

consider Fibromyalgia Syndrome, Irritable Bowel Syndrome, and depressive or anxiety states.

There has been an increase in the reporting of Chronic Fatigue Syndrome over the last few years. In the USA chronic fatigue has an estimated prevalence of 20–25% in the general population, but a firm diagnosis is made in <1%. The aetiology of this condition is unknown. Cocksackie B virus, retroviruses, unidentified new viruses, abnormal interleukin levels, pesticide poisoning and hypothalamic dysfunction have all been reported as possible causes but there is little hard evidence to substantiate any of these claims. Whatever the aetiology, the outcome is uncertain, only a small minority becoming totally symptom free, but fifty to sixty per cent show some improvement over a period of years. According to one survey, 'most cases seen do not improve, give up their work, and become permanent invalids'.

Chronic Fatigue Syndrome belongs to that group of ill-defined conditions with no apparent structural pathology, and often an associated affective disorder. It is prudent to be modest in diagnosis, but important to give a label (though not a grouped label, and more specific diagnoses such as IBS, Globus, Fibromyalgia, may be more appropriate depending on the principal symptoms). There is no proven therapy for Chronic Fatigue Syndrome, though cognitive and behavioural therapy may be indicated in some circumstances. Anti-depressant medication may occasionally be appropriate.

#### *Conceptual issues in psychosomatic disease*

The aetiologies of the different psychosomatic diseases are unknown. Our understanding of the interactions between psyche and soma is very limited. In explaining the particular diathesis of some people to somatise disease psychologists have employed many different constructs. Whereas some have investigated whether patients with these disorders have particular personality attributes (e.g. neuroticism, somatopsychic distress, emotion-orientated coping, hardiness, alexithymia), others have focused on lower-level processes more related to bodily symptoms (e.g. somatic amplification, physiological reactivity, somatic attention, attributional style). Personality constructs may prove too vague to explain somatisation, and mid-level processes too specific. Several constructs within each category show considerable overlap, and many have limited validity at present.

Despite the proliferation of psychological constructs which attempt to explain psychosomatic disease, no single unifying hypothesis has emerged. There is no satisfactory explanation of the inter-correlations between the psychosomatic diseases, such as IBS and Chronic Fatigue Syndrome. Also unanswered is the question of why, if psychosomatic disease does have a similar source in the personality of the patient, the focus is not more unified to one particular region of the body? Future research will have to examine these issues in some detail. Until this information is available the tendency to pursue an organic sequence when making a diagnosis will remain—'ruling out the highly rare rather than ruling in the highly likely'. The unfortunate consequence is a consultation from which neither doctor, nor patient, leave satisfied.

He chases his tail  
Like a puppy-fool  
And wonders it tastes stale  
The puppy-fool.

Stevie Smith

## THE NEW GENETICS: A CHALLENGE TO CLINICAL VALUES?\*

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There can be few developments in medicine and science which have the capacity so fundamentally to alter our present and future lives as those emerging from the new genetics. The vast potential of the information derived from the Human Genome Project and the advances in genetic diagnosis cannot be underestimated as forces which will shape present and future societies. They will profoundly affect each of us individually and collectively. Much of the debate concerning genetic information and the uses to which it may be put has been couched in terms of the sophisticated science which it entails. Concentration on this, however, tends to ignore the impact that our new capacities will have on the actual providers of health care and on the patients whom they see. It is this imbalance which I hope to address here.

In 1992, the World Medical Association's declaration on the Human Genome Project pointed to the significance of enquiries into the genetic basis of disease and other conditions. As it said 'In the second half of the 20th century a conceptual revolution occurred when one started thinking of diseases in terms of biochemistry. A new revolution is happening now which locates in the gene the instructions for all the biochemical processes in the body's cells'.<sup>1</sup> This challenge has been taken up by the scientists engaged in the world-wide venture which is the Human Genome Project, whose expressed aim is to acquire '...complete knowledge of the organization, structure, and function of the human genome—the master blueprint of each of us...'.<sup>2</sup>

The so-called 'Holy Grail' of modern medicine is a multi-million pound venture into the unknown. Yet some things are immediately clear about it, not least that the dilemmas which it will pose are significant for individuals and for those involved in the provision of their health care. In countries such as the UK, these health care providers will be both general practitioners who are the most frequently in contact with the affected groups and individuals and whose intervention triggers reference into the high-tech world of hospital medicine, and those working in hospitals and clinics, charged with the responsibility of diagnosing, curing, counselling and caring for affected individuals. In other words, all physicians will share the burden of any ethical and legal consequences which flow from genetic knowledge. As an aside, this may well change the face of medicine by imposing an additional unifying set of problems which serves to break down barriers between specialisms.

Taking a critical, but not cynical, look at the ways in which we can, will or should deal with genetic information is of utmost importance. I intend to seek to do this by posing one central question—that is whether or not the new genetics is likely to present us with new dilemmas or whether it will simply present old problems in a more acute manner. This I try to do by looking at one or two of

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the things that doctors do, the concepts which they (and we) value and testing out whether or not any new tensions emerge. But one *caveat* must be entered immediately. Whether or not the dilemmas are new, we should remember that both their content and their resolution are not value-free. As has been said, 'Feminist critics of the new reproductive technologies have shown how difficult it is to divorce these technologies from their ideological context, and the same is true of genetics and genetic technologies'.<sup>3</sup>

So, the question is, what difference—if any—will genetic knowledge make to the way in which health care is delivered. What dilemmas—if any—will it pose for those at the sharp end of medicine? To a large extent, the impact on health care providers hinges on the effect of such information on their patients. The question, therefore, might be posed in a slightly different way, namely, will genetic information have an effect on the individual? The Danish Council of Ethics is in no doubt about this: '...the completely new information and scope for action destined to follow from the mapping of the human genome will alter fundamental ethical concepts such as autonomy, integrity, privacy, quality of life and so on'.<sup>4</sup> People's knowledge of their genetic inheritance may profoundly shape their response to their environment, their attitude to themselves and their families and their approach to health care itself. And this will inevitably involve their carers in confronting similar tensions and ethical dilemmas. The ripples in the pool will wash over and invade many aspects of the manner and type of health care to be offered. For example, carriers of genes such as those for Huntington's chorea and other late onset conditions may become prime movers in the current debate surrounding the making of advance health care directives or the general issues of euthanasia and physician assisted suicide.

Knowledge of the manner of one's death, or the quality which can be expected of one's dying, may profoundly shift attitudes about the value and importance of autonomy in choosing the method and the time of death, supervening the current, rather emotional, debate. This will clearly have an impact on doctors as well as on patients. Removal of uncertainty in diagnosis and prognosis seems likely to affect the attitudes of those who care for their increasingly weakened or disoriented patients. When coupled with recent research suggesting that many doctors would wish to endorse their patients' reasoned and competent wishes for assistance in dying,<sup>5</sup> it may well be that a powerful force for legal change in this area has already been unleashed and can only gather momentum.

Meantime, of course, the presumption is that the cornerstones of medical ethics—developed over the centuries—will not prove unequal to new challenges. Concepts such as justice, beneficence and non-maleficence have stood the test of time admirably, and we may need to look no further than to them to resolve any questions which do arise. In 1991, the Royal College of Physicians of London made the following point. 'The fact that the problems [of genetic and other screening] are essentially the same suggests that to the extent that certain ethical standards are applicable in other areas of medicine, these will apply equally in the context of genetics'.<sup>6</sup> But they conclude, 'However, some new considerations do arise in genetics, and they at least raise the question of whether the familiar problems should always be approached by means of familiar ethical standards'.<sup>7</sup>

In other words, maybe we will have to rethink, perhaps even modify, our satisfaction with longstanding ethical commitments in the light of what will be known and what, if anything, we can or should do with that knowledge. To

explain what I mean by this, I intend to look at two issues which are likely to be significantly affected by this new genetic knowledge. The first of these is confidentiality in the doctor/patient relationship.

Confidentiality, it is often said, is the cornerstone of the doctor/patient interaction. Without it, patients would not feel free to make disclosure of intimate, distressing or embarrassing information about themselves. Without a commitment to confidentiality it is said that individual health care, perhaps even health care in general, would inevitably suffer. As an English Court put it in the case of *X v. Y*.<sup>8</sup> 'In the long run, preservation of confidentiality is the only way of securing public health; otherwise doctors will be discredited as a source of education, for future individual patients will not come forward if doctors are going to squeal on them.'<sup>9</sup> This case involved the intended naming in the press of two doctors who were continuing to practise while knowing themselves to be HIV positive. And certainly, HIV and AIDS have shown the extent to which tensions exist between the rights of the individual and the rights of the community. Genetic information will enhance these tensions and bring them into even sharper focus.

How will this happen? What this example shows up most acutely is the dilemma posed when an individual has information which affects others, potentially as intimately as it affects the individual. Although confidentiality is taken to be one of the doctor's most sacred trusts, situations can and do arise in which it may or must be breached. We are all familiar with the permitted range of exceptions—so many of them, in fact, that some believe that they have watered down the obligation of confidentiality so significantly that it is increasingly threatened. For our purpose, however, the critical exception is what is referred to as the 'public interest' exception. As Mason and McCall Smith have said, 'The doctor's overriding duty to society represents what is arguably the most controversial permissible exception to the rule of confidentiality in so far as it rests on subjective definitions'.<sup>10</sup>

Not only does the freedom to disclose challenge the doctor as a professional, but it also poses a potential legal threat. How wide or narrow this exception should be is a question which must have troubled many doctors, who are left without much in the way of guidance about when, and in what circumstances, information gained as a result of a professional consultation can or should be disseminated. Not only this, but it clearly represents a genuine and legitimate concern for patients. Ngwena and Chadwick have suggested that '[i]t is apparent from decided cases that the public interest exception can be invoked to protect an open rather than a closed category of interests of which the physical and mental health of an identified individual or class of subjects is but one'.<sup>11</sup>

Why is this of particular significance in respect of genetic information? There are a number of reasons why the acquisition of such knowledge raises acute dilemmas whose resolution is not simple. There are undoubtedly many in the community who—as with HIV status—feel themselves to have a legitimate interest in knowing about an individual's genetic make-up, sometimes so that they can avoid putting the individual in a situation which may trigger a genetic predisposition and sometimes for self-interest. Yet even that self-interest may be more than just that.

Obviously, genetic information, once disclosed, can have extremely important consequences for the individual, in terms of employment, insurance and so on, to

say nothing of self-esteem. At the moment in the UK, there are no laws which would prevent employers and others from demanding that genetic tests are undertaken as a prerequisite of offering someone a job or an insurance policy. The Danish Council of Ethics has recommended that there should be 'absolute confidentiality'<sup>12</sup> regarding such information in respect of these groups, and a moratorium on seeking such information, which expires this year, was agreed between the insurance industry and the Government in the Netherlands. Despite the recommendation of the Nuffield Council on Bioethics<sup>13</sup> that a similar device should be erected here, nothing has yet been done, although the recent Report of the House of Commons Select Committee on Science and Technology has given the insurance industry one year to come up with a suitable strategy, bearing in mind the general principle that genetic information should not be used in a discriminatory manner.<sup>14</sup> In California in 1991, the legislature voted in favour of a Genetic Privacy Bill, which was subsequently vetoed by the Governor, and the matter is under consideration in a number of other US States.

On the other hand, insurers and others might argue that if they take on a 'bad risk', genetically speaking, then their capacity to survive will be threatened, and all of those currently or potentially insured will be affected. The difficulty is in achieving a balance. In 1994, *Time* magazine reported the results of an opinion poll which asked a number of questions about the uses of genetic information. Although the poll showed a variety of responses and attitudes, one matter was very clear: 'Of those polled, 90 per cent said they thought it should be against the law for insurance companies to use genetic tests to decide whom to insure'.<sup>15</sup> Yet, as in the UK, '... such practices are, in fact, quite legal in the US'.<sup>16</sup>

In countries where access to health care depends on eligibility for insurance, concern has already been expressed that 'individuals might be compelled to provide genetic information as a condition of obtaining health care coverage...'.<sup>17</sup> This has led to the recommendation that 'Genetic Privacy should be vigorously protected...'<sup>18</sup> but these same recommendations noted that 'other varieties of health-related information are equally sensitive... Policies intended to protect genetic privacy will need to address the privacy of health-related knowledge in general'.<sup>19</sup> Our current, somewhat relaxed, attitude to the value of confidentiality might, therefore, have to be reassessed. This is an example of the new genetics throwing up old problems in a more acute form. Although this is not, therefore, a new problem it is one which requires serious consideration and re-appraisal of a number of fundamental values, not just confidentiality but also other rights which patients can legitimately expect to see vindicated. As Schmidtko has said: 'No matter what way a person comes to terms with such information—which may either be a blessing or be terrifying—in all societies where maximum priority is attached to the right to self-determination with regard to information there is a consensus that the decision for or against such predictive diagnostics and the result thereof must remain a private matter'.<sup>20</sup>

For doctors, who hold such information, the matter should be resolved by clarifying in a principled way the extent to which their obligations to society, by taking the public interest exception seriously, might override their commitment to the individual patient vis-à-vis respecting their privacy. For the moment, it may seem likely that doctors would have few reservations about maintaining privacy in most cases—the commitment to confidentiality is sufficiently strong for it to be breached only in exceptional cases. However, as the actual toll of

genetic disorder becomes better known, the fourth principle of medical ethics—that of justice—might begin to take on a new meaning. If the impact of confidentiality in its traditional mode is to contribute to a downgrading of health and other services in general by stretching services even further and by imposing additional costs (a scenario which is not in the realms of pure fantasy) what then is the obligation of doctors to the society of which they are a part?

Equally, and probably of more immediate concern, a doctor may find that genetic knowledge requires an evaluation of the rights of other patients. It is relatively easy to reach consensus on the privacy of genetic information when one considers it in relation to outsiders—that is, to third parties whose access to the information might result in serious and irrevocable stigmatisation or discrimination. But, of course, for a doctor, perhaps particularly for a general practitioner, the position is considerably less clear cut. The family doctor may be just that—someone who cares for an entire group of relatives, and not simply one individual. Although arguably the underlying principles of medical ethics are individual-centred, a doctor's ultimate responsibility is to each and every patient—not simply to one. The agonising choice about whether or not to disclose genetic information is heightened in complexity by this fact. As Brown and Gannon have said, 'It is the blatant dilemma that genetic information simultaneously reveals information that relates to others whilst also revealing the essence of ourselves that is particularly problematic'.<sup>21</sup>

And problematic it is, not just for individuals who may have to make difficult choices about whether or not information which they would previously have felt to be essentially and crucially private should be passed on to others, but also for the doctor who is treating not just that individual but also their family. This dilemma brings into sharp focus the need to decide which values take priority. As Suter has said: 'when genetic testing of one person can benefit another family member, privacy and autonomy interests of the former may collide with the relative's interests in protecting her health or planning her future'.<sup>22</sup>

Obviously, each of the values exposed here is of great significance. The right of individuals to expect that their health information will be maintained in strict confidence can clearly come into direct conflict with the duty of the doctor to act beneficently in respect of all of his or her patients, and with the plausible rights of others to be free to make informed choice based on the fullest possible information. We value each of these things, yet must find a way of reconciling them even when they appear to be in direct conflict. As has been said 'Because of the nature of genes, it may be argued that genetic information about any individual should not be regarded as personal to that individual, but as the common property of other people who may share those genes, and who need the information in order to find out their own genetic constitution. If so, an individual's prima facie right to confidentiality and privacy might be regarded as overridden by the rights of others to have access to information about themselves...'.<sup>23</sup> As with HIV status, the question for the doctor is whether, what and to whom, if encouragement of the individual to make the disclosure fails, the information should be passed on.

And this leads directly into the second example which I want to use. The fact that genetic information is not something which affects only one individual is a major reason for the institution and encouragement of pre-conception or pre-

natal screening. The capacity to test for certain inherited characteristics on the one hand gives potential parents the right and the capacity to make free and intelligent choices about what reproductive risks they are willing to run. In the worst case, it permits the choice to terminate an affected pregnancy and—with the assistance of modern reproductive technologies—it may facilitate the selective implantation only of those embryos which it is known do not carry the deleterious gene. On the surface, this can only be for the good. However, already there have been examples of this 'good' being turned into subtle or unsubtle coercion. The *Time* article referred to earlier cites one example of the extent to which reproductive liberty may be threatened by this new knowledge. 'In one case, a California health maintenance organization discovered that the fetus that a client was carrying had the gene for cystic fibrosis. The HMO told her it would pay for an abortion, but that if she chose to have the child, it would not pay for any treatments.'<sup>24</sup> Although in this case the threat of litigation was sufficient to change the mind of the company, we cannot assume that—even in a publicly funded health care system—such allocation decisions will not arise in the future, nor can we be absolutely certain that the legal threat will inevitably work. Decisions to treat or not to treat have hit the headlines in the UK on a number of occasions in recent times, and not all of them have been decisions based on clear medical futility. The possibility of pressurising people into certain reproductive decisions is a real one.

Reproductive freedom and the element of choice inherent in it have been at the centre of a long and hard struggle, beginning with the early feminist movement in the late 19th century and taken up over the years by interest groups, politicians and the law.<sup>25</sup> Although these choices were initially unrelated to genetic knowledge, it cannot be disputed that the new genetics provides one additional, and central, body of information which can facilitate the vindication of this important interest. Even if many conditions are a combination of genetic and environmental factors, the fact that there is any genetic component is surely information that we would wish to have before embarking on parenting. And genetics, we now know, not only play a key role in shaping predisposition to certain diseases, but information about genetic inheritance may allow us to make rational choices about our lifestyle which may reduce the possibility of the onset of some conditions. The importance of this information cannot, therefore, be underestimated. Even with our knowledge still limited, we do know a certain amount about the toll that genetically predicted conditions can have. Writing in 1985, Dan Kevles provided the following estimate of frequency. 'In the United States and Britain, genetic disorders are now known to occur in between three and five per cent of all live births, and chromosomal disorders—for example Down's Syndrome—in at least a half per cent. The percentages may be small, but the absolute annual numbers suggest a wrenching magnitude of individual afflictions...'<sup>26</sup>

For the individual, as I have said, knowledge of the likelihood that a child will be affected by a genetic condition can liberate, even as it distresses. However, there is another side to that coin. Prediction may be of statistical significance rather than certainty. Individuals may wish not to know, and certainly cannot be forced to find out, their genetic constitution. But the widespread and increasing availability of ever more sophisticated screening tests may also pressurise individuals into feeling an obligation to find out the answer to the mysteries of

their genes. As Stone and Stewart have put it, 'It seems that we are being subjected to a second wave of evangelistic screening fervour generated, at least in part, by dramatic advances in diagnostic technology'.<sup>27</sup> This may have two clear effects.

First, the decision to take advantage of available tests might at first sight be seen as a merely private decision, but this is an argument which is open to challenge. As Kevles has said, 'Private decision-making in the realm of genetic disorder and disease may ultimately lead to public consequences, and thus to demands for public regulation of reproductive behaviour. A sizable number of people may argue that the right to have genetically diseased children, or even to transmit deleterious genes to future generations, must be limited or denied'.<sup>28</sup> For those who have observed the recent history of negative eugenics in countries as disparate as the United States and Nazi Germany, this fear is a real one. Yet, failure to seek access to the available tests, especially coupled with private suffering and public and economic consequences, might lead many to see the decision not to avail oneself of the tests, or to proceed with a pregnancy when tests have shown that the child when born will suffer from a particular condition, as being an example of 'reproductive irresponsibility'.<sup>29</sup>

Moreover, the availability of this information might be thought to impose an additional moral obligation on individuals wishing to become parents. The emphasis, rather than being on the rights of the individual to do with their reproductive capacities as they wish, might be skewed into being seen as an obligation—might become dominated by what has been called 'intergenerational justice'.<sup>30</sup> In other words, will we, do we or should we have an obligation not to pass on deleterious genes with all of the suffering which might flow from them? And would our answer be different depending on the nature of the condition—in other words, if the condition will emerge on birth or have a late-onset?

For doctors, the first problem will inevitably be linked to the extent to which at risk individuals, or even those whose genetic make-up is unknown, should be encouraged to undergo screening. Already, this dilemma exists, given that screening in some forms is already available and is often recommended. But advances in knowledge, and in particular in diagnostics, will add to this difficult decision. Obviously, improvements in therapy will significantly reduce this dilemma, but will not remove it, especially when the health service finds itself strapped for cash and resources.

In any event, there are moral dilemmas posed merely by screening itself. A doctor's ethical commitment is to the individual under their care. Screening is designed (at least in some part) to answer questions which may affect others, namely the unborn. Quite apart from the potential this has for branding a woman who is unwilling to undergo screening, for whatever reason, as 'maternally irresponsible' or 'selfish', there is another problem. As Davis says, '... we cannot assume that making use of present patients for the good of future patients is ethically legitimate, particularly since the patients concerned are in no position to volunteer... It could be said of molecular biology that, insofar as human genetics is concerned, it has gained a scientific empire but not yet found its real clinical role.'<sup>31</sup>

And a further problem also emerges when the condition screened for is genetically programmed. A doctor may be able by counselling and care to minimise the impact of genetic knowledge on the individual whose reproductive



choices are under immediate scrutiny, but what if the sister, daughter or other relative of a patient is also a patient of that same doctor and is intending, in ignorance of their shared genetic problems, to embark on parenthood or is already pregnant? Does this doctor have an obligation to pass on this potentially devastating information, thus not only potentially breaching confidentiality but also possibly causing extreme distress, which may in the event turn out to have been unnecessary? How does this square with duties such as beneficence and non-maleficence, and to whom is the major or primary duty owed?

#### CONCLUSION

What I have tried to show is that, although these may be old problems, the new genetics demands a reconsideration of the values which underlie them and a reassessment of the principles which we hold to be supreme. The complexity of these decisions will only increase, particularly when the shortfall between diagnostic and therapeutic capacity is so wide, and seems likely to widen over the next ten years or so that are left of the Human Genome Project.

The task, therefore, is to develop the level of sophistication which renders us capable of managing this information, which can be used for good or for bad. The BMA may be right in saying that 'biotechnology and genetic information are in themselves morally neutral...'.<sup>32</sup> But they are also right that 'The challenge which faces us is to try to achieve an optimal future: one which maximises the benefits of genetic modification and minimizes the benefits of genetic modification and minimizes the harms'.<sup>33</sup> The way in which the information is used will be of critical significance in determining our morality as a community, and must be based on a deep understanding of the likely impact of this knowledge on our role in the world. As has been said, one of the potential implications of these advances is to pit the individual against the community of which he or she is a part.<sup>34</sup> Genetic knowledge may in some ways bring us closer together, but it also may impose on us moral obligations which go a long way towards demanding altruism. In a sense, this may be the truly new dilemma posed by genetic knowledge. For the moment we have no obligation to rescue, but both individuals and clinicians may feel increasing pressure to do just that. In accepting such a responsibility, individuals fundamentally alter their position in society and the doctor must change deeply held commitments to, for example, confidentiality.

Consideration of the potential of genetics suggests that '... a decisive stand on the new challenges must be based on a choice between the two overall approaches: the utilitarian view or the approach based on the help motive and respect for the individual. The question, in other words, is: 'must the principle purpose of applying human genetics be formulated in terms of the gain for the common good or in terms of the individual?'<sup>35</sup> Moreover, it leaves us needing once again to consider the actual relevance of genetic information, when faced also with knowledge about the impact of environment. As has been succinctly said 'Humanity cannot be cut adrift from its own biology, but neither is it enchained by it'.<sup>36</sup>

It is relatively easy, of course, to pose the questions—much less easy to answer them. One consensus does emerge from all the reports and writings in this area and that is that the questions will be easier to answer when the public (including the scientists) are better informed both about the science and about the ethical

issues. This point has been emphasised by, amongst others, the Nuffield Council on Bioethics and the House of Commons Select Committee on Science and Technology. Unusually also, this was recognised *ab initio* by the Human Genome Organisation in the USA, which set aside between 3 and 5 per cent of its funding for consideration of the social, ethical and legal implications of the project. But as the German writer Junger said in a different context, 'We see the [ethical] dilemmas go round in circles, while the experiment proceeds through and beyond them into practice. What practice yields will only be known after generations. At present one can say that it is moving in the intermediate area at the Wall of Time and is rich in undefinable and uncontrollable features'.<sup>37</sup>

However difficult, now is the time for exploration of the ethical problems which we can foresee. They may only be the tip of an iceberg, but they are certainly enough to be going on with. Control is needed if we are not to be swamped by problems. And, in conclusion, this control will almost inevitably come from the law. Laws, which may reflect and certainly should take account of the morality involved can only be good if they too are based on information, education and ethical constraints. As Diana Brahms has said: 'Society will expect the law to protect its wider ideals and, in particular the individual citizen, from the excesses of over-enthusiastic doctors and scientists, greedy corporations and immoral profiteers and manipulators. The law will have to balance the need for future research against the need to protect society from its dangers and evils'.<sup>38</sup> If the House of Commons recommendations are adopted, the UK at last will have gone some way towards this balancing act.<sup>39</sup>

But the law should, indeed must, protect and help realise the benefits which will flow from the new genetics. If it is to do this, then doctors, individuals and politicians will need to ask these difficult questions, and provide some comment on what are the most important values to be protected, otherwise any legal control will be at best inefficient and at worst positively harmful. Much comment on the new genetics might be seen as being 'portentous' laden with apprehension and downright distrust,<sup>40</sup> but genetics also holds out much good for the future. Our challenge is to find a way of reaping the benefits and minimising the problems. This, I would suggest, requires a collaboration between those affected—patients, doctors, researchers and others—unparalleled in our history. But time is running on—it is never too early to start.

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- <sup>31</sup> Davis J. 'Ethical issues', *BMJ* 1992; 310: 858.
- <sup>32</sup> BMA, *Our genetic future: The science and ethics of genetic technology*, Oxford: OUP 1992, at p 4.
- <sup>33</sup> *id.*
- <sup>34</sup> McLean SAM. 'Mapping the human genome—friend or foe?' *Soc Sci Med* Vol. 39, No. 9, 1221.
- <sup>35</sup> Danish Council of Ethics, *supra cit.*, at p 64.
- <sup>36</sup> Rose *et al.*, *op. cit.*, at p 10.
- <sup>37</sup> Junger E. *An der Zeitmauer*, Stuttgart, 1959, at p 351. I am grateful to Professor Dieter Giesen, Free University of Berlin, for bringing this quotation to my attention.
- <sup>38</sup> Brahms D. 'Human genetic information: the legal implications. In: *Human genetic information: Science, law and ethics*, Ciba Foundation Symposium 149, Chichester; John Wiley & Sons, 1990, 111, at p 177.
- <sup>39</sup> This would be achieved by accepting the recommendation that a statutory body, the Human Genetics Commission, should be created.
- <sup>40</sup> Maddox J. 'New genetics means no new ethics', *Nature*, Vol. 364, 8th July 1993, 97 at p 97.

## RESEARCH INTO TREMBLING FINGERS: A PERSONAL EXPERIENCE

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The affection in question consists of a fine tremor, constantly present in typical cases during waking hours, voluntarily controlled for a brief time, affecting nearly all the voluntary muscles, chronic, beginning in very early life, not progressive, not shortening life, not accompanied with paralysis or any other disturbances of nervous function. It resembles to some extent the tremor of paralysis agitans, still more a simple neurasthenic tremor. A most striking feature is marked hereditary or family type, and its transmission along with other nervous diseases. Dana, 1887.<sup>1</sup>

One of Dana's patients was a watchmaker who had acquired the reputation of being the best craftsman in the district. Dana wrote—'I have myself seen him pick up a piece of delicate machinery of a watch in his forceps, carry it to the place where it should be fitted, the hand trembling like an aspen until just before it reached its destination, when it suddenly became firm and steady and deposited its burden just in the right place'.

The first professor of physiology in Glasgow was Andrew Buchanan who held the post from 1835 to 1862.<sup>2</sup> He was also a surgeon to the Glasgow Royal Infirmary from 1835 to 1862. He had a tremulous head and hand.

As far back as the fifties, in the morning on which he had an operation to perform, he would keep his right hand supported in his buttoned coat, not even shaking hands with anyone till the operation was over.

Being born in 1798 and not dying until 1882 the tremor indeed did not shorten his life.

### LITERARY REFERENCES

Acute emotion certainly causes tremor. In a biblical concordance under the headings 'tremble', 'trembled', 'trembles' and 'trembling' are numerous references.<sup>3</sup> In the first of these (Genesis XXVII, 33) is the account of how Jacob, on the instructions of his mother, impersonated his older brother Esau. Old and blind, Isaac was deceived into blessing Jacob, animals skins having been placed on Jacob's hand to mimic the hairiness of those of his brother. When the true Esau returned from hunting and the deceit became apparent, Isaac evidently became very angry

Isaac trembled very exceedingly, and said, Who? where is he that hath taken venison, and brought it to me, and I have eaten of all before thou camest and have blessed him?

Similarly Shakespeare often referred to tremor and its association with acute anxiety. Under the heading 'tremble', 'trembled', 'tremblest' and 'trembling' there are again numerous references in a concordance.<sup>4</sup> One example occurs in Julius Caesar IV, 3, 38.

Brutus—'Hear me, for I will speak. Must I give way and room to your rash choler? Shall I be frightened when a madman stares?'

Cassius—'O ye gods, ye gods! must I endure all this?'

Brutus—'All this! ay, more: fret till your proud heart break; Go show your slaves how choleric you are, and make your bondmen tremble'.

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