



The Left Atrium

Future genetics, futurist ethics

From chance to choice: genetics and justice

Allan Buchanan, Dan W. Brock, Norman Daniels
and Daniel Wikler

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What are the most basic moral principles that would guide public policy and individual choice concerning the use of genetic interventions in a just and humane society in which the powers of genetic intervention are much more developed than they are today?

The authors of *From Chance to Choice: Genetics and Justice* take up this question armed with liberal theories of justice rather than the more familiar bioethical principles of autonomy, beneficence and nonmaleficence. Theirs is a highly articulate analysis of how liberal justice theories both clarify and are challenged by advances in genetic knowledge. Although far from light reading, this volume provides a concise yet thorough review of the history of eugenics, a moral analysis of the distinction between interventions to address disease and those that enhance normal qualities, as well as assessments of our duty to future generations, the right to reproductive freedom, the concerns of disability rights advocates and the role of the state in distributing the benefits of new technologies. In the discursive tradition of John Rawls' reflective equilibrium, the authors consider objections to the use of genetic technologies in their strongest articulation. Nonetheless, they are led to conclusions that would place few limitations on the application of new technologies.

A primary policy concern of the "genetic revolution" will be to allow fair access to genetic services and information, supporting wide reproductive freedom while respecting the best interest of future children and ensuring the equitable social distribution of the advantages of genetic interventions. Although Buchanan and his coauthors do not accept the objections of some disability

rights activists to genetic testing and screening, they do recognize the danger of "backdoor eugenics" and suggest that "the most important policy objective ... will be to ensure that maximum benefit is obtained while avoiding the exclusion and stigmatisation of any of our fellow citizens." But they also argue that the deep entrenchment of reproductive rights and social tolerance make a return to state-based eugenics highly unlikely, even without legal restrictions on individual choice.

The authors challenge value-neutral genetic counselling, recommending that counselling actively encourage the use of genetic services to avoid the conception or birth of children with serious genetic disease. They also argue that parents should have considerable discretion in utilizing genetic tests and interventions — including cloning — to enhance desired traits in their children.

Buchanan and colleagues make a case for public funding of genetic counselling and of access to enhancements if they are important for equal opportunity or competitive advantage. Justice related to genetics is best supported by a national health care system that provides access to services that are important to restoring people to normal functioning. This access must be provided in the context of social reforms that support the status of people with disabilities or genetic disadvantages as valued and equal members of the community. The authors worry that state-sponsored education programs that encourage genetic screening would risk a slide to a view of

some people as less valuable than others. Instead, they support the reproductive freedom of parents to use or not to use genetic technologies and the avoidance of state action that could support unacceptable eugenic attitudes and effects. They argue that the tragedy and social cost of avoidable genetic problems are a reasonable price to pay for maintaining reproductive freedom and an ethic of inclusion.

This volume demands a response from those who claim that genetic prenatal testing implies a devaluing of disabled people. Similarly, those who wish to maintain a moral firebreak between genetic interventions that address disease and those that enhance normal human qualities must respond to the authors' dismantling of the moral relevance of that distinction.

In the authors' view, neither strong obligations to intervene on behalf of future children nor strong prohibitions and extensive regulations will be necessary once the limited effect of genetic knowledge is understood and fair access to health care is assured. Their well-argued and thorough analysis serves to demonstrate that genetic and genomic research

presents less a revolution in values than another round of negotiating familiar themes of justice as it relates to health care, the value of the individual and the issues of distributive justice. Research into

injustices that emerge in the application of genetic knowledge across different health care systems and societies might establish which are truly rooted in the new genetics, and which are more significantly the products of the social and political systems in which new technologies develop and are utilized.

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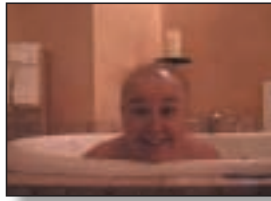
Fred Sebastian

Gerry's wig

My left breast: an unusual film about breast cancer

Gerry Rogers, director; Peggy Norman, camera;
Paul Pope, producer

St. John's, Newfoundland: Pope Productions, Ltd; 2000
57 min. \$24.95; institutions: \$99.95 plus tax and shipping
ISBN 096880820-4 Available: www.myleftbreast.com



Gerry Rogers looks at the camera through the two zeros in the middle of her zany millennium sunglasses and asks, "Should we talk about the year 2000?" The question is addressed to her lover, companion, caregiver and camerawoman, as well as to the viewer of this intimate autodocumentary, *my left breast*. Behind the camera, the voice of Peggy Norman is sceptical: "What is there to say about it?" she asks. "Hopefully," Gerry answers, "the year 2000 will be better than the year 1999 for us, although I still think we were really lucky."

Gerry Rogers' luck fizzled rather badly in 1999, the year she and her partner started a bed and breakfast business in Carbonear, Newfoundland, and then discovered Gerry had breast cancer. Gerry started making this film the day her hair began to fall out during chemotherapy. It was, to use Peggy's word, an "outlet" for her feelings. In the small hours of sleepless nights Gerry points the camera at a mirror and talks about her fears, her sense of isolation, her feelings of loss. She shows us how her hair comes out in tufts, the incision left after modified radical mastectomy, the flushing of her Hickman catheter. She takes us to her chemotherapy and radiotherapy sessions and to follow-up

visits to her doctor. Although centred on self-disclosure, this is an extremely *helpful* film, one that posits a viewer faced with a similar situation herself.

This creative outlet, the film, documents another: the collective project, guided by a professional wigmaker, of making a "healing wig." Gerry asks friends, family, neighbours, the women behind the post office counter, everyone she knows, for a lock of hair. The idea catches on. Offerings arrive by mail from across the country. Samples from entire families, including cats and dogs. A carefully packaged and labelled collection from the children at a school for the deaf. Thick tresses kept in a drawer for 30 years. The hair that a woman had cut off the year she herself started chemotherapy. It's a complex impulse to preserve a lock of hair: a hedge against loss, a nostalgic gesture, an act of hope, a memento mori. These very personal artifacts are given as a benediction, a wish for Gerry's restoration, an expression of solidarity.

Gerry inspires generosity, first because she is so likeable, and second because she so clearly values the love and support she receives. She confides to the camera that "love and tenderness are so important to me right now." Metaphors of battle don't really interest her; the

important thing, she muses, is to be gracious and to do the best she can. This means welcoming the organic produce, herbal potions and (to her mother's consternation) packages of marijuana people give her. It also means submitting to modern medicine's more brutal means. Disfiguring surgery, the infusion of "the red devil" in her veins, skin scalded by radiation: Who can embrace these as an experience of *healing*? This is the most difficult thing: to face unpleasant treatments with feelings of deep ambivalence. Gerry worries about this: To get better, should she not always be thinking positive thoughts?



The quiet triumph of this 60-minute film is that it convinces us that Gerry Rogers *is* lucky. She has a deep respect for herself and others, a buoyant sense of humour, a gift for communication and community building. She knows what she needs and asks for it. She shares, unassumingly, what she learns. Giving and receiving, she achieves an amazing grace.

Anne Marie Todkill
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Room for a view

The gravedigger's bed

When I was a junior intern in Montreal, we had no problems with beds being blocked by patients with chronic conditions, at least not in teaching hospitals. One of the reasons for this was simple: at that time there was no national or provincial health insurance.

Many people had private insurance, but this covered only acute care and usually terminated after two weeks in hospital.

But there were other means of preventing bed-blocking. There was a rule, for instance, that people with stroke, even of recent origin, could not be ad-

mitted to the public teaching hospitals. The justification was that the diagnosis was obvious, and there was no treatment that could not be given elsewhere. When we were on call we might be telephoned in the middle of the night by a harried general practitioner with a stroke