

### **Bittersweet anticipation: the logistics of inheritance**

*Tomorrow Belongs to Me.*

*New Work by Jacqueline Donachie made in collaboration with Darren G. Monckton.*  
Hunterian Museum, Glasgow from 9<sup>th</sup> June to 2<sup>nd</sup> September 2006.

*Tomorrow Belongs to Me (2006)* by Jacqueline Donachie & Darren G. Monckton  
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Myotonic dystrophy is a genetic disorder which is characterised by a progressive weakening of the muscles and reduction of the ability to relax muscles after contraction. Normally myotonic dystrophy (also known as DM) manifests itself in later life and symptoms gradually increase in severity. A particular feature of myotonic dystrophy is the manner in which over successive generations, the condition expresses itself earlier in life and with greater severity. In this way, families can be unaware of having the condition until a child is born with serious muscular problems, the diagnosis of which leads to the discovery that the symptoms displayed by the mother and grandparent, often only retrospectively examined, are related to the problems of the child.

When Jacqueline Donachie's sister gave birth to her second child, a daughter, she was born with congenital myotonic dystrophy. This event brought with it the knowledge that her family had myotonic dystrophy on her father's side.

The genetic laws of inheritance are ones which most of us are familiar with, 'she has her father's nose', 'he's got the curly hair of his grandmother', these concepts of family resemblance through blood lines were recognised long before Gregor Mendel's work on trait inheritance lent them a scientific basis.<sup>1</sup> Modern molecular biology, with the advent of the discovery of genes and DNA as the mechanism by which we receive and pass on our physiological make-up, has enabled us to examine in greater detail the logistics of inheritance. The ability to diagnose genetic illness and predict the likelihood of being affected by a condition carried by a previous generation has increased markedly over the past few decades. Unfortunately, this knowledge does not yet extend into being able to resolve genetic flaws and provide any cure.

When confronted with the cold statistical data that predicts the proportion of offspring that will carry this gene from the mother, that gene from the father, compounded by the bewildering concept that, at some point in its many translations and replications, a great-grandparent's DNA developed a small mutation which has grown large enough to affect the health of your niece, nephew, sister and father, it is impossible not to ask why?

Finding herself to be on the unaffected side of the fifty percent chance of having inherited the condition from her father, Donachie began to research the condition that she previously knew nothing about but all of a sudden was manifesting itself in the cells of members of her close family. This journey, both literal and metaphorical, was presented as *DM* (2002), a narrative in the form of framed digital prints and text as well as re-printed as an artist's book. In *DM*, Donachie voices her personal experience

of discovering how her family were afflicted with myotonic dystrophy and how that brought her and her family in contact with a hitherto unknown world of specialists, geneticists, doctors and other myotonic dystrophy sufferers.

At the early stages of her investigations, Donachie met Darren G. Monckton, Professor of Human Genetics at the University of Glasgow, who became a valuable collaborator on this ongoing project. The exhibition *Tomorrow Belongs to Me* held this summer in the Hunterian Museum of the University of Glasgow, and accompanying publication of the same name, represent the latest outcomes of the collaboration between Donachie and Monckton.

The exhibition and book provide a counterpoint to the personal narrative presented by *DM*. Over the past two years Donachie and Monckton have travelled widely in order to collect the stories told by eleven scientists who played fundamental roles in understanding the underlying molecular mechanisms for myotonic dystrophy and related conditions. It transpired that they were all characterised by the genetic phenomenon of anticipation which provides a reason why, in myotonic dystrophy, fragile X syndrome, Huntington's disease and others, a genetic disorder could manifest itself earlier and with progressively more serious symptoms as it was passed down through the generations of a family.

The resulting video footage has been interwoven into a short projection piece which stands at the heart of the exhibition. The majority of the information, that could not all fit into the eighteen minute film, exists as a DVD archive and has been transcribed and clearly presented in the publication.

The story of anticipation is a fascinating one, not least because it involves scientists from a wide assortment of different specialties who all see things slightly differently and has at its heart the protection of genetics as a credible field. Summarily dismissed as a result of biased statistical data by Lionel Penrose, who worked so hard to move genetics away from the morally dubious eugenic tendencies of early twentieth century studies of inheritance, anticipation was not a popular topic of study.<sup>2</sup> Its reappraisal and subsequent vindication of its existence as an actual phenomenon was, therefore, not only a valuable gain for the communities involved with the conditions that demonstrate anticipation but also demonstrated that there was an alternative to the accepted model of inheritance.

What Donachie has laid before us is a prime example of a paradigm shift, the laying of a ghost with a solution that questions the received dogma of genetic inheritance, presented enthusiastically by a selection of the main protagonists.

In contrast to the personal and moving narrative of *DM*, the film and accompanying transcripts show the other side of genetic disease; that of the clinicians, geneticists, neurologists, and molecular biologists trying to discover the causes and consequences of conditions that affect the lives of so many people. Reduced to anonymous groupings, families become pedigrees and patients are useful case studies. Whilst not uncaring, the stakes on this side of the fence are different; reputations, funding applications and publication of findings, all buoyed along by the prospect of novel discovery and the solving of one riddle that has haunted genetics since its post-war distancing from eugenics.

The idea of collaboration between an artist and a scientist raise certain questions as to the nature of the work that is produced as result of these two areas coming together. Mika Hannula, in his exploration of artistic research, argues that the space shared by the traditionally opposite pursuits of art and science is that of experience. Within the experiential, no one subject can lay claim to being an undeniable authority and so opens the way to everyone concerned to work with each other.<sup>3</sup>

As such, any products of collaboration between two diverse fields are not defined as being from one area or another, nor do they have to adhere to the conventions of either field. The space created by each different collaboration, therefore, is unique and to a certain extent without precedent. Whilst this engenders an exciting potential to open new forms of presentation and engagement with a broader audience, it also runs the risk of failing to match the standards set by its constituent parties and suffer by comparison.

As an exhibition, *Tomorrow Belongs to Me* is a cogent example of the difficulties that arise in the attempt to speak simultaneously to a broader artistic and non-specialist audience whilst creating a resource that can be presented to professionals and patients within the myotonic dystrophy community. The amount of information being presented is bewildering and without a good grounding in genetics, it may be hard to digest the terms being thrown out by the talking heads of the scientists who speak with the casual nature of being well versed in this unfamiliar vocabulary. Unless emboldened to tackle the primary resources and subsequent texts provided, all the audience has to guide them through the tale being presented here are brief information panels and Donachie's pre-existing work *DM*.

Given its university location, the exhibition is perhaps ideally suited to the viewer who has a connection with the conditions that are being explored. The sculptural element of pared-down steel and wooden benches which loosely congregate around the space enhance this impression as their title *Tell Me About Your Father's Side* (a reference to the scientists in the film finally overcoming the doctrine of sex-linked conditions only affecting the maternal line) implies that they should play host to an affected family member talking with an interested researcher.

The publication provides a welcome opportunity to read through the scientists' stories at leisure and the introductory essay by Rebecca Gordon-Nesbitt gives a useful guide to the historical importance of the stories that are being told as well as firmly indicating the anecdotal nature of the history being presented. It can stand both apart from and alongside the exhibition but, like the show itself, it doesn't seem to exert a novel manner of presentation that satisfactorily supersedes the artistic or scientific mode of presentation.

When questioned by Hannula on how she would define research, Donachie replied that 'it was the process by which [she] made work'.<sup>4</sup> For her it is the relationships made and journeys taken by an artist that potentially are the most interesting aspect of research and the exhibition itself is the smallest component. In this project, it is clear that Donachie's role has been that of the informed outsider, bringing voices separated by distance and specialty together and putting them together in order to bring their

joint testimony forward into a public sphere that ordinarily would not be aware of their endeavours.

As in her initial foray into understanding myotonic dystrophy, the research extends beyond the explanations given by consulting professionals and out into the world where she and her sister meet other families affected by the disease, where she and Monckton talk to the scientists whose lives and careers have been defined in relation to anticipation. In seeking to understand more about the disease, Donachie has also succeeded in highlighting the gap that exists between the patients and the scientists who are working to understand their condition.

It is in this manner that Donachie uses the role of artist/researcher to bring together groups that have common goals, yet are separated by the conventions attached to the furthering of knowledge within the modern health care system. From a personal project, combined with established methods of practice, Donachie has developed a strategy which represents the value of artistic research: that artists can play a role in re-evaluating what we believe to be true and how the established norms of disseminating that knowledge can be challenged.

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<sup>1</sup> Mendel, Gregor (1865) "Experiments in Plant Hybridization" [English version at <http://www.mendelweb.org/Mendel.html>]

<sup>2</sup> Daniel, J. Kevles, 'Out of Eugenics' in Daniel Kevles and Leroy Hood (Eds.), *The Code of Codes: Scientific and Social Issues in the Human Genome Project* (Cambridge, Mass.: Harvard University Press, 1992), p.14.

<sup>3</sup> Mika Hannula, Juha Suoranta, Tere Vadén, *Artistic Research – Theories, Methods and Practices* (Helsinki/Gothenburg: Academy of Fine Arts Helsinki and University of Gothenburg, 2005), p.31.

<sup>4</sup> Ibid, p.129.