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Life without Hope? Huntington's Disease and Genetic Futurity

Gerry Canavan

Early in Andrew Niccol's 1997 science fiction film *Gattaca*, we witness the first moments of the life of Vincent Freeman (played as an adult by Ethan Hawke), beginning with his conception in the backseat of a Buick Riviera. "They used to say that a child conceived in love has a greater chance of happiness," Hawke's voiceover bitterly reflects. "They don't say that any more." In the near-future world of *Gattaca*, advances in genetic engineering have led to world of perfected designer babies, each one carefully calibrated to remove hereditary disease and maximize personal potential. Vincent's mother, in contrast to this now-common practice, "placed her faith in God's hands, rather than those of her local geneticist," and the result is a genetic profile prophesying a too-brief lifetime filled with suffering and hardship. Mere seconds after the birth, an analysis of Vincent's unaltered genome generates the list of maladies to which he has been doomed: "Neurological condition: 60% probability. Manic Depression: 42% probability. Attention Deficit Disorder: 89% probability. Heart Disorder: 99% probability. Early fatal potential. Life expectancy: 30.2 years."

As Everett Hamner has noted, this kind of ultra-deterministic discourse around genomic science frequently shifts into a religious register, one that can be "traced to a sense of predestination found as far back as Genesis" (415). Such totalizing claims for the possibilities of genetic knowledge are significantly at odds with what actual genomic science tells us about the complex interplay of heredity and environment:

In the more recent incarnations, biology popularizers and sometimes overzealous scientists themselves speculate about "the homosexuality gene," "the God gene," "or "the

happiness gene,” as if an element of individual character as complex as sexual orientation, faith, or emotional disposition could be decided by a single microscopic on/off switch” (415) [1].

Gattaca, for Hamner, is an especially exemplary expression of this scientifically inaccurate vision of genetic determinism; despite the film’s nominal critique of determinism at the level of plot, Hamner writes,

the [birth] scene so effectively encapsulates the determinism involved in many portrayals of genomics that viewers may lose sight of the critique. The more we learn about genes, the more absurd is this test’s disregard for environmental factors and individual will, but its instantaneous empiricism is nevertheless regularly transferred to the actual science. (420)

In the popular imagination, the total genetic knowledge promised by the beginning of *Gattaca* is seen to be in some basic sense “realistic,” despite the fact that neither genes nor our diagnostic access to them function this way outside the world of fiction.

The actual limitations of genetic science, it seems, do little to detract from the intoxicating fantasy that our futures are encoded in our genes--and that this future might, through the application of science, be directly knowable in the here and now, today. Priscilla Wald has characterized *Gattaca*-style determinism through the grammatical perspective of the “future perfect” tense. The “biological determinism” associated with genetics, Wald writes, suggests a “preordained” future that is simultaneously still to come and already in the past: “what is inscribed in the genes was, is, and always will be” (698). As Wald argues, this exaggerative popular misunderstanding of genomic science “register[s] a response to changes in how science and popular culture imagine the nature of human being” (698), in which an erstwhile conception

of radical “free will” has been increasingly crowded out by a biologism that sees the human (on the levels of both individual subjectivity and species-time) recharacterized as the epiphenomenal expression of an incomprehensibly long process of genetic exchange on a planetary scale.

As we adjust to this new, genomic interpretation of the human species, which threatens to reduce the entirety of human history to an infinite series of chance genetic recombinations, Wald suggests one way we might recover the possibility of human agency is through the positing of genetic engineering (698-699). In the very same moment that genomics seems to radically delimit human agency through reductionistic narratives of genetic determinism, then, it simultaneously re-opens a new horizon for human agency through the possibility that we might rewrite the otherwise immutable laws of heredity through direct and deliberate intervention. In this reading genomic science as a whole becomes a version of Derrida’s famous *pharmakon*: that which kills (our sense of the free human subject) is paradoxically that which cures (by restoring to us the possibility of hope and self-creation).

This chapter explores this dialectic between pessimism/constraint and optimism/agency in science fictional treatments of a particular category of genetic information: single-gene disorders like Tay-Sachs, sickle cell anemia, and cystic fibrosis. Single-gene disorders defy attempts like Hamner’s to nuance or qualify the rhetoric of genetic determinism--in sharp contradistinction to the complex interactivity of most genetic traits, here the possession of “a single microscopic on/off switch” turns out to be determinative after all. Indeed, in the case of the particular genetic disorder on which I will focus--the autosomal dominant disorder Huntington’s disease--the *Gattaca* fantasy turns out to be quite literally true: a simple blood test, taken at or even before birth, can not only identify those who will inevitably fall sick from Huntington’s but describe with startling accuracy the circumstances of their lifelong decline,

including the likely age of emergence of symptoms, the progression of symptoms, and their anticipated life expectancy.

Huntington's disease, this is to say, registers a remarkable intersection between "science fiction" and "real life" that emerges out of genomic science--a point where possibilities that seem quite science fictional, even utterly fantastic, turn out to be dizzyingly real. Here, however, the relationship between disease and cure becomes quite complicated; not only does the possession of the Huntington's gene condemn the carrier to developing the disease, the genetic relationship also seems to completely foreclose any techno-optimistic possibility of "cure." Intervention is not imagined to be possible; the possessor of the gene is instead imagined to be simply doomed. Even in science fiction, a "cure" for Huntington's is generally imagined only prophylactically, in negative, in the form of eugenic interventions before conception--a cure that, from the perspective of the Huntington's carrier, is tantamount to the sad wish that they had never been born at all. The Huntington's carrier is imagined, we might say, to be in some basic way indistinguishable from their genetic profile; rather than producing the possibility of a scientific intervention that might cure a debilitating disease, these genetic narratives instead collapse any interpretive distance between the person and their genetic makeup. In the chapter that follows I trace the narrative treatment of Huntington's disease in several works across the science fiction and mainstream literary canons: Ian McEwan's *Saturday* (2005), Kurt Vonnegut's *Galápagos* (1986), Robert Sawyer's *Frameshift* (1997), and Octavia Butler's *Xenogenesis* novels (1987-1989) and short story "The Evening and the Morning and The Night" (1987). My interest in these texts is in unpacking the assumptions about the value of human life that emerge in the face of a prospective genetic disability like Huntington's disease; through them I seek to understand

the status of “hope” for lives that seem, from genomic perspectives both within and without, to have been rendered entirely hopeless.

CAGCAGCAGCAGCAGCAG...: *Saturday*

Although descriptions of Huntington’s sufferers long predate the nineteenth century, the first clinical description of the pathology of the disease came in 1872 from the doctor whose name the condition now bears, George Huntington [2]. Huntington was the first to recognize and categorize Huntington’s as an inherited disorder; in an 1872 paper titled “On Chorea” delivered to the Meigs and Mason Academy of Medicine (when Huntington was just 21), he describes the condition in hushed terms that will still resonate with potential sufferers today:

The hereditary chorea, as I shall call it, is confined to certain and fortunately a few families, and has been transmitted to them, an heirloom from generations away back in the dim past. It is spoken of by those in whose veins the seeds of the disease are known to exist, with a kind of horror, and not at all alluded to except through dire necessity, when it is mentioned as “that disorder.” It is attended generally by all the symptoms of common chorea, only in an aggravated degree, hardly ever manifesting itself until adult or middle life, and then coming on gradually but surely, increasing by degrees, and often occupying years in its development, until the hapless sufferer is but a quivering wreck of his former self. (Huntington)

Huntington’s longitudinal study of families afflicted by the disorder in the East Hampton region of New York--using case history notes originally gathered by his father and grandfather--revealed that the disease bore an unusually strict relationship to heredity:

Unstable and whimsical as the disease may be in other respects, in this it is firm, it never skips a generation to again manifest itself in another; once having yielded its claims, it never regains them. (Huntington)

The remainder of Huntington's paper catalogues the various symptoms associated with Huntington's disease, among them dementia, impulsivity, irrationality, emotional instability, suicide, severe weight loss, and the involuntary bodily movements (*chorea*, from the Greek for "dance") that gave the disorder its original name, *Huntington's chorea*.

The discovery of the gene for Huntington's disease in 1993 began to provide the start of an etiology for the disease. The Huntington's gene is located on chromosome four, in a region alternatively labeled HTT, HD, or IT15 (for "interesting transcription 15"). All humans carry two copies of this gene, one inherited from each parent; the gene codes for a protein labeled *huntingtin* which is needed in neonatal brain development (though its function in adult life, if any, remains unclear). Each copy of one region of the gene contains some number of repeats of cytosine-adenine-guanin (CAG)--what differentiates the healthy HTT from the mutant Huntington's version is the number. A person with under 28 CAG repeats is normal, and will never develop Huntington's disease; a person with over 40 repeats will definitely develop the disease at some point in their lives [3]. The number of repeats also correlates to the severity of the eventual disease, as well as to the age of emergence of empirical symptoms; the more repeats, the earlier symptoms will emerge, and the worse the disease will be, with especially high numbers of repeats culminating in an especially tragic variant called *juvenile Huntington's disease*, which emerges in childhood [4].

The exact mechanism by which Huntington's disease attacks the brain is not yet well-understood. What is known is that the historical understanding of the disease's presentation--a

lightning bolt out of the blue that suddenly strikes sufferers in middle adulthood--is somewhat misleading; in fact Huntington's carriers exhibit a slow diminishment of their cognitive faculties over the course of their adult lives, culminating finally in the emergence of "empirical symptoms" like chorea that can be measured and quantified by doctors. As best as doctors can ascertain, the strain of the huntingtin protein produced by the mutant HTT gene is toxic to the brain, slowly building up over time until a tipping point is reached and critical functions begin to be affected. In particular the disease attacks the striatum region of the forebrain, which is a kind of "executive suite" of the brain regulating both movement and impulse control. Whatever the precise mechanism, possession of a single Huntington's gene with sufficient repeats is enough to cause the disease; the disorder is dominant and (because it is not on one of the sex-linked chromosomes) can be inherited from either parent. Each child of an afflicted parent has a 50-50 chance of inheriting the disease.

For this reason Huntington's disease represents a particularly striking version of the strong genetic determinism suggested by *Gattaca* and critiqued by Hamner. Huntington's disease exemplifies a class of disability that up to now has not received a tremendous amount of attention in disability studies: *prospective disability*, the unhappy knowledge that while one appears healthy now one may (or will inevitably) become permanently disabled at some unknown point in the future [5]. With the development of a genetic test for Huntington's disease, a bizarrely science fictional situation has emerged in the real world for families at risk, insofar as their "destiny" has become literally knowable decades in advance (not just in the womb, but *before* the womb); genetic science here becomes in effect a type of time travel, an actual glimpse of one's own inevitable future. Because the effects of Huntington's disease emerge slowly and unevenly over the course of one's entire life, diagnosis with the HTT gene

significantly rewrites one's sense of the past and present as well, deeply destabilizing the carrier's sense of their own subjectivity and personal history; many who discover themselves to be carriers feel they no longer are the person they had appeared (or believed themselves) to be. And because Huntington's disease as yet has no effective treatment, much less a cure, technoscience can offer only a very painful *pharmakon*: it can absolve, or it can diagnose/doom, but at present it can do nothing else.

The tragic arc of Huntington's disease--from seeming health to total disability to young death in as little as a decade, typically beginning in one's 40s and 50s but sometimes much earlier--has inspired a popular fascination with the disorder that is incommensurate with its frequency in the population at large; although the rare disease affects only 5-10 people per 100,000 (with roughly 30,000 sufferers in the United States), it has become quite well-known in the culture at large. The most famous real-life sufferer of the disease is the folk singer Woody Guthrie, whose death in 1967 from complications of Huntington's at age 55 after a steep lifelong decline popularized knowledge of the disease. HD is now a staple of television medical dramas, appearing on episodes of *Marcus Welby, M.D.*; *E.R.*; *House*; *Private Practice*; *Scrubs*; and others [6]. Of these, only *House*'s version of the story deviates from the standard Huntington's plot, which typically has the tragic "guest star" encounter the regular cast to receive their unhappy future and then vanish forever at the conclusion of the episode; *House*'s Huntington's afflicted character was not a guest star but a regular character, the young doctor Thirteen. However, from another perspective the typical "guest star" plot is fulfilled after all; the revelation of the character's genetic destiny provides the occasion for Thirteen's departure from the regular cast. As will become clear in the discussion that follows, Thirteen's "demotion" replicates on the level of form the abiding sense of alienation, even exile from the family of the

human, that narratives about Huntington's disease typically produce on the level of content; once her prospective disability has been named, the character quite literally has no future on the series.

Ian McEwan's 2005 novel *Saturday* similarly captures--if at something of an extreme--the logic of exclusion that arises from the encounter between a medical "regular cast" and a Huntington's afflicted "guest star." Set in February 2003 against the backdrop of protests against the coming war in Iraq--protests which, from the "future perfect" perspective of the novel's 2005 authorship, necessarily prove futile--*Saturday* sits comfortably in "Fiction & Literature" section of the bookstore, safely protected from infection by "Fantasy and Science Fiction." But I argue the book becomes science fiction--or at least *science fictional*--in its attempt to work through the strange time-travel logic of prospective disability.

Early in *Saturday* its neurosurgeon protagonist Dr. Henry Perowne has a minor accident with another driver, Baxter. Baxter and his two companions exit their vehicle and confront Henry, first demanding money, then becoming violent. Henry then suddenly recognizes in Baxter's uncontrolled movements the tremors and shakes associated with early-stage Huntington's (90-91). No genetic test is needed; simply to see Baxter is enough. Consequently Baxter's entire destiny becomes laid before Henry, as in a science fiction:

Here's biological determinism in its purest form. More than forty repeats of that one little codon, and you're doomed. Your future is fixed and easily foretold. The longer the repeat, the earlier and more severe the onset. Between ten and twenty years to complete the course, from the first small alterations of character, tremors in the hands and face, emotional disturbance, including--most notably--sudden, uncontrollable alterations of mood, to the helpless jerky dance-like movements, intellectual dilapidation, memory failure, agnosia, apraxia, dementia, total loss of muscular control, rigidity sometimes,

nightmarish hallucinations and a meaningless end. This is how the brilliant machinery of being is undone by the tiniest of faulty cogs, the insidious whisper of ruin, a single bad idea lodged in every cell, on every chromosome four. (94)

Baxter's illness has only just begun--but from Henry's anticipatory perspective it is as if it has already happened. From this moment on, Henry's relationship with Baxter is utterly transformed. Although the two men have only just met, suddenly Henry knows everything there is to know about Baxter, past, present, and future:

Henry has heard that early onset tends to indict the paternal gene. But that may not be right. There's nothing to lose by making a guess. He speaks into the blaze of Baxter's regard.

"Your father had it. Now you've got it too."

He has the impression of himself as a witch doctor delivering a curse. Baxter's expression is hard to judge. [...] When Baxter speaks at last, his voice is different, cautious perhaps. "You knew my father?" (94-95)

Now the impending fight is averted, and Henry has Baxter completely in his thrall: "They are together, he and Perowne, in a world not of the medical, but of the magical" (95).

Both Baxter and Henry share an overriding sense of hopelessness about Baxter's ultimate fate, Baxter himself allows for the possibility of effective treatment only "One day perhaps. After I'm dead" (98). But Henry's attitude toward the prospectively disabled goes rather beyond mere pessimism: "There's no way out for him. No one can help," he thinks (99). "At some point he'll find himself writhing and hallucinating on a bed he'll never leave, in a long-term psychiatric ward, probably friendless, certainly unlovable, and there his slow deterioration will be managed, with efficiency if he's in luck" (218). In Henry's cold, objective, scientific gaze, the temporal

distance between Baxter's current state and the final procession of his disease becomes slimmer and slimmer as the novel progresses, until at last Baxter's entire life has telescoped into a single, endless moment of terrible suffering. The full expression of Baxter's Huntington's looms larger and larger in the evaluation of his life until it seems to be the only salient fact about him:

"Anyone with significantly more than forty CAG repeats in the middle of an obscure gene on chromosome four is obliged to share this fate in their own particular way. *It is written*" (217). In this vision all Huntington's sufferers bleed together into a single undifferentiated mass--all Huntington's sufferers are alike.

The result is a construction of Huntington's disease that subtly but definitively pushes sufferers--and, by extension, pre-symptomatic carriers--out of the family of the human altogether. Still living, they are already imagined to be dead. This trajectory reaches its culmination in *Saturday*'s climax, in which events conspire to place a stricken, unconscious Baxter on Henry's emergency room operating table following a failed violent invasion of Henry's home. Now Baxter is no longer an individual at all, but pure object: "Once a patient is draped up, the sense of a personality, an individual in the theater, disappear" (255). Standing over Baxter in the operating theater, with omniscient, total knowledge of how his life will--*must*--turn out, Henry contemplates "Baxter's unmendable brain" (263) and considers (in the absence of a longed-for "healing touch" [263]) that Baxter would simply be better off dead: "There's no tremor in the hands, Henry notices. Sleep is the only reprieve. Sleep and death" (270).

Henry's ultimate decisions to show mercy to Baxter--to save his life, and to insist to his wife and children that they not press charges--are driven ultimately by a negative desire to avoid "whipping a man on his way to hell" (288). The final, total evacuation of Baxter's slim grip on life and personhood--already failing--remains nonetheless his "dim, fixed fate [...] he must

unravel” (289). Before he left for the operation his wife begged Henry not to seek revenge (246), revealing later that she was thinking mostly of what *she* would have done in the same situation (274). In the operating theater Henry’s power over Baxter is total; he certainly could have euthanized him if he chose, and no one would have known. Henry’s final thoughts on why he made the choice to allow Baxter’s life to continue are darkly ambiguous: “By saving his life in the operating theater, Henry also committed Baxter to his torture. Revenge enough” (288).

Better to have never been born: *Galápagos* and *Frameshift*

And I declared that the dead, who had already died, are happier than the living, who are still alive. But better than both is the one who has never been born, who has not seen the evil that is done under the sun. --Ecclesiastes 4:2-3

The dehumanizing, Othering gaze applied by Henry to Baxter, which reframes his life as torture, is just as commonly the way the prospectively disabled Huntington’s carrier views herself. “I feel like killing my brother,” Jean Baréma writes in his Huntington’s memoir, *The Test*, “Just as I would want to be killed when I become like him. An act of love. A death potion” (53). (Later, Baréma resolves to kill himself if he carries the gene, before he grows too sick [143-144].) Alice Wexler’s Huntington’s memoir, *Mapping Fate*, similarly swirls around questions of suicide, especially her mother’s attempt shortly after diagnosis (61-62). Studies have shown the rate of suicide for Huntington’s carrier’s is consistently several times higher than the general population, with one study showing 7.3% of known Huntington’s carriers committing suicide and another showing 27.6% of the afflicted population attempting suicide. The probability of

suicidal despair is undoubtedly a major factor in the decision of the vast majority of at-risk persons to choose not to take the pre-symptomatic genetic test for Huntington's disease; facing a 50-50 coin-flip whose outcome will structure the rest of their lives, most people seem to feel they could not bear to know the truth [7].

This anxiety--the agony of foreknowledge--is at the center of Robert J. Sawyer's *Frameshift* (1997), an early Genomic Age novel that attempts to imagine how the ability to know a person's medical destiny will alter society. Here, the results are quite dystopian: a sinister insurance company uses genetic profiling to murder clients it knows will eventually become disabled, *before* they can begin to file expensive claims. But *Frameshift's* interests in these questions are not just political; they are personal as well. The novel's main character (a geneticist, Pierre Tardivel) discovers upon meeting his biological father as a young man that he is at risk for Huntington's disease. Upon discovering this fact, Tardivel's doctor immediately begins pre-suicide counseling, giving the young Pierre his home telephone number and begging him to call "if you're ever thinking of doing something rash" (37). But the attempted intervention does not stop Pierre from private fixation on "the only way out"; he is soon unconsciously running the edge of the doctor's card back and forth over his wrist, "as though it were a blade" (38-39). For years Pierre refuses to take the genetic test, choosing instead to simply assume he has the gene and resolving to accomplish as much as possible before he develops full symptoms (42-43); it is only at the urging of his girlfriend that he decides to take the test so that they know, one way or the other, before they are married. Being a geneticist, he is able to self-administer the test, stepping outside the usual therapeutic protocols designed to protect patients from depression and suicidal ideation. Unfortunately, his results are positive; he carries the gene, with a relatively high 79 repetitions (104-105).

Immediately upon discovering his genetic fate, he breaks up with his girlfriend, insisting that they cannot possibly marry under the circumstances. Soon after, he relents, and they are married after all. But Pierre insists, and here he will not budge, that he cannot father a child. His justifications for this prohibition shift in the novel. First he worries about genetic anticipation, the tendency of the number of repetitions in the mutant HTT gene to increase when transferred from father to child (106)--any child he had would be at high risk for juvenile Huntington's disease. But even after he is offered the chance to safely implant only non-HD embryos in his wife via the then-new technology of in-vitro fertilization, he still refuses, first on the grounds that as a "lapsed Catholic" he finds the procedure disconcerting, and second that "I can't in good conscience begin a new life that I know I'm not going to be around to see through its childhood" (114). He has no such compunctions about adopting, however, and indeed is perfectly happy for his wife to be impregnated by a sperm donor with the child they will raise together--suggesting some other psychology must be at work in his refusal of IVF.

This aspect of Huntington's disease--the refusal of children--receives parallel treatment in Kurt Vonnegut's million-year evolutionary novel *Galápagos* (1986). The novel concerns the next evolution of the human race into a species of smaller-brained dolphin-like creatures following the end of civilization, who descend from a small group of survivors of a crashed cruise ship on the Galápagos Islands (where Darwin first developed his theory of evolution). While the rest of the human race is rendered infertile by a virulent disease attacking women's ovaries, the isolated group remains unaffected--and one million years hence they are the only humanoid life on Planet Earth.

There is only one male living on the island, the captain of the cruise ship, Adolf von Kleist. But he has no interest in reproducing because he is at risk for Huntington's disease; both

Adolf (who does not carry the gene) and his brother Siegfried (who does) have chosen not to reproduce for what Vonnegut's narrator calls "admirably unselfish reasons" (89). "Of all the horrible diseases known to Mandarax"--a smartphone-like portable computer used in the novel--"Huntington's chorea may have been the worst. It was surely the most treacherous, the nastiest, of all surprises." The von Kleists' father murdered their mother while in the throes of the disease, and each of the two brothers "had been expecting to go crazy at any moment, to start dancing and hallucinating, for twenty-five years now" (90). Adolf ultimately only reproduces when his sperm is surreptitiously stolen by his post-menopausal partner, who uses it to artificially inseminate several of the still-fertile women on the island without his consent. It was only "pure, gambling-casino... dumb luck" (89) that this act didn't result in a near-universal penetration of Huntington's disease in the next evolution of humans--and the book is clear that Adolf, even if he'd known the stakes, would certainly have refused to take the gamble, even at the cost of universal human extinction.

The drive to reproduce is incredibly powerful, on the levels of both biology and culture, leading Lee Edelman to note in *No Future: Queer Theory and the Death Drive* that "[the] Child remains the perpetual horizon of every acknowledged politics, the fantasmatic beneficiary of every political intervention" (3). The centrality of the Child in heteronormativity has deep implications for study of disability as well. To lose touch with this circuit of reproductive futurity--not through personal choice, but with the totalizing force of a moral prohibition--is in a real sense to feel as though you have been cast out from history altogether. As with any other victim of eugenicist discourse, when we deem the Huntington's carrier unworthy of continuation into the future we diminish her very claim to personhood, to humanity as such.

That here the constraint is so commonly self-directed, caused by sad memories of a parent's deterioration or the terrified anticipation of one's own, multiplies this painful sense of being cut off from futurity. As Susan Sontag notes in *Illness as Metaphor*, "Nothing is more punitive than to give a disease a meaning--that meaning being invariably a moralistic one. Any important disease whose casualty is murky, and for which treatment is ineffective, tends to be awash in significance" (58). The "significance" of Huntington's produced by these narratives' prohibition on producing children is, in essence, an assertion of the absolute worthlessness of the life of any Huntington's sufferer--and the punitive character of this moralizing discourse becomes internalized in the at-risk subject as a fantasy of self-erasure, or even self-abortion.

This tragic fantasy has been active in each the texts I have discussed thus far, but it reaches perhaps its fullest expression in the early passages of *Frameshift* in which Pierre meets his biological father for the first and only time:

Pierre squeezed his hand. ... "Do you have any other children?"

"Daughters," said Henry. "Two daughters. Adopted. Dorothy--Dorothy couldn't..."

Pierre nodded.

"Best, in a way," said Henry, and here, at last he let his gaze wander away from Pierre. "Huntington's disease is... is..."

Pierre swallowed. "Hereditary. I know."

Henry's head moved back and forth more rapidly than normal--a deliberate signal all but lost in the muscular noise. "If I'd known I had it, I ... never would have allowed myself to father a child. I'm sorry. V-very sorry." (32)

This encounter, I suggest, is the traumatic primal scene that undergirds Pierre's shifting and inconsistent justifications for never fathering a child, even after the development of IVF intervention that would insure any such child would *definitely* be free from the disease. Pierre takes up his father's dying wish and refuses to reproduce under any circumstances--an interdict which, if applied to Henry counterfactually, would naturally have prevented Pierre's own birth as well. To believe it would be better never to reproduce than to risk passing on your "defective" genes is necessarily to believe it would be better to have never been born at all--it is to believe you should not (or do not deserve to) exist. In this way Pierre's refusal of children looks as much like brutal self-flagellation as it does an ethics; what seems to be ultimately at stake for him is not the safety of any potential child but his own internalized shame, his tragic belief that he is unloved and unlovable as a result of his prospective disability. It is the task of the rest of the novel to heal Pierre, by convincing him otherwise.

No cure, no hope? *Adulthood Rites* and "The Evening and the Morning and the Night"

In the middle book of Octavia Butler's Xenogenesis trilogy, *Adulthood Rites* (1988), we find a rather different science-fictional treatment of Huntington's disease than those we have previously encountered. Butler's Oankali are a three-sexed species of "gene traders" who wander the universe looking for other life forms with whom they might exchange genetic material; they have arrived on Earth following a devastating nuclear war and taken the few survivors into their spaceship to pursue an exchange. They are particularly interested in our cancers, which the Oankali find intoxicatingly beautiful; they believe the careful application of our pliable cancer genes will allow them untold possibilities for future experimentation.

Centuries later, with the earth repaired from the war, the humans are awoken from cryogenic suspension and allowed to return to the earth, where many choose to flee the Oankali encampments and attempt to live on their own. The Oankali have rendered all the humans they rescued infertile, pending their agreement to the trade; in a brutal “forced choice” that would be illegal under the United Nations Convention on the Prevention and Punishment of the Crime of Genocide, only humans that agree to mate with the Oankali, and therefore breed Oankali-human hybrids, are permitted to bear children. Over the course the novel the Oankali are persuaded (through the direct intervention of several of the first hybrids) to relent on this absolutism, and allow humans an opportunity to continue an independent existence as a species apart from the Oankali after all. They cannot offer the humans Earth, which is slated to be consumed and turned into a new Oankali spacecraft--but they can offer the humans a separatist colony on Mars.

To the Oankali this concession is in fact a grave sin; because the Oankali have an innate ability to read and modify the genome as easily as we can taste or smell, they can recognize in human beings a dire genetic flaw, the combination of high intelligence with hierarchical thinking (with the hierarchical thinking the older and more powerful of the two impulses). The Flaw, as it is called in the novels, functions in much the same way as Huntington’s disease: possession of the Flaw (and all humans possess it) necessarily means eventual species-wide disaster. Our genetics are, from the Oankali perspective, self-toxic; we cannot help but destroy ourselves.

Over the course of *Adulthood Rites* the protagonist, Akin, the early human-Oankali hybrid who has persuaded the Oankali to give the humans Mars, has a series of encounters with Tate, a human resistor who carries the Huntington’s gene. Huntington’s is a “nasty little disease,” Tate tells him, “that should have killed me years ago” (117). Only the intervention of the Oankali while she was in captivity temporarily halted the disease’s progression--but now

their stopgap measures are failing and she needs the intervention of the Oankali to fully replace the gene. Only her hatred and resentment of the Oankali for her capture and infertility is stopping her from seeking treatment. “Will you let someone correct your Huntington’s disease genetically?” Akin begs her late in the novel, after treating her from a bad fall. “The disease had become active. It was active when I healed you. I thought perhaps... you had noticed” (267). Tate becomes very frightened at his news, believing (as would have been true in her pre-Oankali life) she has been told that she is doomed--but the miraculous Oankali possess the ability to turn off the gene and reverse any damage that has already been caused. The final argument Akin makes to compel her treatment is a version of the concern over reproductive futurity that paralyzed Adolf von Kleist in *Galápagos*: “You can’t introduce this to the Mars colony. You know you can’t. It would spread through the population in a few generations” (268) [8]. This vision of universal Huntington’s is enough; Tate relents, and agrees to treatment.

Of all the novels that deal with Huntington’s that I discuss in this chapter, only *Adulthood Rites* allows the possibility of a cure, and this is a cure that is only quasi-scientific, based on the intervention of an essentially magical race of aliens who possess a literal version of the “healing touch” Henry longed for in *Saturday*. (McEwan’s novel’s “realism,” of course, denies such a possibility ever existing in the real world.) This absolute insistence on pessimism is puzzling, and quite paradoxical; as *Saturday* itself rightly notes, Huntington’s unique status as a single-gene disorder has not only suggested multiple promising treatment lines for gene silencing, but has produced significant research funding in the hopes that what is learned about Huntington’s can be applied to other, more complicated diseases.

This need to inoculate oneself against what *Saturday* calls “the lure of hope” (224)--even when such hope is actually quite reasonable--is just as strong (if not stronger) in *Frameshift*,

where the proposition “Huntington’s *was* terminal” is Pierre’s “one unshakeable reality” (184). (This, in a novel in which genomic science has allowed for both the successful cloning of Neanderthals and a coding of the gene for telepathy!) Nothing in *Frameshift* ever presents Pierre with any hope that his disease might be cured; instead, the novel presents us with a long and inevitable decline in the character’s once prodigious abilities, culminating in the novel’s closing pages with the tragic revelation of a Pierre who can no longer participate in (or even understand) his own life’s work (336-338).

Huntington’s disease, in short, tends to be presented in these science fictions with an overawing pessimism not commonly seen in other science fictional ruminations on disability--an absolutism that is out-of-sync even with real-world research into possible treatments. There are no cures allowed here, no miracle drugs, no possible prostheses. Indeed, in contrast to real-world genomics, in which genetic disorders commonly convey survival advantages despite their overall health drawbacks (like the increased resistance to malaria conveyed by carrying only one sickle-cell gene), Huntington’s disease is generally imagined to offer no possible compensations whatsoever [9]. The Oankali find even cancer fascinatingly beautiful, but they barely possess the language to articulate their horror at Huntington’s: “I found... something. [...] It was a... wrong gene” (117).

I conclude, therefore, with a science fictional attempt to think beyond this totalizing paradigm of inescapable, hopeless despair. Octavia Butler’s “The Evening and the Morning and the Night”--first published in 1987, at the same time as her *Xenogenesis* trilogy--concerns a fictional syndrome called Duryea-Gode disease. Butler’s own commentary on the story--which she considered her “most carefully developed story [...] from a hard SF standpoint” (McCaffery 22)--notes that DGD combines the progressive presentation of Huntington’s disease with

phenylektonuria (“a recessive genetic disorder that causes severe mental impairment unless the infant who has it is put on a special diet”) and Lesch-Nyhan disease (“which causes both mental impairment and self-mutilation”) (“Evening” 69). The result is an even more nightmarish symptomatology than even Huntington’s, in which sufferers unpredictably “drift” and mutilate themselves or others; only a special diet can temporarily keep the symptoms at bay. Caused by side effects from a “magic bullet” anti-cancer drug called Hedeonco, DGD is even more heritable than Huntington’s; *any* child conceived after treatment with Hedeonco will be born with DGD. (In this way DGD inverts the typical temporality of Huntington’s; in the first generation, at least, healthy, unaffected parents give birth to afflicted children.) Most people with one DGD gene die before age forty; children born to parents who both have DGD experience more severe symptoms, as is the case with people born with two mutant Huntington’s genes as well.

“The Evening and The Morning and the Night” begins much like the other Huntington’s narratives I’ve discussed; specifically, it begins with the narrator’s suicide attempt at fifteen after her first visit to a DGD ward. “I won’t describe the ward,” Lynn Mortimer says. “It’s enough to say that when they brought me home, I cut my wrists” (35). Soon after this, the narrator’s father “drifts,” brutally murdering her mother before killing himself. The story tracks Lynn as she goes to college on a “Dilg scholarship,” named for a foundation that runs convalescent hospices for last-stage DGD sufferers; befriending other DGD patients (including her eventual boyfriend, Alan), Lynn engages in many of the same debates about suffering, suicide, reproductive futurity, and self-erasure found in the other Huntington’s fictions. Both characters wrestle with the same sense of “bitterness and despair” that characterizes narrative depictions of Huntington’s suffering. “If the two of them had had any sense,” Alan says, speaking of his parents with echoes

of Pierre Tardivel's desire for self-erasure, "they would have had me aborted the minute my mother realized she was pregnant. [...] Hell, they should pass a law to sterilize the lot of us." But Lynn's attitude is more significantly conflicted: despite all her reservations about bearing DGD-positive children, feels the eugenic solution would be "like killing part of yourself" (42).

But soon the story takes a turn. Upon visiting a Dilg ward to visit Alan's dying mother, Lynn and Alan discover a presentation of the DGD that is quite different from the one they have experienced in their own scarred pasts. Inside the immense Dilg mansion they find DGD sufferers whose lives are stable and whose symptoms are under control--who, indeed, are producing art and sculpture to be hung in galleries across California or who are busily inventing impressive new gadgets and devices for public use. "Our people work instead of tearing at themselves or staring into space" (48), explains the head of the retreat, a DGD sufferer named Beatrice. "Oh, yes, DGDs create things. At least they do here. [...] Here we can help them channel their energies. They can create something beautiful, useful, even something worthless. But they create. They don't destroy" (48-49). In contrast to the typical late-stage DGD sufferer, who must be tightly restrained in order to prevent violence and self-mutilation, at the Dilg ward the patients are allowed to move freely (53).

Here at last we find a gap between individual and disease that has eluded us in other Huntington's fictions. Here, the Huntington's-cum-DGD sufferer is able to retain their vitality, their creativity, their personhood, despite their affliction--and so here we find the possibility of life *continuing*, rather than ending, with several genetic disease. In fact this controlled mode of DGD turns out to have unexpected cognitive benefits--DGD sufferers are both more creative and more able to concentrate on work than non-carriers (55); the complex palmprint-voiceprint locks in the facility, for instance, turn out to have been invented by a DGD with an average IQ who

didn't finish college, purely from an obsessive, post-symptomatic desire to achieve his vision (65). In this alternative vision of Huntington's, perhaps, we can hear an echo of the startling proposition suggested by Joe Klein in his recent biography of Woody Guthrie, that the progression of Guthrie's Huntington's disease may in fact have driven his prolific creativity:

And while it would be absurd to suggest that Huntington's disease made Woody Guthrie a brilliant songwriter, Dr. Whittier (and, later, Marjorie Guthrie herself) would wonder aloud if the disease hadn't worked like a drug on Woody, as a creative spur (in much the same that some artists use alcohol and other drugs), enhancing his natural rhythmicity, forcing the brain to continually rewire itself as cells died, forcing new, wonderful, and unexpected synaptic pathways to open (which also led to some unexpected and not so wonderful behavior), forcing the brain to become - in effect - more creative to survive...

(Klein 462-463)

Indeed, in September 2012--directly paralleling Butler's story--the *Los Angeles Times* reported results of a new study showing that carriers of the Huntington's gene may actually have *increased* capacity for learning in the period before physical symptoms emerge.

The key to this remarkable reversal in the presentation of the disease is a second complication to DGD that is known only in Dilg wards; it turns out female children of double-DGD patients possess a preternatural, almost psychic ability to stabilize and even command other DGD sufferers. "It's a pheromone," Beatrice explains. "It's only when two irresponsible DGDs get together and produce girl children like me or Lynn that you get someone who can really do some good in a place like this." The Dilg ward more generally provide a context in which the life of the Huntington's carrier can be understood as something other than simple tragedy--as simultaneously a kind of (very complicated, very fraught) gift. Crucially, Beatrice

suggests that Alan and Lynn choose not to have children, “in spite of our need” (61) [10]-- framing the Dilg ward as precisely the sort of *non*-reproductive, queer space for futurity that Edelman offers as an alternative to heteronormativity in *No Future*.

In “The Evening and the Morning and the Night,” then, Butler puts forth the possibility that has eluded so many of the other science fictional treatments of Huntington’s I have discussed: that Huntington’s need not be understood solely as a tragic, ultimately meaningless fall from grace, but a fully human life that can retain its own dignity and vitality despite hardship. “The people of Dilg are problem solvers, Alan. Think of the problems you could solve! [...] They’re working, Alan,” Beatrice enthuses. “The disease hasn’t stopped them, *won’t* stop them” (65). The Dilg ward--a community borne out of and built around shared struggle, shared suffering--offers DGD carriers the chance to retain their individuality, a “chance to live and do whatever they decide is important to them” (66). The Dilg compound is no utopia--and still no cure--but it is a chance, a hope, a life.

And such communities are by no means science fictions. Alice Wexler’s *Mapping Fate* recounts her sister Nancy’s visits to the Lake Maracaibo region of Venezuela, whose high incidence of Huntington’s disease helped researchers isolate the gene. Locals call the disease *el mal de San Vito*, or simply *el mal*: the sickness (182-184). The area as a whole has of course suffered greatly as a result of the disease, both in the lives of individuals and in the “rejection of those outside, who stigmatized the entire community”--but Wexler reports the people of these communities understood that the disease was a hereditary illness, “‘in the blood,’ as they put it, not a punishment from God or a moral curse” (184-185). Nancy Wexler reports in her field notes that “She was struck, too, by the way in which people with Huntington’s seemed to be better integrated into their communities than those in the United States, who were often overmedicated

and hidden away in hospitals or at home” (186). The widespread risk in the community also significantly reduces the loneliness and isolation of being at-risk; the experience is much more widely shared, and while still painful, the burden is partially lifted insofar as it is borne by all (198-199). In her follow-up to *Mapping Fate, The Woman Who Walked into the Sea*, Wexler recounts similar bonds of community and tolerance among sufferers of “St. Vitus’s dance” in the East Hampton community in which George Huntington first identified the disease (49-50, 52).

The fictional Dilg compound, and the real-world Lake Maracaibo and East Hampton communities, make actual the reproductive nightmare posited and rejected by *Galápagos* and *Adulthood Rites*: Huntington’s disease as plague, unleashed social contagion, running amuck across an entire community. But this supposedly unthinkable nightmare turns out to be quite livable after all; keeping in mind Wexler’s observation that “this obviously pathological, genetically determined killer may acquire distinct meanings for different individuals, families, and cultures” (xxiv), we can find in these real and imagined communities an answer to the conviction that possession of Huntington’s disease has only possible meaning. Indeed, such places literalize Sontag’s memorable notion that

Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place (3).

In a sub-subgenre of genomic science fiction filled almost exclusively with hopelessness and dread, “the kingdom of the sick” in “The Evening and the Morning and the Night” stands as a striking alternative to a dominant narrative of resigned and bleak despair, insisting instead that

we maintain the wide gap between individual and illness, between sufferer and suffering--reminding us that disability is not the same as death.

Notes

[1] Barry Barnes and John Dupré have called the mode of genetic determinism Hamner critiques *astrological genetics*--as if a genetic profile might produce a kind of scientifically accurate horoscope--and note that the ongoing popularity of this fantasy in the face of its continual debunking demonstrates that “genomics/genetics confront us not just as practice and technology, and as knowledge and understanding, but as myth and ideology as well” (5-6).

[2] More detailed accounts of Huntington’s discovery can be found in Douglas J. Lanska’s “George Huntington (1850-1916) and Hereditary Chorea” and Alice Wexler’s *The Woman Who Walked into the Sea*.

[3] The middle ranges represent intermediate stages of the disease. A person with between 28 and 35 repeats will not develop the disease themselves, but is at risk of passing the disease on to their children due to *genetic anticipation* (the tendency, here, of the length of the CAG repeat strand to grow longer in subsequent generations, especially when the gene is passed father to child). A person between 36 and 40 repeats is in a different gray zone; they may or may not express Huntington’s symptoms, depending on other life factors.

[4] Even here, it should be noted, we find that the progression of Huntington’s disease is more complicated than the genetic determinist fantasy would suggest. The number of repetitions accounts for approximately 60% of the variation in onset and severity; other, largely unknown environmental factors account for the rest. Symptoms have been known to emerge decades apart

even for people with the same number of CAG repetitions, even in siblings. For more information on this and other elements of the disease, see Walker, "Huntington's disease."

[5] While prospective disability is of course related to the knowledge that every person who survives to senescence will inevitably undergo some diminishment of her mental and physical capabilities, it is important to note that prospective disability is no more reducible to "hyperaging" than any other disability. Prospective disability anticipates *deviation* from the assumed "normal" course of life, rather than its speeding-up.

[6] The disease even recently made an appearance in the fourth season of *Breaking Bad* as a glimpse into the back-story of Walter White, the show's protagonist, whose father was revealed to be a sufferer. Interestingly, according to the timetable presented White himself should also be at-risk; the character's claim that he was tested as a child, with negative results, is impossible given the chronology involved, and sounds instead like a lie told to comfort to a frightened, grieving child. It remains to be seen whether this plot will be taken up further in the show's final season.

[7] Having finally undergone "the test" myself in early 2010, ultimately discovering I do not carry the gene, I can confirm from personal experience that the process of resolving your lifelong uncertainty over Huntington's disease is its own form of deeply terrible existential misery.

[8] Sontag again: "Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious. Thus, a surprisingly large number of people with cancer find themselves being shunned by relatives and friends and are the object of practices of decontamination by members of their household, as if cancer, like TB, were an infectious disease" (6). This sense of isolation and abandonment is commonly reported among those who discover they have the gene for Huntington's, or even discover they are at-risk.

[9] Here, too, real-world science offers a much more nuanced view than science fictional science: a 2007 Tufts University study concluded that Huntington's carriers tend to have more children than non-carriers because the disease "may have beneficial health effects early in life," while a study published while I was writing this chapter in early 2012 suggested Huntington's carriers were at a 53% lower risk for developing cancer than the general population.

[10] Beatrice's rejection of reproductive futurity as the ultimate criterion for human life suggest something like the queer futurity Edelman advocates in *No Future*.

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