

**Reordering Genetic Information: Epigenetics and Mei-mei Berssenbrugge's
'Four Year Old Girl'
[Post refereeing draft]**

Introduction

In *The Story Within* (2013), Amy Boesky collects together a series of remarkable narratives by people who either have genetic disorders themselves or come from families scarred by them. The spirit of these narratives is exemplified by a bold statement by Clare Dunsford, an associate dean at Boston College, who comes from a family that hosts the fragile X mutation: 'those of us living with genetic conditions are at the frontier of science and metaphysics. We are brave adventurers ... into the unknown, as genetics scurries to keep up with lived experience.'¹ These stories about Huntingtons's, cystic fibrosis, hypertrophic cardio-myopathy, retinitis pigmentosa, Duchenne muscular dystrophy, Fanconi anemia, fragile X, and others, raise many important issues. This naming of conditions might suggest confidence in medical certainty about the role of genetic inheritance, but again and again these writers call into question the idea of fixed and direct genetic causality. Misha Angrist cites James Watson's typically ebullient claim that 'now we know, in large measure, our fate is in our genes', and an even more inflated, similar claim by Francis Collins, Watson's successor at the Human Genome Project, before arguing that the 'genomic reality' does not support such claims: 'Even rare and formidable broken genes don't operate in a vacuum'.² The contributors resist the idea of an unchallengeable genetic fate. Dunsford recalls watching her fragile X afflicted son outdoors one day – 'he was for once unafraid, not a victim of his genetic legacy – just a young man open to what might come his way.'³ All the contributors are interested what might come their way, in the importance of environments as well as genetics, and will no doubt welcome the new thinking about environments that is increasingly associated with epigenetics.

Boesky invites readers to consider closely several specific concerns. Genetic diagnoses affect many of us and yet too often this information is associated with stigma and can even result in a hurtful public silence, which as Patrick Tracey says in his history of hereditary schizophrenia in Ireland, has made it hard even to grasp the nature of the problem that afflicts his own Irish-American family. The language of

genetic difference leaves much to be desired, not least because ‘metaphors of deviance or culpability’ and of ‘malfunction’ are unhelpful.⁴ Life writing is often centred on a transformation, yet for people living with these conditions change needs to be thought differently, and consequently they look for narratives that explore other paradigms of temporal identity. Disability too has to be reimagined as something other than the failure to meet a bodily norm.⁵ In conclusion, Boesky hopes ‘for a wider and more capacious understanding of human variation, not only in terms of biological makeup, but in terms of how that variation gets represented and understood.’ Medical researchers increasingly suggest that many conditions which we don’t think of as genetic illnesses, such as heart disease and some forms of cancer, are in fact just as indebted to a difficult genetic load, though spread around many more genes, as the named syndromes.

In this essay I want to explore how a poem, Mei-Mei Berssenbrugge’s poem ‘Four Year Old Girl’ (1998), and a novel, Michael Byers’s *Long for this World* (2003), draw on the resources of the aesthetic to represent and understand such genetic variation at points where this variation generates perceived disability. Although neither text explicitly addresses epigenetics, the same drive to understand genetic information in terms of development and environment which drives biological and medical research in epigenetics is very much present. I shall suggest that we can think of *Long for this World* as an epigenetic novel, and ‘Four Year Old Girl’ as an investigation of the semantic space now being opened up by epigenetics. One of the source quotations that Berssenbrugge chose for the matrix of section three of her poem is a definition of ‘ecogenetic disorder’ taken from the fifth edition of the textbook *Genetics in Medicine*: ‘Ecogenetic disorder: A disorder resulting from the interaction of a genetic predisposition to a specific disease with an environmental factor’.⁶ ‘Ecogenetic’ is still in use to cover a broad range of gene-environment interactions, and is linked to enviromics as well as genomics.⁷ Its similarity to, yet difference from *epigenetics*, the theme of this collection of articles, is a reminder of the complex semantic field around epigenetics. I shall now briefly summarise this field, with the proviso that this is not intended to be authoritative account, but rather to provide context for thinking about aesthetic engagements with shifting forms of genetic determinism.

In the late 18th and early 19th centuries epigenesis was a biological theory that developed in opposition to the theory of preformation - the idea that an adult

organism was somehow contained in miniature form inside the egg or seed - and so until the early 20th century ‘epigenetic’ was normally used only with reference to this theory, and lacked the final pluralising letter. Recent popular books on epigenetics largely agree that the current definition of the term derives from Conrad Waddington, who was aware of the term’s long genealogy when he used it in a new sense to describe the causal processes involved in development, processes that might include ‘equilibrium phenomena’.⁸ Waddington’s intervention was not decisive, and in actual usage the term continued to be highly plastic. Since the 1970s, for instance, Edward O. Wilson has expounded what he calls the ‘epigenetic rules’ that govern human development by combining cultural effects with the effects of natural selection on the history of the human genome. He explains these rules thus: ‘Genes prescribe epigenetic rules, which are the neural pathways and regularities in cognitive development by which the individual mind assembles itself.’ The result is what he calls ‘gene-culture coevolution’ which is a ‘special extension of the more general process of evolution by natural selection.’⁹ During the 1970s and 1980s, the physicist Walter Elsasser also wrote influential articles on what he called epigenetic processes, arguing that any account of genetic causality needed to include reference to environmental history. Even as late as 1993 Harry Rubin could write a paper on what he calls ‘cellular epigenetics’ which argues that cell lines development depends on what he calls their ‘passage history’, the conditions under which they were cultured.¹⁰ Richard Strohman, a retired professor of molecular biology at Berkeley, and an outspoken critic of genetic determinism, similarly argues that ‘the logic of health and disease resides not in genes alone, but in holistic, epigenetic regulatory networks in cells and in all organisms – networks that are coextensive with the external world and which require for a manifestation of wellness the presence of environments reflective of our inherited and conserved genetic and epigenetic capacities.’¹¹ ‘Coextensive with the external world’ – at this point the term ‘epigenetic’ risks disappearing into a mist of everything.

From the late 1980s onwards, others were arguing for a more restricted definition that did not treat the epigenetic as a broad synonym for environment. One of the pioneers of the study of methylation, now believed to be a key epigenetic mechanism, Robin Holliday, writes in his abstract for a 1989 article on ‘DNA methylation and epigenetic mechanisms’ that ‘epigenetics comprises the study of the switching on and off of genes during development, the segregation of gene activities

following somatic cell division, and the stable inheritance of a given spectrum of gene activities in specific cells. Some of these processes may be explained by DNA modification, particularly changes in the pattern of DNA methylation and the heritability of that pattern.¹² It has been this combination of heritability and methylation that has come to circumscribe current epigenetics. In this article Holliday credits Waddington with the coinage of epigenetics to mean ‘the study of the temporal and spatial control of gene activities during development.’ Holliday also argues that at the time of writing there is a need for ‘a conceptual or theoretical framework...to help understand the strategy of genes in unfolding the program of development.’¹³ The conceptual framework remains elusive; recent accounts both popular and specialist tend to concentrate on the molecular biological level. Nessa Carey says ‘when scientists talk about epigenetics they are referring to all the cases where the genetic code alone isn’t enough to describe what’s happening – there must be something else going on as well.’¹⁴ Tim Spector explains what this something else entails: ‘reversible inherited change, which does not alter the DNA structure, is the essence of epigenetics’.¹⁵ Perhaps soon we will have a conceptual framework with its own strong fertile metaphors – but that time has not yet arrived.

It is important to note that some historians of biology sound a note of caution about claims for epigenetics. The current theory to which Carey and Spector allude is the idea that most of the work of switching on and off genes is done by a biochemical process known as methylation, by which 5-methyl-cytosine replaces simple cytosine in the string of bases that comprise the DNA ‘code’. Barry Barnes and John Dupré pointed out in 2008 that although ‘there is currently much interest in methylation as if it were something that happens to or is done to genomes’ in fact ‘the nearest things to such idealized genomes we have experience of are the ‘demethylated’ DNA filaments we specially prepare for sequencing’. They suggest that ‘it is indeed a very strange quirk of terminology that identifies DNA in or close to its normal natural state as part of an epigenome and DNA in a radically modified state as part of a genome, but that seems to be how things stand at the moment.’¹⁶ Only expert researchers will be able to provide further first-hand information about methylation; writers and cultural critics can however investigate the aesthetics of genetic terminology, quirky or not, and how it represents the frontiers of science and metaphysics where so many of us find ourselves.

Epigenetics is therefore a term whose genealogy creates a gravitational pull towards pictures of genetic process as interactions with a variety of environments, resulting in sometimes unintended semantic stretching. Evelyn Fox Keller starts her recent book by noticing examples of such overstretch and suggesting that there is therefore a ‘muddle about the meaning of epigenetic’ in current public discourse that has distorted understanding of the problematic nature/nurture debate by mistakenly claiming to be ready to solve the problem altogether.¹⁷ When she makes her own authoritative claim about the mechanisms by which bodily identity is inherited she deliberately puts the word epigenetic into a medial position: ‘almost all human traits are transmitted from one generation to the next; but at the same time, let us also accept the fact that the mechanisms of transmission are varied. They may be genetic, epigenetic, cultural, or even linguistic.’¹⁸ Epigenetics is discursively placed as a zone between genetics and culture.

One final methodological point is needed. Although I am drawing on widely discussed concepts of the aesthetic, such as those of Adorno, in my attention to the aesthetic in poetry I draw on the thinking of the poet Allen Fisher who participated in the AHRC epigenetics project at the University of Southampton. In a number of recent lectures he has been arguing that ‘all processes in human consciousness have an aesthetic component’, and that this is dominant in art, where this aesthetic activity can be called ‘a pattern of connectedness’.¹⁹ This pattern is never complete, never a perfect fit between consciousness and its objects, so that ‘for the artist the potential is to understand a state which is not reliably coherent, but is not incoherent ... this new position is a state I name as *confidence in lack*.’ To describe this openness to discovery Fisher draws from quantum physics the epistemic metaphor of *decoherence*, which he defines as ‘a state between empirical verification and provable but not witnessed information’. I take Fisher to be saying that aesthetic investigation is a process of inquiry that is integral to both epistemological and ethical projects yet distinct from them. Aesthetic practice creates insight through the discernment and provisional projection of significant patterns of interaction and interconnection.

Poetry and Genetics

A poem such as Berssenbrugge’s ‘Four Year Old Girl’ circulates in a culture that already has a number of expectations about the value and role of poetry that range

from scientific stereotyping of poetry as wild inquiry, to the use of poetry as consolatory blessing, to the idea of poetry as a cultural broker for new ideas (the most widespread mode in which poetry engages with science). To understand how Berssenbrugge's poem can embark on its own cultural venture we need to place it in this wider context, starting with this use of poetry as an abstract sign for uncontrolled rhetorical excess, before considering two other types of cultural work expected of poetry.

The appearance of aesthetic functions in accounts of scientific research in genetics can raise methodological anxieties amongst scientific researchers understandably concerned with rigour. To give just one example: large data sets of probability matrices for empirically collected genetic information can threaten to overwhelm researchers with methodological uncertainty. Aesthetics is therefore sometimes identified as a form of unwanted poetry. This is the charge that a reviewer brought against the science journalist Matt Ridley for his analogy between the human genome and a book, an analogy based on the widely circulated idea that genetic information is an organic archive. For instance, in her study *The Genealogical Science*, Nadia Abu El-Haj cites the director of the Genographic Project asking 'What is DNA, this molecule that allows us to travel so far back into the past—this history book we carry around like a gift from a long line of ancestors?'.²⁰ According to El-Haj, the belief that DNA is a record of human origins and development is now widespread in the anthropological field. The extrapolation of this concept to the more easily grasped image of DNA as a book is the target Anita Allen's sharp critique of Matt Ridley and other popularisers of genomics. She argues that the most damaging feature of Ridley's book *Genome* (2000) is not that it is sexist or teleological, though it is open to the first charge, but 'what we might call Ridley's poetry'.²¹ Ridley likens the genome to a book, and Allen calls this 'poetry, and confusing poetry at that', because the fertile metaphor of the book may illuminate the idea that DNA can be understood as information, but carries with it other inescapable implications, not least the hint of genetic authorship: 'By identifying the genome with a literal book, Ridley implies that our individual or collective humanity is a text designed by someone wishing to record or communicate meanings'.²²

Although Horace's neat affirmation that poetry can at once instruct and delight its readers is almost universally known, it has been less noticed just how often poetry has been a vehicle for specific instruction in science and medicine. Even today, poetry

still plays a modest, largely undocumented role as cultural broker in the public cultures of scientific research. When the ESRC Genomics Forum announced the winners of its poetry competition in January 2011, the deputy director Professor Steve Sturdy said that the winning poems highlighted the ‘sense of uncertainty surrounding genetic technologies and the role they might play in “improving the human”’ and would ‘encourage others to explore their own views on these important issues’.²³ Poetry’s role is to act as a mediator between the genomic knowledge and the ‘views’ or opinions about social policy needed to manage the implementation of this knowledge. This role need not entail excessive deference to scientific authority. The judges’ report says that ‘often what marked a good poem was a sense of ambivalence about the apparent possibilities of genetics, and an ability to consider and illustrate all sides of the argument’.²⁴ The winning poem ‘Forward Deck’ by Sophie Cooke visually mimics the twined helices of DNA, and combines this with an allegory of genetic engineering in the service of eugenic aims, by likening the recipients of such treatment to the ‘genetically wondrous’ crew of a yacht which sails in a straight line on a perfect ocean.²⁵ The crew are people who believe they have ‘drained chance’ from their bones because ‘Cell supplants cell / losing nothing’. ‘You make yourselves new’ the poem apostrophises these genetic marvels - echoing the idea of the self-made man, and also the modernist credo to ‘make it new’ ascribed to Ezra Pound - and in doing so associates poesis with genomics. But the poem does not develop this association and concentrates its satire on the dangers of elitist exclusivity that might be the consequence of a purely genetic improvement of human potential unconnected to any ethical or political principles. Although it does hint at sinister exploitation of others – ‘a bio-fuel / of brothers’ whose ‘wasting shoulders ... pass in flashing turbines’ -- ‘Forward Deck’ keeps things simple. It warns against the dangers of exploiting genetic information, but doesn’t engage with the linguistic, cognitive, historical, etymological and affective complexities of the underlying genomic conceptualisation of inheritance.

‘Forward Deck’ is rightly described as a poem of argument. In our culture most poetry plays a much bigger role as the repository of public affect. This negotiation of many forms of desire and emotion can be seen in the amateur poetry written by families of people with genetic conditions. Samantha Coburn, the mother of a boy with Angelman syndrome, for example ends an already very moving short essay with a poem. Her essay likens the diagnosis and its consequences to a box that

appears to determine the child's future. 'As humans we try to find the place where we fit—our box, the area that defines us to ourselves and to the communities around us. When we have our children we begin the process for them. . . . then our children start to create their own boxes with likes, dislikes, friends, and activities. Sometimes our kiddos are given a box from birth: a genetic disorder, cerebral palsy, autism, the list goes on. As a parent we try to gain an understanding of this box. Sometimes the box is cerebral palsy, only to find out later it is really Angelman syndrome.'²⁶ As if feeling that argument on its own is not enough, Coburn ends her short essay with a highly emotional poem, introducing it with the explanation that sometimes 'words are caught in our bodies, stagnant and causing ill effects on our manner and mien' while at other times 'those words then flow and become wonderful healing opportunities for us'. By implication, prose risks emotional blockage, where poetry can be cathartic. This is the second half of the first stanza, and the first half of the second:

A blessing was born upon a day
 Near perfection in every way
 Gathered in my arms you sleep
 Ever full my heart, sadly it will weep
 Lurking deep within your form
 Missing pieces, will become the norm
 Although my heart will roar
 Nothing will heal this sore

Specialists line up in a row
 Years fly by 'ere we find our foe
 Now the answer is clear
 Darling child, you're an angel dear
 Rendered voiceless though you are
 Opuent your soul shines like a star
 My lamb, how blessed are we
 Each moment with you, our beautiful destiny²⁷

The poem advertises its poeticity through rhyme, a basic iambic rhythm and traditional poetic diction, as well as allusions to the discourse of Christian prayer and

hymns. Faltering rhythms lend authenticity to the emotion. The comma after ‘pieces’ and the consequent stumbling rhythm enact the sense of brokenness, while the over-extended final line’s clumsiness not only projects a sudden heave of emotion, it also reflects the child’s outward lack of perfection coupled with the strong feelings of parental love he elicits.

Other poems in the same collection of writings about Angelman respond more fully to the voicelessness of the condition, intimating that poetry can stand in for an expressivity denied articulation by cognitive deficit. The father of one boy whose sister is about to be married imagines the boy telling his sister that her non-verbal signals are valuable communications for him. The aunt of a child with the syndrome writes a powerful free verse celebration of the child’s physical aggressions:

I bite
 I pinch
 I slap
 I stomp
 I whine
 I’m communicating
 Don’t you hear me?
 My language is not words

 And you will know that when I bite,
 I love you so much I want to eat you all up.

 For the deep sadness and disappointment I feel in how much we are both missing.
 I’m reaching out in the best way I know how
 Using the only real language we both understand²⁸

The poem becomes not only a surrogate voice but a means of facing the child’s silence. By presenting the poem as if the child had written it, it overcomes impossibility by creating an imagined space for intersubjective affects to flourish.

Berssenbrugge’s poem ‘Four year Old Girl’ takes place against this backdrop of expectations about poetry: that it is associated with anti-scientific rhetorical excess; that the best that can be expected of poetry is that it will instruct in a delightful

manner its readers in new scientific ideas; that poetry can offer sanctioned public displays of emotion; and that poetry can represent expressive potentials and intensities which otherwise elude voicing. As my examples of poems about genetic issues also hint, poems that put the language of current medical knowledge under the microscope of informed critique are likely to be rare. Berssenbrugge's poem about the consequences of genetic illness for the sense of self is therefore justly well-known despite the demands it makes on the reader, because of the manner in which it employs advanced poetic techniques to scan the language of genetic medicine for signs of hope and pathology. Berssenbrugge confronts textbook accounts of genetic illnesses such as Fragile X and Angelman Syndrome with ideas about identity taken from psychoanalysts, philosophers and religious thinkers, and does this in a form that invites readers to think of her poem as the articulations of a mother and daughter confronted by some elusive genetic inheritance that may endanger one or both of them. As Eileen Tabios says, Berssenbrugge co-opts and feminizes the technical language which she then opens out to scrutiny and transformation.²⁹

The final line of 'Four Year Old Girl' -- 'The love has no quality or value, but only lasts a length of time, different time, across which unfolds her singularity without compromising life as a whole' — typifies the difficulty that we encounter when translocating poetry into a scientific domain. Love is a value that we are all likely to endorse, but how does it translate into research and policy? Isn't this a reminder that poetry is too removed from the world of scientific knowledge to be of any relevance to it? We are unlikely to ask how a string quartet can help us understand genetics. Poets may write about issues such as injustice and oppression that touch them deeply, but they rarely write direct publicity for, or commentary on, specific scientific discoveries or theories. Poems don't work like this. Poems explore the way we currently use language to think and feel about our lives and the world in which we live, and they often disrupt current epistemic institutional practices for managing knowledge-claims by operating at levels of pragmatic abstraction so high they isolate language from almost all contexts of address. Poems can intimate the inferences to be made from metaphors, etymologies, speech acts, or the interlocking affects and beliefs that inhere in contemporary discursive usages, but they are rarely good vehicles for rigorous analysis or testing of data and arguments. Is there any way, other than by providing explicit, perhaps commissioned epigenetic content, that

poetry could be relevant to the precisions and experimentation on which epigenetic research is based?

Before concluding with a close reading of Berssenbrugge's poem in which I argue that poetry attentive to interactive dynamics between language, body and environment, which also incorporates attentively some of the discourse of genetics and the patient experience, can be relevant in those and other ways, I first want to say more about the aesthetic conditions of contemporary poetry within which she operates. To do this I shall consider another type of aesthetic practice that might seem more suited to these concerns, the realist novel. I shall argue that while the novel can brilliantly simulate the lived experience of those caught up in relationships with genetic disorder, it falters when handling questions of how discourse enframes the science and metaphysics. Novel and poem are more complementary than we sometimes recognise.

Michael Byers' *Long for This World*

In Boesky's collection of genetic narratives, the brother of a boy with Angelman syndrome says hopefully that 'knowing what is scientifically wrong will help you understand situations better'.³⁰ His accidental inversion of the phrase that he presumably intended, 'knowing scientifically what is wrong' hints at a submerged anguish and possibly even anger at the epistemological authority of medical science. 'There must be something wrong with the science' is an understandable, if non-rational, emotional response to the painful situation of living with a profoundly disabled sibling. Yet although the science is not wrong in the sense of being responsible for what has happened to the brother, the possibility of wrongness must not be discounted. Science is always getting it wrong and correcting its mistakes; this is how it progresses. Medicine therefore presents a challenge to non-specialists of all kinds, including brothers of patients and creative writers, the challenge of how to work out what trusting the current science will entail, while remaining alert to 'what is – or might potentially be – wrong scientifically' in the spirit of respectful support for such research.

The main protagonist of Byers' novel, Henry Moss, is a representative of such science, a clinical specialist in a fictional syndrome called Hickman, a genetic

mutation which accelerates the aging process and interferes with normal cell repair to the extent that patients with the condition only survive to their early teens. No patient has lived beyond seventeen. Henry has a number of patients under his care, and at the start of the novel has become especially attached to one of them, a highly intelligent boy of fourteen, William Durbin, whose life expectancy is likely to be measured in months. William's wealthy parents are desperate to find a way to help him live longer, willing to pay whatever this costs, and indeed willing to add to financial incentives as much moral pressure as they can exert on his doctor. The unexpected possibility of a reprieve for William arises from the discovery that the brother of another Hickman patient is a 'positive': he has the fatal mutation and yet is perfectly healthy because of the action of an 'enzyme' that gives him immunity. Henry extracts the enzyme, grows it in the laboratory, and then faces a dilemma. Should he behave as a reputable clinician and refuse to administer it to William before it has had ethical and medical approval, or should he give in to the temptation to test it secretly on this patient he much admires, even at times loves as if he were another son (Henry's own son is the same age)? Henry gives way to pressure, gives William the enzyme, and at first appears to have made the right choice - the sick boy begins to recover some ground. Henry struggles hard with the internal conflict that this breach of medical ethics produces, arguing endlessly with himself: "But what man would have done anything else in his position? If he had said no to William, to Bernie, to Lilian, could he have stood here in good conscience and felt he was a decent man? No he didn't think so."³¹ The internal effects on Henry are severe. He starts babbling so noisily in his sleep that his wife asks him to move out of earshot into the attic.

Such rich emotional and often unconscious interactions are the very lifeblood of the realist novel. I shall argue that in this novel these interactions are also signs of a complex dynamics that far exceeds what a purely scientific medical approach must delimit in order to create manageable objects of inquiry. My starting point is the challenge of any novel would face in representing the genetic science, a challenge due not to the difficulty of gaining first hand knowledge, but arising from the scope of its genre, realist narrative fiction. Unless he were actually a clinical geneticist himself, this author as it turns out could hardly be in a better position to write about genetic illness.

Michael Byers is the son of Peter H. Byers, a professor of medicine who specialises in the study of the role of mutations in collagen genes responsible for

genetic conditions such as osteogenesis imperfecta and Ehlers-Danlos syndrome. A year after his son's novel appeared, Peter Byers published a co-authored paper in *Science* reporting on promising research that could be a counterpart to the fictional research in the novel. Peter Byers's team had investigated the use of targeted stem cells to disrupt a mutant gene *COL1A1* responsible for disruption of the encoding of certain types of collagen in osteogenesis imperfecta or brittle bone disease, a genetic condition that causes weak bones. Unlike the fictional Henry Moss, Byers' team worked on stem cells *in vitro* – and also unlike the novel their conclusion is promissory: 'Our finding of efficient *COL1A1* gene disruption in MSCs demonstrates that gene targeting is possible in nonembryonic human stem cells'.³² In other words, the process 'should be adaptable to clinical trials', but of course, unlike the fictional Henry, they have not attempted such interventions. Michael Byers makes plain in a note at the end of the novel, that he has given careful thought to the fictional construct of Hickman, explaining that it is similar to the real Hutchinson-Gilford Progeria Syndrome, although he has made alterations: 'patients with Progeria do not suffer any cognitive decline, for example, and certain other clinical aspects of Hickman' are his own creation.³³ Progeria is an extremely rare condition (about a 130 cases known since it was first described in the 19th century) that results from a mutation in the *LMNA* gene responsible for a protein which ensures the stability of the nuclear envelope in the cell. This autosomal dominant mutation causes the patients to develop arteriosclerosis as children and usually die in their teens. Recent research suggests that epigenetic factors may be at work in the rapid senescence of Progeria, manifesting themselves as alterations in the heterochromatin.³⁴ It would be reasonable therefore to think of Hickman as itself having epigenetic factors in the stricter sense of inherited alterations of gene expression.

The problems that Byers's novel faces in depicting the effects of a genetic syndrome and its clinical treatment are not therefore due to lack of specialist knowledge. The two problems that the novel has with genetic science that I want to concentrate on, because they highlight the greater potential of poetry to depict such areas, are these: how to represent the genetic dimensions of the existential turbulence of William's lived experience, and how to address the many-sided density of the discourse of genetic knowledge. Or in other words, how to depict the intersection of science and metaphysics in William's life, and how to put the language of genetic difference under the scanner. I shall suggest that the novel inventively does the former

through its treatment of the interactions of the characters as a psychodrama projected from William, and makes a start with the latter by giving him a consoling fantasy of escape that reflexively addresses the whole issue of the possibility of accurate and ethical representation of a genetic syndrome.

The format of the realist novel struggles with a protagonist such as William because the usual working out of the consequences of choices made with a degree of free will seems denied by the unyielding character of the genetic illness. William's physiology, indeed his entire being, can seem to be scripted by the medical literature on his condition, a literature that Henry Moss has helped write. How then can the novel find a means to give William adequate representation as a subject? The solution turns out also to be a tacit critique of the older genetic vision that brackets out all environmental concerns. John Dupré argues that not only are genes and environment utterly intertwined, this environment also includes behaviour, so that evolution takes place in multiple sites: 'genes, environment, behaviour of conspecifics, epigenetics etc.'³⁵ In the metaphorical sense of an epigenetics that is about genes and environment, this is an epigenetic novel.

Byers's novel repeatedly demonstrates that William's genetic illness is embedded in a wider environment represented by the familial dynamics of the Mosses. One reviewer calls the novel Updikean – although this is a feminist Updike, far more attuned to issues of gender politics and the politics of ethnicity than his predecessor – because the novel is largely character-driven.³⁶ Henry's wife, son and daughter are given considerable space in the novel, and each of them is differently and sometimes profoundly affected by William's condition and its magnetic pull on Henry. The medical treatment and research become part of a much wider set of dynamics, processes that range from adolescent physiological maturation to cultural and sporting activities. Henry's wife Ilse, once a high-flying medical researcher in her own right before she came to America from Europe to marry Henry, has become an efficient senior hospital administrator, yet regrets the loss of her own medical career. She buys a scooter for the freedom and excitement it gives her, and then realising that this is only a fantasy solution to her problems, decides to go freelance and set up a charity offering free medical advice to a poor part of the city. Meanwhile her children also become caught up in the drama of William's decline. Sandra, the older of the two, a keen athlete who is considerably bigger and stronger than her brother, comes briefly under the possibly malign influence of the teenage boy 'positive' who is

providing the medicinal enzyme. She only slowly frees herself from what appears, like her brother's attraction to William, to be a symbolic attempt to locate the healing power she intuits that her father has located, as if she can somehow become William and redeem him. Eventually she begins to recognise her own distinctive powers when she attends a basketball camp where her talent shines out, and she begins to negotiate a relationship with an African American boy, far more intelligent and attentive than the 'positive'. Meanwhile Darren starts stealing his mother's scooter at night, and secretly phoning William, eventually taking his sick friend out for a wild night ride.

Although this familial drama could be read as an acting out of the Moss family's unconscious desires set loose by fear of William's imminent death, the novel does I think also want us to see this drama as the voicing of William's condition, the story of his illness as it were. To reinforce this epigenetic narrative, Byers therefore introduces another theme directly through William, his speculation that he might be an alien in the science fictional sense. Clare Dunsford points out that: 'Among the unpleasant things you get used to when you receive a genetic diagnosis is the experience of hearing yourself or your loved ones described in clinical language that you makes you sound like an alien, a primitive, or an animal. Genetic vocabulary sometimes rivals the worst insults.'³⁷ William speculates that he is really a visitor from another planet who finds himself in what to him is an alien and fatal situation on a world and in a time unable to accommodate him safely. This consoling science fiction is generously treated by the novel which thereby tacitly recognises its own fictional status (after all Hickman itself is strictly speaking a scientific fiction) and concedes that from some largely unimaginable perspective William could be literally right – he is of course metaphorically correct. Unfortunately William does look like many cartoon images of aliens: 'Every month William looked more and more like a Hickman patient, as the boy he had been vanished into the phenotypic signs: bulbous head, sunken jaw, ragged teeth, wasted body'.³⁸ William's theory that he is an alien is a means for the novel to elicit a sustained critique of the clinical discourse of his condition as alien to human norms. "So maybe there's a world where I don't have this and we could somehow tunnel between universes" he tells Henry.³⁹ Eventually William arrives at the point where it is the idea of a normal human being that is alien. Out on his one final joyride with Darren, he speculates that he is one of a society of aliens who are time-travellers from the future and eventually everyone will have the injections that William is receiving, and become like him.

Early in the novel Henry says to William's parents that as far as their son's illness is concerned, scientists 'don't really know how it happens' and 'don't know how to stop it'.⁴⁰ William's unrolling fantasy that he is an alien derives from the reading of science fiction that he and Darren indulge. Since the entire novel is a fiction about science, we can think of the failure of this fiction to save William as a comment on the limits of the entire novel which also 'doesn't know how to stop it'. Or to put this more explicitly still, the novel meets one of its sharpest limits when it comes up against scientific epistemology. William's theory is an alternative science, which the novel rightly contextualises as such, and in doing so admits to its own limits in representing the epistemological stakes of genetic science.

Mei-mei Berssenbrugge's 'Four Year Old Girl'

'Four Year Old Girl' is one of eleven poems in the collection *Four Year Old Girl*. Most of the poems explore how aesthetic experiences, ranging from sensory intensities to memories and intimations of mortality, create changing boundaries of self and environment: 'A storm on the horizon creates minute pressures / you feel with your body'.⁴¹ Berssenbrugge is especially interested in borders between self and other: 'You don't have to touch the border to know how it feels, whether a napkin or a rose petal feels softer, the border between you, or the end of her life'.⁴² As the length of this single line indicates, these are poems written in such long lines they approach the form of prose poetry, even though Berssenbrugge retains lineation. Her style is almost anti-poetic, avoiding any obvious metrical regularity or metaphorical compaction. Some poems allow the sentences to extend over line-breaks; 'The Four Year Old Girl' matches sentence and lineation exactly: every line is a complete sentence. The poems also have an extensive internal structure of multiple sections. 'The Four Year Old Girl' has six parts and almost eighty lines as it takes us into the oscillations between three positions: the biomedical understanding of genetic disease; theories of language and subjectivity capable of 'reducing a parent to the universality of signifier'; and a poetic apprehension of experience as fluid intensities whose

elusive and emotional perception is not fully represented by either the medicine or the philosophy.

The poem begins with lines taken straight from a textbook typical of the pedagogic medical texts of the 1990s:

The “genotype” is her genetic constitution.

The “phenotype” is the observable expression of the genotype as structural and biochemical traits.⁴³

As a new reader of the poem we appear to be faced with a situation somewhat similar to that in Byers’s novel. The mother of a four year old girl struggles with what seems to be a genetic fate that has befallen them both. Like the mother in Coburn’s poem, this mother can still recall ‘Joy at birth, a compaction of potential and no potential’ (57). The poem appears to present a dilemma in which both mother and daughter feel ‘inspired to change the genotype’ yet how might they do this? Might the findings of recent epigenetic research help by challenging ideas about genetic determinism of human identity and selfhood, or might they increase the pain by hinting that maternal or even grand-maternal behaviour was in some way responsible for the daughter’s condition? The poem’s answer is complex, though it can be roughly paraphrased as the suggestion that knowledge or comprehension is not a sufficient relation to the world of human experience, and that as the poem puts it, ‘the world of the imaginary exists’. In this imaginary can be found love, which may have ‘no quantity or value’ but nevertheless may be able to sustain the girl and her mother. In the final section of the poem we are told that love has its own temporality ‘across which unfolds her singularity without compromising life as a whole’. It is a measure of Berssenbrugge’s achievement that she enables us to understand how apparently incompatible yet equally valid modes of thought can co-exist.

I have used the precautionary language of ‘seems’ and ‘appears’ because to read this poem as directly autobiographical, or even as a fractured narrative of a fictional mother and child, would be to misinterpret its strategies. Its genesis certainly was personal. Berssenbrugge tells Eileen Tabios that when she wrote the poem she had been ill for several years due to exposure to pesticides, and was reflecting on her mother’s death from asthma. ‘I think a lot about fate and if and how fate can be changed. I’ve had so much experience of illness that I came to see it as a crisis of

being. And I began thinking of how not to pass on illness to my (then) four-year-old daughter...I decided to write about genetics and how to change one's own genetics. This became a poem about how a girl makes her identity if her genetics is disorganized as well as the mother's role in her daughter's fate'.⁴⁴ As Tabios explains in a comment on a line about 'the phenotype', Berssenbrugge's poem argues that 'genetics is not the ultimate definition of a person'.⁴⁵ The poet does anticipate the claim made on behalf of a growing community of researchers in the subtitle of Tim Spector's account of the fruits of medical research on the physiological differences between genetically identical twins, 'Why you *can* change your genes'.⁴⁶

Tabios was given full access to a scholarly treasure trove, Berssenbrugge's notes for the poem and these quickly reveal just how mistaken it would be to think of the poem as offering any sort of specific familial narrative, autobiographical or imagined, in a manner similar to Byers. Tabios schematically displays this archive in the form of an ordered set of more than one hundred quotations from eleven sources identified by Tabios (along with a small number of unidentified ones), quotations from which Berssenbrugge took phrases, ideas and images for the final poem.⁴⁷ These sources include Deepak Chopra's blend of Western and Ayurvedic medicine in *Quantum Healing* (New York: Bantam, 1990), the textbook *Genetics in Medicine*, a book by the Buddhist monk Thrangu Rinpoche on *Buddha Nature*, Sandra Ingerman's unabashedly shamanic account of what she calls *Soul Retrieval* (San Francisco: Harper, 1991), and books or articles by Jacques Lacan, John Bowlby, Georges Bataille, Agnes Martin, and John Cage.

As the titles reveal, Berssenbrugge began work on the poem by convening in her poetic workspace a panel of experts representing very different and often incommensurable epistemologies of human identity. Some speak authoritatively for medical science. The authors of *Genetics in Medicine* tell their readers that 'to give patients and their families the full benefit of expanding genetic knowledge, physicians and their colleagues in the health professions need to understand the underlying concepts of human genetics and the role of genes and environment in normal and abnormal development and in disease.'⁴⁸ The trained physician Chopra, who combines Western medicine with Ayurvedic medicine, adds to the textbook picture an optimistic vision of genetic voluntarism: 'Gifted with total flexibility in our nervous systems, we all have the choice to build boundaries or tear them down. Every person is continually manufacturing an infinite array of thoughts, memories, desires, objects,

and so on. These impulses, rippling through the ocean of consciousness, become your reality. If you knew how to control the creation of impulses of intelligence, you would be able not only to grow new dendrites but anything else.’⁴⁹ Sandra Ingerman steps entirely away from medical science to argue that illness results from what she calls ‘soul loss’. Alongside this spectrum extending from rigorous science to magic, Berssenbrugge also includes philosophers, psychoanalysts and artists. In the first section of the poem Berssenbrugge uses uncredited a memorable image from Lacan’s second seminar: ‘The meaning she’s conscious of is contingent, a surface of water in an uninhabited world, existing as our eyes and ears’. Elements of this line come verbatim from the following passage in Lacan, where he takes characteristic swipes at vitalism and behaviourism, as well as what he believes is the tendency to treat consciousness as the ‘formative force taking effect in the embryo’: ‘However we do know that consciousness is linked to something entirely contingent, just as contingent as the surface of a lake in an uninhabited world—the existence of our eyes or of our ears.’⁵⁰

In addition to documenting source quotations, Tabios reproduces several drafts of the poem. Although tracing the poem’s development in detail is outside the scope of this article, two features of Berssenbrugge’s revisions are particularly relevant. In the process of revision, Berssenbrugge softens the edges of scientifically confident statements about genetic determinism. She deletes, for example, the following draft sentences presumably because each one insists too unequivocally on genetic determinism: ‘In the case of single parent disomy, a pair of chromosomes is inherited from only one ancestor. Genetic predisposition to a specific relation interacts with chance. Her identity is the sum of the effects of genes on a subject at the level at which she constitutes herself out of the effects of words.’⁵¹ While resisting the authority of a purely genetic account of subjectivity, Berssenbrugge also resists a purely Lacanian one too, and eliminates a number of allusions to signifiers and signifieds that derive from his theory of a linguistic unconscious. All these revisions act to diminish the epistemological authority of the various versions of human identity with which she began composition.

Uses of Intertextuality in ‘The Four Year Old Girl’

Reflexivity is intense in this poem: its line by line statements are in the words of the poem, 'observable expressions' and we are invited to be critical, empathetic observers of their behaviour. This is section one of the poem:

The "genotype" is her genetic constitution.

The "phenotype" is the observable expression of the genotype as structural and biochemical traits.

Genetic disease is extreme genetic change, against a background of normal variability.

Within the conventional unit we call subjectivity due to individual particulars, what is happening?

She believes she is herself, which isn't complete madness, it's belief.

The problem is not to turn the subject, the effect of the genes, into an entity.

Between her and the displaced gene is another relation, the effect of meaning.

The meaning she's conscious of is contingent, a surface of water in an uninhabited world, existing as our eyes and ears.

You wouldn't think of her form by thinking about water.

You can go in, if you don't encounter anything.

Though we call heavy sense impressions stress, all impression creates limitation.

I believe opaque inheritance accounts for the limits of her memory.

The mental impulse is a thought and a molecule tied together like sides of a coin.

A girl says sweetly, it's time you begin to look after me, so I may seem loveable to myself.

She's inspired to change the genotype, because the cell's memory outlives the cell.

It's a memory that builds some matter around itself, like time.

Isolating each sentence on a single line underlines the role of the proposition as the inner narrative of the sentence. The line break snaps shut on each statement giving it redoubled assertoric force. Yet although the poem is constructed of a series of such statements, which at times start to build towards lines of argument in the logical space

of reasons, their apposition invites another kind of reading, in which we treat each statement as deserving of observation in isolation, and in which we ask what sort of statements these are. Detached from their sources, lacking authorial warrant, and placed under the microscope of poetic attention, each line invites questions of a Pragmatist kind. What does it mean to utter the first line, for instance? In what context might this be true or relevant? The poem treats these statements not as ready-for-use paraphrases of authoritative knowledge based on authoritative medical research, but forms of usage requiring reflection on every aspect of their ‘constitution’.

Connections between the sentences are often unstable, creating paratactic relations of lesser and greater distance. This type of disjunctive assemblage of sentences is similar, though not quite the same, to what Ron Silliman called ‘the new sentence’, a practice of prose poetry that he attributed to a group of Bay Area poets in the late 1970s.⁵² The new sentence concentrates attention at what Silliman helpfully calls ‘the level of the sentence’. Silliman assumes that the increased attention to the internal dynamics of the sentence, and to its attempts to create syllogistic or narrative links to adjacent sentences, can enable readers to understand better how ideology infiltrates public consciousness by making certain inferences appear obvious. Berssenbrugge’s intermittently paratactic sentences also draw the reader’s attention to features of statement that are ordinarily barely visible, but not just at the sentence level, nor only in order to foster political change as Silliman intends. Instead, her sentences invite enhanced attention to other levels or spaces of attention, especially those of knowledge and reasons, or of epistemology and argument.

The first three sentences of the poem exhibit the type of statements that belong to the genotype of the scientific textbook. What we notice about the first sentence is the sneaky ambiguity of the copula ‘is’, which could be an abbreviation of ‘is defined as’ or could have a much stronger sense: that her genotype is the cause of her own genetic make-up. We also notice that the familiar word ‘constitution’ used to mean the working of our entire physiology also carries a secondary meaning: that the genotype acts similarly to a founding statement of the kind which underpins American political and legal existence. The copula occurs in each of the first eight sentences, gradually undergoing a transition from largely definitional equivalence to more extended and elusive claims about the relations it transacts. This transitional process is started by the seemingly innocent use of ‘is’ as an auxiliary for the participle ‘happening’. Moreover this process that supposedly ‘is happening’ ‘within

the conventional unit we call subjectivity' is taking place in two modes. One mode would assume that what is asked for is an expansion of the definition of subjectivity. The other would assume that this is a cumbersome manner of asking what is going on in her head. The fifth line - 'She believes she is herself, which isn't complete madness, it's belief' - builds on these antecedent tensions between the use of 'is' as copula and the existential claim. Let's unpack this line a little.

'She believes she is herself' would first of all suggest that she is feeling alright. When we say that she is not feeling herself today, we mean that her usual sense of self has been displaced by the sense of being unwell. Here, however, this phrase takes on a second connotation: she believes that she is autonomous, that her selfhood is ultimately independent of determining forces. She believes she has free will. A third meaning also insists on itself. She believes that her sense of being a self, of self-awareness manifest in self-consciousness, is the very core of who and what she is. The poetic line does not allow this statement to go unqualified however, and continues with the apparently dismissive negative - 'which isn't complete madness, it's belief'. So thinking of oneself in some or all of these ways as an autonomous self may be dismissed as a delusion, but the poem is willing to allow that it is at least a belief, however unreasonable it might appear to others - and who we might ask are these others - it is not simply a mental phantom. Beliefs can be reasoned about with others.

The full implications of the cento of quotations with which Berssenbrugge began her poetic symposium of current models of human identity become more evident in section two of the poem. Here she sets out what appears to be a series of diagnostic sentences that refers to Angelman syndrome:

Chromatin fails to condense during mitosis.

A fragile site recombines misaligned genes of the repeated sequence.

She seems a little unformed, gauze stretches across her face, eyelids droop.

When excited, she cries like a cat and fully exhibits the "happy puppet" syndrome.

Note short fingers and hypoplastic painted nails.

Is Angelman syndrome the threat that hangs over the four year old daughter? A few lines later we notice that the poem now appears to be describing a quite different condition, osteogenesis imperfecta (which we might recall is Peter Byers's speciality):

Her skull is large and soft to the touch.

The thoracic cavity small, limbs short, deformed and vertebrae flattened.

All the bones are under-mineralized.

Bluish light surrounds her.

The first three lines are derived from a caption to a radiograph of a premature infant with osteogenesis imperfecta reproduced in the fifth edition of Thompson and Thompson's *Genetics in Medicine*.⁵³ The fourth line about 'bluish light' imaginatively infers that the blue tint that is noticeable in the whites of the eyes of such patients would turn their visually perceived world blue. It's a clever poetic projection that manages to merge the idea of sadness (being blue) with the sacred symbolism of blue light that surrounds the Virgin Mary. Once a reader notices this second syndrome they are likely to begin to pick up more fleeting textbook allusions to other conditions. Crying like a cat is a diagnostic symptom of *cri du chat* syndrome, while 'fragile site' hints at fragile x syndrome – the line 'Chromatin fails to condense during mitosis' comes word for word from the description of the syndrome in *Genetics in Medicine*.⁵⁴

At this point a reader, especially one who has worked through Tabios's detailed accounting of the sources, might wonder how to read Berssenbrugge's poem. Is the reader intended, as with Pound's *Cantos*, to track down the allusions and then treat the poem as a keyboard triggering the organ notes of these allusions? Another possibility is suggested by Peter Nicholls' reading of Susan Howe's poem, *Articulation of Sound Forms in Time*, a text that makes extensive but tacit allusions to seventeenth-century captivity narratives. He discusses Howe's idiosyncratic use of her source texts and then comments: 'it is quite clear that, unlike a writer such as Pound, Howe has no desire to send us back to her sources, or, indeed, to encourage us to read them in tandem as I have started to do here. Perhaps, then, the source is irrelevant, though when we do have it before us we gain a particular insight into Howe's mode of composition'.⁵⁵ The parallel with Berssenbrugge's pre-Google borrowings is obvious. When she wrote the poem, her readers, lacking internet search

engines, would have found it nearly impossible without a listing of the sources like that provided by Tabios to know where many phrases came from. Now thanks to Tabios and Google we can read the poem in tandem with its sources. But should we?

The effects of this relation to sources are evident throughout the poem. The final two lines of section one – ‘She’s inspired to change the genotype, because the cell’s memory outlives the cell. / It’s a memory that builds some matter around itself, like time’ – derive from Deepak Chopra’s book *Quantum Healing*, where he writes: ‘In some way that medicine is just beginning to unravel, a cell’s memory is able to outlive the cell itself’. Jeannie Chiu uses this knowledge that Chopra is the source to argue plausibly that ‘Berssenbrugge implies that memory and matter accruing from experience can be distinct from genetic determinism’.⁵⁶ Chiu also points out how Berssenbrugge subtly calls attention to the overlay of scientific and vernacular meanings of many words. The use of ‘impression’ in the line from section one – ‘Though we call heavy sense impressions stress, all impression creates limitation’ – leads Chiu to point out that ‘impression’ can indicate biochemical imprinting or ‘an influence or image impressed on the mind’.⁵⁷ I think that this recognition of the multiple significances of a term in use both in specialist contexts and in public discourse is a clue to how Berssenbrugge’s use of source texts unidentified in the poem, actually works. In the case of Howe, Nicholls resists the idea that the historical significance of the source material is irrelevant, while conceding that the interpreter should not try to reconstruct within the poem a tacit narrative based on making explicit allusions to source texts. Instead, the reader should acknowledge that Howe is drawing attention to historical losses that cannot readily be put into words, because she believes that ‘poetry shelters other voices’ than those which scholarly history records, even if these voices can only speak in semantically attenuated fragments.⁵⁸ In Berssenbrugge’s poem the poetry appears to speak in its own voice, yet like a voice on a poorly tuned radio station, other voices can be heard overlaying it. This is, as it were, a particularly noisy intertextuality. Berssenbrugge is not calling attention to lost voices but to a multiplicity of voices that need at least to be heard, to be heeded even if they cannot yet at least be reconciled with one another.

I called Byers’s novel epigenetic in the slightly looser sense of the term used by Keller, Dupré and others. Berssenbrugge’s poem convenes a medley of voices articulating epigenetic themes: plasticity in development, influences of environment on genetic inheritance, and questions of how to conceptualise these processes. What I

do not have space to discuss in any detail is the way that Berssenbrugge's poem also challenges linear temporality by circling back and forth across time, and also by creating an intense extended moment of time in which many competing aesthetic experiences converge, notably in the final section. Here the poem contemplates guilt at the thought of 'a particular matriarchy of natural disaster', or maternal responsibility for genetic abnormality ('mother must have done something terrible'), and offers alternative perspectives to such harsh ideas of irreversible genetic causality. Its final, moving line comes close to summing up an alternative: 'The love has no quantity or value, but only lasts a length of time, different time, across which unfolds her singularity without compromising life as a whole'.⁵⁹ This mother enjoys 'serene detachment' although it is ironically as 'abstract as an electron micrograph of protein-deplete human metaphase DNA'.⁶⁰ For a moment science and metaphysics are at one.

Conclusion

Clare Dunsford's portraits of people with genetic syndromes finding themselves at the frontier of medicine and metaphysics while waiting for genetics to catch up with their lived experience, has guided my discussion of how an avant-garde poem might contribute to this catching up. Mei-mei Berssenbrugge's poem works to bring the pragmatics of scientific discourse into proximity with strong emotions by sketching out possible scenarios in which a mother and daughter might struggle to articulate their mutual relations as modes of inheritance and mutable identity, all the while signaling how provisional such constructions must be. Her poem is strongest in areas where the novel is least able to venture, such as the epistemological authority of scientific language. The novel is most effective in the tracing of specific subjectivities under pressure from genetic instability. Neither excludes or displaces the other. If I have concentrated primarily on poetry it is the novel is recognized to be a potentially helpful contributor to debate about the cultural consequences of medical developments, whereas poetry, as the disparaging remarks about Ridley intimated, has been more often thought of as dangerous to rigorous science.

In constructing this essay I have tried to convene the discourses of a number of epistemic constituencies who are not ordinarily in direct touch, letting scientists, clinicians, people disabled by genetic syndromes, philosophers, historians, critics and

writers speak, and as far as possible on their own terms. We are, to twist an old saying, too often divided by a common language. Although my range of contributors is not as great as Berssenbrugge's in 'The Four Year Old Girl', I should add that even to attempt to bring so many different constituencies together has been challenging. I have been emboldened in this attempt to step across the divides in language and knowledge by the experience of the AHRC funded epigenetics project, led by Professor Clare Hanson, in which I was a co-investigator. Many people from medicine, biology, history of science, literary studies, fiction writing, and poetry gave their time and commitment generously to work out how we might better understand what is happening in genetics and epigenetics. Writers and researchers all too rarely meet in the same room to talk openly about their knowledge and uncertainties at the frontiers of their understanding of science and metaphysics. The need is greater than ever for researchers across all those different fields, from clinical medicine to poetry, to listen respectfully to the latest research findings of those in other disciplines, as well as to the words of those who live with genetic strains on their identity and language, is greater than ever.

Notes

I would like to offer special thanks to the clinician Professor Karen Temple (University of Southampton) for her assistance in reading Berssenbrugge's poem in terms of genetic medicine.

¹ Quoted in Amy Boesky, 'Epilogue', in Amy Boesky ed., *The Story Within: Personal Essays on Genetics and Identity* (Baltimore: The Johns Hopkins University Press, 2013), 244.

² Misha Angrist, 'Of Helices, HIPAA, Hairballs ... and Humans', in Boesky, 93.

³ Clare Dunsford, 'The Long Arm', in Boesky, 213.

⁴ Boesky, 'Introduction', 14.

⁵ In this essay I only indirectly address disability issues. Much of what I have discussed could be inflected by the insight of Michael Davidson and others into the ways that disability metaphors have been integral to modernism and to globalisation, because such metaphors have been constantly employed to indicate uneven development or other shortfalls in economic and social justice. Both William in Byers's novel, and the four year old girl of the poem recognise that disability is much more about what Davidson calls 'societal barriers' and 'global human rights' than failing to meet a human bodily norm. Michael Davidson, *Concerto for the Left Hand: Disability and the Defamiliar Body* (Ann Arbor: University of Michigan Press, 2008), 194-195.

⁶ See Eileen Tabios, *Black Lightning: Poetry-in-Progress* (New York: Asian American Writers' Workshop, 1998), 145. The quotation comes from *Genetics in Medicine*, 431.

⁷ The distribution of search results on Medline suggests that the term came into use around the mid-1970s.

⁸ C. H. Waddington, *The Epigenetics of Birds* (Cambridge: Cambridge University Press), 40.

⁹ Edward O. Wilson, *Consilience: The Unity of Knowledge* (London: Little, Brown and Co., 1998), 139.

¹⁰ Harry Rubin, 'Cellular Epigenetics: Effects of Passage History on Competence of Cells for "Spontaneous" Transformation', *Proceedings of the National Academy of Sciences of the United States of America* Vol.90 No. 22 (Nov. 15, 1993): 10715-10719, 10715.

¹¹ Richard Strohmman, 'Toward an Epigenetic Biology and Medicine', *Perspectives* Vol. 1 No. 2. The essay was first published in May 1996 in *Network*.

<http://www.amhc.org/site/article/273-perspectives-vol-1-no-2-towards-an-epigenetic-biology-and-medicine> accessed 24.4.14. I cite this statement simply to illustrate how elastic the concept of the epigenetic remains in public discourse. He outlines similar ideas in his essay 'Beyond Genetic Determinism', *California Monthly* (April 2001): 24-27.

http://www.sbs.utexas.edu/genetics/Literature/articles/general_literature/GeneticEpigenetics-Strohmman.pdf accessed 24.4.14.

¹² R. Holliday, 'DNA methylation and epigenetic mechanisms', *Cell Biophysics* 15.1-2 (Aug-Oct 1989): 15-20, 15.

¹³ Holliday, 20.

¹⁴ Nessa Carey, *The Epigenetics Revolution: How modern biology is rewriting our understanding of genetics, disease and inheritance* (London: Icon books, 2011), 6.

¹⁵ Tim Spector, *Identically Different: Why you can change your genes* (London: Weidenfeld & Nicholson), 39.

¹⁶ Barry Barnes and John Dupré, *Genomes and What to Make of Them* (Chicago: University of Chicago Press), 86-87.

¹⁷ Evelyn Fox Keller, *The Mirage of a Space between Nature and Nurture* (Duke University Press, 2010), 5.

¹⁸ Keller, 80.

¹⁹ Allen Fisher, 'The Aesthetics of the Imperfect Fit', Notes for the Glasfryn Project, 2012. <http://glasfrynproject.org.uk/w/1791/allen-fisher/> accessed 24.4.14.

²⁰ Nadia Abu El-Haj, *The Genealogical Science: The Search for Jewish Origins and the Politics of Epistemology* (Chicago: Chicago University Press, 2012), 219. El-Haj argues that the belief that our genetic inheritance can be understood as a book which records our past, is the latest version of a modern tradition of studying identity from an aetiological perspective as constructed from historical traces which can include 'documents, artifacts, psychic memories and most recently, genetic mutations' (221). Cultural and literary traditions, memories both conscious and repressed, and now genetic legacies, are all taken to be formative of selfhood: 'Contemporary projects in genetic history draw their authority as much from the norms of the historical profession and the assumptions of a modern historical sensibility, first articulated well over a century ago, as from the power and epistemological credibility of contemporary genomics' (221). In other words, though genomics claims to be wholly

objective science, its concepts are unwittingly shaped by a historicism that itself ought to be historicised.

²¹ Anita L. Allen, 'The Poetry of Genetics: On the Pitfalls of Popularizing Science', *Hypatia* 24.4 (Fall, 2009): 247-257, 254.

²² Allen, 255.

²³ 'Winning poem offers a new twist on "improving the human"', *Techzone360* (January 29, 2011). <http://www.techzone360.com/news/2011/01/29/5275875.htm>. Accessed 1.12.2014.

²⁴ The judges were Pippa Goldschmidt, Steve Yearley, Peggy Hughes, and Kona Macphee.

https://googledrive.com/host/0B1arYAWdEZhkbnJcEt2NIY4RTg/judges_report.pdf accessed 24. 4. 14.

²⁵ Sophie Cooke, 'Forward Deck'.

https://googledrive.com/host/0B1arYAWdEZhkbnJcEt2NIY4RTg/forward_deck.pdf accessed 24. 4. 14.

²⁶ Samantha Coburn, 'The Box', in Pamela Jean Lyman ed., *In the Company of Angels* (Mustang, Oklahoma: Tate Publishing, 2012), 213.

²⁷ Coburn, 216.

²⁸ Kathleen Marie Short, 'Language of our Angels', in Lyman, 153.

²⁹ Tabios, 137.

³⁰ Andy Hickey, 'My Life with Samuel', in Lyman, 202.

³¹ Michael Byers, *Long for this World* (London: Granta Books, 2004), 335.

³² Joel R. Chamberlain et. al., Gene Targeting in Stem Cells from Individuals with Osteogenesis Imperfecta, *Science* Vol. 303 (20 February 2004): 1998-1201, 1200.

³³ Michael Byers, *Long for this World*, 433.

³⁴ See Rachel Patton McCord et. al., 'Correlated alterations in genome organization, Histone Methylation, and DNA-Lamin A/C Interactions in Hutchinson-Gilford Progeria Syndrome', *Genome Research* (2013): 260-269; and Parisha P. Shah et. al., Lamin, 'B1 Depletion in Senescent Cells Triggers Large-Scale Changes in Gene Expression and the Chromatin Landscape', *Genes & Development* 27 (2013): 1787-1799.

³⁵ John Dupré, 'The Role of Behaviour in the Recurrence of Biological Processes', *Biological Journal of the Linnean Society* 112:2 (2014): 306-314, 308.

³⁶ Richard C. Lippincott, review of *Long for this World*, *Psychiatric Services* Vol. 54 No. 12 (December, 2003): 1663-1664, 1664.

³⁷ Clare Dunsford, in Boesky, 207.

³⁸ Ibid.

³⁹ Byers, 206.

⁴⁰ Byers, 38.

⁴¹ Mei-mei Berssenbrugge, 'Pollen', *Four Year Old Girl* (Berkeley, Ca: Kelsey Street Press, 1998), 42.

⁴² 'The Doll', 59.

⁴³ 'The Four Year Old Girl', 49. Further refs in text.

⁴⁴ Mei-mei Berssenbrugge quoted in Tabios, 134.

⁴⁵ Tabios, 138.

⁴⁶ Spector.

⁴⁷ Thrangu Rinpoche, *Buddha Nature* (Kathmandu, Nepal: Rangjung Yeshe Publications, 1988), Sandra Ingerman, *Soul Retrieval* (San Francisco: Harper, 1991). Other undocumented sources are likely. For instance, one transcribed source for

section five reads: ‘you can even have the question, posed by Parfitt [sic], re teletransporter as parent to child.’ [Tabios 149]. Tabios does not source this allusion, which finds its way into the final poem: ‘Its materiality is a teletransport of signified protoplasm across lineage or time’. The allusion derives from a thought experiment in which a person on Earth is replicated by a teletransporter on Mars, an experiment outlined in Derek Parfit, *Reasons and Persons* (Oxford: Oxford University Press, 1984), though whether this was the direct source for the poet is unclear. Tabios’s documentation is quite understandably given its enormous scope not always quite accurate and should be double-checked – on p. 148, for instance, a quotation from Bataille is attributed to Sandra Ingerman [i.e. ‘B.40’ should be ‘C. 40’], and on p. 142 the first two quotation sources for section one of the poem are not from Ingerman but from *Genetics in Medicine* – see note 48. These errors are minor issues. Tabios has done readers of Berssenbrugge and other Asian American poets an enormous service by compiling this thorough archival study accompanied by thoughtful critiques of the poetry.

⁴⁸ Margaret W. Thompson, Roderick R. McInnes and Huntington F. Willard, *Genetics in Medicine* Fifth Edition (W. B. Saunders Co., 1991), 1.

⁴⁹ Deepak Chopra, *Quantum Healing: Exploring the Frontiers of Mind/Body Medicine* (New York: Bantam, 1989), 210.

⁵⁰ Jacques Lacan, *The Seminar of Jacques Lacan: Book II. The Ego in Freud’s Theory and in the Technique of Psychoanalysis 1954-1955*, ed. Jacques-Alain Miller, trans. Sylvania Tomaselli (Cambridge: University of Cambridge Press, 1988), 48.

⁵¹ Tabios, 168.

⁵² Ron Silliman, *The New Sentence*.

⁵³ The caption reads: ‘The skull is relatively large and unmineralized, and was soft to palpation. The thoracic cavity is small, the long bones of the arms and legs are short and deformed, and the vertebral bodies are flattened. All the bones are undermineralized.’ Berssenbrugge’s paraphrase leans towards a more vernacular idiom which slightly simplifies the science. *Genetics in Medicine*, 294.

⁵⁴ *Genetics in Medicine*, 81

⁵⁵ Peter Nicholls, ‘Unsettling the Wilderness: Susan Howe and American History’, *Contemporary Literature* Vol. 37 No. 4 (Winter, 1996): 586-601, 596.

⁵⁶ Jeannie Chiu, ‘Identities in Process: The Experimental Poetry of Mei-mei Berssenbrugge and Myung Mi Kim, in Eleanor Ty and Donald G. Goellnicht eds., *Asian North American Identities: Beyond the Hyphen* (Bloomington, Ind.: Indiana University Press, 2004), 92.

⁵⁷ Chiu, 91.

⁵⁸ Nicholls, 599-600. Howe writes: ‘If history is a record of survivors, Poetry shelters other voices’. Susan Howe, *The Birth-Mark: Unsettling the wilderness in American Literary History* (Hanover: Wesleyan University Press, 1993), 47.

⁵⁹ Berssenbrugge, 57.

⁶⁰ *Ibid.*