5. Writing Life – Writing Security: Alice Wexler's *Mapping Faith* and the Emerging Biosecurity Individual

> The primary meaning of existentiality is the future.
> *Martin Heidegger*

"Know your risks" is one of the dominant refrains of our culture today. Like a mantra it reverberates through the most diverse parts of life and seems the unquestionable wisdom of our times. But especially in terms of biosecurity this knowledge is difficult to come by. Biosecurity practices predicting and narrativizing the future are crucial to establish, protect, and maintain (a sense of) security. In this context, genetic testing has become a hallmark security practice, promising to provide knowledge that facilitates security. But what if knowing one's risks does not and cannot lead to security, as in the case of incurable genetic diseases such as Huntington's Disease? What if the mechanisms and technologies developed to calculate risk do not keep their promise and facilitate life, liberty, and the pursuit of happiness? Alice Wexler has dedicated her memoir *Mapping Fate* to precisely this circumstance at a time when genetic testing was just being developed and the era of the gene was still in its infancy. Her memoir with the subtitle "of family, risk, and genetic research" exemplifies both the necessity of narrative to construct a pervasive understanding of security and risk, as well as the inescapable influences of biotechnological developments and their security narratives on life and identity.

Mapping Fate tells the medical history of Huntington's Disease alongside the history of Alice Wexler's family coping with this hereditary disease. Her text explores her mother's suffering from the disease as well as the breach in life which this familial affliction represents for her and her sister Nancy. With the mother's diagnosis the siblings become individuals at risk[1] and need to find strategies to cope with the 50:50 chance of carrying the gene responsible for Huntington's. As such, the text is part of the growing genre of illness narratives, which have attracted a large body of scholarly interest since the AIDS

---

[1] Wexler's story does not primarily deal with the development of this identity in terms of a "risk society" as it is not the newly emerging risk of a Beckean risk society that challenges the individual and produces this risk identity.

crisis in the late 1980s and early 1990s.[2] Spearheaded by intellectuals and academics who have fallen ill, such as Audre Lorde, Susan Sontag, and Arthur Frank the genre and its critical discussion have proliferated. These texts highlight the vulnerability of the individual put at risk by their own corporeality, and the ways that these individuals "become storytellers in order to recover the voices that illness and its treatment often take away" (Frank xii). They exemplify that illness is not merely a biological matter, but is positioned at the intersection of biology and culture, as various scholars have pointed out (Sontag, Davis and Morris, T. Cole, Charon). Although Alice Wexler's text is decisively different from traditional illness narratives since her memoir "is really less about an illness than about the possibility of an illness" (A. Wexler, *Mapping* xxii), she engages in the same discursive space as these narratives. By representing a story of risk and insecurity Wexler also narrativizes security, which is inseparable from the representation of risk and essential for a sense of self for the biosecurity individual. I will therefore focus on the negotiation of what biological security means and how the biologized understanding of security influences the conception of a "good life" and of identity itself.

With Wexler's memoir I will turn to the most traditional form of autobiographical writing and therefore the discursive formation most clearly regarded to be the "genre of the self." What began in eighteenth century Romanticism as a search for origin has become an icon of subjectivity and individualism (Folkenflik, "Introduction" 8) and the epitome of "western" culture. The genre underwent radical changes, especially during the twentieth and twenty-first century, with a thorough theoretical reconceptualization of the genre in the 1980s. But the representations of life have attained their exemplary and didactic purpose already found in Saint Augustine's *Confessions* as much as in *The Education of Henry Adams*. The changing aesthetics of life writing, however, express and expose changes in the perception and understanding of the self, which is a central question of this chapter. Alice Wexler's memoir therefore represents a promising vantage point to study how security is constructed and the ways in which biosecurity narratives influence the understanding of life and self for the growing group of risk individuals.

I will not read Alice Wexler's memoir with regard to its truthfulness or to authenticate the representation of a life *as* an example of a risk identity. This would be what Völz called a "security realism" (Völz, "Aestheticizing" 619) which ignores that literature is much more than a mirror to an extradiegetic reality. I rather perceive the text as a writing of a life and time that is significantly created in its "final" meaning by the text itself and can therefore never claim to be mimetically mirroring a pre-existing truth or reality. Nonetheless, the claim of authenticity, which resonates in this discursive formation,[3] is crucial for the book's reception and for the construction of the security narrative that defines this risk

---

[2] The sociologist Arthur Frank defined illness narratives in *The Wounded Storyteller* as narratives of individuals, who are suffering from an illness and have to therefore renegotiate their life and identity. With the concept of the ill person as a storyteller he assigned the individuals an active role in understanding and negotiating their illness (xi). He categorizes three main types which he terms restitution, chaos, and quest. In contrast, scholars such as Arthur Kleinman and Rita Charon have emphasized the role of the "wounded healer" and the importance of narrative to empathize and bond with the ill person.

[3] Paul John Eakin dedicates a whole book to *The Ethics of Life Writing* dealing with the "truthfulness" of the genre and the representative responsibility of the author.

identity. In this chapter I will therefore focus on how this story of a biologically inflected security is told as a "necessary fiction" indispensable to fully understand the self.

Wexler's text is especially interesting because she is representing a changing understanding of security in the context of Huntington's disease based on biotechnological developments. Though Huntington's was known, diagnosable, and incurable, similar to today, the understanding of the disease, the treatment, and the time of the diagnosis have changed due to the development of genetic testing. The text is not only an example of how biomedical and biotechnological advances have changed our relation to body and self today, but depicts the time leading up to and the anticipation of these changes. While Alice Wexler neither gets tested in the storyline of the memoir nor reveals if she is going to, she negotiates the different possibilities of knowing provided by this security practice. She therefore establishes a relationship to security, which represents the historic moment when the relation to the future and the urge to pre-emptively "do something" is just emerging, appearing as a promise of security; a security that is a seemingly natural desire for many people today, when testing has become a more commonplace practice and a prerequisite for biological security.

Published in 1995, two years after the discovery of the Huntington's gene, her memoir was written amidst extensive discourse on genetic testing and at the beginning of the era of the gene. At that time, the benefits and threats of "new genetics" were frequently debated in the public sphere. *Mapping Fate* represents a negotiation of the utopian and dystopian voices dominating public discussions of the potential benefits and perils of genetic testing.[4] In rendering her identity as a risk individual Wexler makes the act of writing a crucial element of her sense of security and her most crucial security practice. In doing so, she offers a variety of multilayered security narratives that influence and at time contrast and contradict each other, competing over the definition of what security really means for her and how to achieve it. In this exploration emotions play a crucial role to establish the necessary narrative of security and to define her identity as a biosecurity individual. I will therefore highlight the function of affects in those narratives, specifically anxiety and hope. To facilitate a better understanding of these competing narratives I will first offer a very brief introduction to the history of Huntington's disease. I will then show how Wexler renders her risk identity as both an ascription as well as affecting her identity on a more intimate level. I will argue that Wexler re-constructs her identity based on the temporality and logic of an always already precarious normality in which certainty becomes a desired object that stands in for security.

Threatened by Nature and Culture: A Short History of Huntington's Disease

Huntington's disease (HD) is a late-onset neurodegenerative disease, which means that the disease affects the brain and leads to its progressive deterioration. The disease's most characteristic symptoms are involuntary body movements and twitches, which make the affliction highly visible. Because of these movements HD used to be called Huntington's

---

[4] For a thorough analysis of this opposition between proponents and opponents of genetic testing see Shakespeare.

Chorea "on account of the dancing propensities of those who are affected" (Huntington 110), and popularly it had been referred to as St. Vitus Dance.[5] However, symptoms of the disease are more diverse and range from depression and slurred speech to the loss of balance and the ability to control muscle functions. Ultimately the disease leads invariably to the loss of all mental and physical abilities. The disease usually manifests rather late in life, with the first symptoms emerging during the patient's thirties or forties. Only in the more severe form of Juvenile Huntington's disease do symptoms set in before middle age.

HD is caused by a genetic defect on Chromosome 4 and is described as a dominant mono-genetic disease,[6] which means that it is inherited dominantly on just one gene (De Melo). Children of an afflicted parent therefore have a 50:50 chance of inheriting the disease. These individuals are regarded as risk individuals. For a long time the disease could only be recognized once it materialized in outwardly recognizable symptoms. Only the discovery of the genetic marker "G8" in 1986 made it possible to test for HD before the onset of the disease. The discovery of the gene "IT 15" in 1993 further facilitated pre-symptomatic and prenatal testing (National Institute of Neurological Disorders and Stroke). Though presymptomatic testing has made the diagnosis of the disease possible before its onset, Huntington's remains incurable and always fatal. In contrast to other degenerative diseases there are very few possibilities of treating the symptoms and no approved ways of slowing down the degenerative progression of the disease.

Though the condition had been known for a long time, George Huntington wrote the first scientific description of the disease in 1872 and is credited with its "discovery." His famous article "On Chorea" described the disease as a brain disease (110) and already explained its genetic transmission as a dominantly inherited trait, which never "skips a generation" (Huntington 112). He identified the main characteristics that would remain the standard understanding of the disease until the era of the gene initiated the search for the exact gene and genetic location responsible for the condition. Besides the hereditary nature and the late onset George Huntington emphasized the "tendency to insanity and suicide" (Huntington 111) as a recognizable pattern that can be correlated with the disease. In highlighting this aspect, he stresses the burden that the disease represents for those afflicted as well as for their entire families, for "the poor patient presents a spectacle which is anything but pleasing to witness" (Huntington 112). Already this early description thus emphasizes the social implications of the disease alongside its biological description. Huntington seems to recognize that the disease is not only mentally and physically painful but socially stigmatizing. The bodily performance turned patients into social outcasts. The performative aspect of the disease increases the shame that has been associated with the social and physical difference Huntington's disease produces.

---

[5] Saint Vitus dance, or dancing mania, is a phenomenon that occurred in various places in Europe between the 13th and 17th century, and which to date has no conclusive explanation. Huntington's disease is not describing the medicalized version of this phenomenon but was named after it, for the likening to the dance movements (Esterianna).

[6] This represents a decisive difference from most other genetic diseases that are caused by multiple factors and not just one gene (De Melo).

While Huntington stressed that "hereditary chorea" affected "few families . . . almost exclusively in the east end of Long Island" (Huntington 111) and was therefore probably of little interest, eugenicists made the disease one of the flagships to promote their programs of "breeding control" to improve and protect the future of society. While the correlation of mental illness, physical symptoms, and genetics were still difficult and intangible during the 1910s and 1920s, often more a pseudo science than anything else, Huntington's represented "the one clear case of neuropathic entity" (Davenport 283). Davenport explained the urgent need to control the reproduction of HD individuals with his findings that most cases "can be traced back to some half dozen individuals, including three (probable) brothers who migrated to America during the 17th century" (Davenport 283–4). To protect the national body from this form of "contamination" and therefore – in the understanding of eugenicists – to protect national security, Davenport suggested the forced sterilization of afflicted people, as well as of those at risk (A. Wexler "Eugenics" 140).

Patients suffering from the disease were thus recast as a threat themselves – to their fellow citizens and the nation. Both, nation and sick individual, were narrativized as in need of medical protection. Davenport argued, as did most of his colleagues and followers, that measures such as forced sterilization were not just crucial to improve society, but to save the afflicted individuals and their future suffering offspring from this harmful fate. The program is thus not only protecting the healthy nation but the potential future afflicted. The HD individual was thus suffering from a triple injury: that of their disease, that of social stigmatization, and that of state enforced security practices. Such programs of non-consensual and not-informed sterilization continued far beyond the eugenic movement as mentioned before. And according to Alice Wexler's paper on eugenics and Huntington's, the eugenic mindset and their security narrative influenced "the priorities of HD research. Even in the 1960s some of the most knowledgeable geneticists and neurologists seemed to give a higher priority to research on 'early detection' for eugenic purposes than to research on therapies and improved care" (A. Wexler, "Eugenics" 140).

The understanding of unlivable life, or dehumanizing life, which underlies the eugenic mindset is still recognizable in the more contemporary understanding of the disease. This evaluation of the disease as the understanding of what the disease "does" to those suffering from it also emphasizes that illnesses are always both biological and cultural. Threatened by their own corporeality HD individuals face another threat. Since the disease dissolves part of the brain tissue, those affected lose their mental ability and ultimately their ability to remember their past and "who they are," they can no longer tell their story. By losing the ability to know themselves and their "healthy" identities they lose what has culturally been made to represent the essence of humanness.[7] Hunting-

---

[7] The ability to tell one's own life story (and identity) also represents the touchstone of subjectivity and identity and the normative structure which defines us as human subjects. In that sense, the practice of narrating the self is much more than a deliberate act. In a precarious way, this cultural idea of "the narrative self" excludes a large group of persons that are not able to story their life and identity, such as Alzheimer patients who are often described as "socially dead" (Rhodes and Vedder 4).

ton's is therefore understood to not only rob people of their life but of their humanness, similarly to the understanding of Alzheimer's disease. This represents an additionally threatening prospect adding to the threat of a "premature" death due to the disease.

Not surprisingly then, Huntington's represented a silenced family heritage often hidden away and not talked about; a characteristic already Huntington had described in his observations on the disease (111). Also after the era of eugenics people afflicted with the disease suffered from stigmatization and social exclusion. As in the case of Wexler's family, secrecy and the eventual move into a care facility are common features of a HD family story. The collective silence represents an additional burden for the afflicted. Woody Guthrie, probably the most famous person who suffered from Huntington's disease, is a prime example for the material repercussions caused by this silence. Due to misdiagnosis and social misconception the singer spent much of his life branded as an alcoholic and was admitted to various mental institutions before "the cause" of his behavior was recognized as Huntington's disease (National Institute of Neurological Disorders and Stroke).

The late 1960s saw a change in public awareness of Huntington's disease. During that time Alice Wexler's father founded the Hereditary Disease Foundation and other affected families, such as Guthrie's wife also started major funding efforts to combat the disease. Furthermore, Woody Guthrie's death in 1967 brought national attention to the disease. This was achieved in part by Guthrie himself who already "gave a voice" to the illness in his "Huntington's Chorea Blues" during his lifetime (qdt. in Maloney 133), as well as memorial tributes by artists such as Bob Dylan with his "Song to Woody," and the more explicit poem "Last Thoughts on Guthrie." These representations in the public sphere, though still few and far between, changed the perception of individuals afflicted with Huntington's, explaining their "deviant" behavior within a medicalized context and expressing the suffering implied in the behavior. By making HD visible and known, such representations challenged the social stigma that had been attached to the disease for centuries. In a similar way, Wexler's memoir is also part of this "giving a voice" to HD, making it visible and known.

Since the publication of Wexler's memoir, and in response to the genetic test in 1993, literary and cultural production relating to Huntington's has continued to proliferate. Though the disease might remain comparatively little known to the general public, its evocations in discourse about genetic testing have made it more and more present in public space. Today, representations of the disease can be found in many parts of culture, probably most prominently in the many bio-documentaries that flood entertainment culture and the internet. It is represented in documentaries, via the radio, fiction, autobiographies, and film.[8] In the same way as media coverage of medical surgeries represents

---

[8] Documentaries: *Do you really want to know* (2013) by John Zaritsky; CBS Network "Fighting Huntington's Disease" (2010); radio features and podcasts: "What are you doing for the test of your life?", *This American Life:* "It Says So Right Here" Oct 25, 2013 and "Dr. Gilmer and Mr. Hyde"; *WNYC*: "DNA Secrets: The Antidote"; *ABC Health Report*: "Huntington's Disease"; Fiction: Jacqueline Susann (1966) *Valley of the Dolls;* Kurt Vonnegut (1985) *Galapagos;* Nancy Werlin (2000) *Double Helix;* Barbara Vine *The House of Stairs* (1989); Robert Sawyer *Frameshift* (1997); Life Writing: Steven T. Seagal's graphic novel *It's a Bird;* Film *Alice's Restaurant* (1969) by Arlo Guthrie. For a critical reading of biological, or scientific documentaries in entertainment as a succession from the freak show see van Dijck's "The Operation Film as a Mediated Freak Show" in *The Transparent Body* (20–40).

a "normalization of the medical gaze" (van Dijck, *Transparent* 38) these stories represent a normalization of the biologized understanding of security. While earlier representations were often giving a voice to suffering, newer representations seem more focused on the portrayal and evaluation of the medical possibilities granted by genetic testing. Wexler also references this in the title of her memoir. In that sense, many of these representations disseminate biologically inflected security narratives of potential medical salvation. However, this salvation does not take the form of a therapeutic practice – it neither prevents nor cures HD – but offers only hope through a genetic test, predicting either a healthy or a sick future.

Biosecurity, Huntington's Disease, and the Individual at Risk: From a Number to an Identity

Genetic heritage is one of the oldest and at the same time most contested conceptualizations in identity discourses. In the last decades the notion of geneticized identity constructions has resurfaced and gained prominence.[9] In the negotiation of her risk identity Wexler's memoir emphasizes this growing importance of genetic heritage. But she not only highlights the importance of a genetic identity construction and biologized understanding of fate, which she references in her title. She also reveals how this biologically defined identity makes biosecurity and the positioning to biosecurity one of the most important constituents determining her identity. I will therefore consider the implications of her repositioning toward security based on this biologically determined identity, which Wexler renders as ascription as well as self-identification.

Wexler foregrounds the shift in her identity that is caused by her mother's diagnosis with Huntington's. She thus describes her identity in relation to a changed understanding of biological security, which is based on the knowledge regarding her possible genetic make-up. The rupture and plot generator of her life writing text is thus the moment when she and her sister are informed about their 50% chance of having inherited their mother's disease, which they learn about in 1968 in their late twenties. By making this shift the central event of her memoir she emphasizes how central corporeality and biological integrity are to the sense of self and the construction of identity. She renegotiates her mother's identity after she had been diagnosed with Huntington's Disease as well as her own coming to terms with her risk identity. She thus describes her mother's shift from healthy to sick, while she negotiates her own position caught in a transitional zone in which she is marked as "at risk," a transition that does not describe a material reality or intimate experience of a corporeality but a repositioning toward a biological security. It is the moment of consciously becoming a biosecurity individual.

This risk identity is first and foremost a numerical reality and a statistical fact – a biosecurity ascription that Wexler represents as becoming the center piece of her understanding of self and identity. Her narrative establishes clear relations between the

---

[9] The importance of genetics as the basis for identity formation has become so prevalent that Priscilla Wald asserts that "no contemporary discussion of identity can afford to ignore it" ("Future Perfect" 682).

official narrative of Huntington's and her understanding of self and identity, introducing risk as equally consequential as actual disease. Being ascribed this risk identity she becomes part of a group which is defined by genetic belonging and, more importantly, by the positioning toward security implied by this belonging. This emphasis on a genetic and scientifically determined understanding of identity opposes the individualism that is so crucial in U.S. American culture. Identity based on biological security narratives seems to therefore contrast the historic and cultural notions of self-reliance and the American Dream. This "new" biological component deconstructs the upheld ideal that no matter where you are coming from you can "make yourself" and that everybody forges one's own destiny. It ties individuals to groups and collectives: their family as well as other individuals with the same "markers." Wexler's insistence on biosecurity and her risk identity seems to therefore produce first and foremost a collective identity that seems deeply un-American. Wexler's text shows that becoming a biosecurity individual is initially rather a passive form of belonging than an active relational process of positioning and identifying.[10]

This ascribed risk identity is determined by biomedical security narratives and research which heavily influences the understanding of body and self. Wexler accentuates this interconnection with the narrative structure of her text. She tells her family history and her negotiation of being at risk alongside the story of HD research and genetics, which radically changes over the course of her life with the identification of the responsible gene "IT 15" and the development of a presymptomatic test. Her memoir forms a traditional life writing text that portrays her family history embedded in historic context focused on the medical history of Huntington's. Formally the different narratives – medical history and family history – are depicted in separate sections. The text is divided in four parts and every part is preceded by a "title page" featuring an image with an explanatory caption which seem to indicate the general theme of the following chapters. While the first part "The Body in Question" represents the most traditional part of autobiographical writing, part two "Chorea Stories" is more concerned with the social story of the disease. In part three "Maps for Misreading" Wexler focuses on research and part four "Genetic Destinations," the shortest of the sections, tells the story of the discovery of the genetic marker in 1984 and of the responsible gene in 1993. These formal subdivisions, however, rather simulate the possibility of distinguishing medical history as ascribed identity from a more intimate understanding of the self because the narrative deconstructs and diminishes these clear cut divisions. In the text personal memoir and medical history are intertwined, constructing an inseparable strand of illness narrative and disease narrative, a "double helix" as Wexler describes it herself ("Mapping Lives" 166). She thus constructs a hybrid text in which medical history and family history are the two pillars on which she constructs her personal life narrative. The text thus echoes structurally the linkage between science, life, identity, and self that are impossible to separate into entities that can be clearly distinguished.

---

[10] Iris Young has described such a dynamic as a serial identity construction, which exists alongside and in relation to the active identity. In her article "Gender Seriality" she elaborates on Sartre's concept of seriality applying it to the possibility of understanding the group formation of "women" without having to fall back on essentialist ascriptions.

Wexler further emphasizes this interconnectedness with the narrative tone used to represent both the medical history and the illness experience. Both storylines are filled with intellectual and academic reflections on race and gender binaries, and all textual passages are interlaced with endnotes with further explanations and bibliographic references to the sources used for the "history of HD." The text and endnotes are followed by additional explanations on her sources and interviews, as well as by suggestions for further information. The legitimacy and authority the text gains as a historical document by these explanations are mirrored in the personal narrative sections. Here it is quotes of other people, as well as citations from letters and her diaries that provide the authenticity, or rather "proof of truth" for the story told. The life narrative is thus represented in an almost scientific fashion, further underlining the impossibility to fully distinguish between an ascription based on a scientifically defined trait and the self identification which we usually refer to when talking about individual identities.

Wexler portrays the scientific and numerical definition as crucial introducing and defining the sisters mainly by their belonging to the "risk group" and therefore as numbers in a statistical table. The re-positioning towards security based on the statistical numbers is reiterated throughout the memoir interlacing and preparing the personal story with numerical facts about the general population. Already in the introduction numbers, most importantly the 50:50 chance of carrying the gene, set the stage for individual identity formation. Before this statistical and therefore collective identity is individualized by Wexler's narrative, she thus elaborates on her belonging to the group and being ascribed an identity based on her biological security status. She informs the reader that her family belongs to a very "limited population" affected by Huntington's, namely "30,000 in the United States, with another 150,000 at risk" (A. Wexler, *Mapping* xxiv). Without the need to recognize one another, without even knowing one another, the logic of genetic security makes them a group. Their identity as biosecurity subjects is thus primarily forged within the dominant public discourse and public sphere, in which HD individuals and individuals at risk circulate as a series of cases. Accordingly, Wexler describes them as a chain of people "that all come to resemble one another" (A. Wexler, *Mapping* xi). While biological security seems to represent the possibility of individual and unique pathways, biological insecurity makes people appear "the same:" the same bodily expressions and the same fate. They are thus clustered together by their "common" fate that appears to strip them of their individuality as people.

In Wexler's elaborations on the history of Huntington's research she makes this group identity even more central and obvious when representing afflicted individuals in their relation to research. She highlights that the individuals are often marked as objects of research in which they serve as (ex)samples of genetics. The overarching and connecting link that the gene forms between individuals who would not necessarily ever associate with one another is especially poignant when Wexler describes a HD "neighborhood" in Venezuela. This is the world's largest HD community, which offered the necessary genetic material to find the genetic marker and gene. Though Wexler represents the community members as individuals citing individual stories and describing their living conditions, the commonality of belonging to one group is only based on their genetic information, as "vials of blood" (A. Wexler, *Mapping* 196). It is their common biological material, more so than their fate, that defines their belonging. The different individuals are connected as a group because the genetic test for HD, which will eventually become available towards the end of the memoir, is developed based on the knowledge gained by the study of this community. In fact, most of the current molecular genetic research is still based on the HD community in Venezuela.

The generalized biosecurity ascription of risk individuals defines the group identity of these diverse people and experiences. The example of the Maracaibo community shows that the genetic identity marks a group which transgresses cultural, gender, class, and national borders. Wexler does not, however, describe this belonging in the sense of a community of common suffering – as a common precariousness – but rather in terms of practices of security such as testing. The individual identity at risk is thus most overtly produced in relation to the Foucauldian "mechanisms of security" (*Security* 16). The generalized statistical knowledge that defines these individuals produces, pace Foucault, a series of individuals who are only relevant in relation to the security of the population. It thus describes biosecurity individuals who seem to count only in their multiplicity.

However, Wexler shows that in terms of biosecurity the knowledge is at the same time generalizing *and* individualizing.

> The suffering associated with the disease and with living at risk is intensified by the lack of resources available in our privatized, for-profit medical system. Nearly all of the families with HD who testified before the 1977 Congressional Commission spoke of the limitations of health insurance and lack of access to services. (A. Wexler, *Mapping* xxiii)

In the Congressional hearing individuals diagnosed with Huntington's and those at risk are all represented as one group in relation to the nation. Though individual experiences and testimonies are heard and recognized, in this hearing they represent a group in need of protection not only from the disease but from social and cultural repercussions that follow the biosecurity ascription and group membership. It is thus not the experience of risk and disease that makes them all part of one collective, much less an active association. Rather, Wexler makes clear that the group exists on another basis, namely as insurance cases.

The material effects of the "apparatus (dispositif) of security" (Foucault, *Security* 20) based on probabilities and statistics therefore influence individual lives in a more intimate way, though the individual fate is not the object of that form of security narrative. Though the risk identity is largely defined as a group identity, it cannot be reduced to that. Rather, it is deeply felt on an individual level as well.

> The other day I got a copy of my medical records from my new gynecologist. "Patient has a high probability of developing Huntington's disease," he wrote on the record he submitted to the insurance company. I was furious and called him to protest. . . . Doesn't he know that risk for Huntington's is one of the conditions, along with sickle-cell anemia, muscular dystrophy, insulin dependent diabetes, AIDS, for which insurance companies unconditionally deny medical coverage? (A. Wexler, *Mapping* 231)

The involuntary and passive ascription of officially belonging to a group based on the individual's security status turns into a marker of difference, that is reminiscent of

Hawthorne's *The Scarlet Letter*. The "invisible" potential turns into an actual mark that the individual carries in lieu of an actual physical marker. This visible mark, which Wexler is forced to "wear," positions her in relation to biological security on a social scale and makes her a biosecurity individual, if she wants to or not. HD becomes an outward sign similar to the iconic scarlet letter marking the "sin of flesh" in a genetic sense. Though the mark is carried on her insurance paper and not on her breast, Wexler's "scarlet letter" is as heart-felt as Hester Prynne's in Hawthorne's story. As in the novel, the mark of being a risk individual produces material repercussions and represents exclusion that causes an affective reaction. But in contrast to Hester stitching her own scarlet letter, Wexler is hesitant to accept her marker of difference as it makes her "furious." She rather holds on to the rationalizations she has come to believe in, which is the reduction of her risk to 25% due to her increasing age. Regardless, Wexler will have to bear the repercussions of this mark as the material proof of her potential corporeal deviance and belonging to a risk group.

The biologized or genetic identity that is produced by the knowledge of one's risk is thus of course not just a passive "being positioned toward" identity. Besides the passive and inevitable becoming a number in a statistical table defined by an abstract emotionless probability, Wexler highlights that such a belonging is affectively charged. Statistics, as read by Foucault, are an important tool and mechanism of biosecurity in which the general population is targeted rather than the individual. The use of statistical knowledge in Wexler's representation, however, takes on a decisively different form. While the statistic still represents the belonging to a group that is at risk, it becomes a cipher for the individual. Kathleen Woodward has written about the affective and individual ramifications of probability for the individual in "Statistical Panic," highlighting the importance of statistics in our culture, "where bodies are composed of – and harrowingly decomposed by – statistics" (195). She exemplifies this by her reading of Wexler's memoir showing that statistics are not merely objective and emotionless descriptions of anonymous numbers but deeply felt by individuals. This affectivity expands beyond the repercussions caused by genetic discrimination and represents a crucial bridge between ascription and identification. The affects represent the force that individualizes biosecurity narratives and mechanisms. Wexler's representation thus indicates how the understanding of biological security individualizes, forging biosecurity identities rather than merely "describing a multiplicity." The affectivity forces the individuals to position and recognize themselves as biosecurity individuals based on the active negotiation of their risk identity. "I began really to think about being at risk, admitting to myself that perhaps 'I was trying completely to deny the whole thing by pretending it wasn't there.' I knew I had to come to terms with the illness" (A. Wexler, *Mapping* 71). The life narrative therefore becomes a process of understanding and coming to terms with the meaning of being at risk.

With her memoir Wexler clearly declares her own belonging to the Huntington's community and makes her family an example of this community. Her combination of medical history and abstract fact with her personal life writing represents a transition from passive ascription to an act of identification. In this form of active "positioning" by establishing her individual security narrative, Wexler makes her unwanted mark turn into a truly "self stitched" scarlet letter that she comes to wear, like Hester, as a token of pride. But though "self stitched," Wexler nonetheless makes clear how heavily her understanding of risk and security are influenced by biosecurity narratives and the affective attachments they create.

In Wexler's rendering affects are therefore the most crucial element in individualizing the biosecurity narrative which defines the intangible experience of being at risk. The "statistical panic" caused by the probabilities of 50:50 frame the narrative of Wexler's memoir and play a dominant role in marking and making her own security narrative. Fear as one of the dominant sentiments defining risk and security offer in Wexler's narrative "both a sense of imperiling intensity that is the sensation of statistical panic and complex emotional reflections of that experience" (Woodward, *Statistical Panic* 208). But though most commonly read as the representation of risk or threat, or in Woodward's analysis the trigger of panic and confusion, at the same time these statistics also harbor hope. On the one hand the 50:50 chance of being a carrier of the gene that triggers Huntington's made Wexler "scared to death" (A. Wexler, *Mapping* 43), on the other hand it still leaves room for hope. This dyad of despair and hope represent competing narrative elements which determine Wexler's memoir and her understanding of being at risk. To fully come to terms with and understand her new identity Wexler therefore constructs her individual security narrative which determines the meaning of this abstract risk.

Precarious Normality and Troubled Happiness: Defining Security and Risk

The constellation of security and risk in the face of a fatal disease might seem self-evident: health versus pathology, or more radically, life versus death. However, Wexler shows that for the individual at risk this is more complicated since the threat is never fully absent, nor fully present. Her memoir therefore emphasizes the importance of narratives for the construction of what security and risk really mean for the individual, first and foremost on an affective level. In negotiating what being at risk from Huntington's means, Wexler highlights how much this diagnosed risk influences her understanding of self, basing her identity decisively on a biologized understanding of self *and* security.

In her negotiation of her "new" risk identity Wexler makes clear that the risk of the genetic disease does not just appear at some point in life. Nonetheless, she emphasizes how much the knowledge of potentially having Huntington's changes her understanding of her life. For Wexler being at risk does not describe a perceivable physical state but an ambivalent experiential situation marked by a shift in understanding. The moment of knowing is therefore crucial for the presence of being at risk. For the life under the sword of Damocles only becomes a life of constant anxiety when the individual knows about the thin thread that divides their life from death, or rather security and insecurity. The moment of knowledge, which is narrated as a form of discovery or revelation, is therefore crucial in the construction of the security narrative. It represents the instigator of the active re-positioning and re-interpretation of Wexler's identity as well as a structuring element of the narrative.

Wexler portrays the new experiential situation first and foremost as an emotional experience marked by uncertainty and fear. The risk identity triggers in Wexler a "crisis of self confidence" (A. Wexler, *Mapping* 56) and the loss of a happy unburdened life. In her narrative the experience of this performative shift is marked by depression which comes to dominate her otherwise “normal,” rather secure middle-class life. The thoughts and emotions prompted by knowing her risk haunt the narrative as “the question of probability haunted our lives” (A. Wexler, *Mapping* 39). The fears that represent the experience of risk are described as creeping up in moments and intercepting her “normal” life. In many instances Wexler renders these disruptions as dream episodes that interrupt the narrative and become more frequent as the story progresses.

By the constant evocation of fear and anxiety Wexler’s life narrative becomes marked by the oscillating absence and presence of security, narratively recreating the precarious normality that marks her life. Happiness and despair are the dominating and alternating characteristics that Wexler uses to demarcate this alternation of a feeling of security and risk. While freshly in love, she “was often seized with an overwhelming anxiety, as if something terrible was about to happen” (A. Wexler, *Mapping* 58). At the same time “Huntington’s simply did not enter into the conscious emotional landscape of our lives” (A. Wexler, *Mapping* 60), for both sisters “*tried at first to live life as if nothing had changed*” (ibid., emphasis orig.). The possibility of being at risk of carrying the Huntington’s Disease gene is marked by a conditional “as if,” by a sense of indeterminability. And as the experience of risk remains indeterminable in Wexler’s narrative, also the crucial moment of becoming a risk individual is called into question. Her own uncertainty of being at risk is translated into the uncertainty of a determinable beginning, an onset that would demarcate security from risk; an uncertainty which Wexler seeks to resolve by re-reading the past.

In narrating her mother’s illness experience, Wexler shows what the risk of having Huntington’s disease implies. The mother’s suffering from HD and her pathway from diagnosis in 1968 to dying in 1979 when “[w]eak and emaciated, she thrashed about uncontrollably, her arms and legs flailing against the rails the nurses raised at the side of her bed” (A. Wexler, *Mapping* 154) makes the risk of carrying the genetic marker experientially present. Her mother’s corporeality, described as a performance watched by her daughter, make the possible future tangible, giving the fear of an HD future a material and knowable basis. Knowing what could lie ahead – with a probability of 50:50 – is a decisive part of the experience of being at risk and the fear associated with this risk. Wexler’s narrative of the past thus functions primarily as a way of knowing and representing the potential future. The past provides a form of script, not to actively follow as performance (only) but as a way to understand the body that “is and is not mine” (Butler, *Precarious* 26). Like a dystopian narrative it provides a mirror into the potential future. With this image of Huntington’s death, Wexler introduces the disease as “the most diabolic affliction man is heir to” (A. Wexler, *Mapping* 87). In the preface she states explicitly that Huntington’s is incurable and only “death relieves them [the afflicted] of their suffering” (A. Wexler, *Mapping* xii) configuring security in her family history through its absence. She foregrounds the threat of the HD affliction, which negatively defines the horizon of security in the context of this hereditary disease, prior to introducing her own and her family’s story. The disease and its risks thus frame the narrative, effectively eradicating any possibility of security from the family story.

But security is not only absent from Wexler’s life, it is also absent from the narrative as something that is “always already” gone. The memoir starts long before the mother’s diagnosis, with Wexler's childhood, with her parents' and grandparents' history. Descriptions of her kin mirror the prototypical nuclear "American family," the icon of the American Dream of the Fifties. But the depicted memories of the suburban life and the success story of an affluent society fail to "live up" to the images of happiness they convey. The "pursuit of happiness" never reaches the projected future as the stories are both tainted and haunted by the *knowledge* of HD. Wexler constructs the "precarious normality" retrospectively, narratively creating a temporal relation that implies the "always already" presence of a failed future. She thus juxtaposes narrative time and time of narration to emphasize this temporal conundrum of a geneticized understanding of life and precarious normality of health. Good life and happiness are made impossible by the specter of HD, which Wexler conjures by repeatedly foreshadowing the tragedy which is yet to come.

Wexler makes this temporal logic of the "always already" but "not yet" known disease affliction the guiding rationality of her life narrative. She encapsulates it with the anecdote "fish dream," which introduces her memoir:

> Gasping on the rear floor lay a tremendous carp, ancient and ravaged. This carp had apparently survived many years hidden in the murky shallows of a pond in Topeka. No one had imagined the presence there of anything more substantial than small goldfish until Bill, practicing his casting, hauled up this monster.
> . . . After Dad told us the facts of our family history, this carp swam back into my dreams. (A. Wexler, *Mapping* 3)

As the leitmotif of the memoir this anecdote represents the logic of "always already" existing but "not yet" discovered fish. It represents a structural analogy to the presence of the disease in the absence of the event that will reveal it. This temporal logic dominates her desperate search for traces of her mother's "HD-ness" that would allow her to define the onset of HD and thereby to truly understand who her mother was. As the overarching logic of Wexler re-reading her past this temporality therefore defines the moments of security that represented "normal" family problems at the time. She portrays her mother as a highly educated housewife with a background in genetics who showed signs of depression similarly to so many of her female contemporaries living in the "golden cage" of the Fifties, as Betty Friedan has described it in *Feminine Mystique*. But in the case of Wexler's mother the goldfish, symbolizing the "normal" problem of gender inequality, has to be re-evaluated because it might have been a tremendous carp all along. Through the prism of Huntington's in the family any recollection of the past becomes an image of biological insecurity and of the threat that is always already present even while absent in a temporal and ontological sense: lost happiness.

Wexler's memoir is therefore not just a retrospective writing and therefore re-writing and re-interpretation of a life, like most other life writing texts. It is a retrospective search and rewriting for what had been unknown and what became knowable and understandable only with knowledge acquired much later. It is a search for the hidden disease and a re-reading, re-writing, and re-interpretation of life with HD. A similar turning point can also be found in early conversion narratives like Saint Augustine's where life is divided into the time before and after conversion and the moment of revelation. Similarly, traditional illness narratives describe this turning point or "biographical disruption" as Michael Bury calls it, in which the diagnosis leads to a re-evaluation and re-negotiation of meaning in and of life. While this turning point is also contained in Wexler's narrative, the transition referenced here is rather a re-reading of the past on the basis that it is *now* a HD past, while when it was lived it was not and could not have been read or understood as such. It is not the creation of the self as other, as Robert Folkenflik describes it, but the construction of the "new" other replacing the "old."[11] The discovery of the disease thus creates a new identity that extends into the past. Accordingly, the images of the symptom-free mother become descriptions of Huntington's disease, blurring the distinction between pathological and normal, between secure and insecure. With this narrative perspective the memoir reiterates the dominant logic of a genetic security and applies it to identity. Similarly indicated in the title, the genetic defect of Huntington's marks fate, echoing an understanding of the gene as the code of life (van Dijck, *Imagenation*, Nelkin and Lindee), which is always already there and at the same time lies ahead in the future.

The narrative perspective of retrospectivity – the not yet – omits the existential uncertainty of being at risk, which marked the mother's life. More importantly, the logic of "always already" constructed in her mother's past as "pre-symptomatically ill" (Clarke et al., "Biomedicalization") also applies to Alice Wexler, her sister Nancy and their respective risk identity. Not only does the risk of having inherited the Huntington's gene mark their life and health as "precarious" but the logic and narrative structure implies that there is no life prior to HD if a person carries the HD gene. The manifestation of the disease might be absent, but the disease as such is always already present. HD is not something that emerges in the future, though the feared symptoms and proof of HD might or might not, it is always already there. It is therefore knowledge that represents the dividing line "to a 100% certainty that one will or will not develop the disease…" (Wexler, *Mapping* 227) and not the onset of the disease and the presence of disease symptoms. In the absence of such a certainty the knowledge of one's risk replaces the disruption usually associated with the onset of the disease symptoms.

In the absence of a clear demarcation between security/insecurity Wexler searches for "traces of the avalanche that had come crashing into our mother's future" (A. Wexler, *Mapping* 24). In reading her mother's past she is searching for emotions as indicators for the loss of security. "I have no memory, nor does Nancy, of any emotional scene at the time, nor any recollection of Mom's shock or grief" (ibid.). In the absence of her mother's emotional response Wexler seems unable to define the security breach in her mother's life. Flashbacks revealed in comments such as "[y]ears later, Dad would tell us" (A. Wexler, *Mapping* 28) and "could we have known" intersect the reading of the past, which seems to resist to fully express the precariousness Wexler seeks to discover in it. She is therefore never sure of this past she is narrating, never sure when the goldfish turned into a carp; and neither does she seem certain of her own present. She therefore also revisits her own performative shift of becoming a risk individual, in search for any kind of certainty.

For Wexler herself, the knowledge of potentially having HD "melts in [her] memory" with "Russian tanks smashing into Prague, Martin Luther King Jr., dead of a bullet in

---

[11] It does not represent the division of "once I was healthy but now I am sick," but of "once I thought I was healthy though now I know I have always been sick."

Memphis, Robert Kennedy, shot in Los Angeles" (A. Wexler, *Mapping* 42). By using the most affective moments of 1968 as metaphors she approximates her inexpressible pain with expression that belongs to the collective memory of the nation. These metaphors attribute the pain to an outside agent, as a "perceived intrusion" (*Cultural Politics* 27) as Sara Ahmed calls it elsewhere, rather than coming from within. But most importantly, Wexler chooses metaphors that are "events" with immediate material as well as affective impact, all of which represent the loss of a future.

Though the moment of knowing for Wexler is marked and singled out in the representation of these historic events, it does not define a moment of onset, a tangible event. It rather remains a moment of shock that, though felt affectively and physically, remains elusive.

> Words are spoken, but I no longer remember them. I recall the whiteness of that apartment, our three frozen forms like a George Segal sculpture, my sister and I sitting with our arms around each other staring at my father's ten-foot high Mike Olodort painting of a huge upside-down Humpty-Dumpty with tiny arms and legs waving in the air and an enormous, sinister smile on his face. There are no tears, no welling floods of grief or anger, but for me only a numb, anesthetized feeling, like being shot full of novocaine. In an instant I shut out my father's words, which I have never been able to remember, as if denial could undo the event. (A. Wexler, *Mapping* 43)

As in many traumatizing moments, the rational mind seems overruled, leaving the situation vague and almost unreal. Rather than describing a direct emotional response Wexler transfers the confusion and disorientation prompted by the information into the descriptions of the surroundings. Wexler and her sister are described as Segal sculptures, which are life-size plaster figures. She represents the moment of shock as a moment when the self becomes other and is looked upon from the outside, described as something detached and foreign. This image is completed by the painting of Humpty-Dumpty hanging opposite the sisters, perfectly symbolizing the moment in which something fragile is irreparably broken. The experience of the event of learning about the mother's disease and their own risk identity is expressed by using the comparison to being anesthetized. Wexler appropriates medical language to describe her memories of that moment and the lack of emotions she associates with it. The memory of her performative shift becoming a biosecurity individual and the beginning of her risk identity, remains caught in an undeterminable space, as "if we had been experiencing fallout from some unseen bomb for all these years" (A. Wexler, *Mapping* 75). The only material effect, which Wexler can find and hold on to, defining the moment when she was told about her risk is that she "marked a new notebook 'Vol.1, No.1'" (A. Wexler, *Mapping* 57). Rather than a material shift and a determinable change, Wexler has to acknowledge that her risk identity and the insecurity associated with it are emotional states.

By representing risk and insecurity as emotional states and the dominating factors in her life, Wexler also narrativizes that which is absent from her and her family's life, namely security. While the rupture triggered by knowing one's risk is represented by fear and shock, security and what is "always already" lost is the possibility of an unburdened life, of happiness. Wexler visualizes this most clearly with the images that introduce the different sections of the memoir, which are conventional images of a family picture book. They represent images of happiness: one depicts her parents as a young couple in the 1940s, another shows the sisters at Alice Wexler's high school graduation in 1963. Both photographs represent times when none of the people depicted knew about the disease in their family, thus "happy times." It represents the normal as the horizon of security. Though the photographs represent what Sara Ahmed calls "happy object,"[12] the established temporality makes it impossible to read this image of the happy family without considering the future to come: the mother's struggle and long process of dying, as well as the risk that looms ahead for the Wexler sisters. The images therefore become at once signifier for the precarious normality as well as for the desired happiness that stands in as a symbol for security.

Defining security in negative terms, so as the opposite of "the drama of families with Huntington's disease . . . played out with minor variations on stages around the world" (A. Wexler, *Mapping* xi), Wexler draws a picture of what is lost. Since being at risk is neither being sick nor being healthy, what is lost first and foremost is the happiness associated with an unburdened life. While Wexler describes her own life at risk as marked by clinical depression, she also keeps reading her mother's life for traces of lost happiness. In her search for her mother's "true self" she tries "to reconstruct the history of her illness, to date the onset of her symptoms" and asks "what in Mom's behavior was due to chorea? What to character?" (A. Wexler, *Mapping* 69). Her mother's submissiveness and "depressive" episodes take center stage in this distinction: In 6th grade "I wondered in my diary if she was very intelligent, because 'she never says much during more profound conversations, nor has any ideas'" (A. Wexler, *Mapping* 27). Her sister's memories also provide traces of the "always already" lost. As a child and long before the sisters knew about the disease Nancy "had started 'sobbing and shaking in despair, crying that I no longer had a mother, that my mother had escaped somewhere and left a shell, that I didn't want only my father's voice, my father and a shadow, but I wanted two parents'" (A. Wexler, *Mapping* 32). The re-reading of her and her sister's childhood memories are defined by the unhappiness of the situations, which are read as potential indicators for the presence of HD. Her re-reading of her family's history and the search for the moment of knowing the risk in the past are readings of family happiness intercepted by the disease.

The happiness that Wexler represents as being amiss is attached to surprisingly conservative ideals. The potential loss of a future, which Wexler describes as a central characteristic of being at risk, becomes attached to the normatively mandated "purpose" of life, its "reproductive futurity" (Edelman 21). In fact, most of her explicit reflections on "sorrows for myself and for my sister, for our blighted future, for the children we would never have" (A. Wexler, *Mapping* 69) center around the question of reproduction. In this quote, as in many other similar comments Wexler emphasizes the loss of happiness of a heterosexual normative nuclear family life – the normative image of security. The normative script is so forceful, that Wexler, who will come to embrace her homosexuality, is burdened by yet another transgression of norms. Expressing the double burden of being a woman and at risk she is overdetermined and marked as other twice by the biological

---

[12] The photograph represents a happy family as "both an object (something that affects us, something we are directed toward) and circulates through objects" (Ahmed, *Promise* 45).

make-up of her body. Being at risk made her feel "less like a woman" because she is not supposed to have children, and when she does try to conceive (in a relationship with a man) anyway and discovers her infertility she "feel[s] like a diver who can't come up for air" (A. Wexler, *Mapping* 231). Describing her feelings as suffocation, she reveals a further injury to the body that is again both biological and cultural at the same time. She highlights the restrictiveness of social norms, that she has internalized despite her homosexuality – a normativity of the gendered life course in which "'no children' signifies the loss of a fantasy of the future as that which can compensate me for my suffering" (Ahmed, *Promise* 183).

With the construction of healthy happiness vs. disease despair Wexler establishes a rigid and clearly defined binary opposition that undercuts the blurry lines of being at risk. And though the possibility of being at risk by anything else but HD is not absent from Wexler's life writing, other risks disappear behind the intangible threat of HD. Wexler re-reads her parents' failed marriage and divorce on the basis of her mother's changes "from the lively, witty, vivacious woman" to a silent and silenced housewife "obsessed with household chores and domestic routines" (A. Wexler, *Mapping* 28). And though she wonders how much of this is due to the oppressive social norms of the time or her mother's character, Wexler's re-evaluation always falls back onto the distinction between having HD and not having HD. Every problem is always only seen through the lens of HD or completely disappears behind it. This is most revealing, and shocking, when Wexler narrates how her mother, still free of symptoms, is gang raped in Mexico City in 1963 while visiting Nancy. The shocking scene of sexualized violence and female vulnerability, when they "drove her high into the Lomas de Chapultepec, where they dragged her out onto the ground, beat her severely, and raped her, each one sitting on her head while another took his turn" (A. Wexler, *Mapping* 39) breaks with the general narrative of illness. But though this scene exemplifies the biggest risk for women,[13] in the memoir it remains comparatively uncommented and therefore appears rather inconsequential for the mother's as well as the daughter's lives and psyche. In contrast to the ongoing and never ending worries and negotiations of HD and being at risk, this rape scene is marked by its passing character. In contrast to the disease it remains narratively contained to this one scene, an episode that though gruesome is defined by its limits: being kidnapped and raped, being recovered and brought back to the U.S., suffering anxiety attacks for a while, and overcoming the event. With the inclusion of this violent rape of her mother, Wexler highlights that life, and especially for women, is constantly at risk from many things *besides* HD. Yet, differently from the self contained narrative of rape, the risk of having Huntington's Disease is emphasized as something that cannot be overcome. The lack of an "event" in its performative and therefore temporary character represents it as uncontainable.

The indeterminable characteristic of risk and uncertainty, as the lack of a proper event that one can face up to and "come to terms with" further emphasizes the need and desire for certainty, which is the "place holder" for the potential event in the future – the diagnosis or onset of the disease. Knowledge is therefore an object of desire that de-

---

[13] According to the CDC one in three women experiences sexualized violence in her life, while one in five women falls victim to rape or attempted rape during their life ("Sexual Violence").

termines one's being in the world. While Wexler represents uncertainty as the loss of a future, certainty comes to represent security and the possibility of a future.

Reading the Body – Translating Certainty: Performativity and Security

Certainty as "the object of desire" seems unquestionable in light of the suffering which Wexler attaches to the biosecurity identity of being at risk and the uncertainty she foregrounds as "an unbearable tension" (A. Wexler, *Mapping* 81). However, such a certainty as a supposed key to security is not without its problems in the context of Huntington's disease. Rather, it has to be constructed as an object of desire by making it promise security.

The importance of certainty and the need to know in this complex constellation of uncertainty reverberate throughout the text. Knowledge structures the narrative and the notion of knowing and discovery are leitmotifs of the memoir. As the story of the disease and the genetic marker, the exposition of the different family members learning about HD is also structured by the secrets of HD and their discoveries. Wexler introduces her mother's family as surrounded by "mystery" (A. Wexler, *Mapping* 8) and the grandfather's death is described with the same words: "Abraham developed a mysterious illness and died at the age of fifty-two" (A. Wexler, *Mapping* 9). This enigma, which the reader knows to be HD, has to be revealed and discovered, both accidentally and secretly by the different family members. The mother picked up the name at her father's funeral, "words that had sent her off to the library to discover that Abraham's sickness, Huntington's chorea, was inherited, but that only men could get it. At least that is what she told us later, after she herself fell ill" (A. Wexler, *Mapping* 10). Though always present in the body, HD seems to be in need of discovery. Focused on this "naming into being" (Butler, *Bodies* 13) every person's encounter with HD is related and reconstructed in great detail.

Wexler constructs this moment as the revelation of a true identity, as argued before. She describes this moment in her mother's life as "that day in 1968 when our mother's body spoke that (death) sentence. This book, in part, is my translation" (A. Wexler, *Mapping* xix). Explicit in this quote is that this form of certainty can hardly be qualified as security and exemplifies how complicated it is to speak about a form of security in the context of a degenerative genetic and fatal disease. Nonetheless, this example of knowing, and resolving the existential ambiguity of uncertainty by trading it in against what Wexler calls "the death sentence" is represented as a form of security. By making herself the translator and the body the cipher that needs translation she turns herself into a "native informant" for the reader. She is representing certainty as something that though already exposed has to be revealed, and is in need of translation to be understood (properly) as security. By making the body speak an unknown language she emphasizes the performative character of body, biology, and security. She thereby creates a vision of the body, and for genetic identity, that is there and is readable as a text of another language.

Since Huntington's is mostly known by the incontrollable body movements it triggers, certainty relies on performativity, so a physical performance and a witnessing audience. Wexler highlights the performative characteristic of the moment of discovery in her description of her mother's first perceived symptoms. It is not the self that recognizes the first signs of the disease but rather an outsider who perceives the symptoms as deviant behavior. Her mother is described as crossing the street one morning being addressed by a stranger: "'Hey lady,' he called out, 'aren't you ashamed of being drunk so early in the morning?' But she had not been drinking – in fact, she drank very little – and she must have known instantly what the words really meant" (A. Wexler, *Mapping* 44–5). The other is represented as the witnessing and judging audience while the afflicted self is described as a shameful spectacle. The body as spectacle emphasizes the sociality of the body "impressed upon by others, impinging upon them as well" (Butler, *Precarious* 27).

While other disease symptoms might trigger insecurity and anxiety about their meaning and ramifications, HD symptoms are usually well known to those afflicted. As a hereditary disease most have seen family members display the same twitches or other symptoms. This intimate understanding of the diseased corporeality plays an important role in Wexler's construction of security. The individual at risk is able to read and understand the bodily performance in contrast to the outsider witness who misreads the mother's physical difference as social deviance. The understanding of the performativity of the body that just has to be read properly, as well as the experience of being exposed by the betrayal of the body leads Wexler to a form of compulsive self-surveillance: "I watched myself for signs and symptoms. Sitting in the library or playing piano, I would inspect my fingers for jerks and twitches" (A. Wexler, *Mapping* 64). In an attempt to control the uncertainty she reads her body almost obsessively for the disease as well as for certainty, which she so urgently longs for.

However, despite the intimate knowledge of the corporeality of the disease the lay reading of one's own body seems not to be able to provide certainty. Rather the body is in need of a professional reading for a translation of the body and its security status which ultimately lies beyond the individual's understanding. The Wexlers know HD symptoms well. The mother's father, as well as all three brothers had died of the disease by the time the mother shows the first symptoms; the familiarity with the corporeality of HD once it sets in is emphasized repeatedly throughout the book. Nonetheless, Wexler's narrative emphasizes that the intimate and private knowledge is never enough but has to be verified by a professional expert: the doctor as arbiter of security. The ultimate verification of the intimate reading of the bodily performance is therefore relegated to the doctor. His diagnosis is based on nothing more than what the Wexlers know themselves, namely the family history as a disease genealogy and the outward signs of Huntington's that the mother embodies. Nonetheless, the medical reading of the body represents a different form of authority and thereby a different form of certainty. "After seeing her and hearing the family history, the neurologist knew at once. There was never any doubt" (A. Wexler, *Mapping* 45). Though the professional diagnosis neither provides new insights for the family, nor a different possibility or access to security – the disease is present and is going to end fatally – it is considered essential.

The reaction of the Wexler sisters to this diagnosis reveals another crucial element of the security narrative in the context of HD and certainty as something that comes too late. The sisters are hesitant and afraid to talk to their mother about her diagnosis. First of all, it is the sisters and the divorced husband who receive the fatal diagnosis instead of the afflicted mother, who is thereby turned into a disempowered and incapacitated passive patient. Along side the loss of a possibility to return to a healthy and secure life, the mother is initially stripped of her subjectivity and autonomy in an attempt to protect her and to provide at least the appearance of being safe. This withholding the certainty of a fatal diagnosis was common practice during the "regime of silence" that dominated at the time.[14] The sister's hesitation to inform their mother is thus based on an alternative understanding of security which makes clear that the certainty attained by reading the outward signs of the body is insufficient. Though their mother "accepted the information bravely" (A. Wexler, *Mapping* 55) once they told her, the sisters feared that informing her would cause panic and despair. In this instance, as in many others throughout the story, Wexler points out that once the disease starts it is a slow and relentless decline until death. The knowledge and certainty of this deterioration thus cannot provide any possibility of achieving security in terms of health.

The certainty provided by the diagnosis also comes too late in another sense. The outwardly perceivable symptoms of Huntington's are the first signs the individual can perceive, and were for a long time defined as the onset of the disease. Today, however, it is agreed that "[s]ubtle personality changes sometimes precede the involuntary choreic movements by many years, so much so that doctors now refer to a zone of onset rather than an age of onset" (A. Wexler, *Mapping* 48). The understanding of the performativity of security thus has to be extended from corporeality to the performance of self. It is not only the body that is at risk of becoming uncontrollable but initially the self. With this explanation Wexler makes clear that the body as sign and cipher for the truth within, is an unreliable text. The onset of the disease represented by corporeal outward signs comes after the disease has already set in, and after the disease has already started to "alter" the true self. The certainty of the onset of the disease, which lies beyond the experiential realm of a layperson therefore becomes the justification why testing is viable and necessary as a step toward security. Wexler thus constructs a security narrative in which the possibility of testing is represented as a desirable practice of security, though she herself will not make use of it. The certainty obtained by testing is stripped bare of the threatening notion of "too lateness."

While certainty consisting in the knowledge of having HD plays a fundamental role in Wexler's construction of security, she also shows the ambiguity of the construct. In the case of Huntington's certainty represents both, the onset of inevitable and fatal decline, as well as the only gateway to security as knowing one's fate. Wexler does not completely silence this ambiguity but rather reveals the necessity of narrative to make an understanding of security tangible and pervasive. She reiterates the dominant biosecurity narrative and the seemingly unquestionable urge to gain certainty with a diagnosis as early as possible by dramatizing the quest of developing a test. Her representation of the coming of the test, which is by now routinely offered, therefore highlights the variability of meaning of security in different conceptual contexts. Though the test does not represent the possibility of a cure, so the "return" to the security it promises those at risk "to escape the oppressive uncertainty" (A. Wexler, *Mapping* 236) and "painful ambiguity of their lives" (A. Wexler, *Mapping* 237) and is therefore perceived as a crucial security practice.

---

[14] During this so-called "regime of silence," "it was unquestionably clear that the primary duty of the family and the doctors is to conceal the seriousness of his condition from the person who died" (Aries, "Reversal" 138).

Early knowledge and certainty of one's security status is thus represented as something desirable. As a stand in for security proper, this form of certainty promises manageability and controllability of nature's mistakes:

> The issue of control loomed large. Knowledge one way or the other appeared to give a measure of control, or at least of choice, over how one lived one's life: at the very least, knowledge of one's future in relation to Huntington's seemed to increase the terrain on which one could knowledgeably make decisions. Some people wanted to take the test in order to make decisions about having children or, more often, to inform the children they already had about their own risk, particularly if those children were themselves approaching childbearing age. Many people emphasized the extent to which testing involved everyone in the family, not just those who actually got tested. (A. Wexler, *Mapping* 236)

This form of anticipatory knowledge offered by pre-symptomatic testing, represents essentially not a different form of knowledge than the onset of the disease – it is still "this death sentence" the body speaks, as Wexler puts it. However, it is not understood as a loss of future anymore, but turned into the promise of having a future. It offers the possibility of self reliance based on the responsibility of a biosecurity individual. The looming possibility of the test represents a fiction of security that is culturally and narratively produced, rather than a reality. Based on the security narrative of an always already existing precarious normality that simply has "not yet" been apparent to the individual, the diagnosis by onset is marked as insecure, as too late. This narrative, which is based on biological data and scientific findings configures a fiction of security, which motivates individuals to (re)act. The promise of security attached to presymptomatic testing which Wexler represents in her memoir thus reveals that the security narrative has material effects impacting the life choices of individuals.

This importance of knowing and therefore the understanding of certainty as security is further enhanced by Wexler's incessant search for the reasons why her parents kept her potential risk status and HD affliction in the family a secret. Though she is informed about her risk in 1968 when her family attains the certainty with her mother's diagnosis, her parents must have known about the risk already when Alice Wexler's uncles on the maternal side of the family fell ill and died. The secret that curtailed Alice Wexler's "real identity" from her makes her "furious," further emphasizing the urge and importance of knowing the truth. As her search for the motivations and details of this secret becomes another driving force of the narrative, propelling it backwards into her past, providing knowledge becomes defined as a responsibility. And the failure to inform potentially implicated people is represented as an infringement of their right to know. The security practice of getting tested and the security practice of informing anyone potentially affected are both marked as responsibility. The certainty provided by the test eradicates the "too lateness" of the diagnosis as onset, so that individuals can know before passing it on to the next generation.

Though Wexler represents the dominant biosecurity narrative of certainty as security, which can only be provided by a biomedical reading of the body in form of a presymptomatic test, she does not represent it as the almighty and unquestionable narrative of security. The first version of the genetic test was anticipated and celebrated at the time but she does not depict it without its paradoxes. Wexler's memoir makes clear that she herself has reservations about the promises attached to the test. Furthermore, she shows that even the science community itself was "weary of offering the test" (A. Wexler, *Mapping* 224) because of the risk of suicide in those tested positive. She asserts that "[t]here is no question that the worst part about being told you have the gene is the watching and the waiting" (A. Wexler, *Mapping* 237). Wexler's reflections on the test exemplify the disparities between the test embodying the cultural imaginary of security while at the same time providing a "death sentence." Nonetheless, the test offers the possibility of knowing and therefore legitimizes the demand for the security practice, which Wexler reiterates as a necessity and responsibility. The reproachful undertones of her incessant questions whether her parents knowingly put her and her sister at risk mark uncertainty not only as unbearable but represent it as irresponsible. Wexler's narrative exemplifies that "biological identity generates biological responsibility" (Rose, "Politics" 19). Her depiction of this form of "ethopolitics" (Rose, "Politics" 18) as a crucial part of creating responsibility and the urge for biosecurity by transplanting governmentality into the individual ethical choice and practice stresses the importance of affects. The affects invested into the security practice, especially hope, are fundamental to make people feel responsible as well as to shape the understanding of the security practice.

Promising Knowledge and Scientific Salvation

The security narrative of certainty as key to security relies on a broader security narrative of scientific salvation and of hope which is attached to scientific progress. Not surprisingly then, Wexler's memoir establishes a close and obvious association between security and scientific research. She constructs a security narrative in which science and scientists represent the clear arbiters of security and scientific progress embodies the seemingly only source of hope. To make science the main actor that can performatively produce security, she establishes a narrative that negates the ambiguities of the text's introduction. There she mentions the "volatile space" (A. Wexler, *Mapping* xxiii) that genetics inhabit, making clear that genetic research is a "multibillion-dollar industry" (A. Wexler, *Mapping* xiii) and not a philanthropic endeavor. Further, she comments on the implications of the normative power of this "new genetics" and that the geneticized understanding of identity should be watched carefully by society. However, this ambiguity is largely restricted to the introduction and for large parts of the narrative dissolved almost entirely.

More prominently than this explicit critique is the narrative of hope invested in scientific research. Shortly after having informed the sisters about their mother's affliction, "Dad is already full of plans for fighting this illness . . . . The genetic revolution has begun, he says, and everything is possible. Nancy catches his enthusiasm and excitement. They are like two kids spinning out fantastic proposals, already on a crusade" (A. Wexler, *Mapping* 44). While fear and despair dominate the narration and Wexler's experience of being at risk, her father and sister quickly turn to hope as their way of dealing with the situation. The object of their hope is, not surprisingly, science. Wexler constructs a narrative of a biologized security that is potentially attainable. It is therefore the expectation of security, largely communicated as promise and hope, which influences the life narrative. These "passionate attachments" ("Affective" 118) as Ahmed calls them, form the "desired object" that comes to represent the possibility of security, marking security as defined by emotions. Although Wexler herself does not unconditionally share this hope, or the faith in science, it is represented as the only way out. Both the sisters will pass this affective attachment to scientific security on, though on different levels, contributing to the circulation of this security narrative. Together, they will use it as consolation when telling their mother about her HD diagnosis, Nancy Wexler becomes a leading force in scientific research and Alice Wexler writes a memoir on the disease.

The promise of scientific salvation has a long tradition in "western" cultures, representing mastery, control, and security, as I have argued earlier. In relation to the body, it not only represents the ultimate dream of control, but the promise of seeing "the truth" (Foucault, *Birth* 155) as modern medicine challenged the "space in which the bodies and eyes meet" (Foucault, *Birth* xi). Wexler herself warns that the history of science and scientific research is not simply a factual history of re-presentation but a story rendered as perpetually progressing steps of discoveries; she cautions that scientific knowledge is merely represented as naturalized knowledge. Nonetheless, when Wexler explains research findings, such as the discovery of the disease by George Huntington, she echoes the logic and teleology of scientific progress toward controlling nature's mistake and managing biological security. In fact, the promise of science and the hopes invested in its progress dominate the hopeful, almost utopian narrative strand of her memoir.

She traces the dominant narrative of approximating security with the progress of science showing how the scientific "discovery" of Huntington's and its recognition as a biologically caused disease affords afflicted individuals more security. She asserts that the establishing of the disease category provides them with an explanation for their suffering from a "definite illness" (A. Wexler, *Mapping* 46). Though not changing the "Otherness" that was socially and culturally attached to the disease this shift reframed the non-normative behavior and the social reaction to it from revulsion to compassion. Suffering all the same, the medicalization of HD meant the eradication of an epistemological deficiency that puts the individuals at risk of being "queer rather than sick, and affected individuals as mean and malicious rather than ill" (A. Wexler, *Mapping* 46). However, the alienation of families suffering from this neurodegenerative disease did not end with the insertion of the disease into neatly framed knowledge categories of modern medicine.

In following the messianic narrative of medical salvation, Wexler even highlights the research of the eugenics movement as progress toward security, though for other reasons than their original claims and methods. As explained before, Huntington's was Charles Davenport's prime example and favorite research object. Though Davenport's studies were clearly putting afflicted individuals at risk instead of providing security for them, Wexler stresses that his research also "helped [to] call attention to" the disease, instigating scientific research. His studies represent "powerful testimony to the emotional horrors of the disease, as well as the resilience and courage some people mustered in dealing with it" (A. Wexler, *Mapping* 49). The dark past of genetic research, which Wexler does not hide, is not represented as a weakening of "the promise of science" and its incessant progress toward security. She thus reiterates the image of "new genetics" vs. "old genetics,"[15] as I have discussed previously, rendering this past scientific activity as science used and produced for the wrong reasons, as an unfortunate aberration from the proper path toward security. The knowledge produced by this "science gone wrong," however, is still represented as a valuable stepping stone toward security.

Wexler reiterates the narrative of continuous scientific progress that is approximating a security which is just not reachable *yet*. This temporality represents a necessary utopian narrative element to establish and maintain the hope that this time scientific salvation could be within reach. Her father expresses this hope as follows: "[I]n certain respects, the timing of Mom's diagnosis was fortuitous in that it coincided both with a revolutionary expansion on molecular biology and with an awakening of interest and activism focused on the disease" (A. Wexler, *Mapping* 87). What Wexler's father describes as fortuitous is not better treatment or a cure at the time but a promise which is based on faith and hope rather than facts. Scientific progress as an approximation of security is thus established as an "affective fact" (Massumi, "Future Birth" 34). It is represented as a belief that "offered him [the father] hope at a moment when he feared his family might be obliterated" (A. Wexler, *Mapping* 96). This hope is, though narratively present "directed at an object that is not yet present" (Ahmed, *Promise* 181) – a cure, a test, a treatment – and therefore becomes first and foremost an instigator of action. Within the dyad of hope and fear Huntington's turns into a challenge that one has to take on, rather than a fate one has to accept and surrender to.

While the experience of suffering from HD and the unbearable uncertainty of being at risk represent the first part of Wexler's translation of the "language of the HD body" (xix) – the fearful and threatening narrative strand– the competing narrative of hope is represented as the second part of her translation: the translation of science. Since scientific knowledge is highly specialized and not immediately intelligible or self evident, one "had to learn some basic science" (A. Wexler, *Mapping* 88) to understand risk but also to share and partake in hope. She introduces the reader to a new vocabulary necessary to gain access to biosecurity. She explains hereditary rules of recessive and dominant genetic elements, the difference of phenotypes and genotypes, what independent assortment of heritage means, the discovery of the DNA structure as a double helix, and the working of recombinant DNA. In representing her father's genetic education and becoming a bioliterate subject, she educates the reader, establishing the necessary bioliteracy to understand the importance of genetic discoveries. These explanations are crucial for understanding her later representation of more complex genetic research such as discovery of the Huntington's gene IT15 (A. Wexler, *Mapping* 258–259) as a quest for security. Each step and each discovery is contextualized by the possibilities it offered and therefore represented as an approximation of future security.

By explaining the working and meaning of science Wexler partly overcomes the difficulty of presenting genetic research as unequivocally beneficial and an "object of hope." In contrast to the eugenic past, the ambiguities and fears these developments caused at

---

[15] "Some invoke eugenics to distinguish the present from the past: thus contemporary molecular geneticists usually argue that their discipline, in common with the rest of medicine, has decisively rejected eugenics in favour [sic] of individualized, voluntary, informed, ethical, preventive medicine organized around the pursuit of health" (Rose, "Politics" 3).

their respective time remain comparatively unrepresented and hidden.[16] By using figures and animations of science books, she not only educates the reader but makes "the mystery" of genetics more tangible and therefore less threatening. Her representation embodies the scientific knowledge of the time, emulating the increasing visualization techniques that represented major stepping stones in genetic research. She highlights that initially "there was no way to look directly at genes at all. No one knew what a gene was. All measurements of linkage were based on the observation of identifiable traits" (A. Wexler, *Mapping* 91). By doing so she reiterates the link between seeing and knowing (Foucault) and the paradigmatic metaphor of the language of the gene that merely has to be decoded by an able translator, which was championed and circulated widely with the initiation of the Genome Project. With her explanations and the use of these images she does not only translate this "genetic language" but narrativizes it as an increasing approximation of security in a teleological structure of scientific progress.

Wexler further increases this seemingly inherent connection of scientific research as the arbiter of security by the repetitive description of the visualization of genes as a looking at the "actual molecules" representing it as mere observation. She describes this gaze as a descriptive act, rather than an intervention and changing of the "object" that is looked at (van Dijck, *Transparent* 6). This harmlessness of "just looking at," which Wexler depicts in these descriptions has two important sides. On the one hand it portrays research as only trying to understand what is at hand, merely finding new and better ways of imaging and thereby knowing. On the other hand, visualization also represents a form of circulation and the normalization of scientific findings in the public sphere. She traces the improvement of imaging that is so crucial, not only for scientific progress but for generating public understanding of genetics as a practice of security. The portrayal of scientific knowledge and research in Wexler's narrative therefore represents scientific progress while at the same time circulating hope and faith in scientific knowledge.

Wexler emphasizes the importance of this affective attachment and its circulation, which makes the connection of genetic research and security seem all the more natural and unquestionable. By foregrounding her father's and sister's activism in advancing genetic research she retells the enthusiasm of the 1950s and 1960s when "a golden age of biology had just begun" (A. Wexler, *Mapping* 96) and she recreates a "new sense of excitement" (A. Wexler, *Mapping* 187) about each additional development. The narrative chronicles the hypotheses of GABA research (A. Wexler, *Mapping* 126–27) followed by the assumption that Huntington's could be an autoimmune disease (A. Wexler, *Mapping* 128–29), as well as the suggestion that it was caused by a slow acting virus (A. Wexler, *Mapping* 132–33), and other promising but erroneous approaches. Wexler portrays the different discoveries as part of an "affective economy" (Ahmed) in which even the erroneous findings and disappointing approaches contribute to a further circulation of hope. She shows how everything seems to have "generated new hope" (A. Wexler, *Mapping* 97). As such, every report from the different workshops and centennial symposiums, as well as the different scientific hypotheses can be seen as further manifestation and normalization of the link between science and security. Wexler thus reiterates a narrative of sci-

---

[16] For a detailed description of the criticism of genetic research see Bud's chapter "Wedding with Genetics," as well as Shakespeare, and De Melo.

entific salvation and shows how the scientific findings become more and more forceful and stable, for "the more they circulate, the more affective they become, and the more they appear to contain affect" (Ahmed, "Affective Economy" 120).

Wexler further recreates the enthusiasm and affective attachment by rendering the scientific research as a quest which is spearheaded by her sister Nancy. In the narration of discoveries, the overarching logic is the development of a cure, or as Wexler puts it, "an end of Huntington's." The "discovery" of the Huntington's community in the Lake Maracaibo communities in Venezuela therefore represents a watershed event for "they might offer the crucial key" (A. Wexler, *Mapping* 182) to the secrets of Huntington's disease, and therefore to security. The project, which is headed by her sister Nancy receives "glowing report" and had "'high priority'" (A. Wexler, *Mapping* 189). The affective vocabulary that is used to describe her sister's project is intriguing in two ways. It reveals the importance of an "enthusiastic supporter [Carl Leventhal], helping Nancy negotiate the hurdles toward long-term, regular funding" (A. Wexler, *Mapping* 190). Wexler therefore exemplifies how important it is to narrativize scientific research within a security narrative to receive financial support. But the choice of words also exposes that science is not an objective emotionless discipline but a highly affectively loaded and subjective process.

This importance of affects in defining scientific research as progress toward security is further enhanced in Wexler's description of the community in Venezuela. The image of the Laguneta community, which is used to introduce section three "Maps for Misreading," reveals the polyvocality of security narratives, and the colonial perspective that underlies discourses of biosecurity and the bias they create. Individuals born into this community carry the highest risk of having inherited HD in the world and live under one of the worst conditions for HD afflicted people in terms of health care. At the same time, the community embodies the anticipated and needed clue in the hunt to discover the secret of Huntington's precisely because of this high number of afflicted individuals. Wexler renders an image of Laguneta which combines absolute insecurity –the biggest HD community living in absolute poverty – with the shining hope of finding a cure and the genetic marker of Huntington's, so the origin of a possible solution and the recovery of security. Only a large family with many infected individuals could offer the possibility of finding the genetic trace of the disease and "they did indeed meet a large family in which both parents had the disease. Some of their fourteen children had a good chance of inheriting two Huntington's genes. . . . Nancy on the other hand, found the whole experience exhilarating" (A. Wexler, *Mapping* 186). Nancy's professional "exhilaration" about the existence of this family stands in stark contrast to the description of the despair associated with HD "at home." To "stand a good chance" is a decisively different emotional expression from the unbearable tension that defines the life of both of the Wexler sisters in the memoir. While the entire memoir is dedicated to the struggles of two sisters at risk in the United States, the possibility of 14 children with two afflicted parents carrying the disease is described as a victory and a crucial step towards achieving security, or rather a further approximation of security.

While the promise of security in form of a cure remains unattainable throughout the memoir receding with every approximation, the possibility of testing replaces this goal. Over the course of the memoir the possibility of testing becomes more and more possible as the marker for the genetic disease is identified in 1983. Wexler shows how the "coming of the test" represents a further circulation of the security narrative of medical salvation in the public space. She describes how media reports and research panels amplify the narrative of hope and salvation to a broader public. Wexler shows how the development of a reliable test began to also dominate the public imaginary of biosecurity, mainly driven by newspapers and magazine publications that celebrated the discoveries as major milestones of science. "The paper 'A Polymorphic DNA Marker Genetically Linked to Huntington's Disease,' appeared in the November 17, 1983 issue of the prestigious British science journal *Nature*, accompanied by two enthusiastic editorials. *The New York Times, The Wall Street Journal,* the *Los Angeles Times, The Boston Globe,* and *The Washington Post* ran the story on the front page" (A. Wexler, *Mapping* 219). And also Wexler's narrative places these discoveries in a climactic narrative, which represents both big discoveries in the history of Huntington's – the G8 marker and the IT15 gene – as providing the long anticipated and desired key to security.

Nonetheless, Wexler's narrative does not obliterate the disparity between the promised security as cure and the developed test. But while the initial development of the test "opened an abyss in all our lives, a vast space between prediction and prevention" (A. Wexler, *Mapping* 221), its deferral, so the disappointment and failure to provide the promised security seems to heighten the affective investment in its potential. Especially for the discovery of the gene in 1993 Wexler shows how forceful the affective attachment to the narrative of scientific salvation is. She reports how "[t]oday the newspapers all carried the story of finding the gene. They call it 'the longest and most frustrating search in the annals of molecular biology'" (A. Wexler, *Mapping* 258). The hope invested in research is so forceful that when the long anticipated knowledge is found "it didn't seem real" (ibid.). "And Marcy and MacDonald told me, 'When we called people their first reaction was relief – thank God it's over! – and the second reaction was pure joy'" (ibid.). The reactions of these scientists show how pervasive the narrative scientific salvation is, for "it" – the quest for the promised security – is "over" already before it really is. To this day a cure for HD has not been found. But rather than a failure Wexler shows that it is perceived by those involved as a moment of relief. The hopes and desires attached to the narrative of scientific salvation establish the created possibility of testing as the objects of desire and crucial key to achieving security.

Science in Wexler's story is never quite there yet. With the discovery of the gene security further receded, remaining almost in reach but not yet attainable. And also retrospectively Wexler reflects on the discovery as a crucial further approximation of security. Narratively, the discovery of the gene is turned into a necessary approximation because it allows scientists to "explore how those extra CAG repeats interfere with the normal functioning of the gene" (A. Wexler, *Mapping* 260). And though testing does not bring the promised security for the individual she makes clear that it is nonetheless a crucial security practice: "[w]hatever the risks of presymptomatic testing, there was no question that a reliable test indicating which individuals carried the gene could offer scientists valuable data about the early pathology of the illness" (A. Wexler, *Mapping* 222). Despite the insufficiency of the test, and the "not yet" of a cure for Huntington's, science is represented as the unquestionable arbiter of security and only harbinger of hope. Echoing a messianic narrative of scientific salvations, the trials and tribulations on the way to this security are to be endured until science will come and bring security to those afflicted.

And though Wexler does not tell a success story she shows how the scientific findings embedded in this pervasive security narrative create faith: "what has changed is the psychological landscape, the wider horizons of hope before us" (A. Wexler, *Mapping* 261).

In Wexler's narrative this creation and proliferation of faith and hope become the success of the climactic and end directed narrative toward security. The last section of her memoir, "Genetic Destinations" (A. Wexler, *Mapping* 241), is preceded by a group photo of the Huntington's Disease Collaborative Research Group with the caption listing the names of all the participants. The people researching HD in the different fields and disciplines personify the promise of security, which is not unambiguously there at the end of the book. Nonetheless, the image and their scientific achievement – the development of a genetic test – represents the end of a successful mission, "the completion of the operation proper" (*Transparent* 32) as van Dijck reads those images in the analysis of medical documentaries. This form of representation hides the further deferral of the anticipated and promised event.

Wexler's narrative is far from being a simplistic salvation narrative of the messianic "coming of science" though it has close affinities to it. Though her narrative construction follows the formulaic structure of this discourse Wexler is able to maintain a critical stance, reintroducing ambiguities into the text. The main subversion that Wexler offers within this narrative of scientific salvation is her own emotional detachment from the dominant circulation of hope, excitement and anticipation. Initially she cannot share her father's and sister's excitement, and later she quotes emotions of others. It is her father's enthusiasm for new genetics and her sister's enthusiasm for the discoveries in research that she *reports about*. Only when she describes her search for "Venezuela's patient zero" does she actually narrate her own excitement and passion. "We found the Spanish sailor! I remember thinking as a I showed the page to Fidela that I would never again feel such a thrill of discovery" (A. Wexler, *Mapping* 201). In contrast, her personal encounter with research findings, particularly of the genetic marker, are rather framed by fear and anxiety. As mentioned previously, Wexler herself does not get tested and neither does she reveal in her memoir if her sister Nancy is going to get tested.[17] In constructing her individual security narrative she emphasizes different actors and ways of making security, which I will turn to in the concluding section. The story of the research progress leading to the discovery of the gene[18] is told alongside and intersects with the story of the personal life, making them an inseparable part of each other. Discursively they thus establish a "mock" semantic and logical relation of the two success stories: discovering Huntington's, and successfully coping and living at risk. The story presents the coming of age story of science and of the self, which offers a possible subversion of the narrative of scientific salvation.

---

[17] Nancy Wexler revealed in 2020 after 40 years of researching the gene and heading the most prestigious genetic counseling institutions that she herself had tested positive for Huntington's. The New York Times article was fittingly titled "Haunted by a Gene" (Grady).

[18] Wexler does not follow the "traditional" plotting of science stories as van Dijck describes it: "Popular science stories usually present scientific events as a teleological structure: experiments resulting in a discovery. In gene narratives, the order of telling is a reconstruction of the logic of argument, never an account of experimentation" (van Dijck, *Imagenation* 19).

Making Security – Writing Life

I have argued that the security narrative which Wexler offers depicts inescapable despair caused not only by the onset of the disease but the risk identity she and her sister are ascribed, as well as the hope attached to science as the arbiter of biosecurity. Wexler thereby depicts the dominant discourse of scientific salvation, a utopia that is continuously deferred as it does not culminate in a cure but only in further hope for better treatment and a certainty that would resolve the unbearable risk. She makes clear that the dream of control and manageability looms large over the life and identity formation of the biosecurity individual at risk. But her security narrative does not render science as an almighty source of security.

By combining the narratives of her family's activism for and in the Huntington's community as one story with the medical history of HD, Wexler produces an image of making security that goes beyond science as the only harbinger of hope and security. Rather she emphasizes a formation which I would describe as "biosocial security." The term "biosociality" was coined by the anthropologist Paul Rabinow and describes the social relations forged by developments in the field of genetics (*Essays* inter alia 99) as well as the sociality formed on the basis of biology by activism or self-help groups (Rabinow and Rose 197, Rose and Novas 6). The term has been widely adopted and modified, coming to embody a more general field of identity formation. However, I would like to use the term in its more traditional meaning to portray the specific social identity formed in activism, which is crucial for the biosecurity individual and the act of making security.

Wexler's memoir shows that disease activism is a crucial part of "the Huntington's world" and their struggle for security. She stresses that just as her father had done, "several other people with the illness in their family had begun major fundraising initiatives" (A. Wexler, *Mapping* 87). By narrativizing the ongoing struggle and formative influence of her family in the scientific process and progress Wexler makes their actions part and parcel of the security narrative. In that respect it is crucial that she not only tells the story of her sister becoming one of the leading scientists in the Huntington's community and working on the project in Venezuela which offers the "single most important piece of information" (A. Wexler, *Mapping* 253) to solve the Huntington's secret. At the same time, she foregrounds her father's activism in funding and organizing workshops, which she represents as equally important in the discovery of the gene. His activism brings about structures that facilitate the interdisciplinary work, which was formative for this field of research. With the hybridized narrative form of life writing and disease history she manifests the interconnectedness and interdependence of these supposedly distinct forms of making security traditionally recognized in activism and scientific research.[19] By representing the network of different people, institutions, and disciplines involved in the Huntington's community, making security is rendered as a group effort.

While Wexler represents the mutual importance of different actors for reaching security, she also makes clear that the biosocial community and its ideas of security are not homogeneous. The private engagement of people like Woody Guthrie's wife, and the

---

[19] In 2012 Nancy Wexler, at that time a leading geneticist and bioethicist, emphasized the importance of "advocacy driving science" in the eponymous article which highlights precisely these networks.

Wexlers reinforces the narrative of science as salvation, for all stress the importance of research. However, her explanations of their activisms also signal toward different approaches of how to best advance toward security, within this frame of biomedically procured security. They embody a “distinct set of priorities: direct versus indirect support of science and funding of basic research almost exclusively versus diversified spending on science, public education, and patient services” (A. Wexler, *Mapping* 123). These different tactics reveal different interpretations of security. While direct funding leaves no room for other sources of security but biomedicine, the latter emphasizes the importance of educating and mobilizing the public as another roadmap to security. However, since Wexler’s father’s Hereditary Disease Foundation stands for the former, and it is Alice Wexler’s father’s and sister’s experiences that structure the narration of illness and the history of research, this approach dominates Wexler’s narrative. She therefore reiterates and reinforces the dominant security narrative of biomedical salvation.

Above all, the story of “making security” shows that the biosociality does not only exist on an activist basis that stands in opposition to the scientific community. Rather it exemplifies the interdependence of both activism and scientific research. Wexler points out that on the one hand HD afflicted families need the structures of biosociality, such as self-help groups where “hearing other people at risk talk about Huntington’s made it feel less like her individual burden” (A. Wexler, *Mapping* 116). On the other hand, their stories function as a motivation for research:

> Each workshop began by introducing to the group a person with Huntington’s disease, sometimes accompanied by an entire family . . . . A simple neurological exam followed, showing how the disease affected one’s ability to count, to recall, to walk across the room or hold one’s arms straight out in front. Often spouses or siblings would tell their own stories, giving a powerful portrait of how the disease affected an entire family. The emotional representations were always very moving and sometimes shocking to the scientists, who often had no clinical experience and had never seen a person with Huntington’s. (A. Wexler, *Mapping* 111)

The HD afflicted families are at the same time depicted in their serial as well as their biosocial implication. While they clearly function as examples of a bigger group of people, they are at the same time objects of science that are being studied and looked at. More importantly though, their suffering is used as an example to connect the highly specialized research on the molecular level with the impact and implication they have for the lived experience of individuals. It makes the researchers part of the biosocial HD community. This structure emphasizes the importance of narrative for a comprehensive understanding of biosecurity and self. In these cases, the narrative act of telling the life story becomes an important part of making security. In the same way as self help groups and research actively engage in forming a HD community, they are deeply entrenched in the circulation of hope. As an “affective community” (Ahmed) that is unified by the affects attached to certain objects, in this case hope attached to science, they represent and further circulate hope. They are not represented as a distinct group that reacts to and redefines itself on the basis of biosecurity, but rather as part of its narrative construction.

The biosocial identity embodied by the father's as well as the sister's activism is represented as their way of fighting the disease, not only literally in the form of research, but emotionally as a way of coping. "All this activism helped ease the pain of watching Mom's decline, but it could not stop the inexorable progression of disease" (A. Wexler, *Mapping* 63). Though neither form of engagement could ultimately save the mother from Huntington's disease it represents the production of hope for future security. While biosocial activism evidently engenders a hopeful discourse for the greater community of HD, it does so also for the people that are actors within this dynamic of "making security." "As she [Nancy] grew active in the small Huntington's community in Detroit, she began to speak more openly in Ann Arbor about her work, as well as about being at risk" (A. Wexler, *Mapping* 115). Not only does it advance research, it allows for an active way of confronting the disease which stands in stark contrast to the passivity traditionally associated with "being afflicted" and becoming a patient.[20] Despite the beneficial role of the hope attached to scientific salvation in the memoir, at the same time it represents a normative discourse of what is expected. When revealing that, "[f]or a long time I felt ashamed that I was not as active as my father or my sister" (A. Wexler, *Mapping* 71) Wexler expresses a sense of guilt. Similarly to the urge of testing as a moral/ethic imperative and normativity in "surveillance medicine," the engagement in activism seems another one. It represents the imperative of actively facing one's fate and making it one's own.

Wexler's appropriation of her risk identity in the narrative act, so by the writing of her memoir, also represents an act of activism that is aimed at making security. By representing her family's activism and way of coping with the risk identity she herself engages in the very same form of activism. Rose and Novas have attested the importance of "scientific literacy" ("Citizenship" 443) for the formation of a biosocial identity. The memoir with its clear didactic purpose and educational mission embodies precisely that. The extensive representation of genetic and HD research educates the implied reader and embodies this need for knowledge. However, she also raises awareness of the biological as well as cultural meaning imbued in the image of a disease, as her memoir attempts incessantly to untangle the interdependent sources of meaning making.

By writing her memoir and representing herself as a member of the Huntington's community she makes herself a representative of the community, as one of the actors in the long line of HD dramas she lamented beforehand. In doing so she is careful not to obliterate her other intersectional identity markers as setting her apart from many HD experiences. She claims to be "aware of my position as a white, Jewish, upper-middle-class woman" (A. Wexler, *Mapping* xxi). Nonetheless, her fears and depression, and her self-scrutiny are exemplifying a common experience of precariousness. Her parents' failed marriage, her father's affair, her mother's suicide attempt, and her own bouts of depression show a common suffering, despite her privileged position with all support networks in place – psychological as well as monetary. Wexler does not hide that all this suffering as well as the shame associated with HD for whole families are exacerbated by class difference but she establishes commonalities that obliterate this class difference to

---

[20] Alan Petersen suggests that "more and more, in the health care arena, the concept of the active consumer, has come to replace the notion of the passive patient" ("Governmentality" 193). This represents a difference to Talcott Parsons's "sick role" which is usually associated with passivity.

a certain extend. She therefore writes a "community of (in)security" (Völz, "A Nation" n.p.) that is in need of protection by formulating their "narrative of injury" (Ahmed, *Cultural Politics* 32–33). Wexler's proclaimed intent, however, was not just the representation of a group for the outsider. In an article on life writing and responsibility she explains that she "tried above all to speak in ways accessible to those most affected by this story – people in the Huntington's community" (A. Wexler, "Mapping Lives"). This implicit audience of her memoir also determined her choice, which for her was an ethical one, regarding what to include in the memoir. And especially her decision not to reveal if she or her sister are going to be tested is explained with her "responsibility to this community of vulnerable subjects" (A. Wexler, "Mapping Lives" 169).

In making herself an example, she thus introduces an alternate security narrative to the overarching narrative of medical salvation. By narrating her life and assuming an HD identity she depicts her suffering to give the community a voice in the public sphere and therefore establish security by raising awareness. At the same time, she also negotiates and demonstrates her own way of coping with the disease. The life narrative as a process of understanding and knowing the self through the search for her mother's true identity, is thus not only an active negotiation of her risk and a process of finding the self but an act of establishing her own security narrative; one that subverts the normative security narrative of biomedical salvation. The life narrative is therefore a necessary act of making security

Wexler's search for her mother's true self, which I discussed above, and ultimately for herself as a form of knowing and understanding represents Wexler's individual process of "coming to terms with" the threat of Huntington's, which is comparable to her sister's and father's activism. Her narrative is not just a witness account and testimony of suffering but rather an act of "making security:" "If I could catch a glimpse of her whole, perhaps I could look into the mirror each day without the everlasting search for symptoms. Maybe if I could write her story, she would no longer push herself into my dreams, scratching my arms to drag me down with her" (A. Wexler, *Mapping* 5). The haunting presence of HD, embodied by the nightmarish mother "coming back" is connected to not "understanding her whole." This understanding replaces the certainty of a test with the reconstruction of her own identity at risk. Though with the image of the "glimpse" Wexler uses the same trope as biomedical narratives – the seeing of a truth inside as a form of self-empowerment – she does not limit "recognition" to a question of understanding based on observing as knowing. Rather it is the process of writing itself that carries the promise of security in terms of manageability. And though Wexler's life writing and her search for herself are deeply connected to and structured by biotechnology, foregrounding the biosecurity narrative of medical salvation this is not what offers assurance or security to Wexler herself. Rather the practice of writing, as the way of finding the self, becomes her most important practice of security itself. Writing provides the means to narrativize and thereby understand the self in terms of biological security.

At the same time, writing represents the most important proof that the disease hasn't set in, and might even be absent altogether. Writing thus becomes test and cure at the same time, replacing the biosecurity practices prescribed by the dominant security narrative of medical salvation. The book presents security of and for the author because it represents the proof that Wexler is not showing any symptoms of HD, *yet.* This is not only implicitly so but an explicit statement Wexler makes when commenting on beginning to write after her mother's death: "There were practical considerations too. I felt increasingly that my own time might be limited. If I were to go the way my mother, I had better start writing now" (A. Wexler, *Mapping* 166). Though the book and her ability to compose this narration are proof of the presence of security, the plot generator of the memoir is the absence of security. It is the perpetual and constant "might be" and "not yet" of the healthy present that dominates and directs action and narration. The text becomes witness to this "not yet" and turns into Wexler's own mark worn with pride, an "elaborate embroidery and fantastic flourishes of gold thread" (Hawthorne, *Scarlet* 50) that marks Wexler's belonging.

Wexler thus represents a dominant security narrative of science as salvation to subvert it both, discursively and narratively. What she proposes instead is the acceptance of ambiguity as the creation of a 3rd space, which she deliberately borrows from cultural critique, so a space in between as described by scholars such as Gloria Anzaldúa, that offers the possibility for a positive re-interpretation and space of creativity. In criticizing the propagation of the test she asks: "isn't it possible that those who opt not to know are more able to live with uncertainty and ambiguity?" (A. Wexler, *Mapping* 235). The community in Maracaibo embodies this possibility of ambiguity for her. While she acknowledges the dire situation describing it as paradise and hell at the same time, she nonetheless elevates them to an image of security in a decisively different form than offered in her sister's quest for cure. She reports "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" (A. Wexler, *Mapping* 186). Despite obliterating the fact that this "integrative living" might not be as voluntary as it seems for the "outside observer," she projects her longing for happiness into this other. "Being at risk means feeling different from both those who are not at risk and from those with Huntington's. It's an emotional state all its own. The Venezuelans seem to understand this – better, perhaps, than North Americans, who do not tolerate ambiguity well" (A. Wexler, *Mapping* 199). The possibility of happiness materializes as another space and another culture. And though her quest of finding self ends with the union of mother and daughter when Wexler can "remember, I speak this language too, there are no more secrets and you and I are no longer strangers," the possibility of enduring ambiguity remains projected onto the other:

> My mother embraces me at the bottom of Lake Maracaibo. . . . Gently I let go of her arms and she releases me from her hold. As she falls away toward the floor of the lake, she turns into a beautiful golden fish with silky scales and emerald eyes. With a flick of her tail, she vanishes into the depths, while I swim up toward the surface of the water and emerge into the sunlight of the Venezuelan tropics. (A. Wexler, *Mapping* 239)

Repeating the symbolism of the fish, which represented the fearful discovery of the precarious normality, Wexler indicates her changed perspective. Here the mother as the stronghold of Huntington's risk releases Wexler. No longer seen as a carp the mother turns into a beautiful exotic fish. With a clearly colonial gaze of this exotic space of the tropics, Wexler expresses her chosen path of security.

The ambiguity that is the hallmark of the identity at risk is echoed on the discursive level of the narration. The general flow of the narrative in the life narrative sections is often interrupted by paragraphs in italics, which represent most frequently emotional or associative scenes, sketches, or dream sequences. Though all represent interruptions of the storyline, some of these are taken up and commented on in the following narration, others complement the narration in an almost Freudian subconscious mirror of the very reflected and thought-out narratives of the past. She thereby structurally creates a hybrid text with a formal subdivision of dream and "reality." However, over the course of the narrative Wexler starts breaking up the formal structure of the text that has been introduced to the reader as indicators of reality and "dream"; especially after the diagnosis of the mother and the subsequent identity change she is experiencing. She therefore narratively and structurally denies the reader the experience of certainty or security of a clearly structured story in these sections. Though these interjections merely represent short in-between sections in the otherwise clear-cut memoir, they re-embody the ambiguity she decides to represents her own biosecurity identity as.

The example Wexler sets with her memoir is thus a subversion of the dominant security narrative of scientific salvation, which would require a categorization. In opposition to the norms "perhaps I even enjoy the ambiguity, resisting sharp categories and binary definitions, the border guards insisting that we place ourselves in one camp or another" (A. Wexler, *Mapping* 238). Her didactic approach of educating is "in the hope that this story may encourage others to tell their stories as well" (A. Wexler, *Mapping* xxi). She thus aims to encourage others to take "her" path of making security by storytelling. She participates in the circulation of affect attached to an alternate object and participates in forming the Huntington's community that is the key to representation and research as much as for a support group of "shared sufferers." Her representation of HD and the HD community produces a visibility that is crucial for an improvement of the social and cultural construction of Huntington's. The visibility of HD produced by such expressions triggers more understanding in society potentially counteracting some of the social alienation and stigma associated with the disease. The book itself turns into a material object of the security narrative it depicts.

Though Wexler finds and represents her own way of dealing with being at risk by embracing ambiguity, she does not challenge the notion of undesirability of the HD body. The notion of "always already" that characterizes the precarious normality her family lives in reiterates a geneticized understanding of identity, or "genetics as fate," and thereby forecloses a dissolution or challenge of the categories "good" and "bad" life. The positive 3rd space that Wexler claims as her "happiness in ambiguity" is made impossible by this biologized understanding of security. "José has nine children. One son died of juvenile Huntington's at the age of nine. . . . José tells me firmly, 'All my children are normal'" (A. Wexler, *Mapping* 198). José understanding of "normal" remains projected onto the other as a potential but it represents a fundamentally different approach to the "always already" Wexler offers as her guiding logic of security. Furthermore, José remains marked as the voice of the uneducated Venezuelan from the poverty stricken village far away from the U.S.. In contrast, the individual at risk in the U.S. remains the other to the healthy norm under the "regime of total health" (Earle et al. 96). The ambiguity that Wexler represents as her positioning to, or rather between security and risk may describe her "category of identity," but it is a further promise rather than a fulfillment of the happiness she was seeking. Rather than a tangible alternative Wexler creates another hope that stands to contest the unquestionable urge for testing. It is a promise that "is 'ahead' of itself" (Ahmed, *Promise* 181) even after Wexler has seen her mother whole and finding a way to live in-between.