

**Jacqueline
Donachie**

El Mal

Jacqueline Donachie

The Cotton Club, Glasgow, 1983

We drank a bottle of vodka between us before we left the house – parents out – then headed into town. I was the performing monkey, dressed up by my sister and her friends to be their little clone in fishnet tights and heavy eyeliner. 14. 14! But tall and easy to slip in past the doormen. Up the stairs, then dancing, spinning. Soft Cell, Heaven 17. More vodka, or maybe cider or snakebite. Then the vodka caught up, and I was sitting on the floor for a long time. Fourteen, remember. Then swirling and falling and hands lifting me up, carrying me carefully. Toilets first, then down many flights of stairs to the street, the taxi, our parents' house, bed.

It was not a first experience of drinking alcohol, or of hanging out with my sister and her older, glamorous friends, but a strong memory of a time when we were particularly close. Defiantly gothic, we wore long army coats to hide the leather mini skirts and fishnet tights in opposition to a very un-goth, anti-fashion mother; if she caught us and made us change we simply hid the skirts in a pocket and put them on again at the bus stop. Our final layer of make-up was always added on the bus.



Lake Maracaibo, Venezuela, 1983

Nancy Wexler canoes between huts on stilts collecting blood and sperm samples from villagers affected by a genetic disease that had killed her mother. She knows of its strong inheritance pattern, and that it could also kill her and her sister. As a direct result of the massive archive of family samples collated since 1979*, by 1983 they had established a presymptomatic test that shows the affected gene and could therefore identify those who had or had not inherited the disease.

So when my sister was picking me up from the floor of the Cotton Club in Glasgow, Nancy Wexler, having gone to Venezuela to study families affected by Huntington's Disease, was part of a research group that identified a test for the gene. Her mother had died. She and her sister Alice were at risk. So were we, but in 1983 that was all very far off. It was me who was falling then, not my sister.

So how can I read this difference in what sisters do for each other? There is support and there is love, but there is also fear. My sister and I have both had children, a decade or more of picking up babies, clothes, shoes and toys. Now there is a change to who does the picking up, the lifting and carrying, and it is unsettling to try and refer to this through art, difficult to see how anything visual can equate to that journey that Nancy Wexler made in a canoe. Her family has Huntington's, mine myotonic dystrophy. The symptoms are different, but the inheritance pattern is the same.

*'They call it 'el mal de San Vito' or 'St Vitus' dance' and often will call it 'el mal', which was both the word disease, but also the 'bad thing'. And they say that anyone who has el mal or Huntington's in their family inherits the disease. So it's a very different way of thinking about it. In English if you inherit the disease it means you actually inherit the abnormal gene and you were going to get sick. So when we were writing the first pedigrees, they would say, 'and this one inherited the disease, and that one inherited the disease.' So we put everybody HD, HD, HD. So we said 'everyone in the family has Huntington's? What kind of bad luck is this?' And they said 'everyone inherits it, but only certain people get sick' and psychologically that's really true because everybody within a family with any genetic disease inherits it. The people who are healthy, the parents who don't have a genetic risk themselves, but they have sick husbands or wives or children, and so everybody inherits it.'*¹

* Nancy Wexler's most important scientific contribution is the work she has done on Huntington's disease. In 1979, she learned of the world's largest family with Huntington's disease living along the shores of Lake Maracaibo, Venezuela. For 13 successive years she and her colleagues have studied the disease in hundreds of patients and persons at risk. They have constructed a pedigree of over 15,000 people, collecting blood samples from 3,600 people in the family. These samples led to the discovery of the Huntington's disease gene at the tip of human chromosome 4. With this knowledge, a new presymptomatic test was developed which can tell, for the first time, who is carrying the fatal gene and who is free, prior to the onset of symptoms. These same blood samples have also aided in the mapping of other disease genes, including those responsible for familial Alzheimer's disease, kidney cancer, two types of neurofibromatosis, manic depression, and others.

1. Quotation - Nancy S. Wexler Ph.D. Interviewed at Columbia University, New York, USA on the 16th June 2004 for the project *Tomorrow Belongs to Me*; Jacqueline Donachie and Darren G. Monckton. Full interviews published by University of Glasgow, 2006.

I weigh about 57kg, my sister 66kg. She is hard for me to lift, but if she falls I can manage. She cannot lift me at all. She doesn't fall very often, but it is happening more and more. Stairs are very hard, both going up and coming down; the nightclub on the third floor, with no lift, would be impossible now. I have bought a load of equipment that is marketed at old and disabled people. Special stools to sit on in the shower, chairs to help you get in and out of the bath, wheels and sticks and lots of weirdly shaped rubber and moulded plastic things that in some way will make it easier for you to live your life when bits of you don't work. It's an odd collection, mostly new and shiny with lots of aluminium and rubber. She doesn't need anything like this yet – though my father does – so I sit and stare at it all in my studio. Dismantled, they could be parts for many things, strange seats or harnesses; perhaps not so medical. Perhaps aids to sexual or violent behaviour (or both), rather than something to help you get into the bath or out of a chair. So many things to help with life when it's not going the way you want it to go.

I stare at a picture of my sister's eyes; beautiful hazel eyes with very fine stitches from a recent operation to stop her eyelids dropping, another effect of the genes she has inherited. The myotonic dystrophy which she has inherited from our father causes progressive muscle deterioration, and her face is gradually changing as her muscles slacken and fail. She is 42, I am 39. We used to look alike. Now, not so much. We both have children; her son and daughter are affected by a more severe form of the gene, my three sons are not. We have several cousins also affected, and one in particular, a young woman, is desperate to start a family of her own. She knows the risks involved with this through the inheritance patterns of the disease, clearly visible in her cousin, my sister's, children. Appearance and reproduction are huge factors in how we, as women, deal with this; our family inheritance looms heavily above us. We carry a strong family resemblance, and as we age, I wonder when the illness will overtake these familial characteristics. When will I become the only one who looks like we were all supposed to?

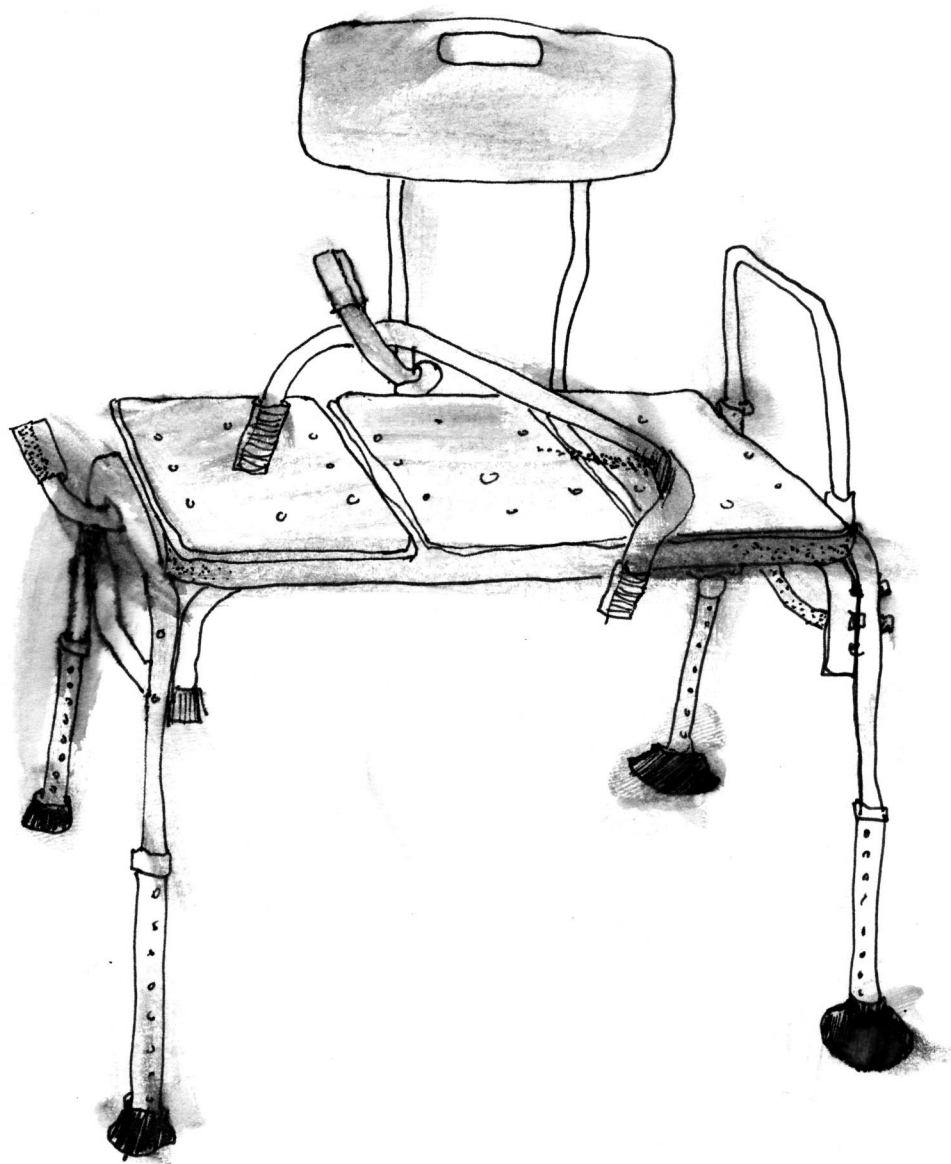
None of this makes me think of the Cotton Club in 1983, or of sailing through Venezuela in a canoe, but all of them are weirdly connected in some way. At the moment I want to bundle up all of the aluminium and rubber sticks, supports and splints and bash walls with them, or smash them up. Like I said, they may not always be used as support mechanisms, there is always the possibility of violence. Violence is never far from fear, and perhaps these things are directing the work more than any amount of research.

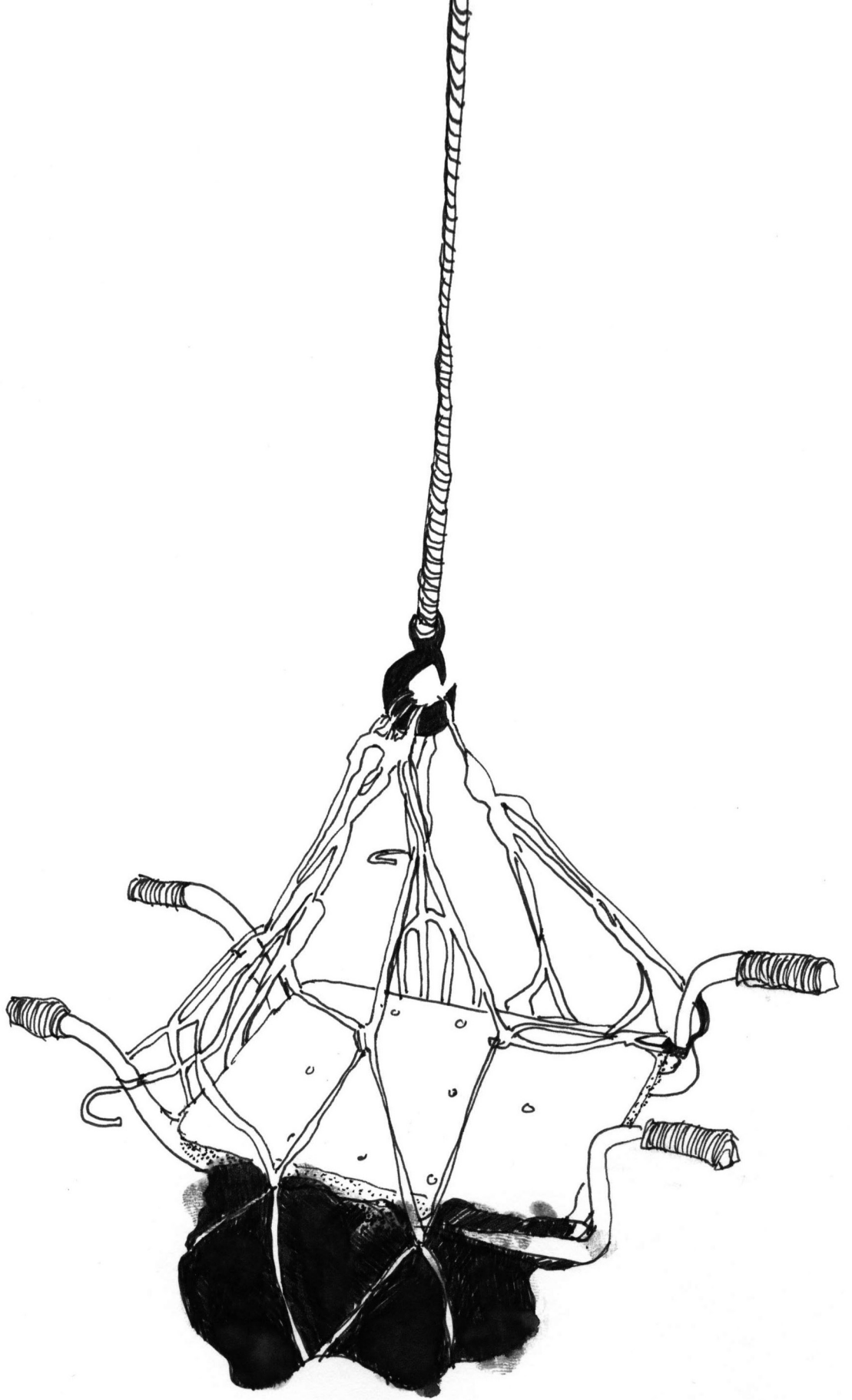
The following artworks:

- No 1 & 2 **Susan's eyes, 2007**
- No 3 & 4 **Preparatory drawings, 2008**
- No 5. **Preparatory drawings, 2008**











Interview

Mika Hannula: Let us deliberately start in a silly way. A hypothetical situation, a not-so-uncommon one. You are sitting on a plane, it is a long-distance flight and the person next to you asks: What do you do? How do you answer?

Jacqueline Donachie: I would say that I am an artist, and if they ask what kind of artist, I would add that I make sculptures and I work collaboratively with other people, sometimes with architects or designers on building projects or public sculptures. Then they look happy, because there is something they can understand. I don't tend to speak about this research side I do, I just say I work with other people.

MH: Has collaboration been part of your practice since the very beginning?

JD: I think so, even when I was still a student. The course I did was called Environmental Art at the Glasgow School of Art, finishing my BA in 1991. Every year we had to do a public art project, making an art work outside the studio or gallery; it had to be somewhere out there so the public could see it. So you would have to think about where the work would go, talk to the people who owned the site etc. For me this process was really fundamental. From the very first year on, I had discussions with people who do not come from an art background, and that was an important part of my education, something that continues to come through in what I do now.

I think I work best when there are some limitations, either with the space or the people involved; my work responds to the situations imposed on it by other people. So working collaboratively is always more interesting for me.

MH: But why do you seek these collaborations if and when we know that they can also become very difficult, vexing and time-consuming?

JD: It makes the process more interesting. I am not a particularly solo person. My brain works better when it responds to other people and other situations. I enjoy working as part of a team, and I enjoy sharing ideas, either intellectually or practically. I also enjoy the managing part. I think I am a bit of a manager! Collaboration is perhaps not the right word then; sometimes it's like I Hoover up people's knowledge and use it. But I find discussing things before doing them is always a very worthwhile exercise.

MH: Is there a part of your practice that you do alone?

JD: Yes, but I do not do it enough. This is what I want to do more, for example, for the exhibition in Gothenburg. In the last five years I have done mainly big collaborative projects, working with organizations and academics, or a team of architects, but at some point I think you have to go back and look at things from your own perspective. I need and want to engage more with the actual production of the art work. You reach a point where you need to progress things on your own.

MH: What do you do then?

JD: I write. When I think about art works that I have made that are important for me, stages that my work has gone through, I can usually trace each stage to a text that I have written. They don't always get published, but they are texts that I write as part of the process. I write all the time, you know, applications and descriptions – I feel like I spend more than 50% of my time at the computer writing e-mails and letters, but the writing I do that informs the art work is not narrative, it's more like poetry, not clearly defined instructions. A clear example is the DM book, addressing issues between my sister and I. It was not originally written as a text for a book, but for myself, to clarify what was going on for us at a difficult time.

The skill of this kind of writing is very like the skill of what, for me, it means to be an artist. I occasionally do some teaching, and whilst I'd maybe not say that I am a great sculptor or painter, one of the things I feel I have really learned working as an artist for 20 years is how to edit. The skill of an editor is very important for an artist. It is not always what's in the art work, it is what you leave out. It's the same with these condensed texts; you write something big and then you start to leave things out. The physical process of making an art work is really very similar.

MH: Funnily enough, what you just said is very close to a core idea of a valid qualitative research method, in which you start with a larger framework and then work through it by making the research question more focused and more precise. You can't address 25 questions; you have to be able to reduce it to less than five to be able to do proper research. This editing and cutting down is also one of the most difficult parts of doing research. But can you be more precise about this editing process in terms of your art?

JD: The best way is to talk through an example of an art work. You always start with an idea, or an idea and a site. The next stage is to think how I want to feel and also how I want other people to feel when they see the art work. I think quite a lot about the audience. I have a very strong sense of how I want people to feel.

In 2001, I made a work called *South* at Spike Island, Bristol; it was a concrete disc, made at the end of a six-month residency in the south of England. The final exhibition was during the wintertime, and my main feeling about the place, an enormous old tea factory that housed artists' studios as well as the gallery space, was how cold it was in winter. There was no central heating, and everyone huddled very close to small heaters in their studios, unwilling to move away because it was so cold. I wanted to make something that would discuss the ideas of formal sculpture, but I also wanted to make a physical piece that would encourage people to stretch out in the central (gallery) space, to open out their arms and sit back, not be huddled next to a heater.

Formally this work was an 8-metre smooth, hard concrete disc installed in a vast exhibition space. But it had a heating system inside it that made the

South, 2001





South, 2001

concrete feel warm, like a south-facing wall or stone steps at the end of a summer day. Everything came about from this basic feeling of wanting to open up and stretch out.

MH: What about the process of editing in this work?

JD: Yes, that's another good example. The exhibition space at Spike is enormous; initially I went through so many ideas for how an art work could make the space welcoming and social. By that time I had made several works based on bars, a piece called *Advice Bar*, for example, and I had also cooked for people, a strategy that was quite popular at the time. So I thought of making a huge bar, turning the space into a social living room but then I started to look at the idea of a formal sculpture, wanting to make a very simple object but also something you could physically interact with. I think when something is supposed to be openly accessible, then it really should be that – so that children can play on it, you can come in with your shoes on, you can lie on it with your beer, things can get spilt and the work won't be harmed.

After doing some drawings, I then decided on this very simple round concrete form. I thought of having three of them since the space is so huge, but the budget wouldn't stretch to three, just one, which I think in the end was a good decision made for practical reasons. This is an important part of the process.

MH: But where do you find the stamina to keep on doing such difficult projects that require so many compromises and negotiations?

JD: I have many of these examples, like the project I'm working on now, a new medical building in Inverness, Scotland (The Centre for Health Science). For this project I have spent two years as a manager, though my official title is Lead Artist, with a remit to incorporate art works into the building from the design and construction stage. These art works are going to be part of the building as permanent works. I have commissioned some other artists to make new works as well, so it's not only me, and that part has been really great (there are five artists participating). The process has been very long though. It started two years ago and the works will be built and installed this summer. Long meetings, trying to make things that involve people, trying to develop art works that people who work there can engage with. Eventually you realize that in the end you have to make something that will function as a good art work. You can never make everyone happy, so compromises have to be carefully negotiated so that the quality of the work doesn't suffer.

The Centre has been built next to a large hospital, and in the basement of the hospital there is an archive of equipment, old knives and all sorts of strange-looking medical equipment, and they really wanted to show some of these items. There are no patients in the new building; its remit is mainly teaching and research. The archive was really just boxes and boxes of old, dusty equipment, and I said if you show it like this, it won't look good. Instead I suggested that we photograph some of them. So then I had these strange objects photographed individually on a white background, making them look quite abstract, and a selection of these will be shown as lightboxes in one of the corridors. I chose things that look interesting to me, purely on visual criteria as I have no medical training, but now all of the medical staff have started to



become quite possessive about some of the images. There are 14 light boxes in all, and staff began to comment that there is nothing about dentistry say, or another of their own specific fields. There have been a lot of arguments, and sometimes I have felt like a referee between departments. One solution to this has been to make two sets of duotrans for each panel, so that staff can change them about periodically, as they wish, when I am long gone.

MH: Any major compromises in this particular case?

JD: Well, the light boxes (each 840 x 594) are one example where the tenants' idea of what they wanted was clearly different from mine. I was not interested in how the instruments and equipment were used, but chose instead to objectify them, which is unusual for me since I am normally very interested in the narratives behind the materials. But there were just so many opinions involved here that I wanted to distance myself from them; the light boxes are there permanently, staff will see them every day when they are at work, so over time they can build up their own narratives about the objects either through their own knowledge and experience or through that of their colleagues.

It was also important for me to distance my art work from the main discussions concerning the whole building. The idea for the work came early on and it has been separate from other aspects of the project. In the whole process, I have become a kind of conduit for everything, not only art, but many other things connected to the building. I am like the lateral thinker. I won't be working there, nor am I the architect or the one who builds it, neither am I its manager, but I am often the connector between different users. So I have spent a lot of time in meetings discussing how to change the layout of the building so that there is enough room for the staff to make a cup of tea in the morning, for example. This really has become one of the biggest things I have done in the project; I have been the one getting people connected, saying you should talk to him about this and so on. I guess I am the ombudsman of the project. I am an observer. So in the Centre for Health Science one of the main changes I have made is to have an extra staff kitchen included; a lot of my work is about places where people meet socially, and so a kitchen, where all the different users of the building interact, is like the perfect intervention for me, as an artist, to make.

Details from *The Collection of Etta Campbell*,
Lightboxes, 2008



MH: OK, you made the light boxes and the kitchen. Did you do anything else there?

JD: There is also the courtyard, which I have worked with a landscape architect to design, and in the centre of this courtyard there is a new version of the disc that I made in 2001 in Bristol. I am remaking it there, and it seems very appropriate to the site as it is in the far north of Scotland, with cold winters. Again it has a heating system, but this time the process has been very different; I didn't want it to be just plugged in, as I felt it was important to have it heated from a renewable or recycled energy source. This was a great aspect of doing something collaboratively since we worked very hard with the building engineers to find a solution. We looked at solar panels and wind turbines for the roof, but they weren't possible in terms of the building design because the site is near where the hospital helicopters land. We finally came up with the plan of using a pump that takes all of the heat to be extracted from the refrigeration units in the research labs and recycles it to heat the disc. The art budget has paid for the pump to take the heat out, and in return the engineers have designed my heating system for me.

As well as the disc there is a careful planting programme that illustrates the use of plants in Highland medicine. Each plant is labelled with details of their traditional (and sometimes current) uses in medicine, and it is hoped that the garden will provide a visual and sensory reference library for the staff and students who work in the building. When it's complete, there will be a series of launch events, so I'm working on some ideas for performances and social events to happen there. The courtyard is an important space for the building as it is where everything connects.

MH: Let us move on to the Gothenburg project. Relating to what you have said, it seems that this work project titled *Weight* has come at a good moment, offering you a counter balance to the more managerial work you have done in Inverness. What's the background for the *Weight* project?

JD: It goes back to the idea of what kind of a feeling I want viewers to have when you encounter a work. When I began to think about the project in Gothenburg, I wanted to show the feeling of something being just above your head. Something that is ahead of you, that could fall – and hurt you. Maybe something that looks quite threatening. I have been thinking about this for quite a long time, and I suppose it is how I think about my future, what is ahead of me. The idea of weight came because it is a notion that covers a couple of areas. People talk about the weight on their shoulders in a metaphorical way, but it could also cover a simple physical weight.

The way I think about it is that the physical part would be the weight of my sister, of my brother and of my father, all of whom I have had to lift recently. They are rather heavy. You know, they have this illness that affects their balance, so sometimes they fall, and when they fall, you have to pick them up. I realize that I'm very conscious of the weight of my sister. There is an artist I read about, living in LA, and he has Multiple Sclerosis, and he falls a lot; he photographs what he sees when he falls over, his view from the ground. I like this idea. There is another American artist, a huge guy called Martin Kersels, who, in his project *Tossing a Friend*, 1996, throws people and takes photos of that. I like this idea of physically lifting or managing people.

MH: Is this idea of weight connected with the previous projects in which you have dealt with this inherited genetic illness?

JD: Not really. This is a recent development, since my original project about the illness was when I made a little book *DM** and then the film *Tomorrow Belongs To Me**, about genetic inheritance patterns. Originally it came through my niece, when my sister had a baby girl who was very premature and didn't develop properly. Everything came about from this sick baby (who is now nine years old). So previously, everything stemmed from this child, a generation younger than my sister and I, but recently I have started to become more aware of the effects on my sister.

My sister's daughter was born with an illness. She has always been disabled. We accepted it because we never knew her in any other way. But for 30 years my sister was my sister and she had no disability. We were very alike and very close, and now I can see physically that we are starting to separate. It's also the same with my brother. Their physical capabilities are becoming less and less. It is obvious that my relationship with the illness has shifted a generation. It has shifted from looking at a sick child, to looking at my sister weakening and deteriorating, and needing more help.

MH: I really don't know how to ask this, but how did you find a way to deal with this illness in your work that allowed you both to address a very personal and a very difficult issue, but at the same time to get the necessary distance from it?

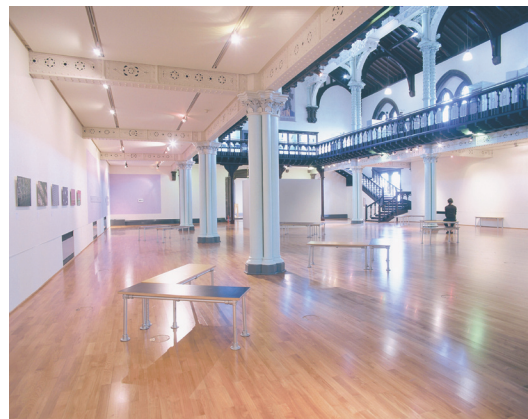
JD: I think it was because I moved away from the purely personal aspects of it. It was partly through initiating collaborations, or actually about making contacts with people, with academics doing research in this field. I spoke to genetics researchers at Glasgow University and they were very interested in working with me. Through them I was able to look at the bigger picture of inherited genetic illness and be quite objective about it, researching phenomena that are not so personal, but are very interesting stories about human inheritance patterns.

I was particularly interested in some papers I read about areas that had a very high density of certain genetic disorders, something that's called a 'founder effect'. So it wasn't specifically about my family, they were separate things.

When I began to work on the book (*DM*), I did start to write a more personal account of how our lives have been affected by the illness. I did try, though, to remain a little bit removed from the emotional parts; there was still a distance in writing it that wasn't there in my life. I suppose it was like the start of that first novel where you write about what you know, but you slightly remove yourself from it. But then I have often written about my family - they have appeared, but not directly.

MH: Have you thought about writing a novel?

JD: Yes, I will write a novel and run a marathon before I am 40! I actually think about it a lot, and the natural thing would be to write about my family. But right now there is a lot of that type of book, literature about people's cancer or their sick children. I am not sure how to set it, nor if anyone needs another one.



Installation views, *Tomorrow Belongs To Me* - New work by Jacqueline Donachie in collaboration with Darren G. Monckton, Hunterian Museum, 2006

Foreground - *Tell me about your father's side*, laquered wood and steel benches, 2006



MH: But how do you deal with this extremely demanding subject?

JD: It is harder for me to deal with it now, that's clear. When I made *DM* six years ago, the focus was different, it was based very much on the birth of my niece. Many families with a disabled child learn to live happily with the situation since the positive sides of it often out-weigh the negatives; they teach you so much about your life and what you should think about as important. The difference now is that the bad times feel much closer. At the time, I remember saying that I wanted to make this work now because I didn't know if I'd be able to make it in ten years. I'm not even sure that I can make any work about this in five years. I guess that's why you have to make a work at a certain time.

So the second collaborative project with Darren Monckton, a professor of genetics, was about the bigger picture, and I think I needed to have that larger framework. Also I felt that my family didn't want me to keep looking at them, particularly my mother, who was a bit upset about the attention we got after the first book (*DM*). Now it would be even harder.

I think you have to go back to what kind of art you want to make - the work has to be more than just a message about a sick family. I suppose that's what I'm trying to do now, because it is too hard to stay on that personal level; when I give presentations about the project I sometimes find it very difficult to talk about my sister. It is clearer now what's going to happen, whereas the images in the book are from five years ago. She has changed a lot in those five years.

So it is about how to make a good art work, and I need to work very hard to use the experience and emotions that I have gone through without being sickly or maudlin. Art should have something to say, but it should be able to relate to the life of the viewer as well as my own. It can't just be that there is a bad thing happening in my life - there are simpler ways to get that message across.

MH: But at the same time, even when it has become more difficult for you, you have again decided to address this topic? Is it something you just can't leave alone?

JD: Well, I think there is an element of my experience that is relevant to other people, and I hope it will make a good art work; the way that I am thinking about physicality will link and lend itself to a sculpture. This idea of lifting someone is not new. At some point everyone has to lift another adult; while you don't do it very often maybe, it does happen - your husband is drunk and you have to help him to get into bed, or maybe an old lady falls in the street and you help her up. You do it all the time with your children and it is interesting how it changes. My oldest son is now eight and it's become more difficult to lift him, he is so big. Naturally he is much more solid than he was when he was four years old. So there is something about this process of lifting a person that is not just reserved for those that deal with the disabled. I am also interested in my own physicality; I'm quite strong and fit, and interested to see what I can do. It is not only about my sister being ill, it is also about me trying to be strong. I don't want it to be just a negative thing. I could write a really sad story about what's happening, I could easily make everyone cry, but I don't want to do that.

MH: Perhaps it's as simple as that for a good story we need to have both sides.

JD: Well, perhaps you can make a good work that is negative, but for me personally, as I talked about before, I think a lot about how people experience my work and I want it to be more than just depressing or sad. I think art is a positive thing. I think beauty is an important element.

MH: For the Gothenburg exhibition you are planning a sculpture and a series of drawings. For the drawings, the starting point is the photos you took of your sister after she had an eyelid operation. What's the next step?

JD: I have been doing these really simple drawings of her eyes with the stitches after she had an operation to try and stop her eyelids drooping so much; the surgeon had to cut off part of her eyelid and then stitch it back together. The drawings are small, like size A5. It will be a series, maybe, of drawings or prints focusing on this thing happening to her eyes. Maybe I will only focus on her eyes, not her face, maybe I will also add my eyes to the series. I don't know, I have to see how the work goes. Right now, it's about her eyes, her bones and how the surgery has affected her.

MH: And the sculpture?

JD: I want to make something that is suspended up in the air, hanging there with ropes and hooks, something slightly threatening above your head.

MH: We will also show your film work *Tomorrow Belongs to Me*. How long did you work on that project?

JD: That was two years, from getting the funding to the finished film. We interviewed 11 scientists from all around the world, and the final film was first shown at a conference in Canada in the autumn of 2006*. It is 19 minutes long.

MH: How much raw footage do you have from all of these interviews?

JD: The average length of each one is 2 hours, which makes over 22 hours in total.

MH: How did you go down from over 22 hours to 19 minutes?

JD: Again, this is a good example of how working collaboratively makes a process clearer. Initially Darren Monckton had worked much more with the questions - at this stage, I was more like a producer, and to be honest, even when the interviews were happening, I wasn't taking in everything that the scientists were saying. Then we finished the interviews in spring 2006, and went back to our lives knowing that we had the premiere of the film set for the following autumn. So the first thing we agreed to do, since it was way too much material to watch through, was to have all the interviews transcribed. Then we each got this huge book, a document with almost 95,000 words in it.

MH: This is very interesting because it is a way to make the process transparent, going through the steps and your decisions.

JD: Yes, OK. Well, then we read this huge document. They weren't transcribed wholly accurately since some of the language was very specific and the person doing the transcription was not a scientist, but we agreed that both of us should read everything and highlight bits that were interesting and worth looking at again. So the first edit was to take a hundred-thousand-word document and make into a 10,000 word document. We both did this individually, then when we got together we had the time codes for bits we thought were good, and we sat and looked at all those bits together. This took about a week, watching them and agreeing whether they were worth keeping or not. Thus, the 10,000 word thing became a 5000 word thing.

Then we watched these bits individually and made more decisions on what to keep, then we had to carefully check that the story would work narratively. The basic story we wanted to show was of how this scientific discovery happened. We then took repetition out, so really it was a quite a natural process. After this we had about 40 minutes of good footage and we had to just make the final decisions at the edit suite with our editor – how to tell the story, who spoke the clearest, who had the best anecdotes.

MH: Was this difficult as a collaboration?

JD: No, it went very well actually. We come from very different backgrounds. Darren was able to edit the final material on the basis of the scientific story, he had the knowledge for that, and I had the artistic skill to edit how it looked and sounded. I could say, for example, that that this is a very good ending, an emotional finale to have this woman saying that everyone is dying. There were different ways we used our knowledge.

MH: At what point did you decide to choose the strategy not to explain at the beginning what it's about? I doubt that anyone with no special knowledge will get the nuances of the story the first time, but you do get the overall picture.

JD: Yes, this decision was made close to the end. During the process, we had many different ideas about music and location shots, and one of the things we wanted to show was the geography of this discovery. All of these scientists were working all over the world collaborating and sharing information as they tried to isolate the genes that caused illnesses such as myotonic dystrophy and fragile x syndrome – and this was before e-mail! We travelled to meet each scientist, and in each place we also made some location shots - it was only in the last stage of the editing that we decided to leave these out when we realised when watching that there were all these different accents of English. The geography was covered through them, you didn't need the location shots.

Another reason why we decided to go straight to the scientific narrative and not to give explanations of them at the start was because this film was always meant to work with different audiences. We wanted to have a work that could be shown to many different groups, from scientific ones to art ones, and to patient audiences. In every case, the film will have its own introduction, depending where it will be shown. It can be a booklet or a written introduction, or at a conference we would introduce it in person. If I introduce it, I would talk about my family and Darren talks about his research. It is not meant to be

shown completely cold. If you have no knowledge of this field of science, you probably do have to watch it two or three times to really understand the process. We had to draw a line to clarify whether parts were too hard scientifically, or just not enough; to test this, we had a rough draft that we both showed to our partners. Darren showed it to his wife, who is a scientist, but works in another field, and I showed it to my husband, who is an artist working a lot with film. We were really lucky to have experts at home that knew nothing about the whole background of the project, but knew a little about the field in question. We showed it to them both without explanation and asked what they thought, and their comments were important for the final version. Like my husband pointed out how fascinated he was by all the different accents in the film. He also said that even if you don't understand the science you can still tell that something exciting is happening by the way these people talk about it. Darren's wife pointed out that there were some words used that even she as a scientist did not understand, and through that we knew we had to change some bits. This testing part was very important.

MH: What you have managed to do in this film is to articulate in a fantastically effective way the history and the process of a scientific discovery – articulated by the scientist in a way that is accessible to anyone paying enough attention, not only to a few specialists. And this is very remarkable. We have access to information through the interviews that is not purely scientific, not purely artistic, but something else, something new. But my last question. Going back to basics. How do you understand it, what is research for you?

JD: It should be reading, but more often it is talking to people. I don't always write it down, but talking to people is a big part. Reading for research is generally a very specific process, whilst other, more observational forms of research can be less specific, more random, which can often lead to unexpected results. It can be in any form as long as it causes you to ask questions about your life.

After the *Tomorrow* film, and after starting to think about what I want to do in Gothenburg, I watched the film *Texas Chainsaw Massacre*, which was on late one night. I had never seen it before, and was really fascinated that in it there is this guy in a wheelchair. It's never explained why he is in a wheelchair, and he really annoys everyone and is not a nice character. Later on, I read more about the film and learned about the reference this character's disability makes to the war in Vietnam, when many men of this generation were coming back with severely disabling injuries. From that point, I started to think about how this disabled person is not the main line of the story and how that could be similar in my life. I have my family, like a huge big cloud above my head and this film made me want to look inside other narratives where disabilities are not necessarily always the main feature. It's funny, but in *Texas Chainsaw Massacre* it also has this bizarre angle that the psychotic characters are all brothers from a single family with a real inherited genetic problem.

So I guess what I am saying is that sometimes the research happens quite inadvertently, you see something, you watch or read something, or you have a conversation with someone and that connects to something you are looking at in another part of your practice. The research process is how these parts are joined together. At the moment, I am researching how the bizarre things that I saw in this movie connect to continuing research that I am doing with the Professor of Human Genetics and my relationship with my family, and my ongoing interest in physical, public space. And I guess you could say that the bit that comes out in the end is art.