents: Empirical Findings and Ethical Implications*, 3 J. EMPIRICAL RES. ON HUM. RES. ETHICS: AN INT'L J. 39 (2008); Comm. on Bioethics, Am. Acad. of Pediatrics, *Informed Consent, Parental Permission, and Assent in Pediatric Practice*, 95 PEDIATRICS 314, 317 (1995), *available at* http://aappolicy.aappublications.org/cgi/reprint/pediatrics;95/2/314.pdf; Seema Shah et al., *How Do Institutional Review Boards Apply the Federal Risk and Benefit Standards for Pediatric Research?*, 291 JAMA 476 (2004).

[184] SHAFFER, *supra* note 180, at 12.

That's next, isn't it?"[185] Dysart discusses Alan's request with Hesther, "He actually thinks they exist. . . . He wants a way to speak. . . . Tape's too isolated, and hypnosis is a trick. . . . Now I am almost tempted to play a real trick on him . . . . The old placebo. . . . he trusts me."[186] In order to reassure Dysart, Hesther observes, "The boy's in pain. . . . [a]nd you can take it away. . . . Then that has to be enough for you, surely?"[187] Dysart cries out:

> *All right! I'll take it away!* He'll be delivered from madness. *What then?* . . . Do you think feelings like his can be simply re-attached . . . ? My desire might be to make this boy an ardent husband—a caring citizen—a worshipper of abstract and unifying God. My achievement, however, is more likely to make a ghost![188]

As with *Equus*, Bernard Pomerance's *The Elephant Man*[189] explores the tension between a patient and his doctor striving for a trusting relationship[190] to create some semblance of normalcy against all odds.[191] Based loosely on the late nineteenth century life of John Merrick and his physician, Treves, *The Elephant Man* illustrates how a man with extraordinary physical deformities from mosaic proteus[192]—which profoundly impairs expressive communication and movement—is helped to thrive and survive longer than expected. Treves proclaims:

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[185] *Id.* at 78.

[186] *Id.* at 78-79. *See also* HOWARD M. SPIRO, DOCTORS, PATIENTS, AND PLACEBOS 119-20, 123-24 (1986); Richard C. Cabot, *The Use of Truth and Falsehood in Medicine: An Experimental Study*, 5 AM. MED. 344 (1903); Nancy E. Kass et al., *Trust: The Fragile Foundation of Contemporary Biomedical Research*, HASTINGS CENTER REP., Sept.-Oct. 1996, at 25, 25-27.

[187] SHAFFER, *supra* note 180, at 108.

[188] *Id.* (emphasis original) It is noteworthy how many of the plays express the image of a ghost.

[189] BERNARD POMERANCE, THE ELEPHANT MAN (Grove Press 1979).

[190] *See* Kass et al., *supra* note 186 (discussing the "fragile foundation" of trust between doctors and their patients).

[191] *See* POMERANCE, *supra* note 189.

[192] *See* Leslie G. Biesecker, *The Multifaceted Challenges of Proteus Syndrome*, 285 JAMA 2240 (2001); M.J. Lindhurst et al., *A Mosaic Activating Mutation in AKT1 Associated with the Proteus Syndrome*, 365 NEW ENG. J. MED. 611, 612 (2011).

> My aim's to lead him to as normal a life as possible. His terror of us all comes from having been held at arm's length from society. I am determined that shall end. . . .For example, he had never seen the inside of any normal home before. I had him to mine, and what a reward. . . . his astonishment, his joy at the most ordinary things.[193]

While the opportunity to study such a rare disorder provides mutual benefits that capitalize on Merrick's fortitude, the medical community's thirst to increase their knowledge of disease processes fuels their fortitude to strive for the betterment of the patient. This ethical paradox ultimately becomes glaring to the treating physician.[194] Like Shaffer's psychiatrist in *Equus*, and as woven through many plays exploring novel methods to improve outcomes in medicine, Treves also questions the presumption that the end is worthy of the means:

> As he's achieved greater and greater normality, his condition's edged him closer to the grave. So—a parable of growing up? To become more normal is to die? . . . He—it is just a mockery of everything we live by. . . . I conclude that we have polished him like a mirror, and shout hallelujah when he reflects us to the inch. I have grown sorry for it. I am in despair in fact. Science, observation, practice, deduction . . . can no longer serve as consolation.[195]

These internal struggles are not unusual for health care professionals treating individuals with chronic conditions, and the recent discipline of narrative medicine has evolved as a creative approach for helping to reflect on these emotions.[196]

Whereas Merrick's rare genetic disorder destined him to a life with abbreviated longevity and severe speech impediment since birth, Arthur Kopit's 1978 play, *Wings*,[197] illustrates the abrupt disruption of cohesive language that can result from a stroke,

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[193] POMERANCE, *supra* note 189, at 28.

[194] *See* ALBERT JONSEN ET AL., CLINICAL ETHICS: A PRACTICAL APPROACH TO ETHICAL DECISIONS IN CLINICAL MEDICINE (7th ed. 2010).

[195] POMERANCE, *supra* note 189, at 64-65.

[196] *See generally* RITA CHARON, NARRATIVE MEDICINE: HONORING THE STORIES OF ILLNESS (2006).

[197] ARTHUR L. KOPIT, WINGS (1978) (Hill & Wang 3d prtg. 1981).

radically changing the course of presumed destiny in a flash. Kopit's main character, Emily Stilson, represents a composite of two actual women who sustained vascular insults and are being treated at a cutting-edge medical facility highly regarded for its stroke research.[198] The playwright presents a striking image where forces combine to slowly modify the destiny of Emily's aphasia through good luck and "trial and error," even though many questions remain about the efficacy of these alternative approaches.[199] In one of the scenes illustrating complementary modalities is a "deep male voice, speaking slowly enunciating carefully, that one hears on the speech-therapy machine known as 'the language master.'"[200] This dramatization, with images of alternative and complementary treatments, echoes contemporary ethical and medical debates over how to integrate and validate new approaches to better address complex medical challenges.[201]

In addition to the value of Emily's fortitude, as fate would have it, she is left-handed, which allows for some functional retention of thought with left-hemisphere damage.[202] And, she has a speech therapist, Amy, who had recovered from aphasia herself and creates many innovative language therapies for Emily.[203] In spite of all these efforts, Emily is still challenged with deficits in expressive language functioning and inquires: "Where do you get names from? . . . Do you know how you do it? . . . how am I supposed . . . to learn?"[204] Amy

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[198] *Id.* at xvi.

[199] *See* E. Ernst, *Prevalence of Use of Complementary/Alternative Medicine: A Systematic Review*, 78 BULL. WORLD HEALTH ORGANIZATION 252 (2000).

[200] KOPIT, *supra* note 197, at 56 (emphasis in original).

[201] *See* Eugenia Chan, *Quality of Efficacy Research in Complementary and Alternative Medicine*, 299 JAMA 2685, 2686 (2008); Ernst, *supra* note 199; Ginger Polich et al., *The Need to Act a Little More 'Scientific': Biomedical Researchers Investigating Complementary and Alternative Medicine*, 32 SOC. HEALTH & ILLNESS 106 (2010).

[202] KOPIT, *supra* note 197, at xvi.

[203] *Id.* at 67.

[204] *Id.* at 70.

gently responds, "I don't really know," humbly acknowledging the limitations of communicative science.[205]

The implications of health professionals pushing for therapeutic advances to modify the destiny of an individual with a communicative disorder are also highlighted in Mark Medoff's *Children of a Lesser God*.[206] Sarah's fate was altered by a sensory neural defect likely caused by prenatal rubella or a familial recessive trait, described by her speech pathologist husband, James, as "not correctable by surgery."[207] Sarah expresses great frustration with what she perceives to be the medical community's attempt to impose their values on her, interfering with her right to decide how best to live her life in a predominantly hearing world whether with sign language, lip reading, or oral communication.[208]

Although this 1979 play was penned well before cochlear implants, the ethical implications raised by attempts to shape a "normal" life with medical advances continue to be debated.[209] Another related contemporary controversy is the ethical dilemma of deaf parents who choose to use genetic technology to create a deaf child, rather than a hearing child.[210] Who decides if new innovations

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[205] *Id.*

[206] *See* MEDOFF, *supra* note 17.

[207] *See Id.* at 39.

[208] *See* Kathleen S. Arnos et al., *Genetic Counseling of the Deaf. Medical and Cultural Considerations*, 630 ANNALS N.Y. ACAD. SCI. 212 (1991); Patrick Boudreault et al., *Deaf Adults' Reasons for Genetic Testing Depend on Cultural Affiliation: Results from a Prospective, Longitudinal Genetic Counseling and Testing Study*, 15 J. DEAF STUD. & DEAF EDUC. 209 (2010); NATIONAL ASS'N FOR THE DEAF, NAD POSITION PAPER ON ASL AND BILINGUAL EDUCATION (1993); NATIONAL ASS'N FOR THE DEAF, POSITION STATEMENT ON AMERICAN SIGN LANGUAGE (2008), http://www.nad.org/issues/american-sign-language/position-statement-american-sign-language-2008.

[209] *See* Robert A. Crouch, *Letting the Deaf Be Deaf: Reconsidering the Use of Cochlear Implants in Prelingually Deaf Children*, HASTINGS CENTER REP., July-Aug. 1997, at 14, 14-15; Harlan Lane & Michael Grodin, *Ethical Issues in Cochlear Implant Surgery: An Exploration into Disease, Disability, and the Best Interests of the Child*, 7 KENNEDY INST. ETHICS J. 231, 237-38 (1997); Neil Levy, *Reconsidering Cochlear Implants: The Lessons of Martha's Vineyard*, 16 BIOETHICS 134, 134-35 (2002).

[210] *See* C. Mand et al., *Genetic Selection for Deafness: The Views of Hearing Children of Deaf Adults*, 35 J. MED. ETHICS 722, 723 (2009); Trevor Johnston, *In One's Own Image: Ethics and the*

are beneficial and to whom? How do these judgments reflect societal norms?

Sarah first reflects:

> For all my life I have been the creation of other people. The first thing I was ever able to understand was that everyone was supposed to hear but I couldn't and that was bad. . . . Well, my brain understands a lot, and my eyes are my ears; and my hands are my voice; and my language, my speech, my ability to communicate is as great as yours. Greater, maybe, because I can communicate to you in one image an idea more complex than you can speak to each other in fifty words.[211]

Later in frustration, James lashes out at her:

> You want to be independent of me, you want to be a person in your own right, you want people not to pity you, but you want them to understand you in the very poetic way you describe in your speech as well as the plain old, boring way *normal* people understand each other, then you learn to read my lips and . . . I want you to speak to me. Let me hear . . . .[212]

James' strivings to make her more "normal" in a hearing world by forcing her to lip read is in direct opposition to Sarah's choice to solely use sign language as her means of communicating with others. This push-pull to control the magic of sound creates great difficulty within their relationship as Sarah and James strongly disagree on how she should connect with both the hearing-impaired and non-deaf community and who holds the key to her destiny?

Who controls the fate of how one's inner thoughts may be communicated to others is also dramatized by John Pielmeier's *Agnes of God*.[213] In this 1982 play, the wonders and enigma of science and fate are brought to life through hypnotism.[214] Experimenting with

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Reproduction of Deafness, 10 J. DEAF STUD. & DEAF EDUC. 426, 430-31 (2005).

[211] MEDOFF, *supra* note 17, at 65.

[212] *Id.* at 67 (emphasis in original).

[213] PIELMEIER, *supra* note 18.

[214] *See* C.L. Copeland & E. Howard Kitching, *Hypnosis in Mental Hospital Practice*, 83 BRIT. J. PSYCHIATRY 316 (1937); Giuliana Mazzoni et al., *Suggested Visual Hallucinations in and out of Hypnosis*, 18 CONSCIOUSNESS & COGNITION 494 (2009); Richard S. Sandor, *Hypnosis as an "Entree" for Consultation-Liaison Psychiatry*, 2 GEN. HOSP. PSYCHIATRY 65 (1980).

this technique as part of a court-ordered psychiatric evaluation,[215] Dr. Livingstone takes control to clarify Agnes's role in the death of a newborn. The battle over the revelation of Agnes's torturous hidden past is played out by the religious Mother and the psychiatrist, and ultimately Agnes's unconscious silence is unlocked through hypnosis.[216] The Mother remains concerned that all the doctor is "looking for" is "Plausibility!"[217] She is distrustful because it is her belief "that it is also the nature of science to wonder, and we can only wonder if we are willing to question *without* finding all the answers."[218] When the doctor declares: "we *can* find them," the Mother remains adamant: "You can *look* for them. There's a difference. You'll never find the answer to everything, Doctor. . . . The wonder of science is not in the answers it provides but in the questions it uncovers."[219] To which Dr. Livingstone firmly replies: "But she's not an enigma. Everything that Agnes has done is explainable by modern psychiatry."[220]

Agnes of God, like *Equus*, dramatizes the ethical and legal implications of a doctor having the power to use techniques that can change a patient's destiny, particularly when the legal system has ordered psychiatric intervention and it is unclear whether the benefits outweigh the risks and for whom.[221] Recent innovations in high-resolution functional neural imaging, used to unveil unconscious or purposefully deceptive thoughts, raise similar issues for society—especially since some critics question their scientific validity.[222]

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[215] *See* APPELBAUM ET AL., *supra* note 124.

[216] *See* PIELMEIER, *supra* note 18.

[217] *Id.* at 61.

[218] *Id.*

[219] *Id.* at 61-62.

[220] *Id.* at 62.

[221] *See* PAUL S. APPELBAUM & THOMAS G. GUTHEIL, CLINICAL HANDBOOK OF PSYCHIATRY & THE LAW (4th ed. 2007); H.W. LeBourgeois, III, et al., *Hindsight Bias Among Psychiatrists*, 35 J. AM. ACAD. PSYCHIATRY & LAW 67 (2007).

[222] *See* THE OXFORD HANDBOOK OF NEUROETHICS (Judy Illes & B.J. Sahakian eds., 2011); George Annas, *Foreword: Imagining a New Era of Neuroimaging, Neuroethics, and Neurolaw*, 33 AM. J.L.

Contrary to the earlier plays that highlight the frustrations with trying to cure neuropsychiatric disorders and the motivations to create and experiment with pharmacological agents, Harold Pinter's 1982 play, *A Kind of Alaska*,[223] illuminates the power of the fate-changing invention of L-Dopa,[224] a miracle drug that enabled institutionalized patients with encephalitis lethargic to instantly wake up after decades of "sleeping sickness" brought on by the 1917 flu epidemic.[225] Inspired by Oliver Sacks' book, *Awakenings*,[226] and part of Pinter's aptly named theatrical collection *Other Places*, the playwright portrays the wonder of science through the dialogue of Deborah and her neurologist Dr. Hornby, who so radically changes her destiny after three decades of a coma-like state.[227] The play also illuminates the very real ethical and medical challenges posed by neurological uncertainty in the context of disorders of consciousness,[228] while several high profile cases have played out in the courts and media.[229] Scientists are now exploring how emerging

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& MED. 163, 167-68 (2007).

[223] HAROLD PINTER, A KIND OF ALASKA (1982), *reprinted in* OTHER PLACES : FOUR PLAYS 11 (Dramatists 1984).

[224] *See* Arvid Carlsson et al., *3,4-Dihydroxyphenylalanine and 5-Hydroxytryptophan as Reserpine Antagonists*, 180 NATURE 1200 (1957)

[225] *See* G.C. Cotzias, *L-Dopa for Parkinsonism*, 278 NEW ENG. J. MED. 630 (1968); R.T. Ravenholt & William H. Foege, *1918 Influenza, Encephalitis Lethargica, Parkinsonism*, 320 LANCET 860 (1982); Ann H. Reid et al., *Experimenting on the Past: The Enigma of Von Economo's Encephalitis Lethargica*, 60 J. NEUROPATHOLOGY & EXPERIMENTAL NEUROLOGY 663 (2001).

[226] OLIVER SACKS, AWAKENINGS (rev. ed. 1990).

[227] *See* PINTER, *supra* note 223.

[228] *See* JEROME B. POSNER ET AL., PLUM AND POSNER'S DIAGNOSIS OF STUPOR AND COMA (4th ed. 2007); Joseph J. Fins et al., *Late Recovery from the Minimally Conscious State: Ethical and Policy Implications*, 68 NEUROLOGY 304 (2007); Nicholas D. Schiff & Joseph J. Fins, *Disorders of Consciousness*, 82 MAYO CLINIC PROCEEDINGS 250 (2007).

[229] *See* GREGORY E. PENCE, CLASSIC CASES IN MEDICAL ETHICS: ACCOUNTS OF CASES THAT HAVE SHAPED MEDICAL ETHICS, WITH PHILOSOPHICAL, LEGAL, AND HISTORICAL BACKGROUNDS 29-55 (3d ed. 2000); SANDRA H. JOHNSON ET AL., Quinlan *and* Cruzan*: Beyond the Symbols*, *in* HEALTH LAW AND BIOETHICS: CASES IN CONTEXT 53-73 (2009); Eric J. Cassell, *The Schiavo Case: A Medical Perspective*, HASTINGS CENTER REP., May-June 2005, at 22; Rebecca Dresser, *Schiavo's Legacy: The Need for an Objective Standard*, HASTINGS CENTER REP., May-June 2005, at 20; Jay Wolfson, *Erring on the Side of Theresa Schiavo: Reflections of the Special Guardian Ad Litem*, HASTINGS CENTER REP., May-June 2005, at 16.

high resolution neuroimaging technologies can more accurately diagnose levels of awareness, to potentially provide a path to rehabilitation for some who are not in a persistent vegetative state.[230]

When Deborah asks Dr. Hornby, "How did you wake me up? Or did you not wake me up? Did I just wake up myself? All by myself? Or did you wake me with a magic wand?" Dr. Hornby explains, "I woke you with an injection," [231] and goes on to clarify:

> I have been your doctor for many years. This is your sister. Your father is blind. . . . Your mother is dead. . . . I lifted you onto this bed, like a corpse. Some wanted to bury you. I forbade it. I have nourished you, watched over you, for all this time. I injected you and woke you up. You will ask why I did not inject you twenty-nine years ago. I'll tell you. I did not possess the appropriate fluid. . . . You see, you have been nowhere, absent, indifferent. It is we who have suffered.[232]

This positive image of Deborah suddenly rising from an unanimated state because of a scientific innovation is juxtaposed with the negative image of the creation of Frankenstein. In fact, during the same time period of Pinter's *Kind of Alaska*,[233] Victor Gialanella authored yet another adaptation of Shelley's *Frankenstein*.[234] This rendition is considered by many scholars to be the most authentic to Shelley's novel since *Presumption; or, The Fate of Frankenstein*,[235] written 160 years earlier. In Gialanella's play, Dr. Victor Frankenstein, his assistant Henry, and the Creature question how the destructive power of technological feats can radically alter the destiny of many. The timing of this play coincided with ethical controversy over gene therapy and concern about modifying the

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[230] *See* Jonathan C. Bardin et al., *Dissociations between Behavioural and Functional Magnetic Resonance Imaging-Based Evaluations of Cognitive Function after Brain Injury*, 134 BRAIN: J. NEUROLOGY 769 (2011); Joseph J. Fins & Nicholas D. Schiff, *The Afterlife of Terri Schiavo*, HASTINGS CENTER REP., July-Aug. 2005, at 8; Nicholas D. Schiff et al., *Deep Brain Stimulation, Neuroethics, and the Minimally Conscious State: Moving Beyond Proof of Principle*, 66 ARCHIVES NEUROLOGY 697 (2009).

[231] PINTER, *supra* note 223, at 15.

[232] *Id.* at 34.

[233] PINTER, *supra* note 223.

[234] VICTOR GIALANELLA, FRANKENSTEIN (Dramatists 1982); SHELLEY, *supra* note 30.

[235] *See* PEAKE, *supra* note 4 and accompanying text.

germ line,[236] as well as the awe and fears of experimenting with artificial hearts in humans.[237]

In a scene vividly capturing the blind ambition of Frankenstein for scientific advancement at all costs, he exclaims:

> Henry, I have reason to believe that I am capable of re-animating life. . . . The creation of life . . . in a man. *(Thunder)*. . . . I have in my laboratory the intelligent brain of one man and the healthy heart of another, kept alive by means of induction through chemicals for well beyond a week. . . . I have only been awaiting a proper vessel in which they are to be implanted. . . . The only struggle that remains is the completion of the surgery before the storm has reached its peak, and in this you can help me. . . . To have control of life and death. Perhaps to remove disease forever from the human frame. To insure eternally the existence of the greatest minds.[238]

After Henry expresses his disbelief that "there is no basis for this procedure anywhere in modern science," Victor proclaims "that, to me, is the great challenge of the sciences; to go beyond what anyone has done before"[239] and with excitement adds: "Can you feel it, Henry? The excitement, the power? . . . The culmination of my work. We stand at the threshold of a new age of man. The dawn of a new

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[236] *See* LEROY WALTERS & JULIE GAGE PALMER, THE ETHICS OF HUMAN GENE THERAPY 76-77 (1997); John C. Fletcher, *Evolution of Ethical Debate About Human Gene Therapy*, 1 HUMAN GENE THERAPY 55, 61-65 (1990); John C. Fletcher & W. French Anderson, *Germ-Line Gene Therapy: A New Stage of Debate*, 20 LAW, MED. & HEALTH CARE 26, 27 (1992); Erik Parens, *Should We Hold the (Germ) Line?*, 23 J.L. MED. & ETHICS 173, 173 (1995); LeRoy Walters, *Human Gene Therapy: Ethics and Public Policy*, 2 HUMAN GENE THERAPY 115, 116 (1991); LeRoy Walters, *Genetics and Bioethics: How Our Thinking Has Changed Since 1969*, 33 THEORETICAL MED. & BIOETHICS 83, 86-7 (2012); Nelson A. Wivel & LeRoy Walters, *Germ-Line Gene Modification and Disease Prevention: Some Medical and Ethical Perspectives*, 262 SCIENCE 533, 535-36 (1993).

[237] *See* George J. Annas, *Consent to the Artificial Heart: The Lion and the Crocodiles*, HASTINGS CTR. REP., Apr. 1983, at 20, 20; William C. DeVries et al., *Clinical Use of the Total Artificial Heart*, 310 NEW ENG. J. MED. 273, 273 (1984); Thomas A. Preston, *Who Benefits from the Artificial Heart?*, HASTINGS CENTER REP., Jan.-Feb. 1985 at 5; James Rachels, *Barney Clark's Key*, HASTINGS CENTER REP., Apr. 1983 at 17, 17; Michael J. Strauss, *The Political History of the Artificial Heart*, 310 NEW ENG. J. MED. 332, 334 (1984).

[238] GIALANELLA, *supra* note 234, at 19-20.

[239] *Id.* at 21-22.

species who will bless us as their creators. (*He moves to the control panel.*)"[240]

Later in the play, Victor reflects on the consequences of his actions to the Creature: "Do you think that I am free of guilt? Of pain? Of Responsibility?" To which the Creature responds: "No. For it was you who gave me life. . . . I have destroyed you and everything you ever loved. I shall die as you are dead." The Creature then adds, "But we will at last be bound together, forever all alone. (*He rises and crosses to the bank of switches.*) And thus the instruments of life become the instruments of death."[241]

ACT IV: AIDS & EVERS

Whereas *Frankenstein* exemplifies scientific innovation that surges out of control, the mid-1980s found both the medical community and the public confronted with a new and poorly understood infectious disease that was raging out of control—Acquired Immune Deficiency Syndrome (AIDS).[242] Several playwrights seized upon the opportunity to portray the evolution of this mysterious killer that would first grip the gay community and highlight the desperate search to gain control through innovations in medicine.

Larry Kramer's Pulitzer prize-winning *The Normal Heart*,[243] provides a memorable platform for the theatre. Kramer's play captures the frustration of medical uncertainty and ethical dilemmas[244] through the character of Dr. Emma Brookner:

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[240] *Id.* at 23.

[241] *Id*. at 60.

[242] *See* Carol Levine & Joyce Bermel, *AIDS: The Emerging Ethical Dilemmas, in* HASTINGS CENTER REPORT (Supp. 1985); *see also* Ronald Bayer & Amy L. Fairchild, *The Genesis of Public Health Ethics*, 18 BIOETHICS 476, 478 (2004).

[243] KRAMER, *supra* note 19.

[244] *See* Renée C. Fox, *The Evolution of Medical Uncertainty*, 58 MILBANK MEMORIAL FUND Q. HEALTH & SOC'Y 1, 13 (1980); Robert Steinbrook et al., *Ethical Dilemmas in Caring for Patients with the Acquired Immunodeficiency Syndrome*, 103 ANNALS INTERNAL MED. 787, 787 (1985).

> And even if they found out tomorrow what's happening, it takes years to find out how to cure and prevent anything. All I know is this disease is the most insidious killer I've ever seen or studied or heard about. And I think we're seeing only the tip of the iceberg.[245]

Emma further clarifies:

> Long before we isolated the hepatitis viruses we knew about the diseases they caused and had a good idea of how they got around. . . . I am seeing more cases each week than the week before. I figure that by the end of the year the number will be doubling every six months.[246]

She desperately experiments with interventions in an attempt to control the ravaging disease of so many of her patients, including gay rights activist Ned Weeks and his lover Felix Turner.[247]

Kramer's powerful dialogue further explores how attitudes on the morality of homosexuality can blind society to the urgency of addressing a stigmatizing, major public health threat—much like the dynamic witnessed in *Spirochete*.[248] *The Normal Heart* captures how complex relationships among the gay community, medical profession and government officials all played roles—both positive and negative—in the search for innovative strategies to understand the cause, prevention and treatment of AIDS.[249] When Ned expresses his fear that "we're just walking time bombs—waiting for whatever it is that sets us off," Emma recognizes that "before a vaccine can be discovered almost every gay man will have been exposed."[250] To which Ned retorts, "Where's the goddamned AMA in all of this? The

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[245] KRAMER, *supra* note 19, at 22.

[246] *Id*. at 27.

[247] *See id*.

[248] *See* Sundgaard, *supra* notes 13, 104-09 and accompanying text; RONALD BAYER, PRIVATE ACTS, SOCIAL CONSEQUENCES: AIDS AND THE POLITICS OF PUBLIC HEALTH (1989); ERVING GOFFMAN, STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY (1963).

[249] *See* Lawrence O. Gostin, *HIV Screening in Health Care Settings: Public Health and Civil Liberties in Conflict?*, 296 JAMA 2023 (2006); Larry Gostin, *Vaccination for AIDS: Legal and Ethical Challenges from the Test Tube, to the Human Subject, Through to the Marketplace*, 2 AIDS PUB. POL'Y J. 9 (1987); Hoffman, *supra* note 112.

[250] KRAMER, *supra* note 19, at 70.

government has not started one single test tube of research. Where's the board of directors of your very own hospital?"[251]

When Emma later suggests to Ned an experimental "treatment of several chemotherapies used together,"[252] she acknowledges:

> [Y]ou won't get particularly good care anywhere, maybe not even here. At . . . I'll call it Hospital A, you'll come under a group of mad scientists, research fanatics, who will try almost anything and if you die you die. . . . you'll just be a statistic for their computer—which they won't share with anyone else, by the way; there's not much sharing going on, never is—you'll be a true guinea pig. At Hospital B, they decided they really didn't want to get involved with this, it's too messy . . . C is like the *New York Times* and our friends everywhere: square, righteous, superior, and embarrassed by this disease and this entire epidemic . . . Why am I telling you this? I must be insane. But the situation is insane.[253]

As it became clear that AIDS was spreading out of control with no hope in sight, the scientists, physicians, community activists, politicians and society at large were struggling to find their moral compass to guide them on how best to control the fate of this disease.

By the beginning of the 1990s the fears, frustrations and stigma of the diagnosis of AIDS were further explored by Tony Kushner in his two plays, *Millennium Approaches* [254] and *Perestroika*,[255] eventually combined as *Angels in America*.[256] The ethical implications of human experimentation and allocation of scarce resources for innovative drugs and new treatment modalities[257] are illuminated in *Millennium*

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[251] *Id*. at 72.

[252] *Id*. at 85.

[253] *Id*. at 85-86.

[254] TONY KUSHNER, *Angels in America, Part One: Millennium Approaches*, *in* ANGELS IN AMERICA: A GAY FANTASIA ON NATIONAL THEMES 1 (Theatre Commc'ns Grp. 2003) (1992).

[255] TONY KUSHNER, *Angels in America, Part Two: Perestroika*, *in* ANGELS IN AMERICA: A GAY FANTASIA ON NATIONAL THEMES 127 (Theatre Commc'ns Grp. 2003) (1992).

[256] KUSHNER, *supra* note 20.

[257] *See* Ruth R. Faden & Nancy E. Kass, *Bioethics and* Public Health *in the 1980s: Resource Allocation and AIDS*, 12 ANN. REV. PUB. HEALTH 335 (1991); Lawrence Gostin & Jonathan M. Mann, *Towards the Development of a Human Rights Impact Assessment for the Formulation and Evaluation of Public Health Policies*, 1 HEALTH & HUM. RTS. 58 (1994); Lawrence O. Gostin & Susan C. Kim, *Ethical Allocation of Preexposure HIV Prophylaxis*, 305 JAMA 191 (2011).

through dialogue between the conservative powerbroker Roy Cohn and his physician Henry. When Henry tells Roy "You have AIDS," Roy rejects that diagnosis and declares "AIDS is what homosexuals have. I have liver cancer."[258] Henry disagrees:

> Well, whatever the fuck you have, Roy, it's very serious, and I haven't got a damn thing for you. The NIH in Bethesda has a new drug called AZT with a two-year waiting list that not even I can get you onto. So get on the phone . . . and tell the First Lady you need in on an experimental treatment for liver cancer, because you can call it any damn thing you want, Roy, but what it boils down to is very bad news.[259]

In *Perestroika*, the ethical implications of experimental interventions, including fair access to clinical trials and randomization,[260] are further examined in dialogue between Roy Cohn and the nurse Belize. "They have you down for radiation tomorrow for the sarcoma lesions, and you don't want to let them do that, because radiation will kill the T-cells and you don't have any you can afford to lose," says Belize. He urges: "So tell the doctor no thanks for the radiation. He won't want to listen. Persuade him. Or he'll kill you."[261]

Although Roy manages to "get in on the azidothymidine [AZT] trials" Belize cautions, "Watch out for the double blind. They'll want you to sign something that says they can give you M&M's instead of the real drug. You'll die, but they'll get the kind of statistics they can publish in the New England Journal of Medicine." Reminding Roy of the reality of gaining access to experimental treatment, Belize adds: "And if you don't sign, no pills. So if you have any strings left, pull them, because everyone's put through the double blind and with this, time's against you, you can't fuck around with placebos."[262] Belize

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[258] KUSHNER, MILLENNIUM APPROACHES, *supra* note 254, at 52.

[259] *Id*.

[260] *See* Robert J. Levine, *The Impact of HIV Infection on Society's Perception of Clinical Trials*, 4 KENNEDY INST. ETHICS J. 93 (1994); Peter A. Ubel & Robert Silbergleit, *Behavioral Equipoise: A Way to Resolve Ethical Stalemate in Clinical Research*, 11 AM. J. BIOETHICS 1 (2011).

[261] KUSHNER, PERESTROIKA, *supra* note 255, at 159–60.

[262] *Id*. at 160.

brings to life the controversy concerning the ethics of randomized clinical trials when there are no other potential avenues for medical or pharmacological intervention.[263]

The financial and institutional implications of bringing forth AIDS research into clinical care are tackled in Larry Kramer's *The Destiny of Me*.[264] This 1992 play, a sequel to *The Normal Heart*,[265] explores the power and limitations of an NIH physician–scientist, Tony Della Vida, attempting to control the fate of AIDS when confronted with both scientific and political challenges.[266] Reading from various journal clippings, Ned Weeks mocks the research establishment:

> '[R]econstituted genes will be introduced in transfusions of the patient's own blood . . . cells given new genetic instructions, to self-destruct if they are infected.' *The Lancet*. . . . 'Conclusion: The success of this theory in *in vitro* experiments, followed by the successful inoculation of three West African sooty mangabey monkeys, leads one to hope that human experimentation can commence without further delay.' The *New England Journal of Monkeys*. I'll be your monkey.[267]

In fact, Ned is desperate to try anything to save his life,[268] a challenge posed by the informed consent process for research when therapeutic misconception clouds one's objectivity.[269] Tony wheels in his "Ex-Cell-Aerator," explaining: "Your reassembled blood will be pumped through it so it can be exposed to particles of—"[270]

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[263] *See* Samuel Hellman & Deborah Hellman, *Of Mice But Not Men: Problems of the Randomized Clinical Trial*, 324 N. ENG. J. MED. 1585 (2001).

[264] LARRY KRAMER, *The Destiny of Me* (1992), *in* THE NORMAL HEART AND THE DESTINY OF ME : TWO PLAYS BY LARRY KRAMER 1 (Grove Press 2000).

[265] KRAMER, THE NORMAL HEART, *supra* note 19.

[266] *See* Harold Edgar & David J. Rothman, *New Rules for New Drugs: The Challenge of AIDS to the Regulatory Process*, 68 MILBANK Q. 111 (Supp. 1990).

[267] KRAMER, *supra* note 264, at 141.

[268] *See* Paul S. Appelbaum et al., *Voluntariness of Consent to Research: A Conceptual Model*, 39 HASTINGS CENTER REP. 30 (2009).

[269] *See* Paul S. Appelbaum et al., *The Therapeutic Misconception: Informed Consent in Psychiatric Research*, 5 INT'L J.L. & PSYCHIATRY 319 (1982)

[270] KRAMER, *supra* note 264, at 228.

Astonished, Ned asks: "Did you dream all this up?" and Tony quickly responds: "I try to be as creative as the law allows."[271] When Ned queries, "Do genes get loose and act uncontrollably, like viruses," Tony confirms: "You bet. It's scary trying to modify nature."[272] The play dramatizes the vacillation between optimism and skepticism in finding the cure that could change Ned's destiny, as well the professional destiny of Tony when forced to consider a multitude of bioethical and political challenges—highlighting the limits of what a scientist can attempt in good faith when trying to discover an effective intervention.[273]

That same year gave rise to another powerful theatrical production that glaringly illuminated the ethical ramifications of withholding advances in medication to vulnerable populations during research protocols.[274] While the AIDS plays reflected the changing landscape where research was sought after as a benefit to attain innovative medicine,[275] David Feldshuh's *Miss Evers' Boys*[276] shines a brutal light on the Tuskegee Study[277] where risks were

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[271] *Id*. at 229.

[272] *Id*.

[273] *See* Renée C. Fox, *Advanced Medical Technology -- Social and Ethical Implications*, 2 ANN. REV. SOC. 231 (1976).

[274] *See* Allan M. Brandt, *Racism and Research: The Case of the Tuskegee Syphilis Study*, 8 HASTINGS CENTER REP. 21 (Dec. 1978); Troy Duster, *Lessons from History: Why Race and Ethnicity Have Played a Major Role in Biomedical Research*, 34 J.L. MED. & ETHICS 487, 491 (2006); *See generally* Dorothy E. Roberts, *Legal Constraints on the Use of Race in Biomedical Research: Toward a Social Justice Framework*, 34 J.L. MED. & ETHICS 526 (2006).

[275] *See* R. Steinbrook et al., *Ethical Dilemmas in Caring for Patients with the Acquired Immunodeficiency Syndrome*, 103 ANNALS INTERNAL MED. 787 (1985); THE MEANING OF AIDS: IMPLICATIONS FOR MEDICAL SCIENCE, CLINICAL PRACTICE AND PUBLIC HEALTH POLICY (Eric Juengst & Barbara Koenig eds., 1989).

[276] FELDSHUH, *supra* note 21.

[277] *See generally* TUSKEGEE'S TRUTHS: RETHINKING THE TUSKEGEE SYPHILIS STUDY (Susan Reverby ed., 2000); FINAL REPORT OF THE TUSKEGEE SYPHILIS STUDY LEGACY COMMITTEE (May 20, 1996), *available at* http://www.hsl.virginia.edu/historical/medical_history/bad_blood/report.cfm.

allowed to fester, and benefits would go to others.[278] Inspired in part by James Jones's true story, *Bad Blood*,[279] the Tuskegee men were inhumanely refused what became standard of care treatment since penicillin was developed soon after they began participating in the syphilis research in 1932 and was withheld for four decades.[280]

Few events in the history of human experimentation have resonated with so much moral disequilibrium as Tuskegee,[281] and are dramatically captured in the dialogue among Douglas, the white field physician from the Public Health Service, Miss Evers, the black public health nurse, and Brodus, the black administrative head of Tuskegee Hospital. "We have a perfect laboratory here: a fixed population, virtually untreated disease," declares Douglas to his colleagues; "A study could be created and carried out with minimal expense. And it would be the most important study of its kind ever conducted."[282]

Evers reacts with concern that "those patients need medicine."[283] But Douglas continues: "We follow these patients for six months. We catalogue what this disease untreated does to them. And then we let the facts speak for themselves,"[284] and "[a]s long as this research continues, any study patient that dies for whatever reason receives fifty dollars, for burial. I could fight and get that much money, Nurse

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[278] *See* Allan M. Brandt, *The Syphilis Epidemic and its Relation to AIDS*, 239 SCIENCE 375, 378 (1988).

[279] JAMES JONES, BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT (1981).

[280] *See generally* A.N. Richards, *Production of Penicillin in the United States (1941-1946)*, 201 NATURE 441 (1964).

[281] *See* U.S. Dep't Health, Ed. & Welfare, FINAL REPORT OF THE TUSKEGEE SYPHILIS STUDY AD HOC ADVISORY PANEL (1973); SUSAN M. REVERBY, EXAMINING TUSKEGEE: THE INFAMOUS SYPHILIS STUDY AND ITS LEGACY (2009); Press Release from Bill Clinton, President of the United States, Remarks by the President in Apology for Study Done in Tuskegee (May 16, 1997), *available at* http://www.cdc.gov/tuskegee/clintonp.htm; *see also* PRESIDENTIAL COMMISSION FOR THE STUDY OF BIOETHICAL ISSUES, "ETHICALLY IMPOSSIBLE:" STD RESEARCH IN GUATEMALA FROM 1946 TO 1948 (2011).

[282] FELDSHUH, *supra* note 21, at 40.

[283] *Id*.

[284] *Id*. at 40.

Evers, if it would convince those men to stay in the study."[285] As some time passes and the deception and experiment continues,[286] Evers speaks up: "I just want to tell the men what's going on. The straight truth. 'There's no mercury in those back rubs. They won't stop bad blood. But you got to stick with it so when new money comes you'll be right up front, first in line . . .' The straight truth."[287] Evers tries to justify her role: "I'm a nurse. I'm not a scientist," but Brodus clearly asserts: "There is no difference. Not here. Not now."[288]

Many decades later, when Feldshuh fictionalizes Evers' testimony before Congress[289] on the continuing unethical practices, Nurse Evers tries to justify why their protocol was not altered despite advances in medical interventions over time:

> When you're up close . . . you don't notice the changes. . . . Unless they catch you by surprise. . . . . I'm not saying there weren't consequences. I'm just saying it wasn't that simple. The disease was not predictable. And there was no money. And the treatment was dangerous.[290]

Evers further reflects: "But 1946 changed all that. Something new arrived, something that changed everything. The 'silver bullet,' they

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[285] *Id*. at 44.

[286] RUTH R. FADEN ET AL., A HISTORY AND THEORY OF INFORMED CONSENT 165-67 (1986).

[287] FELDSHUH, *supra* note 21, at 55.

[288] *Id*.

[289] *See* Rothenberg, *supra* note 2, at 424 n.104; National Research Act of 1974, Pub. L. No. 93-348, 88 Stat. 342. *See also* S. REP. NO. 93-381, pt. 11 (1974) reprinted in 1974 U.S.C.C.A.N 3643, 3655. The nurse on whom Nurse Evers is based, Eunice Rivers, co-wrote an article on her role in the Tuskegee program in 1953. Eunice Rivers et al., *Twenty Years of Followup Experience in a Long-Range Medical Study*, 68 PUB. HEALTH REP. 391 (1953). She never testified before Congress, however. SUSAN M. REVERBY, TUSKEGEE'S TRUTHS: RETHINKING THE TUSKEGEE SYPHILIS STUDY 371 (2000) ("When the story of the experiment broke in the press in 1972, Nurse Rivers retreated into a form of silence. She refused most interviews, did not give testimony before the Senate hearing, and only allowed herself to be interviewed once by the federal investigating team.").

[290] FELDSHUH, *supra* note 21, at 63.

called it: penicillin. . . . And my patients were going to be first in line."[291] However, that never happened.

This historical watershed is further brought to life by Caleb and Ben, two of Miss Evers' "boys," who were unable to attain innovative medicine because of the unethical decisions made by many in the medical and public health community—including Nurse Evers. When Caleb recognizes "how in God's heaven are we going to get well unless we try something new," he shares his observation: "[E]very which way you can see men in this county are lining up getting this medicine and walking out free and easy. . . . [saying] 'I got bad blood. Gonna get me penicillin.'"[292] When Caleb asks, "And what we do?," Ben responds, "Nurse Evers don't want us to get that medicine"; to which Caleb declares: "They all keeping us from that medicine."[293] The dramatic potential of this story of deception and unethical research practices—which led to the promulgation of federal regulations to protect research participants[294]—is reminiscent of many earlier plays, including *Woyzeck* and the legacy of *Frankenstein*. Moreover, as witnessed in *Spirochete*, there became a critical point in time when the discovery of a drug could make all the difference for a blind baby's future;[295] withholding that same innovation destroyed the lives of *Miss Evers' Boys*.

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[291] *Id*. at 64.

[292] *Id*. at 79.

[293] *Id*. at 79-80.

[294] By 1981, the "Common Rule" was adopted. 45 C.F.R. § 46.101(a) (2011). In July 2011, the Federal Register published an Advance Notice of Proposed Rulemaking (ANPRM) regarding amendments to the "Common Rule." *See* HHS, Human Subjects Research Protections: Enhancing Protections for Research Subjects and Reducing Burden, Delay, and Ambiguity for Investigators, 76 Fed. Reg. 44,512, 44,523 (July 26, 2011) (to be codified at 45 C.F.R. pts. 46, 160, 164 and 21 C.F.R. pts. 50, 56). *See* RAND Corp., *Proposed Directions of Change to the Common Rule for Protecting Human Research Participants* (Oct. 25, 2011), *available at* http://www.rand.org/pubs/corporate_pubs/CP659.html; Ezekiel J. Emanuel & Jerry Menikoff, *Reforming the Regulations Governing Research with Human Subjects*, 365 NEW. ENG. J. MED. 1145, 1145 (2011).

[295] *See* Sundgaard, *supra* notes 13, 104-09 and accompanying text.

ACT V: HI TECH, LOW TECH & NO TECH

The discovery of the double helix in the 1950s also set the stage for new scientific discoveries generations later.[296] In 1990, a massive research initiative—the Human Genome Project (HGP)—commenced to map the human genome and generate new information that had the potential to positively contribute to human health.[297] In response to the major societal challenges posed by the HGP, an unprecedented amount of funding was allocated toward research on its ethical, legal, and social implications. [298] How do we allow the promise of science to move forward and at the same time keep in check the perils of what we learned?[299] The HGP raised familiar questions about the social perception of normality and the potential for discrimination on the basis of race, disability, sexuality, class, and gender.[300]

Although the HGP has provided remarkable technological advances that have put quite a distance between genetics and its

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[296] Aaron Klug, *The Discovery of the DNA Double Helix*, 335 J. Mol. Biol. 3, 3 (2004).

[297] *See* Francis Collins & David Galas, *A New Five-Year Plan for the U.S. Human Genome Project*, 262 SCIENCE, 43 (1993). *See generally All About the Human Genome Project (HGP)*, NAT'L HUMAN GENOME RESEARCH INST., http://www.genome.gov/10001772 (last updated Oct. 1, 2012).

[298] *See* Eric T. Juengst, *Self-Critical Federal Science? The Ethics Experiment Within the U.S. Human Genome Project*, SOC. PHILOSOPHY & POL'Y FOUND. 63 (1996); Eric M. Meslin et al., *The Ethical, Legal, and Social Implications Research Program at the National Human Genome Research Institute*, 7 KENNEDY INST. ETHICS J. 291 (1997), *available at* http://muse.jhu.edu/journals/kennedy_institute_of_ethics_journal/v007/7.3meslin.html. *See generally The Ethical, Legal and Social Implications (ELSI) Research Program*, NAT'L HUMAN GENOME RESEARCH INST., http://www.genome.gov/10001618 (last updated July 11, 2012).

[299] *See* Eric T. Juengst, *The Human Genome Project and Bioethics*, 1 KENNEDY INST. ETHICS J. 71 (1991).

[300] *See, e.g.*, TROY DUSTER, BACKDOOR TO EUGENICS (2d ed. 2003); Mark D. Schwartz et al., *Consent to the Use of Stored DNA for Genetics Research: A Survey of attitudes in the Jewish Population*, 98 AMER. J. OF MED. GENETICS 336 (2001); Francis S. Collins et al., *A Vision for the Future of Genomics Research*, 422 NATURE 835, 843-847 (2003); NAT'L HUMAN GENOME RESEARCH INST., A REVIEW AND ANALYSIS OF THE ETHICAL, LEGAL AND SOCIAL IMPLICATIONS (ELSI) RESEARCH PROGRAMS AT THE NATIONAL INSTITUTES OF HEALTH AND THE DEPARTMENT OF ENERGY, *available at* http://www.genome.gov/Pages/Research/DER/ELSI/erpeg_report.pdf. *See generally ELSI Research Priorities and Possible Research Projects*, NAT'L HUMAN GENOME RESEARCH INST., http://www.genome.gov/27543732 (last updated July 18, 2011).

maligned predecessor eugenics,[301] it continues to raise complex ethical issues ripe for dramatization in theatre. Jonathan Tolins' 1992 play *Twilight of the Golds* introduces characters that raise many questions as to who should, or can, control the fate of future generations through the use of emerging prenatal genetic technology.[302] Tensions rise when Suzanne learns that she is pregnant and, along with her geneticist husband Rob, decides to use fictionalized technology to test the fetus for the "gay" gene—preoccupied with the concern that homosexuality will be inherited from her brother David.[303] After learning the test is positive, Suzanne shares her hopes and disappointments: "This baby was going to change our lives and make everything better. Not that things are bad. . . . Now the whole thing is tainted. I wish we didn't know, but we do. And it's a problem."[304]

Such scientific developments raise the familiar question: are some lives not worth living to some individuals? David reacts to his sister Suzanne's decision to seek prenatal genetic testing: "What if you found out the kid was going to be ugly, or smell bad, or have an annoying laugh, or need really thick glasses?"[305] David continues, "But where do we stop? . . . So now we have this technology, what are we going to do with it? It starts with us, Suzanne."[306] Later on, Rob responds, "Don't put the fate of the world on our shoulders. We can't carry the load."[307]

In order to dramatize the promises and perils of genetic technologies on pregnant women, personal relationships, and society

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[301] *See* Rothenberg, *supra* note 2, at 422; *but see* DUSTER, *supra* note 300.

[302] TOLINS, *supra* note 22.

[303] *See* Rothenberg, *supra* note 2, at 426 n.113, 428 n.127 (noting studies challenging reports of a "gay" gene). *See also* Dean H. Hamer et al., *A Linkage Between DNA Markers on the X Chromosome and Male Sexual Orientation*, 261 SCIENCE 321 (1993). *See, e.g.*, Eliot Marshall, *NIH "Gay Gene" Study Questioned*, 268 SCIENCE 1841 (1995).

[304] TOLINS, *supra* note 22, at 78. *See* Karen H. Rothenberg, *The Law's Response to Reproductive Genetic Testing: Questioning Assumptions About Choice, Causation, and Control*, 8 FETAL DIAGNOSIS & THERAPY 160 (1993).

[305] Tolins, *supra* note 22, at 78.

[306] *Id*.

[307] TOLINS, *supra* note 22, at 87.

at large, Tolins juxtaposes Suzanne and David's concerns with Rob's excitement over the potential for science to control fate. While Tolins recognizes the discriminatory potential of genetic testing, he also raises the question of whether scientific explanations will justify the rationale for biological control of homosexuality. In fact, as Rob reflects,

> The power of the creator. . . . [M]y road to a career in genetic research was paved with Lego. I always had a fascination with components; how things are put together, how to take them apart, how to change them. . . . I sit there in the lab . . . and I think, why not with people? There's obviously a lot . . . that needs to be corrected. Or can at least be improved. Just look at the amount of suffering, inward and outward, all around us. Let's use every weapon we have to combat it. Is that such a horrible thing to think?[308]

This question continues to be raised in a number of contexts when exploring the ethical implications of using new innovations in medicine to seek a semblance of normalcy. Yet what is "normal," and who gets to decide? These dilemmas, often raised in dramatic theatre, are again explored in *Molly Sweeney*,[309] the 1994 Irish play by Brian Friel. These concerns are alluded to earlier by the deaf character in *Children of a Lesser God* regarding language technologies,[310] and become heightened when experimental eye surgery is promoted to partially restore the sight of Molly, blind since birth, by her husband Frank and physician Rice. "And if there is a chance, any chance, that she might be able to see, we must take it, mustn't we? How can we not take it? She has nothing to lose, has she? What has she to lose? —nothing! —nothing!," Rice offers enthusiastically.[311]

Rice then considers, "the chance of a lifetime, the one-in-a-thousand opportunity that can rescue a career—no, no, transform a career—dare I say it, restore a reputation?"[312] "So, if her sight were

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[308] *Id*. at 85.

[309] BRIAN FRIEL, MOLLY SWEENEY (1994) (Dramatists Play Service Inc. 1996).

[310] *See* MEDOFF, *supra* note 17, 206-12 and accompanying text.

[311] FRIEL, *supra* note 309, at 13.

[312] *Id.* at 14.

restored," Frank reflects, "everything would have to be learned anew: she would have to *learn* to see. . . . [S]he would have to create a whole new world of her own."[313] "And then with sudden anger," Molly questions:

> [W]hy am I going for this operation? None of this is my choosing. . . . I am being used. Of course I trust Frank. Of course I trust Mr. Rice. But how can they know what they are taking away from me? How do they know what they are offering me? They don't. They can't. And have I anything to gain? – anything?[314]

Ultimately, Frank and the physician Rice question the potential ethical implications of using medical innovations to intervene with fate. While Frank rejoices that " Molly was about to inherit a new world," physician Rice worries that "even though she was in the hands of the best team in the whole world to deliver her miracle . . . I was fearful. I suddenly knew that this courageous woman had everything, everything to lose."[315] This emotional struggle for health professionals concerned with the efficacy of treatment and quality of life[316] is reminiscent of *Equus*,[317] *Elephant Man*,[318] and *Children of a Lesser God*,[319] amongst others.

While the goal of the eye surgeon in *Molly Sweeney* was to use emerging technology to "better" his patient's life, David Rabe's play, *A Question of Mercy*, explores the ethical dilemmas of a physician being persuaded by a patient with AIDS to use technology to hasten death.[320] The dialogue of this 1998 adaptation of Dr. Richard Seltzer's

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[313] *Id*. at 17.

[314] *Id*. at 25.

[315] *Id*. at 27, 32.

[316] *See* D.W. Forrest, *Von Senden, Mesmer, and the Recovery of Sight in the Blind*, 87 AM. J. PSYCHOL. 719, 720 (1974); Daphne Maurer et al., *Effects of Early Visual Deprivation on Perceptual and Cognitive Development*, 164 PROGRESS IN BRAIN RES. 87, 101 (2007); Yuri Ostrovsky et al., *Vision Following Extended Congenital Blindness*, 17 PSYCHOL. SCI. 1009, 1013 (2006).

[317] *See* SHAFFER, *supra* note 180-88 and accompanying text.

[318] *See* POMERANCE, *supra* note 189-96 and accompanying text.

[319] *See* MEDOFF, *supra* note 17, 206-12 and accompanying text.

[320] DAVID RABE, A QUESTION OF MERCY, 10 (Dramatists 1998).

1991 journal[321] illuminates the conscious and unconscious ambivalence of Doctor Chapman—tortured between his desire to create the perfect plan for Anthony's assisted suicide[322] to ameliorate suffering and his longstanding commitment to abide by the Hippocratic Oath "to do no harm."[323]

Dr. Chapman reflects to himself: "My training, my thinking, my philosophy have all been directed toward the preservation of life—that's what I did, what I wanted to do."[324] As Dr. Chapman recognizes:

> Ambivalence is an equal pull in opposing directions . . . his desire is not a stranger to me. I mean, I've thought that I might want to prescribe such pills to myself someday. To relieve pain or to end my own life should the need arise. . . . I've thought of it often, but it's always been slightly distanced. A principled matter. A theoretical option. But then the pain in his voice burst through, and I thought, . . . [i]f I would do it for myself, why not for him?[325]

His concern raises an interesting ethical question about the privilege of a physician having access to take his own life, whereas Anthony is at the "*mercy*" of Dr Chapman.

"He wants me to become his instrument," Dr. Chapman thinks to himself, "[a] means for him . . . to enact his will? . . . Regarding my reservations—that uneasy murmuring just beyond the horizon of my thoughts—ignore that too. Governed only by his aims, I would be like the scalpel."[326] Later on, Anthony reminds him "[b]ut I am the one who is to die."[327] Dr. Chapman calmly explains: "So it's all familiar and gentle. . . . No violence. No death, even, really. Just a

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[321] *See* Richard Selzer, *A Question of Mercy*, N.Y. TIMES MAGAZINE, Sept. 22, 1991, at 32-33.

[322] *See generally* KLEINMAN, *supra* note 55; Daniel Callahan, *Organized Obfuscation: Advocacy for Physician-Assisted Suicide*, HASTINGS CENTER REP., Sept.-Oct. 2008 at 30-32; Sylvia A. Law, *Physician-Assisted Death: An Essay on Constitutional Rights and Remedies*, 55 MD. L. REV. 292 (1996); Quill, *supra* note 55 , at 17; Rawls, *supra* note 55.

[323] HIPPOCRATES, *supra* note 35.

[324] RABE, *supra* note 320 , at 12.

[325] *Id*. at 14. *See also* Randy A. Sansone & Lori A. Sansone, *Physician Suicide: A Fleeting Moment of Despair*, 6 PSYCHIATRY 18 (2009).

[326] RABE, *supra* note 320, at 24.

[327] *Id*. at 40.

pill and then sleep. A trick and then sleep. So it's civilized."[328] But in fact, it wasn't, as Anthony's friend, Thomas, describes:

> I had to call the ambulance, didn't I? What else could I do? . . . He was alive. . . . They said he had to go into intensive care. . . . They pumped out his stomach and washed out his stomach and put him on a respirator. He is being fed intravenously. They said they didn't know if he was going to make it but they were going to try. It was preposterous![329]

Theatre highlights the very real drama faced by many in society when cures, treatments, and palliative care are lacking. As a result, desperate requests for innovative ways to reduce suffering—including the hastening of death through assisted suicide—challenge family, friends, and medical professionals, reminiscent almost a century earlier in *Ghosts*.[330]

In contrast to the self-determined, orchestrated death witnessed in a *Question of Mercy*,[331] Margaret Edson's *Wit*[332] provides vivid imagery of a patient's lack of control when participating in a research study on advanced ovarian cancer.[333] Edson's play received much attention for its themes of empathy and dignity at the end of life by scholars in bioethics and medical humanities.[334] In addition, the

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[328] *Id*. at 54.

[329] *Id*. at 70.

[330] *See* IBSEN, *supra* notes 49-55 and accompanying text. These ethical and legal debates continue to play out in the legislature, the courts, the academic community, the media, and the public at large. *See generally* NEIL M. GORSUCH, THE FUTURE OF ASSISTED SUICIDE AND EUTHANASIA (2010); Yale Kamisar, *Foreword: Can* Glucksburg *Survive* Lawrence*?: Another Look at the End of Life and Autonomy*, 106 MICH. L. REV. 1453, 1453-54 (2008).

[331] *See* RABE, *supra* notes 320-29 and accompanying text.

[332] *See* EDSON, *supra* note 23.

[333] *See* Luca M. Bigatello et al., *Ethical Considerations for Research in Critically Ill Patients*, 31 CRITICAL CARE MED. S178, S179 (2003); Ezekiel J. Emanuel et al., *What Makes Clinical Research Ethical?*, 283 JAMA 2701 (2000); W. Glannon, *Phase I Oncology Trials: Why the Therapeutic Misconception Will Not Go Away*, 32 J. MED. ETHICS 252 (2006).

[334] *See, e.g.*, Linda A. Deloney & C. James Graham, *Wit: Using Drama to Teach First-Year Medical Students About Empathy and Compassion*, 15 TEACHING & LEARNING IN MED. 247 (2003); K.A. Lorenz et al., *End-of-Life Education Using the Dramatic Arts: The Wit Educational Initiative*, 79 ACAD. MED. 481 (2004).

drama presents a rich source for examining the psychological and ethical implications of human experimentation. *Wit* highlights the dangers of overzealousness with a research protocol that ultimately strips away any capacity to control one's destiny, already ravaged by disease. Vivian, a poetry professor, agrees to confront her terminal cancer full-force with Dr. Kelekian, the senior oncologist. Although stoic, she is nevertheless a desperate research participant—akin to Ned in *A Destiny of Me*.[335]

Kelekian explains rather matter of factly: "This treatment is the strongest thing we have to offer you. And, as research, it will make a significant contribution to our knowledge. . . . Here is the informed-consent form. . . . The important thing is for you to take the full dose of chemotherapy."[336] He then adds: "There may be times when you'll wish for a lesser dose, due to the side effects. But we've got to go full-force. The experimental phase has got to have the maximum dose to be of any use."[337] Even though the informed consent process provides her information, and she had comprehension, the reality is that her voluntariness is limited by the parameters of the research protocol that she could not modify.[338]

Later on in isolation, Vivian reflects: "My treatment imperils my health. Herein lies the paradox."[339] Throughout the play, *Wit* dramatizes just how much Vivian gets manipulated as an object for more data and publications:[340]

> I have survived eight treatments of Hexamethophosphacil and Vinplatin at the *full* dose. . . . I have broken the record. . . . Kelekian and Jason are simply delighted. I think they foresee celebrity status for themselves upon the appearance of the journal article. . . . The article will not be about me, it will be about my ovaries. It will be about my

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[335] *See* KRAMER, *supra* notes 264-73 and accompanying text.

[336] EDSON, *supra* note 23, at 12.

[337] *Id.*

[338] *See* FADEN ET AL, *supra* note 82, at 255-57; Appelbaum et al., *supra* note 268.

[339] EDSON, *supra* note 23, at 43.

[340] *See generally* Marcia Angell, *Publish or Perish: A Proposal*, 104 ANNALS INTERNAL MED. 261 (1986).

> peritoneal cavity, which, despite their best intentions, is now crawling with cancer.[341]

Another ethical concern Edson explores in *Wit* is Do Not Resuscitate (DNR) code orders—an issue for many at the end of life.[342] Susie, the nurse, discusses resuscitation options with Vivian and Jason, the oncology fellow, and when they recognize the end is near, Susie reflects with Vivian: "They've learned a lot for their research. . . . There just isn't a good treatment for what you have yet. . . . Well, they like to save lives. So anything's okay, as long as life continues."[343] Although the doctors believe, "[i]t doesn't matter if you're hooked up to a million machines," it does to Susie and Vivian, who both reject any final heroics to save Vivian's life.[344] Jason, like his mentor Kelekian, does not want to give up on their research project: "I wish they could all get through it at full throttle. Then we could really have some data."[345] And when Vivian takes her last breath, the ethical conflict between Susie and Jason escalates, highlighting the struggle between the patient's autonomy at the end of life and the pressures a physician feels in relinquishing control, especially in research. As Jason initiates a full code, Susie screams at him, "She's DNR!" and tries to grab him away. Pushing her, he yells back with authority, "She's Research!" But Susie shouts the last word, "She's NO CODE!" as she throws him off Vivian's bed.[346]

In contrast to the end-of-life conflicts explored in *Wit*, Carl Djerassi's 2000 play *Immaculate Misconception*[347] imagines the tangled

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[341] EDSON, *supra* note 23, at 43 (emphasis in original).

[342] *See* Zoë Fritz & Jonathan Fuld, *Ethical Issues Surrounding Do Not Attempt Resuscitation Orders: Decisions, Discussions and Deleterious Effects*, 36 J. MED. ETHICS 593, 593-95 (2010); Mitchell.T. Rabkin et al., *Orders Not to Resuscitate*, 295 NEW ENG. J. MED. 364, 365 (1976); Jacqueline K. Yuen et al., *Hospital Do-Not-Resuscitate Orders: Why They Have Failed and How to Fix Them*, 26 J. GEN. INTERNAL MED. 791, 791-92, 795 (2011).

[343] EDSON, *supra* note 23, at 53-54.

[344] *Id*., at 54-55,64-66.

[345] *Id*. at 59.

[346] *Id*. at 64.

[347] CARL DJERASSI, AN IMMACULATE MISCONCEPTION: SEX IN AGE OF MECHANICAL

web of intracytoplasmic sperm injection (ICSI)[348] to bring forth new life through modern technologies. Its creator Melanie Laidlaw and her collaborator, Felix Frankenthaler, consider the many ways in which new applications of this technology will be utilized, raising complex ethical challenges for our society over generations. Melanie shares her excitement: "A few more months and I'm ready to try fertilizing a human egg by *direct* injection with a *single* sperm!"[349] Melanie notes that with her ICSI innovation, "women could draw on a bank account of their frozen *young* eggs and have a much better chance of having a normal pregnancy later on in life. I'm not talking about *surrogate* eggs—"[350]

Melanie continues to explain with enthusiasm:

> Each embryo will be screened genetically *before* the best one is transferred back into the woman's uterus. All we'll be doing is improving the odds over Nature's roll of the dice. Before you know it the 21st century will be called 'The Century of Art. . . . The science of . . . A . . . R . . . T (*Beat*): assisted reproductive technologies. Young men and women will open reproductive bank accounts full of frozen sperm and eggs. And when they want a baby, they'll go to the bank to check out what they need.[351]

In recognition of the scope of Melanie's innovation,[352] Felix responds, "The Laidlaw Brave New World."[353] Is this an ethical practice that

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REPRODUCTION (Imperial College Press, 2000).

[348] *See generally* Practice Committee of the American Society for Reproductive Medicine & Practice Committee of the Society for Assisted Reproductive Technology, *Genetic Considerations Related to Intracytoplasmic Sperm Injection (ICSI)*, 86 FERTILITY & STERILITY S103 (2006); Maryse Bonduelle et al., *Seven Years of Intracytoplasmic Sperm Injection and Follow-up of 1987 Subsequent Children*, 14 HUM. REPRODUCTION (SUPPLEMENT) 243, 243-45, 247 (1999); Mark D. Johnson, *Genetic Risks of Intracytoplasmic Sperm Injection in the Treatment of Male Infertility: Recommendations for Genetic Counseling and Screening*, 70 FERTILITY & STERILITY 397, 397, 403-05 (1998); Richard J. Sherins et al., *Intracytoplasmic Sperm Injection Facilitates Fertilization Even in the Most Severe Forms of Male Infertility: Pregnancy Outcome Correlates with Maternal Age and Number of Eggs Available*, 64 FERTILITY & STERILITY 369, 369-73 (1995).

[349] DJERASSI, *supra* note 347, at 16 (underlined rather than italicized in text).

[350] *Id*. at 19 (underlined rather than italicized in text).

[351] *Id*. at 21 (underlined rather than italicized in text).

[352] *See* MARGARET S. MARSH & WANDA RONNER, THE EMPTY CRADLE: INFERTILITY IN AMERICA FROM COLONIAL TIMES TO THE PRESENT (The John Hopkins University Press, 1996).

[353] DJERASSI, *supra* note 347, at 22.

we want to promote or regulate?[354] What implications will these new applications have for future generations and our conceptions of "normal" reproduction?

The mammalian cloning of Dolly the sheep, born February 1997,[355] is another example of how genetic reproductive technology can push both the scientific and ethical envelope even further, capturing our public imagination.[356] Reaching beyond Melanie's "Brave New World," in Caryl Churchill's 2002 play *A Number*,[357] the original son of Salter, Bernard 1 (B1), and his many clones, including Bernard 2 (B2), explore their origins, their identities, and their destinies. Salter inquires if his sons want to know "how far has this thing gone, how many of these things are there," to which B2 reacts, "you called them things. I think we'll find they're people"; then Salter adds, "copies of you which some mad scientist . . ."[358]

A Number vividly provides perspective on what it really means to be a unique human being beyond our genetic blueprint.[359] When B2 queries, "if you're not my father that's fine. If you couldn't have children or my mother, and you did in vitro . . . ."[360] Salter confirms, "I am your father, it was by an artificial [sic] the forefront of science

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[354] *See* DEBORA L. SPAR, THE BABY BUSINESS: HOW MONEY, SCIENCE, AND POLITICS DRIVE THE COMMERCE OF CONCEPTION 26-28 (Harvard Business School Press, 2006); T. Caulfield et al., *Law and Policy in the Era of Reproductive Genetics*, 30 J. MED. ETHICS 414 (2004); Kerry Lynn Macintosh, *Brave New Eugenics: Regulating Assisted Reproductive Technologies in the Name of Better Babies*, 2010 U. ILL. J.L. TECH. & POL'Y 257, 265-77, 292-307 (2010).

[355] *Caught Napping by Clones*, 385 NATURE 753, 753 (1997).

[356] *See* PRESIDENT'S COUNCIL ON BIOETHICS, *Ethics of Cloning-to-Produce-Children*, *in* HUMAN CLONING AND HUMAN DIGNITY: AN ETHICAL INQUIRY 83-116 (2002); Joyce C. Havstad, *Human Reproductive Cloning: A Conflict of Liberties*, 24 BIOETHICS 71, 71-74 (2010); Michael J. Sandel, *The Ethical Implications of Human Cloning*, 48 PERSP. IN BIOLOGY & MED. 241, 241-45 (2005).

[357] CHURCHILL, *supra* note 24.

[358] *Id*. at 10-11.

[359] *See* Karen H. Rothenberg, *"Being Human": Cloning and the Challenges for Public Policy*, 27 HOFSTRA L. REV. 639, 640 (1999).

[360] CHURCHILL, *supra* note 24, at 18.

but I am genetically" related to all the Bernards.[361] Later on Salter acknowledges to B1:

> Nobody regrets more than me the completely unforeseen unforeseeable which isn't my fault and does make it more upsetting but what I did . . . also it's a tribute, I could have had a different one, a new child altogether . . . but I wanted you again because I thought you were the best.[362]

But as B1 reminds us, "It wasn't me again," even with "the same raw materials," and so the father justifies his actions "because they were perfect."[363] Although *A Number* is purely fictional, the play brings to life the ethical challenges at stake with technologies that may enable cloning humans—an idea that society has been unwilling to accept.[364]

On the other hand, the public continues to embrace the drive for creating new innovations in medicine to address human disease. The frenetic race to achieve novel scientific discoveries—in this case, the cure for cancer, is dramatized in *Secret Order*.[365] Bob Clyman's play highlights how the atmosphere of the scientific community both generates excitement for new ideas and the drive to claim success even when the data does not support it.[366] As is typical in an academic medical center, there is a definite hierarchy—Dr. Robert Brock, the Director of a cancer institute, recruits a brilliant

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[361] *Id.* at 19.

[362] *Id*. at 30-31.

[363] *Id*.

[364] *See generally* Timothy Caulfield, *Human Cloning Laws, Human Dignity and the Poverty of the Policy Making Dialogue*, 4 BMC MEDICAL ETHICS 3 (2003); Daniel Sperling, *Bringing Life from Death: Is There a Good Justification for Posthumous Cloning?*, J. CLINICAL RES. & BIOETHICS S1:001(Aug. 2011), *available at* http://www.omicsonline.org/2155-9627/2155-9627-S1-001.pdf.

[365] BOB CLYMAN, SECRET ORDER (L.A. Theatre Works 2008).

[366] *See* Raymond L. Calabrese & Brian Roberts, *Self-Interest and Scholarly Publication: The Dilemma of Researchers, Reviewers, and Editors*, 18 INT'L J. EDUC. MGMT. 335 (2004); Raymond de Vries et al., *Normal Misbehavior: Scientists Talk About the Ethics of Research*, 1 J. EMPIRICAL RES. ON HUM. RES. ETHICS 43 (2006); John Maddox, *Why the Pressure to Publish?*, 333 NATURE 493 (1988); James L. Mills, *Data Torturing*, 329 NEW ENG. J. MED. 1196 (1993).

immunologist, Dr. William Shumway who exclaims: "Everything we've tried . . . surgery, chemo . . . comes at a terrible cost. So it occurred to me . . . three years ago . . . you can't imagine how difficult technically . . . and again it's only one set of experiments, so this is completely premature, but I think I may have figured out how to cure cancer."[367] Brock can barely control his enthusiasm, "Do you understand the magnitude of what you've already done? People have spent the last 20 years trying to figure out how tumor cells trick us into thinking they're one of us. You're tricking tumor cells into thinking we're one of them. This is one of those moments . . . ."[368] "Say the word, and I'll have you in CELL by the spring. I know how to make things happen . . . ."[369]

The presumption is that with innovative ideas and fortitude, Shumway's research would change the fate of those with cancer. Unfortunately, the pressure to succeed blinds his moral compass—with adverse implications to himself, his colleagues, cancer research, and public perceptions of scientific integrity.[370] Shumway ultimately admits to Brock that his experiment has failed, much to their dismay: "I just assumed they were dying, but they aren't . . . ."[371] Brock is astounded: "Didn't you realize . . . ?"[372] Shumway responds defensively:

> Yes! Every day . . . but it was also another day to fix the problem . . . and I knew I could, I just needed a little more time. . . . I never lied or made up . . . these aren't excuses . . . and then one day you said, 'Pfizer' . . . . All my results were in that envelope, but I couldn't show you . . . not the way you were acting. . . . Excited.[373]

Brock snaps back, "I *was* excited, I thought I had a reason to be. . . . Right, a few technical problems, nothing you couldn't

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[367] CLYMAN, *supra* note 365, at 1.

[368] *Id*. at 4.

[369] *Id*. at 5.

[370] *See* Brian C. Martinson et al., *Scientists Behaving Badly*, 435 NATURE 737 (2005); Patricia K. Woolf, *Pressure to Publish and Fraud in Science*, 104 ANNALS INTERNAL MED. 254 (1986).

[371] CLYMAN, *supra* note 365, at 66.

[372] *Id.*

[373] *Id*. at 66-67.

solve."[374] And Shumway quickly answers, "I never actually told you I solved them, and you never asked. . . . I knew publishing was a mistake." Brock clearly announces, "Realizing you had a serious problem, then sitting on it and ducking questions for the next six months. . . . Why the hell did you wait so long?"[375]

In fact, the consequences of Shumway's unethical behavior go far beyond publishing misleading data and the integrity of the scientific community to the fate of those with cancer.[376] As Alice Curiton, Shumway's student lab assistant points out, "Don't you realize what you've done?! If you had told people there was a problem, someone else might've solved it a month ago . . . and we'd be one month closer to a cure. Did you ever think about how many people will die in that month?"[377]

Cassandra Medley's *Relativity*[378] also explores how data can be manipulated to advance both scientific and political agendas.[379] In this 2006 play, Claire, an African-American psychotherapist and educator, and her colleague-boyfriend, Malik, a sociologist, promote the theory that "people of color, or 'melanated people' possess greater quantities of life-enhancing properties of Melanin" to explain why they "excel athletically, culturally, intellectually, and spiritually."[380] Rejecting this theory, her daughter, Kalima, a Harvard graduate with a PhD in molecular genetics, is more interested in

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[374] *Id*. at 66, 68.

[375] *Id.* at 68. *See also* Public Health Service Policies on Research Misconduct, 70 Fed. Reg. 28370, 28377-78 (May 17, 2005); Fiona Godlee et al., Editorial, *Wakefield's Article Linking MMR Vaccine and Autism Was Fraudulent*, 342 BMJ 59, 64-66 (Jan. 2011); Douglas J. Opel et al., *Assuring Research Integrity in the Wake of Wakefield*, 342 BMJ 179, 179-180 (Jan. 2011).

[376] Brian Vastag, *Cancer Fraud Case Stuns Research Community, Prompts Reflection on Peer Review Process*, 98 J. NAT'L CANCER INST. 374, 374-75 (2006).

[377] CLYMAN, *supra* note 365, at 76.

[378] CASSANDRA MEDLEY, RELATIVITY (Broadway Play Publishing 2006).

[379] *See* Adele E. Clark et al., *Biomedicalising Genetic Health, Diseases and Identities*, *in* HANDBOOK OF GENETICS AND SOCIETY: MAPPING THE NEW GENOMIC ERA 21 (Paul Atkinson et al. eds., 2009); Deborah A. Bolnick et al., *Genetics: The Science and Business of Genetic Ancestry Testing*, 318 SCIENCE 399, 399-400 (2007); J. Kimmelman, *The Post-Human Genome Project Mindset: Race, Reliability, and Health Care*, 70 CLINICAL GENETICS 427, 430-31 (2006).

[380] MEDLEY, *supra* note 378, at 5.

exploring new and exciting genetic technologies.[381] Presumptions about the power of science and technological innovations to control destiny are influenced by the experiences of different generations with different perspectives. From Claire's point of view:

> This new technology is potentially a breakthrough for all humanity . . . but just where will this bold new technology take us? Replicating organs . . . replicating people. . . . If we do not stay on top of this new cloning technology, our bloodlines will continue to diminish, while the non-melanated will have found a way to preserve theirs.[382]

As Malik reminds Kalima, "Your mom critiques the racist and ethical implications of this new cloning technology. . . . And you'll challenge these latest DNA findings."[383] In turn, Kalima defends her position, "what am I to challenge, exactly? The human genome is the human genome. . . . Their claim that race has no biological basis in fact. Is so—confirmed."[384] She adds "how do 'we' deal with the facts that . . . the genomic sequencing proves that there's more variation *within* groups, than between the groups we perceive to be different. . . . The sequencing shows humans are all ninety-nine-point-nine percent genetically identical."[385] To which Malik volleys back, "Right. And the same so-called 'data' also 'proves' that humans share ninety-eight percent of their genes with the chimpanzee. . . . Seems like that 'two percent' difference makes *all* the 'difference.'"[386] In fact, as the Human Genome Project has evolved, so too has the scholarship on race and ethnicity in the context of genomic research.[387]

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[381] *Id.* at 4.

[382] *Id.* at 4, 6.

[383] *Id.* at 14.

[384] *Id.*

[385] *Id.* at 15.

[386] *Id.* (emphasis in original).

[387] *See* Troy Duster, *Medicine. Race and Reification in Science*, 307 SCIENCE 1050 (2005); Dorothy E. Roberts, *Is Race-Based Medicine Good for Us?: African American Approaches to Race, Biomedicine, and Equality*, 36 J.L. MED. & ETHICS 537 (2008).

By 2003, the mapping of the human genome was complete and the scientific community was excited to create the technology that had the power to control our fate.[388] Over fifty years before, Rosalind Franklin was painstakingly creating the images that would later contribute to the discovery of the double helix by Watson and Crick[389]—so well illuminated in Anna Ziegler's 2009 play *Photograph 51*.[390] While Franklin thinks: "You know, I think one sees something new each time one looks at truly beautiful things. . . . But they need to be so much clearer . . . If we're ever to find the structure. . . . It's going to get to the heart of everything. . . ,"[391] Watson is thinking "more than ever—that the gene's the thing. I mean, we have to get to the bottom of it—discover how it replicates itself. And so we need its structure. . . . It's just incredibly exciting. . . . To be born at the right time. There's an element of fate to it, don't you think? And I don't believe in fate."[392]

In a twist of fate, just as the image became clearer to her that, "It's a perfect X. It's a helix,"[393] Rosalind runs out of time, both because of her perfectionism, as noted by her colleagues, and her premature death from ovarian cancer.[394] While Rosalind "realized the best thing is just to do one's work and not worry so much about anything else. It doesn't matter anyway," Watson bellows "But it does matter! It did matter. You can't be in the race and ignore it at the same time! That's where she went wrong."[395] Shortly before she

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[388] *See* Collins et al., *supra* note 300.

[389] *See* ANNE SAYRE, ROSALIND FRANKLIN AND DNA 24 (1st ed. 1975) (To this day there remains controversy about whether Watson and Crick sufficiently recognized Franklin's contributions).

[390] ANNA ZIEGLER, PHOTOGRAPH 51 (2009) (Dramatists 2011).

[391] *Id.* at 21-22.

[392] *Id.* at 23.

[393] *Id.* at 35. *See* A. Klug, *Rosalind Franklin and the Discovery of the Structure of DNA*, 219 NATURE 808, 808 (1968).

[394] *See* Klug, *supra* note 393, at 808.

[395] ZIEGLER, *supra* note 390, at 37. *See generally* BRENDA MADDOX, ROSALIND FRANKLIN: THE DARK LADY OF DNA 319 (1st ed. 2002).

dies, Rosalind reflects: "The work is never finished and in the meantime our bodies wind down, tick slower, sputter out." While her colleague, Wilkins, notes in the end: "But we lost," Rosalind, being a true researcher to the end, answers back with more questions, "Lost? No . . . We all won. The world won, didn't it?"[396]

Another theatrical production that reflects back in time and personalizes the challenge of controlling one's fate in the light of incurable cancer is *Freud's Last Session*.[397] Mark St. Germain's play dramatizes a fictionalized conversation in 1939 between the frail and elderly Dr. Sigmund Freud and young C.S. Lewis, a lay theologian and literary critic, exploring their different perspectives on the meaning of life.[398] Frustrated by the inability of the medical profession to change the course of his disease and create innovations to alleviate his pain and suffering, Freud morally justifies his decision to control his ultimate fate with assisted suicide.[399]

Freud reveals to Lewis: "My mood these days is ruled by my body. . . . It's the prosthesis. It doesn't fit properly; it chafes my mouth. Anna calls it 'The Monster.' I must clean it and call her to readjust it. . . . No one but Anna touches it. . . . Especially not the doctors. Thirty operations and I should have learned from the first."[400] "It's nearly eaten through my cheek. It is inoperable. It's only a matter of time . . . for me to decide. Dr. Schur and I have a pact. He promised me at the beginning he won't desert me at the end."[401] Startled, Lewis asks, "Are you saying you'll commit suicide?" And Freud quickly replies, "I'm saying I will kill myself before the cancer does. Don't look at me that way. You don't need to say it: Suicide is wrong and a sin! . . . look into my mouth and you

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[396] ZIEGLER, *supra* note 390, at 57 (alteration in original).

[397] MARK ST. GERMAIN, FREUD'S LAST SESSION (Dramatists 2010).

[398] *Id.*

[399] *Id.* at 27. *See* KLEINMAN, *supra* note 55; Pierre Gagné et al., *Psychopathology and Suicide among Quebec Physicians: A Nested Case Control Study*, 2011 DEPRESSION RES. & TREATMENT 936327 at *3 (2011); Quill, *supra* note 55, at 17.

[400] ST. GERMAIN, *supra* note 397, at 23.

[401] *Id.* at 27.

will see hell has arrived already."[402] As a physician, Freud has access to the knowledge and the means to carry out his plan for terminating his own life—just like Dr. Chapman voiced in *A Question of Mercy*.[403]

Moisés Kaufman's *33 Variations*[404] juxtaposes characters of the past, including Beethoven, with the present to explore the limits of innovation when confronted with the neurodegenerative disease amyotrophic lateral sclerosis (ALS),[405] for which science has yet to offer hope for a cure or dignified death.[406] This play revolves around Katherine, a musicologist who has been diagnosed with ALS; Clara, her daughter; and Gertie, a friend and professional colleague whose aunt had died of ALS. Although technology provides for an augmentative speech device to assist Katherine in communicating with others, as the disease progresses it is clear that she is losing control of her body and thus is determined to seize control of her final destiny, as explored in so many earlier plays from *Ghosts* to *Freud's Last Session*.

Katherine declares: "I want to live," yet clarifies, "But only while I can still communicate. If I cannot make myself understood, I want to be given morphine and left to die. I want that to be clear." [407] When Clara questions: "And who will be administering the morphine?," Katherine's plan is clear: "Gertie has agreed to do it."[408] And when Clara expresses with concern: "What happens if after you can't communicate you change your mind and you want to go on living?," Katherine quickly lets her know: "That won't happen."[409]

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[402] *Id.*

[403] RABE, *supra* note 320, at 14.

[404] KAUFMAN, *supra* note 25.

[405] *See generally* John T. Dimos et al., *Induced Pluripotent Stem Cells Generated from Patients with ALS Can Be Differentiated into Motor Neurons*, 321 SCIENCE 1218 (2008).

[406] *See* Harold D. Foster & Abram Hoffer, *The Two Faces of L-Dopa: Benefits and Adverse Side Effects in the Treatment of Encephalitis Lethargica, Parkinson's Disease, Multiple Sclerosis and Amyotrophic Lateral Sclerosis*, 62 MED. HYPOTHESES 177, 181 (2004); David J. Oliver & Martin R. Turner, *Some Difficult Decisions in ALS/MND*, 11 AMYOTROPHIC LATERAL SCLEROSIS 339, 339 (2010).

[407] KAUFMAN, *supra* note 25, at 85.

[408] *Id.*

[409] *Id.*

But in fact, it sometimes does. Patients are often left in a neurological state where it is not always possible to determine their wishes—a difficult ethical dilemma intensified by cutting-edge technology.[410]

Following Katherine's death, Clara reads, at her mother's request, her final lecture that ends with a quote from Beethoven, the composer who had slowly become deaf in adulthood and had inspired much of Katherine's scholarship and philosophy on life:

BEETHOVEN: Let us begin with the primary cause of things.
Let us begin with how something came about.
Why it came about in that particular way
and became what it is.[411]

ACT VI: GENOMES & UNKNOWNS

Over the last decade, particularly in the context of the genomics revolution, expectations have increased to better understand the causes of disease and disorders, as well as the promise of innovative treatments—echoed by Kaufman's Beethoven in the context of his world three centuries ago. *Lucy*,[412] the 2009 play by Damien Atkins, examines the frustrations of Vivian, an anthropologist, as she tries to discover the origins of her daughter Lucy's "autistic" behavior with Morris, Lucy's therapist: "I've been looking at autism triggers . . . there's a lot of conflicting information."[413] When Morris notes that "it's an evolving study," Vivian adds: "But most scientists agree that there has to be a genetic *component*. . . . they've been able to isolate a couple of potential autism genes . . . ."[414] Morris adds, "But there may be as many as a *hundred* involved, we don't know. . . . there are

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[410] *See* Joseph J. Fins & Nicholas D. Schiff, *Neuroimaging & Disorders of Consciousness: Clinical and Ethical Challenges for Research and Practice*, *in* NEUROETHICS IN PRACTICE (Anjan Chatterjee and Martha J. Farah et al. eds., forthcoming 2012); THE OXFORD HANDBOOK OF NEUROETHICS, *supra* note 222, at 343-494; Ruth Macklin, *Bioethics, Vulnerability, and Protection*, 17 BIOETHICS 472 (2003).

[411] KAUFMAN, *supra* note 25, at 103.

[412] ATKINS, *supra* note 26, at 55.

[413] *Id.*

[414] *Id.* at 55

lots of people trying to figure out where it came from. I'm just trying to figure out how to fix it now that it's here."[415]

The back and forth dialogue between Vivian and Morris illustrates the continuing controversy on how to treat a complex disorder in the midst of not truly understanding the interactions between genetic and environmental factors.[416] Moreover, even if we have a clear sense of the scientific basis for the cause of Autism Spectrum Disorder, challenges would remain, particularly given the variability of expression and permutations in functioning.[417] Typical of how parents feel with this level of uncertainty, Vivian is puzzled: "You want to fix it, but you don't even know *what it is* yet."[418] When Morris responds defensively, "That's not true, it's just, it's *complicated*. . . . [T]here are a lot of theories out there and not enough proof," Vivian continues, "*I'm* confused—you keep telling me that you know what you're doing. . . . that you're on the *cutting edge*. . . . why don't tell me something you *do* know!"[419]

Although the scientific landscape changes over time, we are still faced with the reality of the limits of our knowledge.[420] Contentious

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[415] *Id.* at 55, 57.

[416] *See generally* Fiona Godlee et al., Editorial, *Wakefield's Article Linking MMR Vaccine and Autism Was Fraudulent*, 342 BRIT. MED. J. c7452, 64 (2011); Anna Kirkland, *The Legitimacy of Vaccine Critics: What is Left After the Autism Hypothesis*, 37 J. HEALTH POL. POL'Y & L. 69 (2012); A.J. Russo & Robert deVito, *Analysis of Copper and Zinc Plasma Concentration and the Efficacy of Zinc Therapy in Individuals with Asperger's Syndrome, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) and Autism*, 6 BIOMARKER INSIGHTS 127 (2011).

[417] *See* Daniel B. Campbell et al., *Association of Oxytocin Receptor (Oxtr) Gene Variants with Multiple Phenotype Domains of Autism Spectrum Disorder*, 3 J. NEURODEVELOPMENTAL DISORDERS 101 (2011); An Crepel et al., *Narrowing the Critical Deletion Region for Autism Spectrum Disorders on 16p11.2*, 156 AM. J. MED. GENETICS PART B, NEUROPSYCHIATRIC GENETICS 243 (2011); Guy Horev et al., *Dosage-Dependent Phenotypes in Models of 16p11.2 Lesions Found in Autism*, 108 PROC. NAT'L ACAD. SCI. U.S.A. 17076 (2011); Veronica J. Vieland et al., *Novel Method for Combined Linkage and Genome-Wide Association Analysis Finds Evidence of Distinct Genetic Architecture for Two Subtypes of Autism*, 3 J. NEURODEVELOPMENTAL DISORDERS 113 (2011).

[418] ATKINS, *supra* note 26, at 57 (emphasis in original).

[419] *Id.* at 57-58 (emphasis in original).

[420] *See* Gary E. Marchant & Jason S. Robert, *Genetic Testing for Autism Predisposition: Ethical, Legal and Social Challenges*, 9 HOUS. J. HEALTH L. & POL'Y 203 (2009); Matthew W. State & Pat

debate continues on how to categorize the wide spectrum of behavioral and neurological manifestations that have societal and financial implications for medical and education benefits[421] while trying to minimize stigmatizing labels.[422] Theatre vividly captures the dramatic implications of familial struggles to search for causal explanations and effective treatments[423] to control the fate of individuals with neuropsychiatric disorders.

Lisa Loomer's *Distracted*[424] further explores these themes through Mama, the central character, and her husband Dad, who question the role of heredity and environment in explaining their son's diagnosis as Attention Deficit Hyperactivity Disorder and the treatment alternatives[425] to make him act like a "normal" child. On a more fundamental level, they wonder whether his behavior is a function of our distracted society rather than a medical disorder.[426] Through a series of dialogues with each other, and with a revolving door of doctors, they discover the risks of and limitations with current

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Levitt, *The Conundrums of Understanding Genetic Risks for Autism Spectrum Disorders*, 14 NATURE NEUROSCIENCE 1499 (2011).

[421] *See* Sheryl Dicker & Emily Bennett, *Engulfed by the Spectrum: The Impact of Autism Spectrum Disorders on Law and Policy*, 45 VAL. U. L. REV. 415 (2011).

[422] *See* Marja-Leena Mattila et al., *Autism Spectrum Disorders According to DSM-IV-TR and Comparison with DSM-5 Draft Criteria: An Epidemiological Study*, 50 J. AM. ACAD. CHILD & ADOLESCENT PSYCHIATRY 583 (2011); James L, Sanders, *Qualitative or Quantitative Differences Between Asperger's Disorder and Autism? Historical Considerations*, 39 J. AUTISM & DEVELOPMENTAL DISORDERS 1560 (2009); Sami Timimi, *Autism Is Not a Scientifically Valid or Clinically Useful Diagnosis*, 343 BMJ d5105 (2011); Lorna Wing et al., *Autism Spectrum Disorders in the DSM-V: Better or Worse than the DSM-IV?*, 32 RES. DEVELOPMENTAL DISABILITIES 768 (2011).

[423] *See* Allison E. Golnik & Marjorie Ireland, *Complementary Alternative Medicine for Children with Autism: A Physician Survey*, 39 J. AUTISM & DEVELOPMENTAL DISORDERS 996 (2009); Susan E. Levy & Susan L. Hyman, *Complementary and Alternative Medicine Treatments for Children with Autism Spectrum Disorders*, 17 CHILD & ADOLESCENT PSYCHIATRIC CLINICS OF N. AM. 803 (2008).

[424] Loomer, *supra* note 27.

[425] *Id.* at 25; *see also* Eran Ben-Arye et al., *Attitudes Toward Integration of Complementary and Alternative Medicine in Primary Care: Perspectives of Patients, Physicians and Complementary Practitioners*, 70 PATIENT EDUC. & COUNSELING 395 (2008); Kathi J. Kemper et al., *American Academy of Pediatrics: The Use of Complementary and Alternative Medicine in Pediatrics*, 122 PEDIATRICS 1374 (2008).

[426] LOOMER, *supra* note 27, at 50.

approaches for explaining and controlling this disorder—just like Autism Spectrum Disorder in *Lucy*.[427]

When Mama goes to Dr. Waller looking for answers, this neuropsychologist opines: "Studies indicate the best course of treatment is a combination of behavior modification and medication."[428] Mama then consults with Dr. Zavala and is glad when this child psychologist confirms that "you're right to try everything else first, every conceivable good option," and Mama asks, "[L]ike neurofeedback? Orthomolecular therapy? Herbs? . . . Would Ritalin . . . get him out of his pajamas?"[429] However, Dad is not happy after Dr. Zavala says, "When Ritalin works, it can seem like a miracle," and declares: "No way am I putting my kid on Ritalin!"[430] But Mama keeps on asking: "Would Ritalin be a better mother than I am? . . . if it's a real disease—like diabetes—then shouldn't one thing work. Like insulin."[431] This dialogue so well captures the frustrating reality that a "quick fix" does not always work given the wide variability with many neuropsychiatric disorders.

And so the parents keep searching for an innovation to modify their son's fate. Whereas the next psychiatrist, Dr. Jinks, explains: "The brain is highly complex. . . . ADD is a neurological condition. . . a *hereditary* condition,"[432] Dad questions yet another, Dr. Karnes, to "explain the BioMeridian machine that you use to diagnose the food and environmental allergies you say my son has?"[433] And Dr. Karnes admits, "The truth is, I don't fully understand how it works myself, I

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[427] *Id. See* Atkins, *supra* notes 26, 412-23 and accompanying text. *See also* Ginger Polich et al., *The Need to Act a Little More 'Scientific': Biomedical Researchers Investigating Complementary and Alternative Medicine*, 32 SOC. HEALTH & ILLNESS 106 (2010).

[428] LOOMER, *supra* note 27, at 31.

[429] *Id*. at 41, 45.

[430] *Id*. at 45.

[431] *Id*. at 45, 48.

[432] *Id*. at 48 (emphasis in original); the diagnosis of ADD, Attention Deficit Disorder, is now referenced as ADHD, Attention Deficit Hyperactivity Disorder.

[433] *Id*. at 60

just know from my own clinical experience in addition to reports from Europe that it does. . . . Imbalances in various organs are believed to—."[434] Like so many of the earlier plays, *Distracted* captures the ethical challenge of reaching the appropriate balance between encouraging the creation of innovation and protecting the public from ineffective interventions.[435]

In the same year, Brian Yorkey's Pulitzer Prize winning musical *Next to Normal*[436] depicts the desperate search for medical innovations to control Diana's severe psychiatric disorder—depression with delusional episodes and a history of sixteen-years of medication.[437] The show revolves around Diana, her family, and her many doctors struggling to find an effective treatment regimen and the implications of these exhausting attempts to get her to function at least "next to normal."[438] Through a series of powerful musical numbers and dialogue, Diana and the psychiatrists explore how the evolving list of different medical interventions from psychopharmacology to

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[434] *Id*.

[435] *See* Pediatric Research Equity Act of 2007, 21 U.S.C. § 355c (2006) (mandating pediatric studies of some drugs under the authority of the FDA); Ruth L. Fischbach & Gerald D. Fischbach, *Neuroethicists Needed Now More Than Ever*, 8 AM. J. BIOETHICS 47 (2008); Aaron Levin, *Did FDA's Limited DBS Approval Create New Set of Problems?*, PSYCHIATRIC NEWS, Mar. 18, 2011, at 6; Press Release, U.S. Food & Drug Admin., FDA Directs ADHD Drug Manufacturers to Notify Patients about Cardiovascular Adverse Events and Psychiatric Adverse Events (Feb. 21, 2007), http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/2007/ucm108849.htm; Press Release, U.S. Food & Drug Admin., FDA Launches a Multi-Pronged Strategy to Strengthen Safeguards for Children Treated with Antidepressant Medications (Oct. 15, 2004), http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/2004ucm108363.htm.

[436] BRIAN YORKEY, NEXT TO NORMAL (2009) (Theatre Communications Group 2010).

[437] *Id; see also* Shadi Beshai et al., *Relapse and Recurrence Prevention in Depression: Current Research and Future Prospects*, 31 CLINICAL PSYCHOL. REV. 1349 (2011); Timothy I. Mueller et al., *Recurrence After Recovery from Major Depressive Disorder During 15 Years of Observational Follow-Up*, 156 AM. J. PSYCHIATRY 1000 (1999); Richard C. Shelton & Madhukar H. Trivedi, *Challenges and Algorithm-Guided Treatment in Major Depressive Disorder*, 72 J. CLINICAL PSYCHIATRY e14 (2011).

[438] *See* YORKEY, *supra* note 436; *see also* Paul S. Appelbaum et al., *Therapeutic Misconception in Clinical Research: Frequency and Risk Factors*, IRB: ETHICS AND HUM. RES., Mar.-Apr. 2004, at 1.

hypnosis to electro convulsive therapy (ECT) may control her fate—and theirs—for better or for worse.[439]

After Doctor Fine sings, "The round blue ones with food but not with the oblong white ones. The white ones with the round yellow ones but not with the trapezoidal green ones. Split the green ones into thirds with a tiny chisel," Diana describes her reality: "I've got less anxiety, but I have headaches, blurry vision, and I can't feel my toes."[440] "So we'll try again, and eventually we'll get it right," Doctor Fine responds, trying to reassure her—and himself.[441] To which Diana observed: "Not a very exact science, is it?"[442]

Some time later, another psychiatrist, Doctor Madden, recommends ECT therapy,[443] calmly offering that "the electricity involved is barely enough to light a hundred-watt bulb," minimizing the frightening concept of being shocked.[444] Diana reflects on her experience with the latest treatment in song:

> In an instant, lightning flashes
> And the burst might leave me blind—
> When the bolt of lightning crashes
> And it burns right through my mind.
>
> It's like someone drained my brain out,
> Set my frozen mind to thaw.
> Let the lethargy and pain out
> While I stood and watched, in awe.

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[439] *See* YORKEY, *supra* note 436; *see also* John A. Cohan, *Psychiatric Ethics and Emerging Issues of Psychopharmacology in the Treatment of Depression*, 20 J. CONTEMP. HEALTH L. & POL'Y 115 (2003).

[440] YORKEY, *supra* note 436, at 17-18.

[441] *Id.* at 18

[442] *Id.*

[443] *See generally* THE ECT HANDBOOK: THE THIRD REPORT OF THE ROYAL COLLEGE OF PSYCHIATRISTS' SPECIAL COMMITTEE ON ECT 12 (Allan I.F. Scott ed., Bell & Bain Limited 2d ed. 2005); Matthew V. Rudorfer et al., *Electroconvulsive Therapy*, *in* PSYCHIATRY 1865-901 (Allan Tasman et al. eds., 2d ed. 2003).

[444] YORKEY, *supra* note 436, at 53.

> I am riding on the brightest buzz. . .
> I am worlds away from who I was. . .
> And they told me it would change me—
> Though they don't know how it does.[445]

Once again, a character dramatizes both the promises and perils of medical interventions, and the uncertainties of their futures.

The motivation to use medical innovations to control the fate of future generations has been accelerated by the promise of emerging reproductive and genetic technologies.[446] Dorothy Fortenberry's *The Good Egg*[447] examines how a fictionalized pre-implantation genetic diagnosis of Bipolar Disorder has the potential to prevent its heritable transmission.[448] The tension set up in this 2010 play revolves around Meg, who wants to become pregnant through assisted reproductive technology, and her brother, who is diagnosed as Bipolar, just like their dad who committed suicide.

When Meg tries to justify: "it's done all the time . . . to make sure the baby's healthy and normal and—" Matt quickly interrupts, "Not bipolar."[449] He further adds: "You said they were checking for diseases." Meg confirms, "For Huntington's and Parkinson's and Alzheimer's and MS and—." "Me?" Matt shouts. Meg goes on to explain: "It's a new test. They just located the genes recently, and—." Interrupting again, Matt declares: "You're taking advantage of the technology. Like 'New! Improved! Now with no bipolar!'" Trying to

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[445] *Id*. at 60.

[446] *See generally* R. Alta Charo & Karen H. Rothenberg, *The Good Mother: The Limits of Reproductive Responsibility and Genetic Choice*, *in* WOMEN & PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 105 (Karen Rothenberg & Elizabeth Thomson eds., 1994).

[447] FORTENBERRY, *supra* note 28.

[448] Assisted reproductive technologies have evolved primarily in the private sector, largely because there has been little federal funding in this controversial area. Note, *Guiding Regulatory Reform in Reproduction and Genetics*, 120 HARV. L. REV. 574, 548-79 (2006). Historically, it is professional organizations that have established medical and ethical guidelines, rather than government regulations, for these emerging technologies. *See* Naomi R. Cahn & Jennifer M. Collins, *Eight is Enough*, 103 NW. U. L. REV. COLLOQUY 501, 507-08 (2009).

[449] FORTENBERRY, *supra* note 28, at 14.

calm Matt down, Meg lets him know: "It is a totally routine, common thing to do, just to be on the safe side."[450]

The dialogue highlights how advances in assisted reproductive technology generate new opportunities for Meg to be able to use innovative genetic tests[451] prior to implantation[452] to select what type of child she would be willing to parent, reminiscent of *Immaculate Misconception*.[453] The synergy between the utilization of these cutting-edge technologies and the value-laden choices these innovations create, raise complex ethical dilemmas for individuals, families and society that center on the fundamental question of whether there should be limits on how these technologies are used to change the fate of others.[454]

Wanting his sister to reconsider her pursuit of genetic testing, Matt tries to make Meg feel guilty and adds: "Mom would never have."[455] Meg snaps back: "You don't know what Mom would have said about it, they hadn't even invented genetic testing."[456] Matt is unrelenting: "Mom just had a kid like normal people have kids," and Meg reminded him: "We don't live in that world anymore."[457] In an emotional turmoil, Matt declares: "You are genetically editing me from the code of who we are. You're eliminating me and you're

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[450] *Id.* .

[451] *See* Tiffany A. Greenwood et al., *Further Evidence for Linkage of Bipolar Disorder to Chromosomes 6 and 17 in a New Independent Pedigree Series*, 14 BIPOLAR DISORDERS 71, 72, 75 (2012); Radhika Kandaswamy et al., *Tests of Linkage and Allelic Association between Markers in the 1p36 Prkcz (Protein Kinase C Zeta) Gene Region and Bipolar Affective Disorder*, 159 AM. J. MED. GENETICS. PART B, NEUROPSYCHIATRIC GENETICS 201 (2012).

[452] *See* Robert Klitzman et al., *Preimplantation Genetic Diagnosis on in Vitro Fertilization Clinic Websites: Presentations of Risks, Benefits and Other Information*, 92 FERTILITY & STERILITY 1276 (2009).

[453] *See* Djerassi, *supra* notes 347-54 and accompanying text. *See also* Andrew B. Coan, *Is There a Constitutional Right to Select the Genes of One's Offspring?*, 63 HASTINGS L.J. 233, 234-235 (2011).

[454] *See* ANNE KERR & TOM SHAKESPEARE, GENETIC POLITICS: FROM EUGENICS TO GENOME (2002).

[455] FORTENBERRY, *supra* note 28, at 29.

[456] *Id.*

[457] *Id.* at 30.

eliminating Dad."[458] As the play concludes, Meg reflects: "I thought about it, calling up to cancel . . . but I couldn't do it. I couldn't handle the thought, the guilt of saying to a child 'I could have prevented your feeling this way, but I chose not to.'"[459] This technological imperative of "reproductive accountability"[460] and her personal experiences are just too powerful for Meg to resist.

Because values among individuals are so diverse and fluid, the powerful role of relationships within a family varies across a continuum from gently guiding, to denouncing a woman's choice, to the threat of severing all ties, as we witnessed in *Twilight of the Golds*.[461] Different judgments about "what is normal?" are shaped by our experiences and cultural expectations, which directly impact on how we frame our identities and those of others within the context of families and society—a message that has evolved from the disabilities community.[462] In turn, these perceptions color our presumptions about the power of science and technology to control destiny. Despite Matt's strong feelings, Meg is adamant in her beliefs that the use of innovative technologies would provide the path to a better place.

As we have witnessed in so many plays, the challenges posed by chronic neuropsychiatric and neurological disorders motivate the quest to discover and experiment with all modes of medical interventions.[463] In the last play explored, Sharr White's 2011

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[458] *Id*. at 51.

[459] *Id*. at 53-54.

[460] *See generally* Charo & Rothenberg, *supra* note 446.

[461] *See* TOLINS, *supra* notes 22, 302-08 and accompanying text.

[462] *See* Adrienne Asch et al., *Respecting Persons with Disabilities and Preventing Disability: Is There Conflict?*, *in* THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES: DIFFERENT BUT EQUAL 319 (Stanley S. Herr et al. eds., 2011); PRENATAL TESTING AND DISABILITY RIGHTS (Erik Parens & Adrienne Asch eds., 2000); JEROME EDMUND BICKENBACH, ETHICS, LAW, AND POLICY (2012); DAVID T. WASSERMAN ET AL., QUALITY OF LIFE AND HUMAN DIFFERENCE : GENETIC TESTING, HEALTH CARE, AND DISABILITY (2005).

[463] *See* HARVEY, *supra* note 14; ONE FLEW OVER THE CUCKOO'S NEST, *supra* note 151; EQUUS, *supra* note 180; AGNES OF GOD, *supra* note 18; KIND OF ALASKA, *supra* note 223; LUCY, *supra* note 26, DISTRACTED, *supra* note 27; NEXT TO NORMAL, *supra* note 436.

production *The Other Place*[464] brings to life many of the themes and images dramatizing attempts to manipulate fate through medical science. The main character, Julianna, is a brilliant scientist who has devoted her professional life to finding a cure for Alzheimer's disease.[465] While presenting at an academic meeting, she suddenly loses her memory and stops talking—thinking that she has had a stroke or possibly brain cancer. As fate would have it, imaging technology confirms that it was neither of these, but rather she is afflicted with the very disease that was her scientific specialty.[466]

With her husband Ian and nurse Bobby, Julianna finds the support to participate in experimental treatment. One can only wonder, when reflecting on the principle of social justice, whether this access to experimental treatment would have been as readily available to patients not connected to the scientific community.[467] Juliana reports: "had my first injection, been given my pill . . . and suddenly I feel . . . I don't know. I can't explain it." She rejoices, "It can't be true, I'm just being hopeful. . . . Well I just feel this morning as if . . . I'm . . . as if a . . . *something*. That was in front my eyes. Has been lifted . . . this is why you use a, a, whatever—. "[468] Bobby helped her find her words, "Test group? Placebo . . . ?"[469] As a scientist, Juliana clearly recognizes the power of a placebo,[470] and acknowledges, "Yes; we just want so badly to think we feel better."[471]

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[464] WHITE, *supra* note 5.

[465] *See* Paul Hollingworth et al., *Common Variants at Abca7, Ms4a6a/Ms4a4e, Epha1, Cd33 and Cd2ap Are Associated with Alzheimer's Disease*, 43 NATURE GENETICS 429 (2011); Adam C. Naj et al., *Common Variants at Ms4a4/Ms4a6e, Cd2ap, Cd33 and Epha1 Are Associated with Late-Onset Alzheimer's Disease*, 43 NATURE GENETICS 436 (2011); Nidhi Subbaraman, *Alzheimer's Genetic Map*, 29 NATURE BIOTECHNOLOGY 179 (2011).

[466] *See* Li Liu et al., *Trans-Synaptic Spread of Tau Pathology in Vivo*, 7 PLOS ONE e31302 (2012).

[467] *See* Jeffrey L. Cummings, *Alzheimer's Disease Clinical Trials: Changing the Paradigm*, 13 CURRENT PSYCHIATRY REP. 437 (2011); THE OXFORD HANDBOOK OF NEUROETHICS, *supra* note 222, at 516 (discussing fair subject selection).

[468] WHITE, *supra* note 5, at 41-42.

[469] *Id.* at 42.

[470] *See generally* Michael Specter, *Annals of Science: The Power of Nothing*, NEW YORKER, Dec. 12, 2011, at 30.

[471] WHITE, *supra* note 5, at 42.

As the play ends, Julianna expresses her hopes that the experimental drug will diminish the progression of her disease, while still recognizing its limitations:

> A new version of Identamyl is, we're certain, hard at work. Though neuron death is still occurring, our hope, however, is that it is slowing, or even coming to a halt. Regardless of treatment, the memories I had will never be restored. Neither will my very sense of self. . . . Not being myself is, oddly, who I am. Very rarely, triggered by who knows what, visions—ghosts really—of my past life *do* appear quite vividly. . . . I'm also taking a new drug meant to help *clear* these plaques, but because it's made by a competitor, if you ask me what it is . . . I'll tell you I don't remember. . . . There are many conversations I do not retain. . . . I am a woman in-between: The sky and the earth. The past and the future. This place . . . and the other.[472]

Because of her firm belief in the miracle of science, she holds on to the presumption that innovations in medicine still have the power to enable her to control her fate by leading her away from "the other place."

EPILOGUE

This selection of theatrical narratives represents but a small sample of possibilities to spark the "moral imagination"[473] and facilitate interdisciplinary discourse on the ethical, legal, and social implications of transformative medical technologies over time. These plays provide a unique creative and analytical stage for imagining our bioethical past and future and our attempts to control our fate through innovations in medicine. At the same time, they also raise our sensitivity toward human conflicts ''just because it is not our life, places us in a moral position that is favorable for perception and it shows us what it would be like to take up that position in life."[474] By

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[472] *Id*. at 42-43 (emphasis in original).

[473] *See* R.S. DOWNIE & J. MACNAUGHTON, BIOETHICS AND THE HUMANITIES: ATTITUDES AND PERCEPTIONS 134 (2007).

[474] MARTHA C. NUSSBAUM, LOVE'S KNOWLEDGE: ESSAYS ON PHILOSOPHY AND LITERATURE 162 (1990).

fostering an emotional engagement with the actors (or by portraying a character) we can gain an appreciation for, and recognition of, how advancements in technology shape both translational clinical practice and its ensuing ethical challenges—especially on human relationships.

While the complexity of medical innovations has evolved over time, the human response towards attempts to modify our destiny has remained relatively consistent—as witnessed in classic and contemporary theatre through the lens of history. This historical perspective provides the broader contextual script, while theatre allows us to effectively experience and imagine the actors through a more personal lens—potentially facilitating insight and expanding our understanding of ethical and societal implications through the lives of others. As the poet Percy Bysshe Shelley, spouse of the original *Frankenstein* creator Mary Shelley, observed:

> *[History is the] cyclic poem written by Time upon the memories of men. The past, like an inspired rhapsodist, fills the theatre of everlasting generations with [her] harmony.*[475]

[475] Augustine Birrell, *The Muse of History*, *in* OBITER DICTA: SECOND SERIES 184 (1887) (quoting PERCY BYSSE SHELLEY, IN DEFENCE OF POETRY (1821) (alteration in original)).