The Diagnosis (oil and chalk pastel on canvas, 140x100cm)
“Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick.”
(Susan Sontag)
DRAWING WOMEN’S CANCER
art, science and the lived experience

Drawings by Jac Saorsa

DOUG

ORIEL, The Senedd, National Assembly for Wales, Cardiff Bay, CF99 1NA
Exhibition 19th November - 25th November

Cardiff Metropolitan University, School of Art and Design
Cardiff University School of Medicine, Cardiff and Vale University Health Board

Kindly sponsored by Lesley Griffiths AM, Minister for Health and Social Services,
Assembly Minister for Wrexham
When I first read the motto entering into the Medical School in Sheffield (Art is Long, Life is Short), little could I imagine the new meaning it would come to have for me over a quarter of a century later. As a women’s cancer surgeon and researcher at Cardiff University, I was introduced to Jac Saorsa, an artist at Cardiff Metropolitan University. Jac wanted to draw women’s experiences of cancer and I wanted to find a way of helping to explain to women what it would feel like after surgery, rather than just what it would look like. Drawing Women’s Cancer is the result. The drawings in this first exhibition represent visual interpretations by the artist of the experience of a vulval disease, based on conversations with patients, health care professionals and scientists. The exhibition is designed to raise public awareness of the disease and provide the catalyst for an information booklet for women undergoing surgery.

Vulval intraepithelial neoplasia (VIN) is a skin condition affecting the vulva in women of all ages. The name comes from the appearances of the disease when seen down the microscope, and literally means ‘abnormal cells in the skin of the vulva’. The condition causes itching, burning and pain and may develop into cancer if it is not treated. Standard treatment is surgical removal, but this does not guarantee that the condition will not come back – it does in about fifty percent of cases - and the surgery leaves behind scarring, which can cause physical and psychosexual problems. There is little information available for women who decide to have surgery and part of the Drawing Women’s Cancer project was therefore to provide a booklet for women about the surgery, covering both practical and emotional aspects. The intention was to explain both with words and with visual imagery what the treatment would feel like.

There is much research going on to try to understand VIN and to test new treatments. Scientists in the HPV (Human Papilloma Virus) group at Cardiff University Medical School are at the forefront of this. Some of them have also shared with the artist their experiences of working in this important area of research.

Women often suffer with vulval illness for a long time before seeking or receiving help. This is due largely to embarrassment, lack of awareness, and a reluctance to speak about their problem. The Drawing Women’s Cancer project hopes to help change this situation by using the language of drawings to explain the illness - in other words, the subjective overall experience of disease. There is no name for the illness associated with VIN; this exhibition will help to give it a voice.

The exhibition is a result of encounters between the artist and women who have undergone surgery, the nurses and doctors caring for them and the scientists in the laboratory. I hope you are as moved and inspired by the result as I have been.

Dr Amanda Tristram, November 2012
“Nothing was going to happen for a long, long time not even on our wedding night. It was probably harder for him than for me because it’s different for women I think.”

“I was angry more than anything. I felt that all my womanhood had been taken from me.”
VIN in culture (graphite, charcoal, ink on paper, 60x60cm)
Before surgery

Hours after surgery

Weeks after surgery
At 40 years old I learnt that I had VIN 3 through an HPV infection and that surgery, a partial vulvectomy, was the recommended course of action. I agreed to surgery, as most women would, just wanting the disease to be cut away quickly thinking and hoping that would be the end of the disease. But I learnt later this is not always the case with VIN.

My surgery was painful and disfiguring; scar tissue became very tight and still causes me problems seven years later. Sexual function was affected for many months afterwards. I later learnt that many women of all ages, just give up on ever trying sex again. There is a mental and physical upset to this area of surgery.

Within three months I was told VIN had returned but was fortunate to have support from my Gynaecological Oncologists who believed surgery alone, does not need to be the only path forward.

I was given the topical cream Cidofovir to use for three months. The cream was easy for me to apply at home and I felt happier and more relaxed in doing this. I could still function sexually and I could still go to work. I did not feel half a woman and psychologically this gave me my confidence as a woman back. There was no scarring and no body change but more importantly, there was no sign of VIN or any active HPV at the end of the treatment.

I still remain symptom free.
I have tried to study, I have been cramming my head with facts and learning a new language from new books and Internet trawls. Amazon profits on my anxiety while medical sites are stacking up in the bookmarks file on my Mac. She is so very young looking - a blonde whirlwind. I watch her race across the concourse at the hospital reception towards the kiosk in the corner. It feels like an airport in here. Lots of shops and cafes, but there are no carefree smiles, no uniformed flight attendants waiting at the gates, no suitcases bursting at the seams with stickers and coloured ribbons tied to the handles. Instead there are careworn faces, brave smiles, white coats and blue nurses uniforms. There are people bound in plaster casts and wheelchairs, families and friends carrying magazines and overnight bags. I watch as I sit, quiet, sipping on a regular Americano in Costa. Is that her? If it is her, she will wait – right by there. ‘Meet you at the reception’ she had said, as if she was afraid an academic, an artist, would get lost in the vastness of this clinical space. She was probably right.

She stops, waiting, looking at her shoes – tiny ballet pump kind of things. Are you Tiff? I ask and her huge smile lightens the concourse. We race off at her speed to the labs. ‘You need one of these I’m afraid’ she says apologetically as she throws me a white coat. ‘This is where I am. This is my room’. A small room, almost claustrophobic both after the expanse of the concourse, and in comparison to the parameters of the lab it was clearly once a part of. ‘May I record this?’ ‘Yes of course. Well, what do you know about vulval neoplasia?’

This is my chance, my opportunity to impress her with my new-found knowledge, but I do not do well. Not dying cells really, but rather cells that are abnormal. There are three grades of VIN, which can progress naturally and inexorably towards vulval carcinoma. She shows me VIN 3 cells, the lines cloned from an original biopsy taken from a patient with HPV infection. HPV: Human Papilloma Virus. Her project is an exploration for a ‘treatment strategy’, an extension from a pilot where Cidofovir as a topical cream was applied to the infection site by twelve subjects. ‘I think the regression from VIN 3 to VIN 2, 1 or normal was high so there is potential there’.

She is so enthusiastic, so excited even, and totally involved in her work. Her cells contain HPV16, an infection that differs in type if not in result from Lichen Sclerosis. The pilot was interested only in HPV16. We talk some more about what she is doing. ‘What does that actually mean – cold knife surgery?’ I ask. Tiff screws up her face as she explains
excision. ‘A lot of the ladies, they get recurrent disease. They go back, I read that some ladies go back two or three times. ‘She pauses – the room seems to take on even smaller proportions as she forces herself to think outside its objective, scientific comfort zone. ‘I can’t imagine what they go through having their vulva removed. Especially if it’s extensive. It’s psychological, psychologically…sexually demoralising. If it were me I think I would want to keep myself to myself for ever.’

‘In the pilot study’, she tells me, pulling herself back into the safer, scientific world, ‘the results were encouraging so, ‘they decided they need a large scale study to see how the drug works…so that we can see – clinically – if its having an effect at a molecular level how exactly the drug is causing that regression from high to low grade or, you know….’ She pauses again. This time for a less emotive reason. I know that she is struggling to find the language that I can understand. The layman language. It is strange how so much of what she says is resonant of horticulture, of working with nascent life. She talks of growing, of nurturing, of cultivating. She talks, even sings to her cells and they respond by multiplying and replicating – blooming?

The flow of information is relentless. Tiff speaks as fast as she moves. I move a little slower. ‘How many ladies? ‘There are around two hundred subjects in the study which, she explains, is not just about Cidofovir but also about a second drug - an immune response modulator which helps activate the body’s natural immune response to drive out the HPV virus.

As she goes on to explain the details of the intricate processes of cell culture I understand how much she is struggling to keep technical language to a minimum. She talks about biopsies, about previous studies that have led to hers, about creating cell lines stored in liquid nitrogen waiting for her to create populations of clones in the bottom of small glass dishes, or ‘plates’. She talks about ‘passages’, about dosing and counting, selecting and quantifying, about ‘stripping off and about extracting DNA and RNA. She wants so very much for me to understand and I am so very glad of all the reading ‘prep’. We get to the difference between true cancer cells and the ‘primaries’ that she is using. These come directly from the neoplasia biopsies taken previously and are therefore, although abnormal, not yet cancerous. These are ‘mortal’ cells; they can die. Cancer cells are ‘immortal’. They have the innate potential to proliferate very rapidly and continuously.

‘Have you heard of HeLa? She says. ‘These cells would just grow, grow, grow.’
Transience (chalk pastel on oil ground, 320x120cm)
During Tiff’s explanation I am peering through her microscope at cell structure in different stages of growth and development and images begin forming in my mind that blur the spaces between her words. She mentions a book, a life, a world in which cells are taken, without the patient’s knowledge or permission, from a cervical cancer tumour. These cells, now a global phenomenon, are bought and sold on the commercial medical research market. They ‘grow and grow and grow’, and have been the catalyst for many a breakthrough in medical science. Henrietta Lacks has become a figure looming large in my visual reverie.

Tiff brings me up short with ‘So,’ and verbally hurries on, hardly drawing breath with me running alongside as best I can. ‘I am not using the immortalised lines that Aine is looking at’ (Aine, a fellow PhD researcher and my next interviewee). ‘I’m using the VIN lines so that at the moment I’ve got a thousand in there’ (she points to her fridge) ‘waiting to start a dosing regime and I’ve done one before and also validated it and we did cell counts after dosing and there’s a reduction in the number of cells which kind of ties in with the apoptosis because it means that the cells are dying.’ We both draw breath. ‘So’ (again) ‘there is a reduction in cells but we have to look at it in more detail. There are particular stains you can use that stain the membrane and that can tell you what is happening and I will be going on to that at a later date.’

I am becoming more and more fascinated as she continues to tell me details of what she is doing and what she expects to do. We peer together at microscopic cell structures and she bemoans the fact that there is ‘not much for you to see’, especially after she had so many more growing cells the week before. She explains methods of counting cells, how she counts them in a grid down a microscope but how ‘flow cytometry’ which uses a laser beam is a far more accurate way. I have a picture in my mind of cells flowing one by one through a tube as a laser counts each and every individual stained with something called ‘annexin’. These are precipitating apoptosis – their own death. These are mortal cells.

She goes on to tell me about a further project that is being carried out but she becomes frustrated, self-conscious. ‘This is confusing. I’m saying things so simplified. I’m saying things so wrong!’ I need to reassure. We move into the personal, toward womanhood and away from the scientist and the artist. I ask, cautiously. ‘How far removed do you have to be from that sort of thinking, in doing what you are doing, I mean actually relating the human experience of the disease to what you are trying to do. Do you have to cut yourself off from that?’ She pauses, sighs, draws breath again. It is as if she had been waiting for this. ‘OK, when I’m in the lab it’s just the lab and in the papers I’ve read about vulval
disease and the surgical techniques it is never very close to me, its never very emotional. About a year ago I was in the office typing up and there was a knock on the door. It was a VIN patient. I’d never had any contact with anyone with VIN, I didn’t see anybody in any clinics because I’m not a clinician, I’m a scientist and I’m literally in the lab all the time so the closest I’d been to VIN on a clinical level was reading a paper about the disease. She came in and she was the loveliest woman ever and Aine and I were both there, and it was so emotional, and it made me and Aine, both of us think, actually think, about the disease. Not that we don’t normally think about it, its just that when you see someone in front of you who’s been through vulval surgery, and how grateful she was, coming on about sponsoring the department, “I sponsor the department all the time. What’s your project? I am so grateful to people like you.” I don’t know, it made us feel that we were doing something to help on a daily basis because we don’t see the disease in patients everyday we are just literally doing our work. When I met that lady it really, really, really made me feel quite good about what I’m doing. It was a bit emotional because I’m a woman as well and you do think, you do relate things to yourself, and Aine and I both said it made us realize what we are actually doing this for, rather than just a list of projects.’

Tiff’s whole persona has changed. Her voice has a softer edge, her speech is slower, she has a wistful look. We talk about my work, about the allusions to gardening. She becomes excited again and thinks of her cells. ‘I wonder if you want to see some more cells. I don’t think I can show you right now, they’re not grown.’
“I was very surprised and shocked when they discovered it wasn’t just something simple like I thought it was going to be... The wait between the biopsy and the results was very hard. You start imagining the worst. I was sort of thinking, ‘well, this is it now. This is me finished now.’”

“To me it was a massive relief ‘cause there was one stage when I thought I was going mad...a freak of nature ‘cause nobody seemed to know what I was talking about and yes, it was a massive relief. I didn’t even care that it was abnormal skin cells that could one day develop into cancer – I had an answer!”
The cells before cancer (*chalk on paper, 24x18cm*)
“Sexual desire is not just one thing it is a multitude of things isn’t it? First of all there’s the psychosexual effect of their cancer, which attacks their sexual life, and then there is the surgery, which has secondary effects on their sexual life. So you got to ask a few questions – ask what is actually bothering them – just figure out what you can do to help them.”

“I used to keep crying with my patients, but then I thought, as a doctor you can’t do that!”
The Cut (chalk pastel on paper, 60x60cm)
“It’s weird because when somebody says it might be cancer you always think, well I haven’t lost weight...you know there’s always got to be some other symptoms...I didn’t really want to believe it when the biopsy results came back...I didn’t feel ill.”

“It was awful. You couldn’t even go to your friends and expect them to understand because they’d never heard of it...I couldn’t explain but in the end, after seeing all the doctors and medical students, you can talk about those body parts like you would talk about your arm. I’m quite open about it now. It doesn’t bother me anymore.”
Notes (oil and chalk pastel on canvas, 140x100cm)
“I did find people say ‘Don’t go see counsellors, they don’t do much for you’, but it did help me a lot. Sometimes I would go in and talk in riddles, but she would understand and just sit there and listen to me.”

“I’m a positive person. I’m stronger than I’ve ever been. I do think about it every single day but it’s in the back of my mind, not the front. It’ll never go away – that word cancer – it’ll never go away.”
Acceptance (chalk pastel on paper, 80x60cm)
My thanks to all those who have supported this idea and without whose help it would not have been realised. To Dr Amanda Tristram for believing in the project, and to Catherine Morgan for organising me, Mr Kenneth Lim, Dr Mahalakshmi Gurumurthy, Cardiff and Vale University Health Board and all the theatre and administration staff at Llandough and Heath Hospitals who I have met during the process. Also to all members of the HPV Research group at Cardiff University who gave of their time and experience, and to staff, students and colleagues at Cardiff School of Art and Design. Thanks also to the Minister for Health and Social Services, Lesley Griffiths AM, for kindly sponsoring the Drawing Women’s Cancer exhibition, and the events team at the Senedd for their patience and their hospitality.

Finally, my most especial appreciation of course belongs to all of the patients who gave so generously of their time and their trust to work with me on this project.

Dr Jac Saorsa
November 2012

All art materials supplied by Jacksons: http://www.jacksonsart.com