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31 Colwyn Street, Christchurch 8005, New Zealand

c/o Darryl Macer, RUSHSAP, UNESCO Bangkok, 920 Sukhumvit Rd, Prakanong, Bangkok 10110, THAILAND

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Editorial address:

Prof. Darryl Macer, RUSHSAP, UNESCO Bangkok,
920 Sukhumvit Rd, Prakanong, Bangkok 10110, THAILAND
Fax: Int+66-2-664-3772
Email: d.macer@unesco Bangkok.org

Deadline for the November 2007 issue is **30 October, 2007.**

Editorial: Solidarity and responsibility

- Darryl Macer, Ph.D.

UNESCO Bangkok, Thailand

This issue of the journal includes several papers on the important ethical principles of solidarity and responsibility, which derive from justice and beneficence. The most recent statement of the HUGO Ethics Committee is on "Pharmacogenomics (PGx): Solidarity, Equity and Governance", and it follows up the Statement on Benefit Sharing in the general sense, to the specific issues raised by PGX. There are two further papers in this issue on genetic ethics, which explore how the UNESCO 1997 Declaration on the Human Genome and Human Rights can be applied to application of genetic technology. The papers by Ann Boyd and colleagues re-examine the ethical principles underlying the recommendations for more ethical application of genetic medicine, and explore the relationship of the other ethics principles to non-maleficence.

There is a paper by Silvie Poeth on corporate social responsibility (CSR), which includes case studies of several multinational corporations. The ethical obligations of companies to share in the solidarity to society are becoming more commonly expressed in the context of CSR, and at UNESCO Bangkok we are undertaking some work on how to measure CSR in alternative ways. The concept of social responsibility is also stressed in the UNESCO Declaration of Bioethics and Human Rights, which is the most recent reaffirmation of rights to health care, food and water, which are human right questions that are hotly debated because they could also pose stricter obligations upon states to provide health care and a minimum quality of life to citizens. The issue also overlaps with the current debates on compulsory licensing of some life-saving medicines for vulnerable groups in Thailand, Brazil and other countries.

There are also two papers on evolution, and climate change. A new project on Ethics of Energy Technologies will be starting at the end of September 2007 in Asia-Pacific with UNESCO and other partners that I hope will join. Environmental ethical obligations of human beings are being increasingly recognized, and thus the circles of moral solidarity that do include not just family, and society but also the environment are important for our shared future. Perhaps the terms "common future" and "shared future" are difficult to grasp given the inequities within our societies and between them, but morally we need to be increasingly reminded of solidarity and equity, and apply these principles to better govern ourselves. All of us in society are making attempts to develop solidarity but there is still ground to make the interactions of professionals, clients, states and companies more ethical.

HUGO Statement on Pharmacogenomics (PGx): Solidarity, Equity and Governance

Reason for Statement

The HUGO Ethics Committee

- Recognising that there have been significant discussions of the ethical issues arising in the application of genetic knowledge¹
 - Recognising that PGx has the potential to maximize therapeutic outcomes and minimize adverse reactions to therapy, and that it is consistent with the traditional goals of public health and medical care to relieve human suffering and save lives.
 - Recognising that the ethical, research and policy issues that need to be considered in PGx include:
 - the ways in which PGx requires a novel focus on families, populations and communities;
 - the impact of 'personalised' medicine on a society;
 - the implications for populations in developing countries, including access to therapies for neglected diseases;
 - the impact of PGx on health care costs and policies worldwide;
 - the significance of PGx for research priorities;
 - the importance of re-evaluation of prior clinical trial data for efficacy among particular genotypes (as in resuscitation of abandoned drugs);
 - the significance of PGx for existing, as opposed to new, drugs;
 - the fear that PGx could reinforce genetic determinism and lead to discrimination against, and stigmatization of, individuals and groups;
- hereby identifies a pressing need to reach consensus on the most important ethical principles that are applicable, and for workable guidelines in clinical and public health settings.

Definitions and scope

There has been extensive discussion of the relative benefits of using the terms pharmacogenomics (PGx) and pharmacogenetics, and various definitions have been suggested. To some extent the terms have been used interchangeably. Although both 'genetics' and 'genomics' are popularly used in different ways in different cultures, and have different meanings in a variety of languages, in this statement we use the term *pharmacogenomics* (PGx) and understand 'PGx' to mean the total sum of genetic variation that affects response to therapeutic agents.

The Committee recognises that principles developed in this Statement on PGx also apply to other therapeutic modalities such as ionising radiation and biologicals, and to variation in response in contexts such as nutrition, environmental exposures and toxicology.

Principles

Past HUGO Ethics Committee Statements have reflected a commitment to the view that the highest ethical priority in implementing genomic knowledge is that of saving life and reducing suffering, but the Committee considers it urgent that the ethical principles of solidarity and equity be given increased attention

- **Solidarity:** Because of shared vulnerabilities, people have common interests and moral responsibilities to each other. Willingness to share information and to participate in research is a praiseworthy contribution to society.
- **Equity:** To reduce health inequalities between different populations, and to work towards equal access to care is an important prerequisite for implementing genomic knowledge for the benefit of society.
 - while also reaffirming the following long-accepted ethical considerations:
 - Respect for human rights
 - Protection of confidentiality and privacy
 - Avoiding harm
 - **Beneficence:** there is an obligation to do good, and to maximise the possible benefits of genomics, which should be regarded as a global public good
 - **Autonomy:** the freedom of persons to make decisions regarding their medical care is fundamental to the modern practice of medicine
 - The authority of communities to participate in decisions that affect them
 - The fundamental relationship between the quality of scientific research and its ethical acceptability

Recommendations

1. Research priorities

- 1.1. There needs to be a careful consideration of research priorities in PGx and translational research for each society and these should not merely be led by economic priorities determined by market forces.
- 1.2. The continuing creation of a sound scientific basis for PGx should be pursued, such as: identification of genetic factors, including genes, haplotypes, SNPs and copy number variants (CNVs) with significant pharmacogenomic effects; identification of interactions with other genetic, environmental and social factors among drugs currently in common use in different countries; meta-analyses for consistency of data; ongoing development of methods for bio-marker analyses that are suitable for large scale studies.
- 1.3. The continuing creation of a sound corpus of research on ethical and legal issues, appropriate governance, social science and policy research, and methods of community and public dialogue and participation.

2. Governance of research

- 2.1. There needs to be appropriate governance at national and international levels of the collection, storage, utilization, sharing, and protection of data and biological specimens.
- 2.2. There is an urgent need for institutions and scientists to apply the principle of open access and sharing of data, consistent with the protection of personal privacy of the persons contributing to the database, in order to maximise benefit.
- 2.3. The establishment of necessary infrastructure, including international initiatives for sharing data between biobanks, should be supported.
- 2.4. There should be support and encouragement by research funding agencies to require and support the sharing of data
- 2.5. HUGO should consider establishing mechanisms for on-going international co-ordination and evaluation of developments in PGx, with special reference to harmonising

¹ The Universal Declaration on Bioethics and Human Rights was unanimously adopted on 19 October 2005 by all member countries of UNESCO. It follows two specific Declarations on ethics of applications of genomics that all member countries of UNESCO have agreed to; the Universal Declaration on the Human Genome and Human Rights (1997), also adopted unanimously by all UN members in 1998, and the International Declaration on Human Genetic Data (2003). In addition there have been many declarations and scholarly articles, and proclamations by agencies and committees of national governments, which provide insight into the theoretical issues and practical applications of ethics to issues raised by genomics, that we draw upon herein.

standards for reliability and replicability of PGx association studies.

2.6. While many institutions have developed governance mechanisms, such as ethics committees, attention should be paid to preparing them to assess appropriately the benefits and risks of PGx protocols.

3. Maximising the benefits of research

3.1. It should be recognised that PGx can be of benefit to communities as well as to individuals, even in the absence of optimal infrastructure/resources

3.2. In order to reduce health inequalities, there is a need both to develop new drugs for people with certain genetic variants, especially in the case of neglected and orphan diseases, and to consider the possibility of resuscitation of abandoned drugs for particular population groups.

4. Participation in research and social responsibility

4.1. All stakeholders in PGx research should exercise their ethical responsibilities in a spirit of equity and solidarity.

4.2. Voluntary participation of members of a community in PGx research provides an opportunity to actualise the principle of solidarity. Researchers have an obligation to engage the community while maintaining the highest standard of research conduct to earn the trust of the community.

4.3. The participation of all stakeholders, including the wider community, in such research requires public and professional dialogue and education in the science and ethics of PGx.

5. Clinical implementation

5.1. The principle of equity implies that therapies should be made equally available to those with equal needs. If this were not the case, the translation of genomic knowledge into clinical practice would aggravate disparities among people.

5.2. Barriers to translation of genomic knowledge into practice should be identified and addressed, e.g., by training of appropriate personnel; by working towards more equitable health care systems, etc.

5.3. An individual's serious side effect, or absence of response, may have important implications for drug treatment of blood relatives. The unit of care with respect to drug treatment may include the family as well as the individual e.g., physicians should be alert to the implications for the relatives of a patient who suffers a serious adverse drug reaction, and should initiate genetic counselling.

5.4. Voluntary sharing of PGx information within families should be encouraged.

6. Monitoring and quality control:

6.1. There needs to be agreement upon a standard set of data to be collected and a common format to facilitate international data sharing.

6.2. Systematic recording of clinical drug reactions to obtain data useful for PGx research should be encouraged.

6.3. Robust mechanisms of quality control need to be in place to minimise the possibility of error in individual PGx testing and maintenance of patient records.

6.4. Regulatory agencies should address the implications of PGx practice on a wide scale, including the possibilities of off-label use and liability issues.

7. Education, training and awareness

7.1. In the light of the rapid growth in PGx knowledge there is an urgent need to increase the level of awareness, education and training in the above issues for all stakeholders, including researchers, clinicians, policy makers, social scientists, patients and publics.

The HUGO Ethics Committee

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 Professor Ishwar Verma (Vice Chair), India
 Professor Zhai Xiaomei, China

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Physician Pharmaceutical Industry Interaction: An Indian Outlook

- Ganesh Athappan, M.D.

Dept of Medicine, Madurai Medical College, Madurai, India

Email : ganeshathappan@gmail.com

Gone are the days of beneficence and non-maleficence in medical practice. The lust for bills has superseded them giving rise to a well organized system of extortion, deception and conflict of interest. Currently drug prescriptions are made neither on the basis of scientific grounds or cost but on the effectiveness of the drug company's marketing and advertising efforts which have increased cost and negative health outcomes. In reality, physicians are often enticed to prescribe and over-prescribe certain medications in return for incentives. Herein I report a typical scenario and discuss the ongoing trends in physician-pharmaceutical industry-patient relationship and possible solutions from the perspective of a developing country like India.

A 40 year old man, a known alcoholic and chain smoker presented with acute abdominal pain for the past eight hours associated with vomiting after a binge of alcohol. The pain was dull aching in nature, radiating to the back, aggravated on lying supine and relieved in intensity on sitting erect. There was no fever, icterus or pedal edema. Examination of other systems was unremarkable but for epigastric tenderness. Investigations revealed a hemoglobin level of 14g/dl, hematocrit of 41 %, a total leukocyte count of 18,000/mm³, blood sugar of 180mg/dl. Serum amylase, LDH and AST levels were 1100, 160 and 41IU/L respectively. Renal function tests, liver function tests, serum electrolytes, ABG and chest radiography were normal. An ultrasound of the abdomen revealed enlarged pancreas with decreased echogenicity and no evidence of obstruction. A diagnosis of acute pancreatitis (AP), Ranson score of 1 was made and patient was treated for the same. The orders were as follows: 1. Nil Per Oral; 2. Injection Tramadol hydrochloride for pain as needed ; 3. Injection cefeperazone /salbactam intravenous 1gram twice daily; 4. Injection Octreotide 0.1 mg subcutaneous twice daily; 5. 0.9% NaCl at the rate of 75 ml/hr.

Octreotide in AP- To use or not to use

Octreotide is a synthetic octapeptide analogue of naturally occurring somatostatin with similar pharmacological effects. Somatostatin and octreotide were suggested for the treatment of acute pancreatitis several decades ago based on their pathophysiological properties of inhibiting exocrine pancreatic secretions, effects on the immune system, RES and modulation of cytokine pathway by which they exert an

organoprotective effect [1]. However none of these physiological effects have translated into significant clinical benefits of any proportion in clinical trials. A few trials that showed beneficial effect had serious limitations in their methodology as well as sample size [1]. The most comprehensive large, placebo controlled trial by the German Swiss group found no benefit of octreotide in acute pancreatitis [1]. The most recent meta analysis did not find any beneficial effect of octreotide either subcutaneous or intravenous in terms of surgical interventions, sepsis, mortality or overall complication rates [2]. The cost effectiveness of octreotide also comes under scrutiny as a standard therapy used in the clinical trials would cost around 10,000 to 20,000 INR. [41 INR = 1 US\$]

Therefore the final verdict goes against the use of octreotide in acute pancreatitis till further evidences surface for its beneficial role both clinically and economically. Despite limitations in the use of octreotide it was initiated, raising doubts. This is a not an isolated incident in itself but one in several million similar questionable practices by physicians under the influence of incentives by pharmaceutical companies.

Physician Pharmaceutical Industry Symbiosis

Pharmaceutical industries play a pivotal role in delivering health care by ferrying new drugs into the market which form the backbone of the medical industry. A decade and a half of research with 5000 to 10,000 unsuccessful molecules and millions of dollars, to the tune of \$839 to \$868 million dollars are pumped into the production of block buster drugs of which only one in five undergoing clinical testing finally make it to the market [3]. This low turnover from molecule conception to market delivery reflects on the slowness of research productivity unpredictability associated with the drug industry. Therefore in order to recoup the expenditure on wasted molecules and still make profits and sustain growth, the pharmaceutical industry resorts to extravagant promotion and advertising targeting doctors who by virtue of their powers to prescribe drugs are the favored targets. The policies adopted by the pharmaceutical firms [4] to influence physicians to diverge from the fiduciary nature of the patient – physician relationship include (a) Offering vacation/travel expenses; (b) Gifts of substantial value; (c) Lavish meals and entertainment; (d) Offering cash/commission for prescribing a particular brand/drug; (e) Offering money for drug trial; (f) Samples and promotional material; and (g) CME funding and honoraria, medical journal ads (h) direct to consumer ads.

Despite substantial evidence to contrary, most physicians deny the influence of pharmaceutical companies on their prescribing practice [5]. A review published in the *JAMA* showed that physicians push drugs when they may not be required and pick a particular drug over another because of the incentives associated with them [5]. Doctors who welcome incentives were found more often than not to hold preferences for new products with no demonstrated benefits, prescribe the sponsor's drug in an irrational and incautious pattern and deny the bias associated [5].

This denial by most physicians can be explained by a "self-serving bias" that is both unintentional and unconscious that skews judgments about what is fair in their own favour unaware that behavior that they feel is fair may be judged otherwise by people not sharing the benefits [6].

Physician patient interaction

Despite a worldwide shift from the ideas of paternalism, which empowered doctors to exert power over their patients, to enhanced autonomy or shared decision making, India remains unmoved. Indian physicians tend to look upon their expertise as undisputed and normative whereas patient ideas are conceived as worthless preformed misconceptions [7]. This to a large extent has been possible because 70% of

Indians live in rural areas or are uneducated patients unwilling or unable to exercise their rights, in fear [8]. This fear is brought by a serious lack of communication on part of the physicians who tend not to talk, explain, or discuss but dominate the entire encounter [8]. There is a serious lack of transparency coupled with lack of consumer redressal systems in the Indian health care system which heightens the already present fear factor among patients. Indian patients thus end up being mere pawns in the hands of doctors.

This dominant role of physicians in the physician patient encounter serves to perk up the physician pharmaceutical industry symbiosis for several reasons. First, the paternalistic approach to patient care allows for indiscriminate use of experimental drugs with no proven benefit by physicians in exchange for incentives provided by pharmaceutical companies as seen in this case. Second, ignorant patients get enrolled into unethical drug trials, not possible in the west, in exchange for lucrative perks to physicians from pharmaceutical companies. Third, pharmaceutical companies successfully dump products banned in the western world like nimesulide into developing countries like India to recoup their costs on these products via their relationship with physicians.

In a win win position for the physician pharmaceutical industry combine, there is an urgent need for regulations to control this evil to restore the trust in our profession and prevent the sinking ship from sinking further.

What needs to be done

Preparing future doctors:

Catch them young . Today's students are tomorrow's doctors. Regulations must thus begin at the grass root levels. The Indian Medical curriculum needs to be revisited and restructured to include:

1. Ethical considerations are of least priority in medical education in India. They need to be incorporated in the core curriculum in medical schools in India in order to prepare tomorrow's doctors to conduct themselves morally with both patients and pharmaceutical industries.

2. Undergraduate training in medical schools must include classes on handling pharmaceutical representatives in line with US medical schools to equip future doctors to handle marketing pressures.

3. Teaching at the undergraduate level must involve such areas as drug auditing which involves safe drug prescribing, prescribing on sound evidence, weighing potential benefits and hazards of treatment. This will prevent doctors from practicing non evidence based medicine as is so commonly done in India.

4. Undergraduates need to be trained to interpret and use statistical packages in order to understand information provided in medical journals. This will help them from being carried away by the biased literature provided by drug companies.

Inclusion of the above in medical school curriculum will help future doctors understand the ethical issues concerned with drug company interactions, counter the promotional strategies of pharmaceutical representatives who most often provide "information packages" where "drug oriented" information is often flawed, biased, or misleading, and pharmacological or molecular effects are exaggerated and handle them in an efficient and professional manner.

Professional bodies:

There is no lack of professional bodies but there is a lack of their effective functioning in delivering health care. Individual specialties and subspecialties should set up working active professional bodies with the aim of maintaining and monitoring the competency of their members, provide training and continuing medical education in use of new devices and drugs. These professional bodies should also lay down guidelines for treatment and ensure that treating physicians adhere to them and provide evidence based

medicine and not pharmaceutical industry driven medical practice.

Appropriate steps need to be taken to provide rigorous and stringent re licensure tests to physicians on a regular basis in order to maintain high standards and competency of health care delivery. At present there is no system of re licensure in India which has led to complacency and inefficient health care delivery.

Policies:

It is rather strange and disappointing that the Indian Medical Council, in its new Code of Ethics Regulation, March 2002, does not have a policy that prohibits doctors from accepting gifts or cash incentives from drug companies while most other countries have taken steps to regulate physician pharmaceutical industry interaction by passing stringent laws [9]. It is high time for the Indian medical council to take similar steps to curb inappropriate relationships between doctors and pharmaceutical companies and set boundaries to this relation. Individual institutions and hospitals must follow US hospitals in implementing rules to check promotional activities by drug companies and gift acceptances in order to maintain the trust and best interest of the patients.

Payment System & Patient doctor working groups:

The need for third party payment system needs to be recognized to provide effective affordable health care delivery and curb doctors from over-prescribing drugs, recommending unnecessary investigations and treatment. In order to protect the best interests of the patients and move away from the paternalistic approach to practicing medicine effective patient empowerment bodies and patient doctor working groups need to be formed. The concept behind them being that the patients' side supports the ideology of doctors acting in patients' best interests when doctors' definitions are the same as patients', but it challenges doctors if interests are in conflict thereby safeguarding the patient's interests [10].

Conclusion

As summed up by George Bernard Shaw, money is "the most important thing in the world: It represents health, strength, honor, generosity, and beauty as conspicuously as the want of it represents illness, weakness, disgrace, meanness, and ugliness. Physicians have given in to its temptations by partnering drug companies and placing self before patients thereby loosing their trust in society. The time has come for us to introspect physician-pharmaceutical industry interaction and regulate the same if we are to regain trust of patients and society.

References

- Greenberg R, Haddad R, Kashtan H, Kaplan O. The effects of somatostatin and octreotide on experimental and human acute pancreatitis. *Journal of Laboratory and Clinical Medicine* 2000 February;135(2): 112-121.
- Heinrich S, Schafer M, Rousson V, Clavien P.A. Evidence based treatment of acute pancreatitis. *Ann Surg.* 2006 February; 243(2): 154-168.
- Adam PC, Brantner VV. Estimating the cost of new drug development : Is it really \$802m? *Health Affairs* 2006 Mar-Apr;25(2):420-8.
- Verma SK. Physician- Pharmaceutical Industry: Changing dimensions and Ethics. *Indian Pediatrics* 2004; 41:29-36.
- Wazana A. Is a gift ever just a gift ? *JAMA.* 2000;283:373-380.
- Rogers WA, Mansfield PR, Braunack-Mayer AJ, Jureidini JN. The ethics of pharmaceutical industry relationships with medical students. *MJA* 2004; 180 (8): 411-414.
- Fochsen G, Deshpande K, Thorson A. Power imbalance and consumerism in the doctor patient relationship: Health Care Providers experiences of patient encounters in a rural district in India . *Qual Health Res* 2006;16:1236-1252
- Kumar S . Seen and not heard. *BMJ.* 2003 June 14; 326(7402): 1295

- McGuaran A . Royal college issues new guidelines on gifts from drug companies. *BMJ.* 2002 September 7; 325(7363): 511.
- Williamson C. The rise of doctor patient working groups. *BMJ.* 1998 November 14; 317(7169): 1374-1377.

What happened to Neanderthals?

- K. K. Verma, Ph.D.

Retd. Professor of Zoology, HIG1/327, Housing Board Colony, Borsi, Durg (C.G.), 491001, India

Email: kkvermain@yahoo.com

- Rashmi Saxena, Ph.D.

Assistant Professor of Zoology, "Sopan", 71 Madhav Vihar, near Govt. Senior Secondary School, Shobhagpura, Udaipur (Raj.), 313001, India

Email: ks_pim@yahoo.co.in

Neanderthals were a distinct species of humans, distinct from the modern man (*Homo sapiens*). They were a cousin to the present day humans. *Homo neanderthalensis* lived in Europe and south-west Asia till about 30,000 years ago, and then disappeared, as is often supposed, due to extinction. But Finlayson et al. (2006) discovered Mousterian tools in a cave in Gibraltar. Such tools are known to have been made by Neanderthals exclusively, and have been named after Le Moustier archaeological site in France. On basis of the nature of deposits, in which the tools had been found in the Gibraltar cave, they were estimated to be 24,000 to 28,000 years old. Hence continued existence of Neanderthals in southern Europe till 28,000 years back has been inferred.

Homo neanderthalensis and *H. sapiens* have descended from an immediate common ancestor, as has been inferred from recent DNA sequencing studies. The time of divergence of the lineage, leading to the Neanderthals, from that leading to the modern humans, has been estimated to be 516,000 years back by Green et al. (2006), and as 706,000 years ago by Noonan et al. (2006). As Dalton (2006b) has pointed out, "Within the large margins of error typical of such analyses, these (two) conclusions could turn out to be the same". Neanderthals evolved in isolation, which has generally been ascribed to the glacial climatic conditions in the Pleistocene in Europe and south-west Asia. (Both Green's team and Noonan's team analyzed Neanderthal DNA from the same source, some well preserved bones, 38,000 years old, discovered in a cave in Croatia.)

How different were the Neanderthals from the modern humans?

Some more obvious characteristics of the Neanderthals, which put them apart from the present species of human, are:

- Cranial capacity was large for a primitive human, about 1400 ml. (In modern humans – 1200 to 1600 ml.)
- Brain case or cranium presented side-way bulging.
- Forehead was markedly receding.
- Prominent and continuous supraorbital ridge.
- Protruding mid-face.
- Powerful mandible, without chin protuberance or prominence.
- Cheek bone sloping posteriorly.
- Curvature of the spine much more poorly expressed than in the modern man.
- Knee joints not fully straightened.

The feature 8 and 9 suggest a clumsy gait and a little forward drooping posture. In general Neanderthals were short statured and stocky in build. As Green et al. (2006) have

pointed out, the Neanderthal characteristics gradually became more marked and distinct in more recent remains.

How did Neanderthals go out of scene?

Two different explanations have been put forth for disappearance of Neanderthals, (i) that they went extinct, and (ii) that they lost their identity through interbreeding with moderns, and became assimilated in the modern human gene pool. The generally held view is that Neanderthals became extinct as they proved the losing side in competition with invading moderns, who were superior competitors, due to their gracile body, better technology, and better developed social network.

Figure 1: Skulls in lateral profile

(a) of a modern man (*Homo sapiens*).
(b) of a Neanderthal (*Homo neanderthalensis*).
(Figure based on Nesturkh, 1967.)

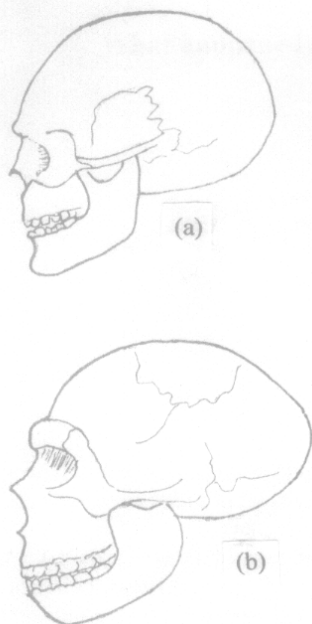
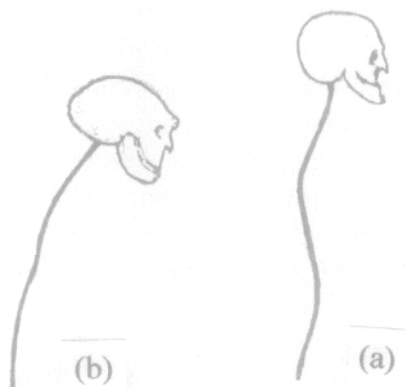


Figure 2: Spine curvature, diagrammatically indicated.

(a) in a modern man, (b) in a Neanderthal.
(Figure based on Nesturkh, 1967.)



Finlayson (2006) has pointed out an alternative view for extinction of Neanderthals: that mostly it has been due to climatic changes. The primitive man could not do well in the glacial climate of the north, and, due to the incoming glacial period, its range contracted to the southern parts, extending north during interglacial period. This happened because the size, shape and proportions of the Neanderthal body did not give it any thermoregulatory advantage. When steppe conditions crept in and it became colder, they suffered from

several disadvantages, as "Neanderthal locomotion was energetically costly...and thus unsuited for open environment. Cultural responses were insufficient to deal with the encroaching steppe when climate cooled....However, the gracile morphology of the modern humans, linked to endurance running in the open environments...enabled (them for).. exploitation of the mammoth steppe...."

Goebel (2007) has said that delayed spread of modern humans in north-west was due to "more time for adaptation to cope with colder temperatures, drier climates, and – most challenging of all - Neanderthals". Thus changing climate as well as competition with moderns seem to have led to extinction of Neanderthals.

Now let us discuss the other view, that the Neanderthals interbred with moderns. Some facts support this view:

1. As per our present knowledge Neanderthals survived in southern Europe and southwest Asia till about 28,000 years back, and the moderns appeared in these parts about 40,000 years ago. Hence the two lived contemporarily for more than 10,000 years. In view of this some interaction between them, including some interbreeding, was likely.
2. After their arrival in Europe/South-West Asia the moderns might have occupied the same regions. Dalton (2006a) points out, "In some Jonzac sediments dated to about 36,000 years ago, tools from the Mousterian and Aurignacian lie close together." (Mousterian tools are regarded as exclusively made by Neanderthals, Aurignacian artefacts are taken as left behind by early moderns.) This again points to the possibility of some interaction between Neanderthals and early moderns.
3. Remains of Lagar Velho child show features somewhat intermediate between those of Neanderthals and moderns, and, therefore suggesting that it was a Neanderthal-moderns hybrid. The remains have been dated as 24,500 years old. Now, with Finlayson et al. (2006) demonstrating that Neanderthals lived up to 28,000 years ago, such a hybridization looks chronologically feasible. But the juvenile features of the Lagar Velho remains make it difficult to visualize what the adult features would be.
4. Green et al. (2006), on basis of their sequencing study of Neanderthal DNA, have inferred some limited interbreeding with moderns. They have said, "However, both morphological evidence and the variation in the modern human gene pool support the conclusion that if any genetic contribution of Neanderthals to modern human occurred, it was of limited magnitude."
5. Trinkaus (2007) has pointed out that certain morphological features of early modern European humans indicate a modest level of interbreeding with Neanderthals.

Concluding remarks

In the present state of knowledge the following may be inferred:

1. That Neanderthals evolved by allopatric speciation in isolation, and survived till about 28,000 years ago.
2. That they became extinct due to climatic changes and also due to competition with invading modern humans.
3. That limited interbreeding between Neanderthals and moderns might have taken place.

As Dalton (2006b) has pointed out, we need studies on more DNA material from Neanderthal remains to get a clearer picture of their history and plight.

References

- Dalton, R., 2006a. Decoding our cousins. *Nature* 442 (20th July 2006): 238 – 240.
- Dalton, R., 2006b. Neanderthal genome sees first light. *Nature* 444 (16th Nov. 2006): 254.
- Finlayson, C., 2005. Biogeography and evolution of the genus *Homo*. *TREE online* (doi:10.1016/j.tree.2005.05.019).
- Finlayson, G., Allue, E., Preyster, J.B., Caceres, I., Carrion, J.S., Jaluo, Y.F., Gleed-Owen, C.P., Espejo, F.J.J., Lopez, P., Saez,

- J.A.L., Cantal, J.A.R., Marco, A.S., Guzman, F.G., Brown, K., Fuentes, N., Valarino, C.A., Villalpando, A., Stringer, C.B., Ruiz, F.M., and Sakamoto, T., 2006. Late survival of Neanderthals at the southernmost extreme of Europe. *Nature online* (doi: 10.1038/nature 05195).
- Green, R.E., Krause, J., Ptak, S.E., Briggs, A.W., Ronan, M.T., Simons, J.F., Du, L., Egholm, M., Rothberg, J.M., Paunovic, M., and Paabo, S., 2006. Analysis of one million base pairs of Neanderthal DNA. *Nature online* (doi: 10.1038/nature 05336) (printed version: *Nature*, 444: 330 – 336).
- Goebel, T., 2007. The missing years for modern humans. *Science* 315: 194 – 196.
- Nesturkh, M., 1967. *The Origin of Man*. Progress Publishers, Moscow.
- Noonan, J.P., Coop, G., Kudaravalli, S., Smith, D., Krause, J., Chen, F., Platt, D., Paabo, S., Pritchard, J.K., and Rubin, E.M., 2006. Sequencing and analysis of Neanderthal genomic DNA. *Science* 314 (17th Nov. 2006): 1113 – 1118.
- Trinkaus, E., 2007. European early modern humans and the fate of the Neanderthals. *PNAS online* (doi: 10.1073/pnas.0702214104)

Bioethics and Climate Change: Systems Theory and Future Health Challenges

- Arthur Saniotis
Discipline of Anthropology, School of Social Sciences
The University of Adelaide, Australia
Email: saniotis@yahoo.co.uk

Introduction

In this paper I will examine systems theory in relation to global warming and climate change. The use of systems theory has been significant in the last twenty five years due mainly to the efforts of thinkers such as Ervin Laszlo and Fritjof Capra. Both Laszlo and Capra have given an alternate discourse on ecology which encourages a change in our attitudes towards nature. Their insights also support the view for the creation of evolutionary societies based on solidarity between human beings and the non-human world (Laszlo 1994:60). Their ideas offer a source of knowledge for co-evolving with nature and for dealing with oncoming climate change and its subsequent health impacts on human beings.

Present studies into global warming and climate change have predominantly come from climatologists and public health scientists. The former have diagnosed global warming via climate models which predict various scenarios. However, climatologists do not share a consensus on the extent of global warming. Indeed, a degree of non-consensus exists. For example, 2006 climate reports of the glaciers of Mount Kilimanjaro in Kenya hypothesised its extinction in twenty years. This theory has been rejected. Present estimations suggest that the glacier will evaporate by mid century. Alternately, public health analyses into global warming and its health impacts on human populations have been more forthright. Noted studies done by Ebi et al (2005), Kovats et al (2005; 2006), McMichael et al (2001; 2003), Patz et al (2005), Desai (2003), have examined heat stresses and vector borne diseases as a consequence of climate change. Public health studies have also been concerned with adaptation strategies in mitigating foreseeable health problems to human populations. From a bioethical viewpoint, human population health is at much risk by both climate change and the unequal distribution of material and social resources between nations which disadvantage poorer nations. Saniotis (2006) cites that that adverse climate change will hamper the ability of developing nations to

implement mitigating strategies. The demographic 'rankism' evident in the North/South divide is likely to be exacerbated by climate change. This view is shared by Selgelid who notes: "The fact that those who are worse-off in virtue of their poverty thus have their misfortunes compounded – as they are more likely to fall victim to disease – will strike most of them as an injustice in itself" (2005:280).

At present, many developing countries are being ravaged by the three interlinking epidemics of HIV/AIDS, Tuberculosis and Malaria. 2006 estimations of people living with HIV in 2006 was over 39 million, while malaria infects over 500 million people per year. These figures are predicted to increase due to poor access to education, employment, and living conditions. Other tropical diseases known as 'orphan' diseases such as Lymphatic Filariasis, Chagas disease, Schistosomiasis, African Trypanosomiasis, Leishmaniasis, Dengue, Onchocerciasis, Trachoma, and Leprosy also affect large populations in developing countries. The ethical dilemma here is that these diseases are not considered high priority, although, they threaten over one billion people. They, therefore, receive less funding in combating them. Climatological studies seem to indicate that the burden of these diseases may increase due to changes in seasonal rainfall, ecosystems, ecological degradation (contamination of fresh water systems and deforestation), and increasing vector spread (Woodruff 2005:109). While it is presumed that developing countries will create adaptational strategies and public health responses for preventing disease outbreaks this will not be emulated for most of the developing countries which are inadequately resourced. Studies done by Cattand et al (2006) indicate the profound adverse social and economic impacts of tropical diseases to human populations. In countries like Cambodia, expenditures in treating Dengue for a family member may "lead to debt and poverty" (Cattand et al 2006:455), while African Trypanosomiasis can burden communities by diminishing the labour force and "interrupting agricultural activities", thereby "jeopardising food security" (Cattand et al 2006:456). The lack of adequate treatment for African Trypanosomiasis, Dengue, and Leishmaniasis is exacerbated by the uses of antiquated and toxic drugs (Cattand et al 2006:463). Notwithstanding the toxicological problems of drug therapies for these diseases, new generation drugs will take at least another decade to emerge. Such drugs do not take into account for the change in vector distribution of these diseases in the next fifty years where new epidemics may emerge.

Adaptation Responses to Future Climate Change: Systems Theory

One of the major concerns emerging from climate change is its potential to cause widespread civil and social disruption. Increasing world population (mainly in the developing world), loss of agricultural land due to soil erosion, diminishing freshwater, deforestation, and encroaching seas along global coastlines may cause massive social dislocation which will adversely impact on global capitalist systems. This will have grievous effects on international public health systems since surveillance and monitoring of massive population movement will be impossible. Street et al note that global health security requires adequate surveillance of populations (2006:210). Future forced migration of refugees as a consequence of climate change and natural disasters may compromise international capacity to adequately respond. Current IHR (international health regulations), last revised in 1981, lack collaborative mechanisms while WHO requires more "specific measures to prevent international spread of disease" (Street et al 2006:211). The present fear of Avian flu and its possible threat to bird and mammal populations manifests the inadequacy of international health systems. This was certainly the case in the United Kingdom during the 1990's with 'Mad Cow Disease' (Bovine

Spongiform Encephalopathy), and its human equivalent Creutzfeldt-Jakob disease. Having been recognised in cattle in 1985, it led to the culling of 50% of the United Kingdom's cattle population, media hysteria, and plummeting beef sales (Murphy 1996; Darnton 1996). The emergence of BSE was vehicled by feeding cattle with sheep and cow offal as protein supplements designed to increase meat and milk production. This practice was not exclusive to the United Kingdom alone. In 1989, the US fed approximately 800 million pounds of animal remains to US cattle and cows (Stauber 1996). "Of the ruminant protein available in the US, it is estimated that 13 percent is fed back to cattle, 34 percent goes into swine diets, 34 percent goes into pet food, 17 percent into poultry diets and 2 percent falls into a miscellaneous category" (Stauber 1996). These practices indicated a disturbing negligence for safety concerns without consideration of long term implications of feeding herbivores with animal remains. The point here is that such a lapse to understand nature's principles in favour of improved economics is also evident in current human responses to anthropogenic climate change. The US and Australia's failure to become signatories to the Kyoto treaty to diminish carbon emissions characterises the sovereignty of economics over environmental issues.

Systems Theory

At this point, I would propose the incorporation of a systems approach to adaptation strategies for challenging climate change. The basis of systems theory as elucidated by Laszlo (1972, 1994, 1996) and Capra (1997, 2002) views living systems as being integrated and inter-dependent. Furthermore, living systems are autopoietic, that is, they are autonomous, self organised, self regulating, and emergent. Living systems are sustained by co-operative networking that enables them to increase in complexity and feedback mechanisms. Systems theory also considers that mind is not an object but rather a process which is immanent in all organic and social systems (Bateson 2002; Maturana & Varela 1980). Biological and social systems are based on co-operative relationships, or what Maturana and Varela call 'linguaging.' Linguaging is one of the crucial determinants in forming intense consciousness in human beings. In this way, human beings have a penchant towards creative communication involving complex networking and linguistic variation. The 'semantic domain' is emergent of mind (Capra 1997).

According to Capra (1997:289), systems theory enables us to foster 'ecological literacy.' Understanding ecology means comprehending how living and social systems are posited on inter-dependent and co-operating networks. As Capra states, "the basic pattern of life is a network pattern" (1997:290). Thus, when systems theory is shifted to understanding human social systems such a model can be useful in delineating how social systems are constituted, and to what extent they can be improved. In relation to climate change systems theory foregrounds the development of proactive networks by human beings at local, regional, national, and international levels. Moreover, different cultural models are important since they offer "different approaches to the same problem" (Capra 1997:95). Capra points out that cultural diversity can be advantageous in adopting adaptational strategies when social members view each other as being inter-dependent which fosters network integrity, flexibility, and sustainability (1997:295).

Systems Theory and Climate Change

A systems approach to challenging climate change is multi-valent. Living and social systems are based on five criteria for sustainability: "interdependence, recycling, partnership, flexibility, and diversity" (Capra 1997:295). Compromise to any of these components threatens the integrity of living and social systems. The fact that climate change has the capacity for adversely affecting social

systems needs addressing. For example, the devastation caused by Hurricane Katrina (category 5 hurricane) in 2005 exposed to what extent the United States was ill equipped for dealing with a kind of natural disaster which may be repeated in the future. The failure of various national organisations to marshal adequate public safety and health procedures to many New Orleans residents was a much publicised fault. In this case, adaptation measures were needed to be modified in order to ensure a more viable integration of public health services that would reduce adverse health risk (Sharpe 2005:260). However, the lack of co-ordination which faced Mississippi and national United States public health services is a problem facing many developed nations. Sharpe comments that more adequate networking and collaboration is needed in public health sectors "in order to modify its policies and practices" in other areas of "risk management processes" (2005:258). Street et al (2005:182), aver that human communities' vulnerability to natural disasters are:

1. Lack of social and material resources (i.e. protective technologies).
2. Lack of access to health services – information.
3. Exposure to hazards.
4. Reduced capacity to cope and recover.

Importantly, these four factors need addressing since a critical threshold of these may lead to social chaos. In systems theory, the idea of convergence emerges when an open system (third state system) reaches a critical threshold where it can either creatively adapt or de-evolve (Laszlo 1987). In the former, convergence is generated by modifications in interaction between individuals or between collectivities which increase co-operation (Laszlo 1987:91). Any modification is a creative response to a particular disturbance that has the potential for convergence (Capra 2002:108). A systems approach to improving adaptational strategies in the public health sector in response to climate change could include:

1. Development of advanced early warning systems, improved monitoring and surveillance methods and risk assessment (Street et al 2005:183).
2. Greater collaboration between social sectors and health systems (Street et al 2005:183), and the creation of grass-roots public health groups.
3. Improved communication across board, particularly amongst minority and socially disadvantaged groups.
4. Increasing research that would inform climate change policy (Street et al 2005:183).
5. Improving infrastructural development (i.e. improved sanitation practices, public transport systems) (Street et al 2005:183).
6. More cost effective and energy efficient housing and buildings and amenities (i.e. greater use of solar panels). In the developing world this could include using more traditional kinds of housing which are energy efficient and less polluting.
7. Developing programs which address immediate and long term health impacts due to climate change. These would include identification of issues, evaluation, and understanding the specific vulnerabilities to communities across the globe. This means implementing a non-blanket approach.
8. The widespread use of Insecticide-Treated Nets (ITNs) and indoor residual spraying to provide protection against vector borne diseases (Brenman et al 2006:421). ITN programs in Tanzania (Abdulla et al 2001; Armstrong-Schellenberg et al 2001), China (Tang 2000), and Vietnam (Hung et al 2000), have made a decisive impact against vector transmission.
9. The widespread use of solar water disinfection in areas of compromised fresh water quality. This method is particularly useful in rural and remote areas; requires no medical knowledge and is efficacious in reduction of diarrhoea episodes by 35%, and Cholera reduction by 88% (EAWAG 2007). This method will be increasingly useful due

to diminishing and contamination of freshwater sources in both the developed and the developing world.

10. Initiatives towards stabilising resource consumption in developing countries (Rowley & Holmberg 1992:338).

11. Integrating resource management and consumption with population planning (Rowley & Holmberg 1992:338)

Conclusion

For Paul Ehrlich (2000:317), our experience of the environment is an emergent property of the "complex interaction" between nature and our psycho-physical organization and cultural programming. He goes on to state that the rise of environmental ethics can be considered as a powerful bulwark against anthropocentric ethics (Ehrlich 2000:317). Certainly, the growing ecological movement in the West and increasing awareness of the global crisis surmounts to what systems theory calls a creative convergence in which human ingenuity is informing its own evolution as well as the evolution of the planet.

Human assault on biodiversity is unprecedented in the last sixty-five million years. In addition, human movement towards urbanised cultures in the last six thousand years has propelled the human species on a collision course with the natural world. The size of the current human population combined with its environmentally unsound practices is unsustainable. Anthropogenic climate change is symptomatic of our mismanagement of the earth. The need for ecological reparation is also an ethical issue since the basis of our environmental mismanagement has been informed by ethical and religious systems which privilege the human species over the non-human world. This can not be over emphasised. Changes in our cultural attitudes and values, albeit difficult, are crucial in order to advance genuine ecological reparation. However, according to Gorke (2003:328), we have been unable to view our actions as being a part of a collective of ecologically degrading actions. Political and economic measures must be implemented in order to support individual responsibility (Gorke 2003:329). Wendell Berry notes that individuals' use of proxies in the form of governments and corporations in developed countries which provide their consumptive lifestyles must be supplanted by individual economic responsibility (Berry 2002:200). For Berry the current "environmental crisis" is also a human moral crisis (2002:200).

I have suggested that increasing levels of co-operation at every level can provide environmental improvements and increased quality of life. Many examples of integrated environmental development projects have been successful in developing countries and provide poignant examples of the benefits of systems thinking in ecological management. In India, women from 3000 villages developed a program which resulted in improved sanitation, literacy levels, health, and environmental stewardship (Rowley & Holmberg 1992:331). Raised environmental awareness is depicted in the spread of chicken farms, smokeless stoves, and biogas units, as well as villages becoming re-vitalised with new knowledge and vigour (Datta 1991; Rowley & Holmberg 1992:332).

I have argued that the use of systems theory in relation to global warming and climate change may prove beneficial in understanding the requisite strategies which will need developing this century. Emphasis must be placed on efforts towards changes in consumer ethics, use of "environmentally benign technologies", population control, and economic incentives for environmental management (Rowley & Holmberg 1998:344).

References

Abdulla, S., Armstrong-Schellenberg, J. R., et al 2001. "Impact on Malaria Morbidity of a Programme Supplying Insecticide Treated Nets in Children Age Under Two Years in Tanzania Community Cross-Sectional Study." *British Medical Journal* 322: 270-273.

Armstrong-Schellenberg, J. R., Abdulla, S., et al. 2004. "Effect of Large-Scale Social Marketing of Insecticide-Treated Nets on Child Survival in Rural Tanzania." *Lancet* 357:1241-1247

Bateson, G. 2002. *Mind and Nature: A Necessary Unity*. Cresskill, New Jersey: Hampton Press.

Berry, W. 2002. "The Idea of a Local Economy." In Stephen R. Kellert & Timothy J. Farnham (eds.), *The Good in Nature and Humanity: Connecting Science, Religion, Spirituality with the Natural World*. Washington: Island Press. Pp. 199-211.

Brenman, J. G. et al. 2006. "Conquering Malaria." *Disease Control Priorities in Developing Countries (2nd Edition)*, ed. New York: Oxford University Press. Pp. 413-432.

Capra, F. *The Web of Life: A New Synthesis of Mind and Matter*. London: Harper Collins.

Capra, F. 2002. *The Hidden Connections: A Science for Sustainable Living*. New York: Anchor Books.

Cattand, P., Desjeux, P., et al. 2006. "Tropical diseases Lacking Adequate control Measures: Dengue, Leishmaniasis, and African Trypanosomiasis." In *Disease Control Priorities Project*. Washington DC: The International Bank for Reconstruction and Development / The World Bank. Pp. 451-466.

Darnton, J. "For the Tories, a Prime Disaster." *New York Times*, March 27, 1996.

Datta, B. 1991. "Focussing on Women in Karnataka." *People* (IPPF. London), 18: 2.

Dessai S. 2003. "Heat Stress and Mortality in Lisbon: An Assessment of the Potential Impact of Climate Change." *International Journal of Biometeorology* 48: 37-44.

Ehrlich, P. R. 2000. *Human Natures: Genes, Cultures, and the Human Project*. Washington D.C. & Covelo, California: Island Press.

EAWAG (The Swiss Federal Institute for Environmental Science and Technology) Aquatic Research April 24, 2007. Sodis solar water disinfection <http://www.sodis.ch/>

Gorke, M. 2003. *The Death of Our Planet's Species: A Challenge to Ecology and Ethics*. Washington: Island Press.

Hung, I. Q., Vries, P. J., et al. 2000. "Control of Malaria: A Successful Experience from Vietnam." *Bulletin of the World Health Organization* 80 (8): 660-666.

Kovats, R. S., Haines, A. 2005. Global Climate Change and Health: Recent Findings and Future Steps." *Canadian Medical Association Journal* February 15, 2005; 172 (4). <http://www.cmaj.ca/cgi/content/full/172/4/501>

Kovats, R. S., Ebi K. 2006. "Heatwaves and Public Health in Europe." *European Journal of Public Health* 16: 592-99.

Laszlo, E. 1972. *The Systems View of the World : The Natural Philosophy of the New Developments in the Sciences*. New York : G. Braziller.

Laszlo, E. 1987. *Evolution: The Grand Synthesis*. Boston: New Science Library.

Laszlo, E. 1994. *Vision 2020: Reordering Chaos for Global Survival*. New York: Gordon & Breach.

Laszlo, E. 1996. *Changing Visions: Human Cognitive Maps: Past, Present and Future*. London: Adamantine Press.

Mad Cow Disease: The BSE Epidemic in Great Britain. 1996. An Interview with [Dr. Frederick A. Murphy](http://www.accessexcellence.org/WN/NM/madcow96.html). <http://www.accessexcellence.org/WN/NM/madcow96.html>

Maturana, H., Varela, F. 1980. *Autopoiesis And Cognition*. Dordrecht, Holand: D. Reidel.

McMichael A. J., Githeko, A. 2001. "Human Health. Climate Change 2001: Impacts, adaptation and Vulnerability." *Third Assessment Report of Intergovernmental Panel on Climate Change*. J. J. McCarthy, O. F. Canziani & NA Leary, et al. (eds.), Cambridge University Press: Cambridge. Pp. 451-85.

McMichael A. J., Woodruff, R. E., Whetton, P. et al. 2003. *Human Health and Climate Change in Oceania: A Risk Assessment*. Canberra, Australia: Commonwealth Department of Health and Ageing. p.116.

Patz, J.A., Campbell-Lendrum, D., Holloway, T., Foley, J.A. 2005. "Impact of Regional Climate Change on Human Health." *Nature* 438: 310-317.

Rowley, J., Holmberg, J. 1992. "Living in a Sustainable World." In Johan Holmberg (ed.), *Policies for a Small Planet: From the International Institute for Environment and Development*. London: Earthscan Publications. Pp. 321-346.

Saniotis, A. 2006. "Ambiguous Futures: Global Warming and the Third World." *Journal of Futures Studies* 11 (2):15-34.

Selgelid, M. 2005. "Ethics and Infectious Disease." *Bioethics* 19 (1):272-289.

- Sharpe, M. 2005. "International public health policy case study." In Kristie L. Ebi, Joel B. Smith and Ian Burton (eds.), *Integration of Public Health with Adaptation to Climate Change: Lessons to be Learned and New Directions*. London: Taylor & Francis. Pp. 258-269.
- Street, R., Maarouf, A., Jones-Otazo, H. 2006. "Extreme Weather and Climate Events — Implications for Public Health." In Kristie L. Ebi, Joel B. Smith and Ian Burton (eds.), *Integration of Public Health with Adaptation to Climate Change: Lessons to be Learned and New Directions*. London: Taylor & Francis. Pp. 161-190.
- Tang, L. 2000. "Progress in Malaria Control in China." *Chinese Medical Journal* 113 (1): 89-92.
- Woodruff, R. E. 2005. "Epidemic Early Warning Systems: Ross River Virus Disease in Australia." In Kristie L. Ebi, Joel B. Smith and Ian Burton (eds.), *Integration of Public Health with Adaptation to Climate Change: Lessons to be Learned and New Directions*. London: Taylor & Francis. Pp. 91-113.
- 1991 USDA report "BSE Rendering Policy" cited in John Stauber, "Apocalypse Cow," PR Watch, First Quarter 1996 3 (1).

Life Beyond the Genetic Blueprint

- Ann Boyd and Denise Hise

Biology Department, Hood College, 401 Rosemont Ave,
Frederick MD 21701, USA

Correspondence to Prof. Boyd, Email: boyd@hood.edu

Introduction

E.B. White's children's classic, *Trumpet of the Swan*, offers a touching fantasy of a young trumpeter swan, Louis, who unlike his siblings is born without the ability to trumpet. Lacking this natural ability, Louis will never be able to attract a mate and live a complete life [1]. Recognizing this reality, his parents intervened. His father flew into a nearby town and stole a trumpet, which Louis learned to play, and thereby earned not only a living but also his mate's heart. Stealing the trumpet compromised the integrity of Louis' father and Louis made restitution by paying the debt for the instrument. The substitution of an instrument for the natural call of the trumpeter swan is of course what charms the reader – while one is left to ponder how many substitutes for natural abilities might lie in the hidden storehouse of genetic knowledge.

Hailed as the biological age, the twenty-first century offers through the Human Genome Project the blueprint of the human being. A map of every gene, the relationship between genetic sequence and disease is an alluring storehouse of knowledge. Unfortunately the DNA sequence does not encode moral wisdom in how to use the information. In a world of instant gratification we hope the promises of science are true, that doctors will fix that which is broken in our lives and modern medicine will give us disease-free existence for a full century. No longer resolving to simply age gracefully, our aversion to impermanence drives us to the pharmacist or plastic surgeon. We know having children is now more choice than chance as in vitro fertilization (IVF) coupled with preimplantation genetic diagnosis (PGD) allow us to ignore the biological clock and reproduce on our chosen timeline, selecting the embryo with the more attractive traits, free of any compromising abnormalities. We look forward to the not too distant future when genomic knowledge will empower us to eliminate heritable disease one embryo at a time and various intervention therapies will correct whatever we miss. It's only a matter of time and money we're told, until the privileged may come with high hopes to this new field of dreams.

But is the free market the only counsel we should seek? Where's the dialogue, the oversight, the restraint? Are we equipped to make such decisions and do we have the right to determine who among us is entitled to life? The need of a paradigm for universal discussion and respectful dialogue

among people in order to extract wise guidance on how to use this new genomic information could not be more urgent. The United Nations' Educational, Scientific, and Cultural Organization (UNESCO) 1997 Declaration on the Human Genome and Human Rights uses the language of respect for persons, beneficence and justice in offering guidelines for dialogue about genetic knowledge and its putative applications. The declaration is a good start in framing ethical considerations in ways persons and nations could find useful. Protecting individual rights as a function of government will likely be interpreted in diverse ways within and among nations. If individual choice is paramount without consideration of the common good of humanity and the ecosystem, we risk allowing autonomy to trump justice. The policies and legislative process should be sensitive to individual autonomy and collective justice.

Coveting Trumpets

Given the chance, it can be presumed, science eventually will decipher the genomic code and it will be left to us to decide if we will restrict application of genetic discoveries to particular diseases and traits or use the knowledge to satisfy our most frivolous whims through physical enhancement or improvement. There will always be some level of ignorance and chance remaining, so we will never rid our species of all its ills and some of our actions may well do more harm than good. Humankind has been endowed through evolution over millions of years with a fabulous wealth of features suited to our continued survival and in the face of such decisions involving unquantifiable risks and illusory benefits, we should question our ability to better that. Historically, we have not always shown ourselves to be the most prudent of decision makers, often pursuing superficial objectives over substantive ones. We are frequently shortsighted, intolerant and resistant to change – unless of course it promises immediate gratification. Yet we purport to be on the whole good, mostly rational, and at times even creative. Perhaps a short review of our track record at attempting to 'improve' purebred dogs can illuminate our path or give us pause.

The prestige associated with possessing a prize-winning purebred dog has led to the selective breeding of animals with specific traits that conform to narrowly-defined standards of perfection. Seeking to perfect characteristics may bring home the blue ribbon today but are subject to change tomorrow and are not always good for the future well-being of the breed. While strength, skill and intelligence were once considered important, physical appearance now is paramount and breeders have obliged by fostering the reproduction of attractive but unhealthy animals. [2] More wrinkles on a Shar-Peis may increase the price on his head but at the cost of congenital skin disorders for his kin. The emphasis on long noses and closely set eyes in Collies may be contributing to the retinal disease that plagues these purebreds. [2] Sloping hips on a German Shepard may catch the judge's eye but compromise the skeletal health of the breed. After many generations of selective breeding, some of these animals have trouble even walking and breathing. Our frivolous goals have compromised the overall health of purebred animals, leaving "selective" breeds suffering from heritable disorders of unknown cause or cure while the innocent motive was merely improvement.

Breeding for a particular trait requires mating between animals that share the trait; oftentimes, this is achieved through inbreeding. As in any animal, inbreeding risks a reduction of genetic diversity and fitness. Loss of heterozygosity can mean sacrificing untold genetic advantages since one functional copy of a gene is often protective and knowledge of the function of many specific genes is yet to be obtained. Breeding in loss of genetic variability merely to satisfy human desires may lead to unanticipated harm and therefore to act without knowing the

consequences seems irresponsible at best. Introducing and perpetuating genetic defects for purely self-serving motivations is unconscionable. If applied responsibly, however, the power of such selection could also be used for good. Excluding affected animals from breeding programs could potentially control known diseases and overall breed health could be rapidly improved in this manner, especially if some degree of certainty could be obtained concerning unintended consequences of particular genetic interventions. But there is no certainty in life. As genomic information becomes increasingly available, the ability to eliminate whole groups of deleterious genes from a population brings with it the possibility of great good or great harm and care must be taken to ensure that such information will be applied knowledgeably and ethically. [3] The question is where to draw the line between enhancement that is beneficial vs. the putative unknown harm associated with the intended improvement. (Another question is what happened to the time when dogs were valued most for their companionship and what really mattered was whether or not it was a "good dog".)

While inbreeding of human beings for purposes of enhancement is not a consideration, the possibility that an individual could one day decide to genetically endow the embryo seems a plausible option in a market-driven environment lacking stringent regulatory guidelines. Cynics of the new genetic data may imagine parents choosing the genetic profile of their offspring: eye color, height, IQ, but real consideration is being given to the eradication of birth defects, disabilities, mental illness, any and all heritable diseases and their attendant societal burden. Why not then insert or delete a gene or two to make us all ultra-intelligent, disease resistant, living indefinitely with a retractable third arm – weightless of course? Too cynical you say? Exaggerating the possibilities without any insight into the reality of genetic medicine? We came of age in a world where the first test tube baby was born and life-saving organ transplants became commonplace. Today our children and grandchildren are learning that IVF is where babies come from and that in the face of overwhelming demand, scientists are attempting to grow organs for transplant in Petri dishes! Nothing has deterred us from cosmetic surgery, gastric bypass, liposuction, implants or transplants if they offered a better life and we could afford them, and that is the reality of our young people. What will motivate them to deny their children future beneficial offerings? Thoughts of genetic selection and enhancement may wake you up in a cold sweat, but in a market-driven economy where the seemingly bizarre and futuristic come to life with regularity and nothing seems impossible, they may not be as far-fetched as at first they seem. (Juxtapose this scenario with the sobering realization that while we deliberate over our children's eye color, much of the world is denied basic medical care and you won't get to sleep at all.)

But are we so simple to genetically manipulate and predict? Will we allow our science to continue to imitate our science fiction or will we begin to appreciate the limitations of science, the delicate balance of nature, and the power science offers us to destroy that balance?

Limitations, Balance and Power

Access to enhancement and selection of superficial physical characteristics, it can be presumed, will be limited enough to make them the very least of our concerns for now. (Guess that third arm will have to wait.) But eliminating disabilities and heritable disorders usually place high on the list of reasons given for pursuing genetic screening and intervention. Perhaps all of us good, rational people will agree on a modest list of genetic diseases that ought to be targeted for elimination. However, not all agree that an anencephalic newborn or a fertilized embryo held in reserve during treatments for infertility ought simply to be discarded;

therefore it is likely that not everyone will agree on which genetic traits ought to be priorities for negative selection. The most likely candidates initially would be early onset, dominant conditions that cause unrelenting suffering and early death, but others such as mental illness, alcoholism and substance-use disorders with genetic underpinnings have also been suggested as targets in light of the medical burden they place on society. Clearly, the specific diseases and conditions we would vote to eradicate would vary according to our experience and our perspective, but that is just one of the many reasons we should carefully consider this course of action.

Science is an ever-expanding spiral of knowledge where new theories continually refine or replace long-held beliefs. The central dogma describing genetic information transfer from DNA to protein, once the keystone of molecular biology, is now believed to be an oversimplification as mounting evidence has revealed a much more complex scenario. Rather than one gene expressing one protein, most genes can be alternatively spliced to produce a number of proteins and each gene is regulated in a variety of ways so its expression can be precisely controlled. Identifying disease genes can be an arduous process even for Mendelian traits and in many cases our knowledge is still too limited to accurately predict the gene underlying a disease phenotype. [4] Many common diseases involve multiple mutations or gene interactions. Different mutations have been found to produce the same phenotype while the same mutation can result in phenotypically variable effects. Additionally, social and environmental factors frequently contribute to clinical variability of disease, at times even determining the probability of disease onset.

Genetic differences must exist between individuals in order for natural selection to result in evolutionary change. Artificial selection through genetic screening or intervention could eventually compromise our diversity and thus diminish our responsiveness to environmental challenges. Most genetic defects are autosomal recessive traits and natural selection is believed to maintain these mutant DNA sequences in populations. Different relative fitness levels of heterozygotes compared to either of the homozygotic genotypes in particular environments may suggest that genetic variation is maintained in populations for purposes related to survival. Seemingly defective genes can confer advantages we may only become aware of in particular circumstances. To rid the human gene pool of such mutant sequences could upset the fragile balance of which we remain largely unaware. The evolutionary advantage of increased resistance to malarial infection bestowed by the sickle cell trait is not likely to stand alone and comparable advantage may be imparted in many instances, although the intricacies of gene action have not yet been unraveled. The advantage for cystic fibrosis heterozygotes for instance is theorized to be resistance to dehydration effects of diarrhea and heterozygote advantage at HLA class I loci has been demonstrated for some infectious diseases such as hepatitis B and HIV. [5]

We are often mistaken in our perceptions and we are responsible for the deep human sorrow we cause. Our ignorance and fear prejudice us against that which is different and make us intolerant of it. For example, we have always had a difficult time understanding mental illness, so we may justify our decision to eliminate it altogether, citing severe and unrelenting suffering of the afflicted. By the same token, we may choose early intervention when we see that extra copy of chromosome 21 to eliminate even the chance of Down's syndrome because the mere presence of that chromosome cannot tell us how mild or severe the retardation effects will be. We may choose to select against the embryo with any one of a thousand different mutations that can cause cystic fibrosis in the one allele, cystic fibrosis transmembrane

regulator (CFTR) although, again, the precise form of the manifestation cannot be predicted. We may decide lives that will almost certainly be interrupted by late onset diseases like Huntington's aren't worth beginning. The haunting questions that arise: Who decides what quality of life is worth living? Who counts as a person? What constitutes societal burden and at what point does that outweigh personal autonomy?

That which is considered normal or acceptable by society's judges is subject to interpretation and change. Temperaments or behaviors may be better tolerated within certain environments or at particular times, as is the case with bipolar individuals in artistic or literary circles where inherent creativity is paramount. [6] Additionally, not so very long ago, left-handedness was considered 'wrong' and children were forcibly taught to use the right hand. In today's world, this is no longer an issue and either hand is acceptable. The same could be the case for other genetically-determined proclivities currently thought to be unacceptable and we must be sure when called upon, our judgment will not be clouded by prevailing viewpoints or historical context.

Mystery abounds in the realm of genetics and much remains beyond our comprehension. The example here is bipolar disorder, a devastating inherited disease that has long been linked to creativity yet a popular potential candidate for elimination through genetic screening once we can detect the genetic abnormality that predisposes individuals to the disorder. Multiple genes are believed to contribute to the variable manifestations of the disorder, in conjunction with environmental components, which can precipitate episodes of some phases of the disease. [7] Depressive phases may entail a significant amount of suffering for the most severely afflicted individuals – debilitating depression, suicidal melancholy, mercurial temperament, incendiary tempers and uncontrollable rage, while the manic phases are associated with heightened mental acuity, clarity, ebullience, creativity and phenomenal bursts of energy and productivity. [6] Alongside being fundamentally good people, bipolar individuals can be charismatic leaders and that quality has led evolutionary psychologists to suggest a role for them in the formation of early societies. Predicting which individuals would be severely affected by this complex disease on the basis of genotype is simply impossible. The overlap or even causal relationship between manic depressive illness and creative temperament prompts us to consider what other value hidden in the genetic storehouse of knowledge we may miss in our myopic pursuit of eliminating an incalculable risk of suffering.

Regulation or moral guidance in the use of existing technologies is sorely lacking, an unwise precedent for the biological age. Willing to deny use of surplus embryos for the creation of stem cells, ironically, the United States has no governmental regulations or legal oversight for IVF or PGD. Using embryos obtained by IVF, one of the cells of the three day embryo is removed for genetic testing, presumably for those traits that would cause unrelenting suffering for the offspring and its family. In the context of selecting embryos that are not carrying life-compromising genetic traits, it is not clear where the restraint lays, in the autonomy of the substitutive judgment of the parents, or by direction of a genetic counselor, insurance company as third party payer, or some combination of these agents. Absent answers on what the moral or ethical grounding is for making selective decisions about an embryo's genetic qualities and hence implantation, PGD has been used in the United States to avoid births with "serious genetic defects" since 1990. [8] (It is still too soon to know if the selections made were able to fulfill the hopes of the moral agents.)

Examining Therapeutic Options

Without gaining consensus on which genetic traits ought to be eliminated, or just rooting for morality and compassion to win the day, perhaps the alternative path is to

fix that which is impaired. It is the hallmark of biomedicine to explore the cause of disease and find a therapeutic solution. In principle, gene therapy should be applicable to the management or correction of many diseases for which effective treatment is lacking. But gene therapy has turned out to be somewhat more complex than anticipated, requiring interdisciplinary collaboration between many competent professionals in a wide range of fields. More than twenty years of research has resulted in only limited success [9] and more than a few unforeseen repercussions. Two readily come to mind: Failure to monitor toxicity levels of transgenic material and magnitude of host immune response to delivery vectors has resulted in patient death. [9] Successful treatment of infants with X-linked SCID in a retroviral gene therapy trial was followed only three years later by development of T cell leukemia in an unexpectedly high percentage of the patients as a result of insertional mutagenesis near a known oncogene (cancer-causing gene). [10] While lessons have been learned, remarkable advances have been made and extraordinary potential is still promised, the reality is that we continue to search for efficacious delivery vectors that can direct transferred genes to specific cell types or tissues and are still attempting to achieve and maintain appropriate expression levels for correction of specific disease phenotypes. Fulfillment of promises is years away even for disorders involving single defective genes.

In lieu of that, perhaps genetic research in pursuit of better treatment options would be the most viable alternative. If biomedicine can reach the gene level and distinguish between gene variants that confer disease risk or protection, both new and existing drugs or therapies could be more discriminately administered with potentially increased success rates. Additionally, the dawning era of pharmacogenomics heralds specifically designed pharmaceuticals particular for each individual's genetic composition, thereby offering greater safety and efficacy than conventional therapies. Gene variants or alleles certainly exist within populations and an individual's response to a particular treatment may vary accordingly, so personalized medicine sounds like an idea to be pursued, although the initial cost will likely be prohibitive for most. Alleles are even known to have different ethnic distributions and which alleles a population carries can influence their risk of acquiring the disease associated with their particular gene variant, so the appeal of race-specific drugs is growing as their potential to reach underserved populations is pitched. This despite the contention of scientists that there is no biological basis for the concept of race and the fact that very few drugs have actually demonstrated even the possibility of differential benefits among ethnic groups with regard to safety or efficacy. [11] Segregating medicine sets an inadvisable precedent and will not address the underlying causes of health care disparity.

Genetics is not Destiny

Before we get our hopes up over these new therapeutics, it is important to realize that except for single-gene diseases, the influence of most known genetic variations on disease susceptibility is relatively modest. [12] While the potential risk of disease may be indicated by the presence of particular gene variants, genetics is not destiny as many other genetic and environmental factors can interact to influence the ultimate outcome. There is a rather high P value on genetic diagnoses and the uncertainty associated with genetic information heightens the confusion for a public increasingly expected to decide for themselves how best to use that information.

In many ways more educated than ever and better able to make health care decisions independently, it is still unclear if personal genetic profiles will be digestible enough to be of use to the general public in identifying their potential susceptibilities and implementing any behavior modifications that could alleviate their risk of disease. It will be interesting to

see the results of the study being conducted by the NHGRI to determine just that [12]; meanwhile, we are free to speculate. In an increasingly competitive medical marketplace, the public has been inundated with advertisements prompting them to question many aspects of their normalcy and then ask their doctor if yet another drug is right for them. It is fair to assume that those advertisements would not run for long if no one was asking. Individuals claim the right to make decisions regarding health care, willingly engage in self help and readily seek ways to diagnose themselves, which the market then eagerly provides. Consumer-direct marketing has resulted in everything from home pregnancy and HIV tests to websites such as DNA Direct offering genetic tests for breast, ovarian and colon cancer risk, diabetes and cystic fibrosis risk, infertility and drug metabolism disorders, among others (www.dnadirect.com), making it possible for any person with access to a computer and a credit card to determine their health status without consulting a doctor or other health professional. Such autonomy may be attractive to those who fear discrimination by an employer or insurance provider, but exposes inequities in health care access based on inability to pay as well as a dire need for oversight and regulation of the selling or overselling of these services and the consequences posed by misinterpretation of the results.

As genomic diagnoses mature and our susceptibility to more and more genetic disorders can be discerned or our response to particular drugs can be determined, it seems reasonable to assume that at least some people will be receptive and attempt to include the information in their decision-making processes concerning a course of treatment or lifestyle modification. Initially, this information will be requested on an individual basis and sought after some treatable health problem has surfaced. But eventually, it can be presumed, many of the tests will become a normal part of pre-natal or early childhood care and the decision on the part of the parents to 'know' or not may well be more dramatic than the one they face today concerning the gender of their fetus. Some disorders may not be preventable or curable while others may be nearly impossible to accurately predict on the basis of genotype alone. Will we be left to sort this out for ourselves as well? Will we want to know for ourselves, let alone our progeny? If for ourselves, and we can act, will we? If for our children, will society and insurance companies pressure us to act in a prescribed fashion? Fearing lawsuits, will physicians be forced to advise preemptive action based on genetic predisposition even for diseases we may never get? As the competitive market responds to the growing demand for these informational goods, who will offer assurance that the best interests of the consumer are being looked after?

A Role for Dialogue

Where mystery abounds, ignorance thrives. The novelty of genomic science and technologies is leading researchers to be aggressive in their attempt to learn as much as they can in a short period of time, and not without competitive motivations. We the people are only too ready to believe and base major life decisions on the claims of exuberant investigators and the media, whose enthusiasm has been known to lead to mistaken perceptions of the development and success of medical approaches. It is imperative that their sense of responsibility be enlisted in fully considering the consequences of the knowledge they impart to a public body anxious for treatment advances and possibly less than completely informed as a result of attempting to stay current through headlines and sound bites. First and foremost, information must be presented as realistically and as comprehensively as possible so the public can make informed choices about their lives.

An illustrative albeit unscientific case in point begins in the field of alcohol research, where investigators are all but

trumpeting the news that they are making progress in identifying specific genes that may be related to the disease phenotype and claiming that through genetic counseling, at-risk individuals will soon be able to make informed choices about their lives. But alcoholism is a multifactorial disease believed to involve variations in many different genes and their modulating factors as well as a host of social and environmental influences. Several types of analyses have begun to converge on a number of regions on chromosomes 1, 2, 3, 4, 5, 6, 7, 8, 13 and 16 that researchers believe may contain genes that could affect the risk for alcoholism either positively or negatively. [13] In addition, many environmental factors have been reported to contribute to the occurrence of disease including psychiatric comorbidity, exposure to high-risk environments such as alcoholic households or childhood sexual abuse, and a few studies have even identified apparent associations between risk for alcohol dependence and such factors as family religious background or place of residence. [14] While the literature states that the continued study of genetic and environmental interactions is important, the strongest suggestion is that the solution will be found in the genes and any environmental impact could only increase the risk for dependence. Most disconcerting is the statement that individuals who are both genetically and environmentally at high risk for alcoholism but remain unaffected "may carry genetic factors that help protect against the development of alcoholism". [15] Undoubtedly some variants of implicated genes will be protective; nonetheless, it is clear that the nature of the studies done thus far (whole genome linkage analysis, family studies, electrophysiological measures) are biasing researchers to miss a very important group: those individuals who were both genetically and environmentally at high risk for alcoholism but remained unaffected not necessarily because of their genes but because of another environmental factor that positively influenced them, perhaps a friend or relative, a teacher or even a total stranger, a book, a movie, a dream: something that could pierce the darkness and make them aware that life could be different than what they knew. One of us (Hise) along with two younger siblings is descended from two long lines of alcoholics and was raised in a high-risk environment that included psychiatric comorbidity. But all three siblings, now squarely in their forties, remain unaffected although, typically, each took a turn on the dance floor with alcohol in their youth. While they may be something of a statistical anomaly, when asked the reason they believe they didn't succumb to alcoholism, each would credit the echoes of their maternal grandmother resounding in their ears, repeatedly reminding them of the perils of alcohol and impelling them not to be like the rest of the family. Consequently, they were able to make better choices than those before them, without ever consulting their genetic report card. The power of positive influences in our lives should never be discounted. But here, where investigators primarily intend to make a case for their research, no mention is made of anything like that to present a complete picture to the interested public, even in publications expressly dedicated to the education of the layman. Until the science is a bit more definitive than shown in these studies, the omission deserves at least to be noted.

The scientific community has virtually convinced the public that genes are deterministic and with time they will enable us to manage if not prevent even complex, multifactorial diseases. The reality is that the presence of susceptibility genes in itself does not necessarily indicate eventual disease manifestation, and even if it did, we cannot control every aspect of our lives to prevent those diseases. But to have value, life does not have to be perfect or everlasting; in fact we learn more from it if it isn't.

As potentially helpful as genetic testing may be to individuals who have access and choose to use the information, genetic testing is not likely to be universally

available. Like expensive therapeutic drugs and treatment for infectious diseases, genetic medicine may serve only those whose birth lottery places them in a position of privilege. The ideal embraced in the human rights movement rests on the cardinal axiom that all human beings are born free and equal, in dignity and rights, and are endowed with reason and conscience. The Declaration of Human Rights crafted in 1948 calls forth an ideal of human community – an ideal far from our shared reality. The U.S. did not ratify the declaration until after the civil rights were separated from economic and political rights in 1992. Subsequently we ratified the civil rights portion leaving the economic package untouched. Given this history and the grounding of the Declaration of the Human Genome UNESCO document in human rights, it is reasonable to be concerned about fair and universal access to genetic applied knowledge for all persons of “equal dignity of respect.” Dialogue and oversight can provide guidance to help us all keep the promises of science in perspective, to enable us to understand that genomic research is still in its infancy and allow us to imagine novel ways of realizing collective benefits through fair, ethical distribution.

Conclusion

Louis, the trumpeter swan settled into life with his mate and their cygnets after restoring the honor of his father. “As he relaxed and prepared for sleep, all his thoughts were of how lucky he was to inhabit such a beautiful earth, how lucky he had been to solve his problems with music, and how pleasant it was to look forward to another night of sleep and another day tomorrow, and the fresh morning, and the light that returns with the day.” [1, p 210] Gratitude for life does not depend on perfection but on a value for the gift.

References

- White, E.B. *The Trumpet of the Swan*, New York: HarperCollins Publishers, 1970.
- Lemonick, M.D. A Terrible Beauty. *Time*, 1994. 144(24).
- Meyers-Wallen, V.N. Ethics and Genetic Selection in Purebred Dogs. *Reprod Domest Anim*. 2003 Feb; 38(1): 73-76.
- Botstein, D.; Risch, N. Discovering genotypes underlying human phenotypes: past successes for Mendelian disease, future approaches for complex disease. *Nat Genet*. 2003 Mar; 33 Suppl: 228-237.
- Wang, S.S.; Hildesheim, A.; Gao, X.; Schiffman, M.; Herrero, R.; Bratti, M.C.; Sherman, M.E.; Barnes, W.A.; Greenberg, M.D.; McGowan, L.; Mortel, R.; Schwartz, P.E.; Zaino, R.J.; Glass, A.G.; Burk, R.D.; Karacki, P.; Carrington, M. Human leukocyte antigen class I alleles and cervical neoplasia: no heterozygote advantage. *Cancer Epidemiol Biomarkers Prev*. 2002 Apr; 11(4): 419-20.
- Jamison, K.R. *Touched with Fire*. New York: Free Press, 1993.
- Malkoff-Schwartz, S.; Frank, E.; Anderson, B.P.; Hlastala, S.A.; Luther, J.F.; Sherrill, J.T.; Houck, P.R.; Kupfer, D.J. Social Rhythm disruption and stressful life events in the onset of bipolar and unipolar episodes. *Psychol Med*. 2000 Sep; 30(5): 1005-1016.
- Handyside, A.H.; Kongogogianni, E.H.; Hardy, K.; Winston, RML. Pregnancies from biopsied human preimplantation embryos sexed by Y-specific DNA amplification. *Nature* 1990; 344: 768-770.
- Fischer, A. Cautious Advance: Gene therapy is more complex than anticipated. *EMBO Rep*. 2000 Oct; 1(4): 294-296.
- Dave, U.P.; Jenkins, N.A.; Copeland, N.G. Gene Therapy Insertional Mutagenesis Insights. *Science*. 2004 Jan. 303(5656): 333.
- Kahn, J. Race in a Bottle. *Scientific American*. 2007 Aug; 297(2): 40-45.
- Soares, C. Attitude Screen. *Scientific American*. 2007 Aug; 297(2): 25.
- Edenberg, H.J. The Collaborative Study on the Genetics of Alcoholism: An Update. *Alcohol Research and Health*. 2002; 26(3): 214-218.
- Heath, A.C.; Nelson, E.C. Effects of the Interaction between Genotype and Environment. *Alcohol Research and Health*. 2002; 26(3): 193-201.
- Bierut, L.J. et al. Defining Alcohol-Related Phenotypes in Humans. *Alcohol Research and Health*. 2002; 26(3): 208-213.

Genetic Testing and Moral Freedom

- Lawrence W. Watthey and Ann Boyd
Biology Department, Hood College, 401 Rosemont Ave,
Frederick MD 21701, USA
Correspondence to Prof. Boyd, Email: boyd@hood.edu

As scientific progress is made, it is often stated that if something is possible, then it should be done. Otherwise known as the “biotechnological imperative,” the maxim suggests that whatever is possible is desirable and available to all persons. The imperative is therefore false in suggesting that all things possible are desirable and that all persons have the option of using all technological possibilities. Ethical guidelines can aid politicians and public policy makers on how best to use the advances in the biomedical world risk bringing humans directly into the path of the run-away freight train named, progress. It would be unwise to trust that political forces would be any different than the power of the autonomous individual if the maxim of whatever can be done ought to be done is embraced. We stand at the transition phase in human scientific progress where our relentless pursuit of natural truth as led to an unprecedented ability to manipulate nature for ends not clearly defined or foreseen. Much like taking copper and zinc to make brass, humans can now manipulate life and the machinery of life in the form of proteins and DNA in ways never before imagined.

Indeed, just recently scientists working for shotgun sequencing entrepreneur J. Craig Venter have taken major steps to create artificial life by replacing the genome of one bacterium with that of another.[1] This is a major step towards creating artificial life designed for specific purposes desirable by humans for any number of reasons. With such advances, are we really far removed from designing an entire genome, inserting it into a stem cell and replacing genomes at will? Perhaps such technology will usher in a new age of gene therapy that is so far unrealized. If so, what will we choose? Who will choose? What role should government take in regulating the access to these choices? These weighty issues will be played out over the next few years as people make their choices and politicians watch and decide how to act. Such questions demonstrate the ethical problems brought about by the rapid advancement that characterizes this age of human scientific discovery. Perhaps the information is not revolutionary, but the application of it is nothing short of world shaking and paradigm shattering.

Joining humanity on this ride is the Pandora's Box of diagnostic testing. Genetic testing can be predictive and/or diagnostic. When the exact mutation is known to cause a particular disease the test is diagnostic; when the change in DNA sequence means the person with the sequence might develop disease then the test is predictive. As the genome yields its secrets, genetic testing and the subsequent manipulation become possible or so we are promised with the decision to fund and pursue the Human Genome Project. While watching and participating in this scientific thrill ride is a wonderful experience, it is also appropriate that we take a collective pause (however briefly) and take note of the ethical considerations that arise from our technological advancements. This discussion will delve into the murky waters of the ethics of genetic testing and what criteria should be used for making selections based on the results. In addition, the consideration of what tests might be offered and whether or not counseling should be offered (or to what degree it should be offered) in conjunction. Moreover, the risks and benefits of screening and therapy will be evaluated while examining the political and social influences on the process. Ultimately, the criteria for genetic selection and possible enhancement will be explored, all while keeping an

eye on the ethical ramifications of humankind engaging in such activities.

Simple Genetic Disease Testing

Genetic testing has been around since the 1960s when babies were tested for phenylketonuria.[2] Today all newborn children (in countries where such testing is offered) are tested for the telltale signs of high phenylalanine levels.[3] Within forty years, we have gone from near ignorance to having the ability to test every child for this genetic disorder. If the parent of this newborn is living in a place where PKU testing is offered, it is a wonderful option, because the disorder is treatable once detected, and the affected children can lead almost completely normal lives. The interventions are dietary and not linked with the difficult choices inherent in more pernicious disorders posing a choice between a termination of the pregnancy and the birth of an affected child. We hear little ethical debate about fairly neutral inborn errors of metabolism, which have conventional therapies and can be detected prior to injury to the infant. It would be easy to conclude that such testing is not only permissible by informed parents but that health care plans, be they universally provided by the government or private pay, should minimally recommend them if not mandate such testing for all newborns. Would making one genetic test mandatory be consistent with the UNESCO Declaration on the Human Genome and Human Rights?

Framing the Ethics Debates

As the UNESCO Declaration codifies the collective ethical thinking of the international community regarding matters concerning the human genome and how genetic information may impact human rights, the document uses the language of respect for persons, beneficence and justice but there is less prominence given to the role of nonmaleficence. Is the omission deliberate or does the obligation to do good by removing harms within the principle of beneficence make nonmaleficence unnecessary? The subtle difference in meaning in which nonmaleficence obliges us to not do harm intentionally, the beneficent act may provide benefit(s) even when some harm is necessary for the benefit to be achieved. It seems likely that in decisions to test for genetic traits, the claimed benefit is to prevent a compromised quality of life for the individual with the "mutation." Who is benefiting from genetic testing? The parents clearly may benefit if the results of a PKU test simply mean using a particular diet and having a "normal" child. If the test is not mandated, will the parents choose to have the test, in circumstances where the child must be taken to a testing facility (however distant) in the first 48 hours of life? Will every parent choose to test? Would not it be more beneficent on the whole to just require all babies be tested? It would appear that basic ethical reflection would support a simple PKU test – and provide the appropriate support for the diet that would prevent mental retardation if the newborn tests positive. Then it dawns on the ethically wise that every parent in every time and place in our world might not have access to testing, or the easily preventable diet. If one part of the world mandates testing, provides treatment, while allowing the remainder of the global population to lack the same "benefit" has the principle of beneficence been met?

Article 12 (part a) of the 1997 UNESCO Declaration states: "Benefits from advances in biology, genetics, and medicine, concerning the human genome, shall be made available to all, with due regard for the dignity and human rights of each individual." [4] As we have tried to show in the simple case of PKU testing, making the test available to all is a goal worthy of effort but one not easily realized. "Due regard for dignity" is vague and could mean anything from respecting autonomy absolutely to simply making sure the person is informed. It seems cruel to inform a person and not provide

the testing, so it is likely that the average reader will see in this phrase the primacy of autonomy. So the individual has the "right" to choose: if there is a choice!

Context Sensitive Interpretation

While the UNESCO Declaration seeks to provide guidance for a difficult topic and frame the ethical considerations in ways useful for persons and nations, one can imagine a constitutional amendment in the USA: "The right of the citizens of the United States to express his or her own human genome via naturally or artificially aided reproductive processes shall not be infringed, denied, or abridged by the United States Government or by any state." The protection of individual rights as a restriction on government interference is a strong value. Taken literally, such an amendment would allow anything in genetic manipulation from diagnosis, preimplantation genetic selection, to cloning...all resting in the autonomy of the parent(s), if both parents have equal say in the matter – a point not yet clear. The simple interpretation for political fodder could be: the government should not tell people how to reproduce. The policies and legislative process would address reproductive issues in ways that guarantee the rights of everyone, unless the embryo-fetus were counted as person, in which case the conflict of whose rights has primary sway would evolve. Not only does the "freedom clause" allow exclusion of the embryo or fetus from the free expression of individual rights, it also fails to address the concern that such services are available to the wealthy and those with less access will be unable to exercise their "rights."

Proponents of human rights in strongly libertarian cultures may simply argue that reproductive advantage has always been to the strong and best adapted. The healthiest most aggressive lions or gorillas mate with the best females. While, one should strive to be morally superior to the lions and gorillas, it is enough to safeguard rights and make resulting options available for those who choose to exercise them. Whatever is lawful is just according to Hobbes. The genome project has provided information that is relevant to human reproduction and health. A policy that rests on a technological maxim with a side dish of libertarian Hobbesian justice will lead through the gate of autonomy to injustice.

A Triad of Principles

UNESCO wisely proscribed three principles, autonomy, beneficence and justice. Avoiding the primacy of autonomy much removed from the original Kantian concept of moral responsibility in which the right and the freedom of choice of the individual trumps any consideration of the "other" is helpful in constructing an ethical framework. It is not however enough to restrain an individual who thinks control over the genetic makeup of the next generation is a matter of using the right tests and making the best choices. It may be subjective judgment in what is the "right" and "best" choice, presumed to rest in the autonomy of the parent who acts in the best interest of the future child. Hoping for the perfect child under the alluring promise of the human genome databank leads some to fear that any imperfection, again a subjective opinion, will be subject to social neglect or worse. Intolerance is a concern that we ought to take seriously when we advocate autonomy as the *sine qua non* of ethics. Trusting that beneficence and justice will balance the imperialist tendency of autonomy risks a plurality of understanding as well.

If beneficence is taken as the positive benefit of genetic testing, selecting the best embryo from in vitro fertilization (IVF) on the basis of the genetic scorecard of positive traits, we are left to wonder who will have the "benefit" advantage. If it were possible to tinker with the DNA sequence of a single fertilized zygote, perfecting the sequences related to positive traits, the absence of disease bearing genes, and offer the parents one fine "perfect" embryo, successfully gestated to

birth as the desired newborn child, would we be satisfied? Would beneficence then find alignment and balance with autonomy? Is the benefit sought found in the "perfect child"? If perfection is the goal, then positive selection and enhancement cannot be far behind in the technological imperative lurking in the name of scientific progress. It may be that few human beings would consent to such drastic means of having a "perfect" child, but what are the imagined consequences of acting on such a "good" intention? If the genetic blueprint of the human being is known in detail and understood in terms of causation, can it be that a perfect child is a realistic hope? The mere suggestion that a genetically perfect individual can be constructed carries serious risks, including but not restricted to the ultimate reductionistic value of human life. If a person is no more than the sum of his or her genes, what is to inspire moral development, ethical responsibility, or will each "perfect" heir merely act on his/her genetic controlled phenotype? These are not rhetorical questions, but serious risks associated with allusions to perfecting human beings by way of genetics. It is obvious that interpretations of beneficence as wanting the best child, free of disease, unburdened by susceptibility to cancer or infectious disease would be very attractive to those with the means to pursue such an objective. Science is dedicated to making life better and we expect the products of scientific research to offer us not only cures of disease but disease free futures, as if through science we can achieve immortality, at least for a few. The designer future child with all threat of disease and vulnerability removed by genetic editing may or may not have compassion for those genetically less fortunate. To argue that freedom to choose such an advantage without concern for fair access is egocentric and short sighted. History is full of examples of how resistant human beings are to being treated as inferior.

Arguing that justice in terms of access is satisfied on the basis of freedom finds its grounding in the primacy of the individual. The truth is that in every geographical location, regardless of political ethos, there is diversity among individuals, in talents, in resources, in health. Long recognized that the most predictive measure of health is wealth, persons of privilege often fail to see the inequality that calls for a better concept of justice than everyone having the freedom to choose. Freedom to choose the best genetic offspring will find resonance in the ultimate free expression of individuals, as a basic element of "rights". National and international policies seek to construct fair laws and guidelines that treat people with "respect and dignity".

Having respect for the dignity of person requires more than freedom of choice. It ultimately requires that individuals collectively recognize that human beings are relational beings, interdependent and thrive best in supportive social systems. Pursuit of happiness at the individual level can never reach its goal without ensuring equal opportunity to all. None are free until all are free. Justice requires a larger context than individual freedom of choice. Individuals suffer lack of choice from social systems that ignore need and misdirect resources. In a society where too many lack basic access to health care based on their inability to pay for it is a system that also promotes individual freedom, but that freedom is won at the cost of limited freedom for others. Such a system is inherently flawed when the extent of choices ensured by freedom is enjoyed by some and withheld or limited for others.

To argue: "society is best off when we provide the maximum of freedom, not a maximum of equal outcomes" promotes the status quo of the privileged over the humanity of the neglected. Pursuing the best in humanity at the genetic level is the ultimate in free expression of individuals promotes autonomy in the name of justice. While many fine philosophers and ethicists have posited numerous constructions of justice, a libertarian view of justice is inadequate to the task genetic knowledge poses for humanity.

In the range of genetic tests, selections, and putative enhancements on the horizon of humanities future, a more communitarian view of justice is desirable. If justice means correcting injustice, we move toward a more common view of our shared humanity. In this construction we would root out the causes of injustice, the limited choices for some would reveal to the privileged a new choice that aims at correction. To advocate for justice while respecting the freedom of choice of individuals means that systems must be equalized that provides choices to all.

Equality of choice would mean that one person could use testing to avoid a genetic trait only if every person had the same option but no person was required to make the same choice. In this construction, as with PKU, justice would mandate testing and provide treatment. Until all persons everywhere had access to PKU testing and treatment, no more genetic tests would be made available. It is unlikely that freedom proponents would be willing to restrict genetic medical progress on the basis of such idealized systems of justice, but until the full inclusive value of every human being is integrated into policies guiding use of genetic information, the pursuit of individual happiness is open to systemic injustice.

References

1. Lartigue, C; Glass, J.; Alperovich, N.; Pieper, R; Parmar, P.; Hutchinson, C.; Smith, H.; Venter, J. (2007), "Genome Transplantation in Bacteria: Changing One Species to Another." Science: DOI: 10.1126/science.1144622.
2. Paul, Diane B, "Appendix 5. The History of Newborn Phenylketonuria screening in the U.S. LSU Law Center's Medical and Public Health Law, (1995), Louisiana State University @ <http://biotech.lsu.edu/research/fed/tfgt/appendix5.htm>.
3. Voet, Judith G and Voet, Donald. "Biochemistry", 3rd Ed., Hoboken, New Jersey: Wiley, (2004).
4. Records of the General Conference, twenty-ninth session. Paris, 21 October to 12 November 1997. Universal Declaration on the Human Genome and Human Rights, 11 November 1997, Part 16.

HIV/AIDS Exposes Gender Injustice

- Ann Boyd, Ph.D.

Professor of Biology, Hood College, 401 Rosemont Ave., Frederick, MD, 21701, USA

Email: boyd@hood.edu

Twenty-five years after the discovery of the human immunodeficiency virus (HIV) that causes Acquired Immunodeficiency Syndrome (AIDS) science has an accurate pathobiology of the virus. Having infected 65 million persons since isolation in 1985, HIV/AIDS has caused the deaths of 25 million while 40 million live with HIV. The United Nations (UNAIDS) reports the epidemic is slowing globally, but new infections continue disproportionately among poor women exposing the gender inequality perpetuated by cultural, legal, medical, and social practices (1).

Testing is accurate and yet knowing if one is infected too often leads to social stigma, loss of job, and rejection by family. Knowing also raises questions about who to tell, and how to deal with the risk of infecting others. For privileged persons with access to therapy, HIV infection can be tamed to a chronic disease, but for persons living in poverty being HIV-positive means AIDS is your path to death. The pandemic reveals disproportionate severity in Sub-Saharan Africa dwarfing the number of infections elsewhere in the world (2).

AIDS, like poverty, has a disproportionate impact on women and girls. Of the 1.2 billion people living on less than \$1 a day, 70% are women (3). Women own a small

percentage of the world's land and yet produce two-thirds of the food in the developing world. Women are the primary caretakers of children, orphans, and the sick. Women represent 60% of the HIV infected persons in Sub-Saharan Africa and half of all HIV infected persons globally (1). Being economically dependent on males, first the father and then the husband, women have too little choice or control over their sexual experience. Widows whose husbands die of AIDS suffer discrimination, abandonment, fail to inherit the land or property of the household, and are more at risk of violence. Driven from their physical home, devoid of livelihood and possessions, women are forced into risky behaviors to provide basic human needs for themselves and their children.

An African American woman is more likely to die of AIDS than any other cause if she is between the age of 15 and 49 (4). Women typically acquire the virus through heterosexual intercourse in monogamous relationships. Failure to diagnose and treat sexually transmitted diseases increases the risk of HIV infection. Prevention efforts must increase as must more comprehensive access to treatment and care. To achieve these goals, three interventions are recommended: recognizing and promoting the human rights of women, reducing violence against women, and ensuring education for women.

Like a harsh and unforgiving light, the AIDS pandemic has exposed ugly fault lines of disparity and injustice between and within societies, but it also has clarified where future efforts should be focused. Manmade inequalities create a wall separating AIDS patients in low-income circumstances from treatment. Decisions made in boardrooms populated by males with privileged social and economic position ignore the gender relations in impoverished households. The wall must be dismantled allowing a sea change in global politics and ethics if equitable treatment of women and men is to stem the tide of the HIV pandemic (5).

The intent of this paper is to revisit the HIV pandemic through the experiences of poor women, using cases from the United States and Kenya. (The names used in the case studies are fictional to protect the identity of real women whose situation makes the cases relevant and real). These two locations provide contrasts of overall health, wealth, legal and cultural practice, and yet the social and economic vulnerability for a black woman in either location is alarmingly similar. The new trends in HIV infection rates among poor women call for a new approach to ethical reflection. If we continue down the road of justification by mere words with ambiguous meaning, the history of HIV/AIDS is poised to write another chapter in the discrimination against women.

HUMAN RIGHTS for WOMEN

CASE: Mary is a woman in Kenya, whose husband died of AIDS. Mary has two children and all three are HIV-positive. It was at the birth of her second child that Mary discovered she was HIV-positive. Her husband was very sick at the time. When she returned home she urged him to go for testing but he refused. When his family came to visit, he told them she was HIV-positive but not about himself. When he died, they came and drove Mary and the children out of their home with only the clothes on their backs. With no place to live, no land to farm, and no family or community to help, the small band of three made their way to the nearest city, begging for food, vulnerable to abuse, and prime for selling the only commodity left, sex.

CASE: Martha lives in the United States, is twenty-one and is HIV-positive. Martha married at the age of 17, has one child who was diagnosed with HIV at birth and subsequently learned she also was positive and was infected by her husband. When Martha confronted her husband, he simply left her and the child. Lacking a high school degree, Martha works a minimum wage job full time for an annual income of just over \$10,000, which is \$6000 below the poverty level in

the USA. Martha is qualified for Medicaid, which provides ART for her and her child. Because she is HIV-positive, Martha's parents refuse contact with her and refuse to help care for the child. Legally the father owes child support but he died before the court could locate him.

UNAIDS Global Coalition on Women and AIDS correctly stresses the importance of protecting the rights of women to own land, inherit property, and acquire education and skills that allow her to be economically independent. HIV prevention can take the form of economic security relieving women and girls from vulnerability to unsafe sex, and domestic violence. The Young Widows Advancement Program (YWAP) provides HIV positive widows help in combating social stigma and provides legal assistance to empower widows to protect the family property, inheritance and other human rights. Although statutory laws prohibit gender discrimination, local customs and failure of government to enforce laws result in women being barred from inheriting property and being stripped of their possessions by relatives.

Human Rights must include civic, social and economic realities. Only one out of six persons who need ART actually receives it. The estimated 8.9 billion dollars devoted to AIDS for 2006 falls short of the 14.6 billion needed, leaving open the question, "who will receive treatment?" Unfortunately, rationing strategies reflect the injustice of local and international policies (5). Economic rights are no less important than civic rights. Consider the following example of the good that can be achieved through small increments of progress towards social justice.

Jane works on a tea plantation in southern Kenya. The owners supply housing and pay workers by the kilogram of tea picked. Jane picks 7 kg less tea per day than her healthy counterparts and earns 18% less. The Walter Read Project in collaboration with Kenyan MOH offers testing, counseling and ART on the plantation. Receiving ART when her CD4 count is low, Jane is able to work at her previous level and recover her income earning capacity. The nurse in the lab, a Kenyan native, reported the dramatic effect: In her words, "despair turned to hope."

In Kenya 253,831 persons qualify for treatment but only 38,000 (16%) receive ART (2). Decisions about allocation are influenced by transnational decisions and by distribution choices within the country. Regions without clinics, roads, and supply networks are less likely to receive testing or therapy. Polices such as "abstinence, be faithful and condoms" are statements of privilege, blind to the reality of life for women living in poverty. Where HIV information campaigns, voluntary counseling and testing programs have gradually slowed infection rates, access to antiretroviral treatment is slowly improving. In part this is due to infrastructure improvements that have made clinics more accessible in rural regions. At the same time, Kenya is struggling to raise awareness that HIV infection occurs within marriage and long-term relationships, decrease violence against women, and to protect economic and human rights of women (6).

The Convention to End Discrimination against Women (CEDAW) supported by money from the United Nations Development Fund for Women (UNIFEM) promotes women's human rights, urges political participation by women in setting policies and advocates for economic security. CEDAW posits 8 goals to address and overcome sexual stereotyping, physical vulnerability and exploitation of women (7). Elimination of discrimination against women will require that statistics about HIV infection, prevention, and treatment be reported according to gender in order to expose gender injustice masked by conflated reporting practices. Gender related abuses are a significant part of the complex socioeconomic web. When gender injustice is considered simply a matter of culture or private exception, it fails to be seen as a breach of human rights (7).

Reduce Violence against women

CASE: Joan is ten years old and lives in southeastern Kenya. Her father accepted a bride price from a 40-year-old man. Joan will be his fourth wife. Unable to carry wood and water at the pace of the older wives, Joan is frequently beaten for being late and inadequate. When Joan fell further behind in her duties, the violence increased.

CASE: Joyce lives in the USA, is thirty-five, has three children, and a high school diploma. Her husband is a successful businessman but he drinks too much and becomes abusive. She has been to the women's shelter three times in the last five years but when she recovers from the beatings, she returns home, afraid to leave the children with him and unable to secure income enough to support herself and her children. Counselors at the abuse shelter have suggested protective custody for the children, legal proceedings against the husband, and other means to help Joyce leave this abusive relationship. Joyce blames herself for the abuse and makes excuses for him.

The November 25, 2005 issue of the journal, *Science*, reported the increase in violence against women throughout the world (8). The Millennium Development Goals commit the 191 member states of the UN to sustainable human development and recognize that equal rights and opportunities for women and men are critical for social and economic progress (Resolution A/55/2, the United Nations Millennium Declaration United Nations, New York, 8 Sept 2000). Despite international declarations calling for an end to violence against women, policy makers in local and national offices see it as merely a social problem. A WHO sponsored global study indicates that violence against women occurs at the horrendous frequency of one in three women! [Based on thousands of interviews with women aged 15-49 in developed and developing countries (Bangladesh, Brazil, Ethiopia, Japan, Peru, Namibia, Samoa, Serbia, Montenegro, Thailand, United Republic of Tanzania). In thirteen of 15 sites participating in the survey, 33 to 75% of women reported having been physically abused or sexually assaulted at least once since the age of 15 with the majority of such violence perpetrated by a domestic partner (8).]

The most disturbing part of the report was the revelation that "50-90% of women think it is acceptable for a man to beat his wife for one or more of the following circumstances: if she disobeys her husband, refuses him sex, does not complete the housework on time, asks about other women, is unfaithful, or is suspected of infidelity. The prevalence of partner violence and women's belief that such violence is normal or justified is one of the most salient finds of the WHO study" (8). Social and cultural systems must resist the impression that violence can be justified; there are no acceptable reasons to beat a partner.

Successful strategies for overcoming violence against women require a change in social custom condoning violence. Change can be accomplished only when young people are given skills for healthy relationships and women's access to education and economic empowerment are taken seriously. Attitudes will have to change for the status of women and the dignity of their partners to improve.

Perhaps because women represent 70% of the individuals living in poverty, they experience a disproportionate amount of violence. It may be the case that men also are victims of violence perpetrated by social and economic vulnerability. The inequality trap of social and economic inequality encircles men and women pointing to the need for more focused work on individual human rights (9, 10).

Education for women and girls

CASE: Alice is nine years of age and lives in a small village in rural Kenya. Her father became sick and her mother cared for him until he died, then she too became very sick, and Alice

dropped out of school to care for her mother. The two brothers, age 4 and 6 remain in school but fees for books and uniforms are beyond the reach of the family. Alice has to find some way to make money if her family is to survive. The only way she can find to provide food for the boys is to have sex with anyone who will pay for it.

CASE: Anita lives in the US and is in the 8th grade at a city school. Anita's mother has AIDS and can no longer work. Her father left the family years ago, and left no forwarding address or information. Anita tries to care for her mother and go to school, but her grades are failing and she cannot concentrate because she is fearful that her mother will die and leave her with no family, home, or means of support. She talks frequently to an older man in the apartment building who promises to take care of her when her mother dies. Anita knows that he has many female companions who seem to have plenty to eat and fancy clothes. Anita does not know what is required of these women for such support. Unless Anita finds alternative support, she too will become one of "his girls," a polite euphemism for prostitute.

It is sadly ironic that HIV/AIDS increases the number of children deprived of education, as it is the very thing needed to acquire safety from HIV infection. AIDS affected households and communities impose economic and social burdens, disproportionately shouldered by girls. To care for a parent who is sick and dying, children drop out of school. When one or both parents die, the children are faced with economic demands without the benefit of knowledge, skills, and opportunities gained from education. Education for women and girls is a fundamental requirement for a productive life and economic independence (11,12).

UNAIDS has shown that educating girls dramatically lowers their vulnerability to HIV. Attending primary school reduces the risk of HIV infection. Each year of education empowers girls, equipping them to make decisions about their sexual experiences and improves their earning potential. Supporting the completion of primary education for young girls could reduce new HIV infections by as much as 7 million cases. When orphans have no source of income and schools require payment for uniforms, books and tests education is beyond their reach. Lowering or waiving school fees puts education in reach for many children as it did in Kenya where enrollment increased 22% with abolished fees (13).

In the USA, approximately 1 million persons are living with HIV, but one third of them do not know they are infected. Testing is available but not mandated. Patients who know they are HIV-positive have access to treatment, but for 43 million citizens of the US who lack medical insurance and make too much money to qualify for Medicaid, therapy may be hard to access. In the developing world only 1 in 5 HIV infected persons are currently receiving treatment (14).

Knowledge about HIV/AIDS

A Hood College honors student, Sarah Schefers (15), conducted a survey of what students know about HIV transmission, testing, treatment and behavioral practices. More than 66% of the students were aware of transmission risks, but failed to protect against exposure in more than 50% of sexual engagements. Schefers paper entitled, "Educating the next generation about HIV/AIDS – where have we gone wrong?" shows nearly two-thirds of the students could not correctly answer specific questions about HIV transmission, risky choices in behavior, diagnosis (testing), and treatment. The focus groups included men and women, 66% Caucasian, 34% minority. One-third of the students answered very few questions correctly, one third answered correctly questions about HIV transmission but could not answer questions about diagnosis or treatment, and one third answered all questions correctly. Overall, students know how HIV is spread but have little or no information/knowledge about testing, symptoms, and treatment. The primary source of students' information was TV commercials.

CDC reported in 2003 that in 33 states within the US, 211 children under the age of 14 were diagnosed with HIV along with 3,847 persons ages 15-24. A middle school principal interviewed reported: "for the girls most of their partners are older men. It is a recent trend, older men wanting these younger girls --- they think younger girls are not diseased [HIV positive]". Girls from lower socioeconomic status and broken homes looking for financial security and love as young as 5th and 6th grade become prey to such predators. When the girls contract STDs or become pregnant, the men abandon them (4). Better sex education is needed in school at earlier stages than is the current practice.

Schefers concludes that people in the US are still contracting HIV because they don't believe they are vulnerable to the disease. They live with the myth of "risk groups" that they "don't belong to," or think they can recognize a person who is infected. Some teens simply believe they are invincible. The survey, limited as it is to college students, suggests preventive strategies will require more specific education approaches that break through willful ignorance and the phobia of talking about sex (15).

Are microbicides progress?

A microbicide is a substance that can significantly reduce transmission of HIV and/or viral, bacterial, fungal or protozoan sexually transmitted pathogens when applied topically to genital mucosal surfaces. Microbicides can be contraceptive or noncontraceptive. Acting through one or more mechanisms, microbicides are designed to kill or inactivate pathogens, create a physical barrier to prevent infection, inhibit replication and boost natural defenses. This exciting and putatively helpful scientific research is currently evaluating 15 candidate microbicides in clinical trials, five of which have entered phase III (16-19).

Perhaps the development of microbicides is progress to the extent that women would have more control over sexual exposure to infectious agents. Developing a safe, effective and affordable microbicide could contribute to several important goals. It could provide an intervention that places control over reproduction and sexual risk of HIV infection in the hands of women. It could reduce HIV transmission to women and thus to their children. Five microbicides have reached phase II or III in clinical trials and anticipate having at least one effective agent available by 2010, the same year that ART is targeted to be available for all who need it. If an effective microbicide offered 40% protection, millions fewer HIV infections would occur (20). Current research with microbicides requires shorter follow up than vaccine trials, tests women for HIV more frequently, and may discover other gynecological conditions for which local treatment may be unavailable. If women are to bear the burden of HIV infection and become the ones expected to prevent transmission by use of agents e.g. microbicides, then treatment for any condition acquired during participation in research ought to be the standard of care. Of course this takes us to the whole abstract reasoning of whose standard of care is to be imposed and the risk of reducing research progress – another example of rational justification using minimalist ethical principles.

The development and testing of microbicides follow guidelines set for vaccine trials and occur in similar geographic and political contexts. Investors are calculating the global market for microbicides before we know the safety or efficacy of their use. Economic calculus that focuses on profit as the sole criterion for development of drugs or any other medical intervention is myopic. The forecast for microbicide market is 70.5 million women in the developing world and 16.5 million women in the developed world. Surveys show that in the US 25% of women expressed an interest whereas in Kenya interest was 60%. Pricing is expected to begin at 5x the price of a condom. The US

market for condoms is \$295 million annually. Microbicides are not likely to be more effective than condoms but if or until women gain control of sexual experiences, microbicides may provide interim relief. Funding for birth control pills faced similar economic and political oppression in the 1950's until two women, Margaret Sanger and Katharine McCormick, set events in motion that led to the development of the contraceptive pill. McCormick invested \$ 2 million (equivalent to 30 million today) in 1951-1959 to fund research that produced a contraceptive (20, 21).

Development, testing, and marketing are dominant economic and scientific strategies lacking in the humane sensitivity regarding social and economic impoverishment of women. "Claiming to add a weapon" to the AIDS arsenal uses dominant language that risks making women the victim of responsibility in social systems of oppression. Until women's rights are seen as human rights and social and political justice is achieved for all persons, microbicides may offer women some better protection, a small and potentially positive step toward greater equality.

Seeking Justice

Women are victims of structural systems of power and structural weaknesses within and among countries as a consequence of patriarchal dominance in political and social custom. Human rights fail in such systems of oppressive inequality. Unless rights pertain to all human beings, human rights discourse cannot correct the injustices exposed by HIV/AIDS.

Corrective action requires that the civil rights of women protect women against violence. Economic rights of women mean legal and political means of protecting women's rights to own property and inherit property. Legal enforcement of women's rights according to the goals of CEDAW as ratified by the 104 countries and the UN General Assembly demand a change in social and political discrimination against women and call for greater inclusion of women in policy setting bodies. Women need food, water, and freedom to live lives of dignity, free from domination and violence (22).

As things now stand, women are not independent equals but dependent nonequals. Seeing and facing the social inequality between men and women in the world is the first step in crafting a system of true justice. Failing to recognize the root cause of injustice and making excuses for injustice on the basis of social tradition are deceptive masks blocking progress toward a more just society. It is not sufficient or desirable for women to seek mere equality with men in the sense of becoming like men. The self-defined sense of behaviors, values and virtues of the powerful, mostly men, have led to systems of grave injustice. Women seeking parity with such men does little to improve the status quo, for men also subordinate other men in systems of classism, racism, in layers of self-serving egocentrism (23,24).

Alternatively a diversity approach to gender injustice calls for strategies to liberate the oppressed and interventions that dismantle the walls of domination on the basis of race, class, religion, sexual preference, economics, or nationality. The equality principle, with a humane imperative, tolerates diversity by allowing social and economic difference. While women claim equality with men, both men and women are victims of social and economic subordination. We need a better vision of equality, one that grants full dignity status to human beings regardless of attributes of differentiation. Rather than the traditional focus on independent rational agents, we need to imagine mutually interdependent communities that see communal health from a holistic perspective (25).

It is time to relinquish the rhetoric of autonomy for a closer look at global injustice exemplified by discrimination against women. Women are persons whose dignity and rights deserve respect. Justice that allots to each a fair share leads

us to craft distributive strategies for resources, but each person within the commons will not require the same amount of care. Since some will contribute more than others and some will withdraw more than others, limits cannot be defined on purely economic grounds or on the differences between nations. Humanitarian posturing for elimination of suffering must acknowledge the disproportionate burden of HIV infection borne by women.

The Declaration of Human Rights of 1948 offers an ideal of human commonality. If the language of human rights is to be the lingua franca then both women and men must count as human beings. While differences of culture conditioned norms change with time and place, common necessities of human life raise the possibility of common, mutual, interdependence and hence the possibility of social justice. Relativists are right to claim that notions of equality, mutuality and equity apply within a cultural context and its chosen polity, but often neglect to recognize the universal assertions of human rights. If there are essential and basic elements in the human experience that can be defined as common, then justice can take the shape of supporting and insuring the viability of all persons. Justice corrects injustice, liberates the poor and oppressed, takes the side of the vulnerable and protects the rights of the privileged as well as the marginalized. Human rights claim the goal of sustaining life by ensuring economic, social, political and personal freedoms. Respect for freedom of conscience respects plurality of values but does not sanction discrimination against one group.

The common ground of human existence is the individual relationship. We live in communities in which all persons are equal in human dignity but diverse in terms of talents and opportunities. From family to tribe to nation, the relational character of persons is held in all anthropological and historical accounts of human life. Human rights are not singular or individualistic but relational. From the relational perspective, human rights are reminders of our duty to our neighbor. Rights language is good when it promotes the dignity of persons but deficient if it rests on the individual good over community flourishing. We need a way to resolve the conflicting claims and the authority to protect and enforce social rights in circumstances that limit resources and where distribution of resources is unequal and unjust. A person is not a mere means, rather she is an end and morally responsible for fulfilling her destiny. Human rights provide the freedom and opportunity for each person to achieve her destiny (26).

Making choices between lesser and greater evils when resources are limited and perfect justice is not within reach calls for systematic and progressive increments of progress. Justice that is restricted to a redistribution of goods has failed to achieve the desired goal as currently practiced. The feminization of AIDS is a microphone for the voice of the oppressed and stands as a testimony to the failure of current redistribution schemes. Justice takes injustice seriously and makes a commitment to mutual responsibility in which the entire human community experiences a restoration of the fundamental relational nature of all women and men.

An Inspiring Example

In closing I have searched for a model in our world that could stand as an example of how we might proceed. The one I have chosen is the Peace and Reconciliation work in South Africa. Apartheid was a horrific system of powerful oppression and genocide. When the system failed, rather than reverse the domination, those newly in power chose reconciliation as a higher road to peace and social justice. Being able to move forward meant dealing honestly with the sordid past as philosopher George Santagayana taught, "Those who forget the past are doomed to repeat it." National amnesia would not suffice, and the Nuremberg model of retribution seemed only to reverse power and dominance.

The election of Nelson Mandela, April 27, 1994, was a metamorphosis, the prisoner became President and formed the Truth and Reconciliation Commission to deal with the past. Amnesty was offered if the guilty simply confessed their wrong doing. The basis of the choice is *Ubuntu*, the essence of being human. The term encompasses the English connotations of generosity, caring, compassion. The human being is human because she or he belongs, participates, and shares life with other human beings. Social harmony depends on mutual respect expressed in the African idiom: "a person is a person through other persons."

Working for reconciliation held forth the vision that members of the human family are bound together in a delicate network of interdependence. The Truth and Reconciliation Commission began the process without expecting to achieve social equality immediately. The project was national in scope seeking to include every South African, to learn the language and culture of others, learning to admit wrong and apologize, and working for a new culture that respects human rights. Here is an excerpt from the interim Constitution that served as a bridge to democracy and a foundation for the work of the Truth and Reconciliation Commission:

"This Constitution provides a historic bridge between the past of a deeply divided society characterized by strife, conflict, untold suffering and injustice, and a future founded on the recognition of human rights, democracy and peaceful co-existence and development opportunities for all South Africans, irrespective of color, race, class, belief, or sex. . . The adoption of this Constitution lays the secure foundation for the people of South Africa to transcend the divisions and strife of the past, which generated gross violations of human rights, the transgression of humanitarian principles in violent conflicts and a legacy of hatred, fear, guilt, and revenge. These can now be addressed on the basis that there is a need for understanding but not for vengeance, a need for reparation but not for retaliation, a need for *ubuntu* but not for victimization." (27)

The process in South Africa offers us the hope that the dignity of every human being can be respected by taking human rights seriously. The ideal of the common good is difficult in a pluralistic contemporary society driven by economic and political motives. The common good may be a pluralistic ensemble, but supporting the dignity and human rights of every woman and man requires a new vision of our relational nature as persons.

References

1. www.unaids.org accessed 5/30/2006
2. www.who.org accessed 5/30/2005
3. United Nations Development Program, Human Development Report, 2002, pdf www.un.org
4. www.cdc.gov accessed 5/30/2006
5. Rennie, Stuart and Fieda Behets, "AIDS Care and Treatment in Sub-Saharan Africa," Hastings Center Report 36 (2006): 25-31.
6. DeCock, Devin, M., Rebecca Bunnell, and Jonathan Mermin, "Unfinished Business – Expanding HIV Testing in Developing Countries," New England Journal of Medicine 354 (2006): 440-442.
7. CEDAW "Turning the Tide" United National Development Fund for Women @ www.unifem.undp.org
8. Garcia-Moreno, Claudia, Lori Heise, Henrica A.G.M. Jansen, Mary Ellsberg, Charlotte Watts, "Violence Against Women," Science 310 (2005): 1282-1283.
9. Marks, G., Crepaz, N., Senterfitt, J.W. Janssen, R.S. "Meta-analysis of High Risk Sexual Behavior in Persons Aware and Unaware they are Infected with HIV in the United States: Implications for HIV prevention Programs," Journal Acquired Immune Deficiency Syndrome 39 (2005): 446-453.
10. Bunch, Charlotte, "Women's Rights as Human Rights: Toward a Re-vision of Human Rights, pp 77-82 In: Larry May, Shari Collins-Chobanian, Kai Wong, (eds) *Applied Ethics: A Multicultural Approach*, 3rd Edition, Upper Saddle River: Prentice Hall, 2002.
11. "Economic Security for Women Fights AIDS, Global Coalition on Women and AIDS" www.womenandaids.org

12. www.unfpa.org "Media Advisory: the 2006 high level meeting on AIDS," UNFPA highlights increased feminization of HIV/AIDS access, 5/30/2006.
13. "Double Standards: Women's Property Rights Violations in Kenya," vol 15 # 5 March 2003; "Kenya's unfinished democracy: A Human Rights agenda for the new government" Vol 14 #10, Dec. 2002 @ www.hrw.org.
14. Wright, Alexi A, and Ingrid T. Katz, "Home Testing for HIV," *New England Journal of Medicine* 354 (2005) 5.
15. Schefers, Sarah, "Educating the Next Generation about HIV/AIDS, Where have we gone wrong?" Honors Paper, Hood College, 2005.
16. www.global-campaign.org/about_microbicides.htm
17. www.ipm-microbicides.org/research/English/screening.htm
18. www.oar.nih.gov/public/pubs/fy2007/VI_Microbicides.pdf
19. www.arhp.org/files/microbicidesfactsheet.pdf
20. Michael M. Lederman, Robin E. Offord, and Oliver Hartley, "Microbicides and Other Topical Strategies to Prevent Vaginal Transmission of HIV," *Nature Reviews Immunology* 6 (2006): 371-382.
21. Global Campaign for Microbicides - www.global-campaign.org/un aids.htm.
22. UNAIDS, "HIV Infection Rates Decreasing in Several Countries but Global Number of People Living with HIV Continues to Rise" Nov. 2005, www.unaids.org
23. International Community of Women Living with HIV/AIDS www.icw.org
24. Emma Bell, "Advocacy Training by the International Community of Women Living with HIV/AIDS," *Gender and Development* 13 (2005):70-79
25. Kittay, Eva, *Love's Labor: Essays on Women, Equality, and Dependency*, New York: Routledge Press, 1999.
26. Alex John London, "Justice and Human Development," *Hastings Center Report* 35 (2005): 24-37.
27. Desmond Tutu, *No Future Without Forgiveness*, New York: Doubleday, 1999, p45.

Corporate social responsibility, human rights and pharmaceutical companies

- Silvie Poeth

Master in International Law, Maastricht University, The Netherlands; RUSHSAP, UNESCO Bangkok, 920 Sukhumvit Rd, Prakanong 10110, Bangkok, Thailand
Email: s.poeth@unescobkk.org

Abstract

Pharmaceutical corporations are important actors that can have great influence on access to medicines. Although, their first and primary goal is to achieve as much profit as possible, the perspective on the role that companies should play in society has changed. In this context, an important development is the concept of corporate social responsibility (CSR). Within their respective spheres of profit-driven activity and influence, pharmaceutical companies increasingly take into account human rights. They have developed internal codes of conduct and signed several international guidelines and standards. In this paper, the activities of three pharmaceutical companies towards accessibility and availability of AIDS medicines have been explored through analysing their websites and reports. It shows to what extent these pharmaceutical companies take into account human rights and whether they comply with it through corporate social responsibility (CSR).

Introduction

As a result of the expansion of trade and finance and the liberalisation of national and international markets over the

past decades, multinational corporations and financial institutions have ever greater influence over global society. This development together has been aided by progress made in science, technology and communication, and has led to *globalisation*.² So to speak, the world has become our backyard.

Globalisation has positive as well as negative impacts. The enhancement of free trade leads to progress in social welfare. On the other hand, uncontrolled economic growth increases the gap between the rich and the poor, and reinforces the inequalities between developing and developed countries. Multinational corporations, such as pharmaceutical companies, play an important role in the process of globalisation. Many belong to the world's largest corporations that often have annual revenues greater than the Gross Domestic Product (GDP) of many developing countries in the world.

These companies have an enormous economic power and are in the position to influence States and their public health policy in a matter that can affect the respect for and protection of human rights in a negative way. For example, due to pressure of the pharmaceutical industry, the free trade agreements between the US and some developing countries contain TRIPS-plus provisions, which set a higher standard of patent protection. This arguably can impede access to medicines and thereby affects the public health situation in developing countries.³

The former Secretary-General of the United Nations, Kofi Annan, also repeatedly articulated the need to recognize the fact that, in addition to possibilities of globalisation to improve human life, the process also threatens the enjoyment of human rights.⁴ The above mentioned globalisation has led to a different view on expected behaviour for corporations and to corporate social responsibility (CSR).⁵

The concept of corporate social responsibility

Although profit still remains an important goal for corporations, only financial achievements will no longer be sufficient, as for example Nike experienced when it was discovered that children in developing countries made Nike's shoes under poor conditions. Because of several of these incidents, companies started to rethink their attitudes towards society.⁶ The way, in which companies achieve their goals, increasingly plays a role in the appreciation and public trust a corporation receives in society. In this regard, the concept of CSR received more attention.

The concept of CSR is described as the development that companies should integrate specific social and ethical interests, such as compliance with human rights and the care for the environment, in their business objectives. CSR aims to

² N. Jägers, *Corporate human rights obligations: in search of accountability*, Antwerp/Oxford/New York: Intersentia 2002, School of Human Rights Research Vol. 17, p. 1

³ More often, the pharmaceutical industry is lobbying the government to use its immense lobbying and trading power to let countries sign TRIPS-plus agreements in bilateral or regional "free trade agreements" (FTA). In these FTA's, countries are pressed by the US to sign intellectual property rights commitments that go far beyond the minimum standard required under TRIPS. For instance, TRIPS-plus legislation can contain a provision that extends the minimum 20 years' patent protection.

⁴ Preliminary report of the Secretary-General of the United Nations, *Globalisation and its impact on the full enjoyment of all human right*, UN Doc.A/55/342, 31 august 2000.

⁵ One must keep in mind that there are still companies, which are not socially conscious or at least do not act in that way. For more information see <http://www.business-humanrights.org>.

⁶ See controversial activities of Shell in Nigeria and British Petroleum in Colombia, Human Rights Watch reports, available at www.hrw.org/advocacy/corporations/colombia and <http://www.hrw.org/advocacy/corporations/index.htm>.

find a fair balance between the three P's: profit, people and planet. The three P's indicate the care for business, environment and society.⁷ If a company takes these aspects into account, it leads to more social appreciation and in the end also to more economic benefits and further growth.⁸ As a result, companies developed a broader policy.

As part of this policy, most pharmaceutical corporations have adopted an *internal code of conduct*, which prescribes certain standards of corporate behaviour. Although they differ from company to company, in general, they deal with all kind of issues such as the conduct of their employees (corporate citizenship), the policy towards stakeholders, suppliers and key business partners, marketing practices, safety, health and environmental protection, the behaviour in competition, respect for local laws, but also human rights. The codes can be qualified as "soft-law" as they are voluntary and non-binding. In this regard, it may seem tempting to ignore the requirements of one's own code when serious profits are at stake. However, non-compliance with the codes can have negative effects for companies, such as reputation damage.⁹

International guidelines/recommendations

At the international level, certain non-binding guidelines and standards also have been developed which can be applied to regulate the activities of pharmaceutical corporations.

Universal Declaration of Human Rights

The Universal Declaration of Human Rights (UDHR) is cited in many corporate responsibility codes and principles as a basic standard. It enshrines the concept of human rights and is addressed to "every individual and every organ of society".¹⁰ There have been several interpretations of this sentence, but in general it is argued that it urges business to comply with the UDHR. Although the UDHR is not legally binding, it is accepted as customary international law.¹¹

UN Global Compact

The UN Global Compact is an initiative of UN Secretary-General, Kofi Annan, and was launched in July 2000.¹² It is seen as the first initiative taken by the UN in the field of

human rights and corporate social responsibility. The UN Global Compact consists of nine principles in three areas: environment, human rights and labour standards. The first two principles deal with human rights and set out that businesses should "support and respect the protection of internationally proclaimed human rights within their sphere of influence" and "make sure that they are not complicit in human rights abuses."¹³ Its aim is to "mainstream the nine principles in business activities around the world and to catalyse actions in support of UN goals."¹⁴ The UN Global Compact is a voluntary initiative and should not be seen as a binding document.

OECD

The Organisation for Economic Co-Operation and Development's guidelines for multinational corporations ("the OECD Guidelines")¹⁵ are among the most comprehensive of corporate responsibility tools and were first promulgated in 1977. The OECD promotes policies that contribute to economic growth and development. As stated in the OECD Guidelines, "the Guidelines are recommendations addressed by governments to multinational enterprises. They provide voluntary principles and standards for responsible business behaviour."¹⁶

The OECD Guidelines have made a significant contribution to CSR by developing several CR-related principles. The Guidelines specify a minimum set of principles that multinationals should strive to achieve on a range of rights, including human rights. In 2000 the OECD Guidelines were revised in which explicit reference was made to human rights. It now obliges corporations to "respect the human rights of those affected by their activities consistent with the host government's international obligations and commitments."¹⁷ It also encourages corporations to contribute to economic and social progress.

ILO

The International Labour Organization is an UN specialized agency which was established in 1919. It focuses on international labour standards to further social policy, human rights and labour rights. The ILO formulates international labour standards in the form of Conventions and Recommendations setting minimum standards for basic labour rights. The Tripartite Declaration of Principles concerning Multinational Enterprises and Social Policy (ILO Declaration) was launched in 1977 and aims to "encourage the positive contribution which multinational enterprises can make to economic and social progress."¹⁸ It recommends that governments and multinational corporations operating in Member States observe a set of principles, relating mostly to employment practices.¹⁹ The ILO Declaration also calls on multinationals to respect the Bill of Rights.²⁰

Universal Declaration on Bioethics and Human Rights

Article 14 of the Universal Declaration on Bioethics and Human Rights from UNESCO in 2005 is on social responsibility and health. It stresses that "progress in science

⁷ T.E. Lambooy, 'De problematiek van het maatschappelijk verantwoord ondernemen en corporate governance', in *Maatschappelijk Verantwoord Ondernemen: Corporate Social Responsibility in a transnational perspective*, J.J.A. Hamers, C.A. Schwarz and B.T.M. Steins Bisschop, Intensia 2005, p. 53, 58.

⁸ Heineken, a Dutch brewery, provides long-life aids-treatment to its employees, their wives and their children. While the costs are relatively low, the financial benefits are enormous. For example, the brewery has to train less new people, as less employees die of Aids. Also, HIV-infected employees are less absent due to aids-medicines. Alongside the fact that aids-treatment is beneficial to the labour market, it is also beneficial for the market as such. Not only do you need people to produce beer, you also need people to drink beer. In that regard, the social appreciation of consumers also plays an important role. It is thus in the interest of Heineken to have a comprehensive aids-policy. One could also say that it is part of good entrepreneurship. See *Volkskrant*, 'Aids maakt ook je markt kapot, Bierconcern Heineken geldt als voorbeeld voor bedrijven in strijd tegen aids', 16 August 2006, p. 7.

⁹ K. Hermans, 'Enforcement of corporate governance', in: *Maatschappelijk Verantwoord Ondernemen: Corporate Social Responsibility in a transnational perspective*, J.J.A. Hamers, C.A. Schwarz and B.T.M. Steins Bisschop, Intensia 2005, p. 42. A recent article in the *Volkskrant* underlines this as well, see *Volkskrant*, 'Apple in verlegenheid door iPod-fabrieken in China', 16 June 2006.

¹⁰ See Preamble of the *Universal Declaration of Human Rights*, available at www.udhr.org.

¹¹ D. Leipziger, *The corporate responsibility code book*, Greenleaf Publishing Limited, Sheffield (2003), p. 86.

¹² UN Global Compact, available at www.unglobalcompact.org. Also see Speech made by the UN Secretary-General, Kofi Annan, at the World Economic Forum in Davos, Switzerland, 31 January 1999, see www.un.org/News/Press/docs/1999/19990201.sgsm6881.html.

¹³ UN Global Compact, available at www.unglobalcompact.org.

¹⁴ Idem.

¹⁵ See Organisation for Economic Co-Operation and Development's, the OECD Guidelines for Multinational Enterprises (hereinafter OECD Guidelines), available at www.oecd.org.

¹⁶ Idem.

¹⁷ Organization for Economic Co-Operation and Development, *The OECD Guidelines for Multinational Enterprises: Revision 2000* (2000), II.2, available at www.oecd.org. See also Ferreira, p. 1168.

¹⁸ Preamble of Tripartite Declaration under 2, available at <http://www.ilo.org/ilolex/cgi-bin/lex/pdconv.pl?host=status01&textbase=iloeng&document=2&chapter=28&query=declaration&querytype=bool>.

¹⁹ See Tripartite Declaration, under 7.

²⁰ See Tripartite Declaration, under 8.

and technology should advance: (a) access to quality health care and essential medicines, especially for the health of women and children, because health is essential to life itself and must be considered to be a social and human good, (b) access to adequate nutrition and water; (c) improvement of living conditions and the environment; (d) elimination of the marginalization and the exclusion of persons on the basis of any grounds; (e) reduction of poverty and illiteracy". This is a reaffirmation of the responsibilities of states to maintain a quality of life for their citizens, but can be applied to other bodies who possess means and methods to improve the lives of persons.

There is also article 15 on benefit sharing, which is important in the context of sharing science and technology, and the fruits of research, with others who do not have the capacity including national infrastructure to conduct the research.

UN Sub-Commission on the Promotion and Protection of Human Rights

The most important guideline in the context of this paper are the Norms on Responsibilities of Transnational Corporations and Other Business Enterprises with regard to Human Rights (hereinafter Norms).²¹ It outlines thirteen different norms in all kinds of economic activities and contains a Commentary to clarify the interpretation of the Norms. The Norms reaffirm that States still bear the primary responsibility for promoting and protecting human rights, but recognize that transnational corporations and other businesses, as organs of society, carry responsibilities as well. The first Article states that the responsibilities apply to businesses "within their respective spheres of activity and influence." Of special importance is Article 12 of the Norms, which states that companies "shall respect economic, social and cultural rights ... and contribute to their realization, in particular the rights to ... the highest attainable standard of physical and mental health, and shall refrain from actions which obstruct or impede the realisation of those rights." The Norms contain a comprehensive overview, developed by the UN Working Group on the Working Methods and Activities of Transnational Corporations, which are part of the UN Sub-Commission on the Promotion and Protection of Human Rights (hereinafter the Sub-Commission). The Sub-Commission is a body of independent human rights experts, who are elected from all regions of the world by the UN Commission on Human Rights (hereinafter CHR), which oversees the Sub-Commission's work. The Sub-Commission adopted the Norms in August 2003 in its resolution 2003/16 and transmitted them to the CHR for information and consideration.²² The adoption of the Norms by the CHR would strengthen the legal effect, as the CHR is a formal UN Body, composed of governments.

The international guidelines mentioned above are not binding and internal codes are only a self-regulating mechanism. In so far, they are of relative value. However, they do provide some guidance on how corporations should behave. In fact, one can discover a trend towards more responsibilities for corporations. While the UN Global Compact and the OECD Guidelines state that business

should "support and respect" the protection of human rights and "encourages corporations to contribute to economic and social progress", the Norms set out that companies shall *contribute to the realisation* of economic, social and cultural rights. Thus, the Norms incorporate and encourage further evolution of human right standards in business policies. A confirmation of this trend can also be found in the fact that the Norms discuss how they can be implemented by businesses themselves through monitoring, establishing avenues for workers to file complaints and making periodic reports.²³ Finally, another indication for this trend is the adoption of the resolution by the CHR and the appointment in July 2005 of the Special Representative of the UN Secretary General on business and human rights. The Special Representative has been mandated to identify standards of corporate accountability for businesses; elaborate on the role of States in effectively regulating the role of business, including through international co-operation; and compile a compendium of best practices of states and businesses.²⁴

Below I will examine whether pharmaceutical companies refer to any of the above mentioned guidelines, and comment on the CSR activities of three particular pharmaceutical companies.

CSR in practice

On particular websites, and through annual reports and press releases of pharmaceutical companies one can examine how they acknowledge their social responsibility. On the basis of their size, and to illustrate corporations with headquarters in different countries, the following three international pharmaceutical companies were selected and analysed.

GlaxoSmithKline

One of the world's largest research-based pharmaceutical companies is **GlaxoSmithKline** (GSK). It has its headquarter in the UK and operations in 119 countries with over 100,000 employees. GSK has an estimated seven per cent of the world's pharmaceutical market. The turnover in 2005 was £21.6 billion (US\$37.6 billion) and the profit after taxation was £4.8 billion (US\$ 8.4 billion). The company invested £3.1 billion (US\$5.6 billion) in R&D in 2005.²⁵ These figures give insight to the enormous economic power and therefore the great influence GSK has.

On their website is a special link to "responsibility" where we can find information on activities taken in the field of CSR. The section outlines the values and policies that GSK takes to act as a responsible company and to ensure that their business decisions take account of ethical, social and environmental concerns. The latest GSK's Corporate Responsibility Report sets out the company's performances towards human rights, access to medicines and community investment in 2005. In order to improve access to aids-medicines, GSK has entered into new collaborations to develop innovative vaccines for HIV/Aids patients. It has also sent 126 million preferentially priced tablets for HIV/Aids to developing countries. In addition, five voluntary licences were granted for the manufacture and supply of generic versions of their antiretroviral medicines in South Africa. GSK also supports public and community health initiatives in developing countries through donations of preventative medicines and,

²¹ Sub-Commission on the Promotion and Protection of Human Rights, *Norms on Responsibilities of Transnational Corporations and Other Business Enterprises with regard to Human Rights*, UN Doc.E/CN.4/Sub.2/2003/12/Rev.2 (2003), available at [http://www.unhcr.ch/huridocda/huridoca.nsf/\(Symbol\)/E.CN.4.Sub.2.2003.12.Rev.2.En?Opendocument](http://www.unhcr.ch/huridocda/huridoca.nsf/(Symbol)/E.CN.4.Sub.2.2003.12.Rev.2.En?Opendocument).

²² Sub-Commission on the Promotion and Protection of Human Rights, *Responsibilities of Transnational Corporations and Other Business Enterprises with regard to Human Rights*, Resolution 2003/16, UN Doc.E/CN.4/Sub.2/2003/L.11 (2003).

²³ D. Weissbrodt and M. Kruger, Current developments: Norms on Responsibilities of transnational corporations and other business enterprises with regard to Human Rights, *97 American Journal of International Law* 901, Vol. 97, 2003, p. 915, 916.

²⁴ Resolution 2005/69 of the United Nations Commission on Human Rights.

²⁵ Annual Report GSK 2005, published 3 March 2006, available at http://www.gsk.com/responsibility/cr_report_2005/index.htm.

financial and practical support. Through public-private partnerships GSK brings together different partners to address health problems in developing countries. An example of this is the Accelerating Access Initiative (AAI), a partnership between UNAIDS, WHO, World Bank, UNICEF and UNFPA and seven research-based pharmaceutical companies, which was launched in 2000.

Pfizer

Another large pharmaceutical company is **Pfizer**, which has its headquarter in New York, USA. The company employs more than 115,000 people in 180 countries. In 2005 their revenues were US\$ 51.3 billion and the profit after taxes were US\$ 8.1 billion. Pfizer invested US\$ 7.4 billion on R&D.²⁶ In the field of CSR, Pfizer is committed to a few special programs to help ensure access to medicines. One of these programs concerns the prevention of HIV/Aids globally, the *International HIV/Aids Grants*. Since 2002, Pfizer has awarded more than US\$ 2 million in grant funds to support international organisations working in HIV/Aids in developing countries. Pfizer is also committed to the *Southern HIV/Aids Prevention Initiative*, which has strengthened the capacity of community-based organizations to reach and serve their communities. In this regard, Pfizer has donated US\$3 million over three years in the US.²⁷ In the *Diflucan® Partnership Program*, Pfizer donated the aids-medicine Diflucan through governments and NGO's in developing countries. On the basis of this program, it provided this medicine in South Africa. As of April 2004, Pfizer has extended the Diflucan Partnership Program to include 18 other African countries, as well as Haiti, Cambodia and Honduras. The company has also expanded the eligibility criteria for the program to include all developing countries with an HIV/Aids prevalence of greater than 1 percent. Pfizer has committed \$110 million to the program, has distributed more than 7 million free doses of Diflucan and trained more than 20,000 healthcare workers.²⁸ Hence, Pfizer does pay special attention to the problem of access to medicines for the poor. However, Pfizer does not address human rights issues specifically and rather views them from a corporate citizenship perspective, in which they are, for example, committed to the development of and implementation of HIV/Aids in the workplace policy only.²⁹

Boehringer-Ingelheim

Boehringer-Ingelheim is headquartered in Ingelheim, Germany, currently with 37,000 employees and affiliated companies in 88 countries. In 2005 it achieved the strongest growth of the top 20 pharmaceutical companies. Its net sales were € 9.5 billion and its income after taxes contained € 1.5 billion. The company invested € 1.4 billion on R&D. To improve access to aids-medicines Boehringer-Ingelheim supplies Viramune (Nevirapine) free of charge or at reduced prices to treat the transmission of HIV from mother to child during birth. They donate this product to some 140 programs in 60 countries and five voluntary licences have been granted to generic manufacturers in Africa. The company has also undertaken initiatives in South Africa as the "Turning the Tide" program to train and educate health professionals in HIV and the Student Education Programme in collaboration with the University of Cape Town, which provides their full financial support for medical students from disadvantaged backgrounds.³⁰ In addition, Boehringer-Ingelheim is one of the founders of the AAI as mentioned earlier. However, the

company does not frame its policy in terms of human rights, but mainly in vague terms, like "our caring culture", "our commitment", "for our people", "for our environment".³¹

Evaluation

It is remarkable that the websites are not very transparent, except the one of GSK that follows the most comprehensive CSR approach. In general, important issues such as health care, innovation, commitments and social responsibility are not clearly separated. Their business conduct is mainly focused on integrity towards the market, stakeholders, shareholders, employees and community. Special attention is drawn on workplace policy. The companies do mention concrete activities. For instance, cooperation with NGO's and special programs to train healthcare givers. They also have granted voluntary licences to several developing countries. However, we cannot exclude that this has been done due to competition and for economic reasons. In addition, they provide developing countries' patients or their employees and relatives with free or reduced priced, aids-medicines and financially support diverse health care programs. The problem is that it is difficult to measure the scope and effectiveness of these activities of corporations in relation to the whole of their economic and financial possibilities. Besides, it lacks a specific structural policy towards pricing of aids-medicines. In my opinion, their CSR view is often based on philanthropy, with the exception of labour relations and labour related issues. Investigating the sites of other pharmaceutical giants like Merck and Roche, one can come to the same conclusion.³²

One of the most interesting points is that the companies regard access to and pricing of medicines not as a specific human rights issue, but as a general social and ethical problem, which they have to solve together with other actors. They do not approach health care as a human right, but in their view human rights are the traditional rights such as the right to freedom of speech, the right to form a trade union and the right to freedom of religion.

Furthermore, although a growing number of pharmaceutical corporations refer to the UDHR and have committed themselves to the UN Global Compact,³³ the websites do not refer to the Norms. To take these Norms into account would be a meaningful step forward in identifying clearer boundaries for business responsibilities. Let us examine how this links to rights.

Vertical and horizontal applicability of human rights

The norms of human rights have evolved over considerable time, although the UDHR was a significant stimulus for global acceptance of these norms. In the past few centuries, human rights have been increasingly applied in the public sphere, where States are the primary duty bearers and have the responsibility to respect, to protect and to fulfil human rights obligations. The reason for this can be found in the view that the relationship between the State and the individual involves unequal power. Individuals need to be protected from the stronger, more powerful party, the State. This has been qualified as vertical applicability, *i.e.* the individual has rights *vis-à-vis* the State. Because of globalisation, this traditional perspective has changed in

²⁶ 2005 Annual Report, published 23 February 2006, available at http://www.pfizer.com/pfizer/are/investors_reports/index.jsp.

²⁷ 2005 Pfizer Corporate Citizenship Report, p. 22. See http://www.pfizer.com/pfizer/subsites/corporate_citizenship/report/cc_report_2005.pdf.

²⁸ *Idem*, p. 18.

²⁹ *Idem*, p. 13.

³⁰ See http://www.boehringer-ingelheim.com/wecare/en/subpages/worldwide_southafrica.htm.

³¹ See *Annual Report 2005*, published 15 February 2006, available at http://www.boehringer-ingelheim.com/corporate/news/publication_download.htm.

³² It is interesting to mention SOMO, a non-profit research- and advice agency. SOMO examines the consequences of business policy and behaviour of multinational corporations on developing countries. In this regard, it has also done research on CSR policies of pharmaceutical companies. See www.somo.nl.

³³ For examples, see the websites of www.gsk.com, www.merck.com and www.roche.com. Also see <http://www.business-humanrights.org/Categories/CompanyPolicySteps/CompaniesWithHumanRightsPolicies> for a list of companies referring to the UDHR.

contemporary society.³⁴ As examined by some authors,³⁵ human rights can also be applicable in horizontal relations, in other words, between private parties. Illustrative is the preamble of the UDHR, which provides that the rights in the Declaration apply to “every individual and every organ of society”.³⁶ According to Jägers, the general provisions laid down in the UDHR do not stand in the way of horizontal applicability.³⁷ It depends on the object and nature of the right whether it has horizontal reach. Studies of Jägers and Chirwa, who analysed the provisions of certain human rights conventions, further demonstrate that in this respect, the right to health and the right to life can be applied in horizontal relations.³⁸ An argument in favor of this opinion regarding the right to health can also be found in the General Comment No. 14 in which the ICESCR Committee explicitly states: “While only States are parties to the Covenant and thus ultimately accountable for compliance with it, all members of society - ... as the private business sector- have responsibilities regarding the realization of right to health.”³⁹

If the right to health and the right to life can be applied to corporations, the question is whether a parallel can be drawn between their position and those of States regarding human rights obligations. Do corporations have such obligations in the same way as states have and can individuals enforce their human rights against these corporations? If this would be the case, one could speak of horizontal applicability. Below I will deal with this question.

Obligations vs. Responsibilities of pharmaceutical corporations

It is important to distinguish between negative obligations, positive obligations and responsibilities. Contrary to negative/positive obligations, responsibilities do not create a strict legal obligation. States are the primary bearers of human rights and have both negative and positive obligations in that regard. It can be argued that not only States, but also companies have at least a negative obligation to respect human rights. On the one hand, this can be deduced from case law. In the Grootboom-case, the Constitutional Court held that in the context of the right to access to adequate housing, that there exists “at the very least, a negative obligation upon the State and all other entities and persons to desist from preventing or impairing the right to access to adequate housing”.⁴⁰ A parallel can be drawn with the right to health. On the other hand, it is also possible to imply a negative obligation for companies through the exercise by the State of the obligation to protect citizens. The discharge of the obligation to protect may require companies to refrain from interfering in the enjoyment of the right to health.⁴¹ Corporations need to abstain from actions that may cause a violation of human rights. If they fail to do so, the State has the obligation to take necessary steps to bring about this compliance.⁴² Following that compliance by companies in

advance could be seen as a progressive development of the law.

The key question, however, is whether pharmaceutical companies also have positive obligations. While the obligation to respect is negative in nature, the obligations “to protect” and “to fulfil” require positive action on the part of the bearer. However, it has not yet been recognised under international human rights law that corporations have to take positive action. No legal basis can be found for that. The most important indication that companies do not have positive obligations can be found in General Comment No. 14 paragraph 42. States are held primary “accountable” and the private business sector, among other “members of society”, (only) has “responsibilities (and not obligations) regarding the realisation” of the right to health. An argument can also be found in the enforceability of those obligations. International law does not go that far yet that non-compliance with positive obligations “to protect” and “to fulfil” by pharmaceutical companies can be invoked against them before an international court or supervisory body.⁴³ Moreover, it is already difficult to enforce negative obligations of corporations.⁴⁴

States also have a certain margin of discretion regarding their positive obligations. If States have this margin, it is likely to assume that corporations also have a margin and that the positive “obligations” they have are rather weak. Different countries have a different level of development and abilities towards the enjoyment of human rights. Because of that, their view towards the priorities of each of these rights could differ. Therefore, there is no general standard of the positive human rights “obligations” they have to comply with. The absence of such a standard is also an argument to assume that corporations do not have such obligations at the moment.

To summarise, from an international perspective, pharmaceutical companies are obliged to comply with the negative obligations of human rights. But with regard to the positive human rights obligations the situation is rather diffuse since most see corporations only having responsibilities regarding the realisation of human rights instead of strict legal obligations. The responsibilities could be seen as moral and decent obligations, which only lead to a public accountability to comply with human rights.

Positive trends towards social and ethical behaviour

In so far, this may sound somewhat pessimistic but, fortunately, we see a development towards an extension of these responsibilities. Several initiatives are worthwhile to mention with regard to a greater attention for business and human rights. For instance, the Business & Human Rights Resource Centre is an independent, international, non-profit organisation, in a collaborative partnership with Amnesty International sections and leading academic institutions. It promotes greater awareness and informed discussion of important issues relating to business and human rights. Another global non-profit organisation is Ashoka. It invests in social entrepreneurs around the world in relation to human rights to solve large-scale social problems. Also, the Business Leaders Initiative on Human Rights, is an initiative of several companies to find practical ways of implementing human rights in their business policy.⁴⁵ Furthermore, media attention and court cases have led to the granting of several

³⁴ Jägers, p. 36.

³⁵ See Jägers, Chirwa, Coomans and Vlemminx.

³⁶ Universal Declaration of Human Rights, adopted and proclaimed by the General Assembly resolution 217 A (III) of 10 December 1948.

³⁷ Jägers, p. 40.

³⁸ Chirwa D.M., ‘The right to health in international law: its implications for the obligations of state and non-state actors in ensuring access to essential medicines’, 19 SAJHR (2003), p. 562.

³⁹ General Comment No. 14, paragraph 42. (Emphasis added)

⁴⁰ *Government of the Republic of South Africa v. Grootboom*, 2001 (1) SA 46 (CC), paragraph 46.

⁴¹ D.M. Chirwa, p. 562.

⁴² General Comment No. 14, paragraph 39. See also A.P.M. Coomans and F. Vlemminx, Als men de vos niet vangen wil, kan men geen honden vinden; de mensenrechtelijke aspecten van de zaak Vos BV, in: Niet-staatelijke actoren en de rechten van de mens : gevestigde waarden, nieuwe wegen, C. Flinterman, W. Van

Genugten, Schoordijk Instituut, Onderzoekschool Rechten van de Mens, Den Haag (2003), p. 61, 64.

⁴³ Jägers, p. 38.

⁴⁴ Coomans and Vlemminx, p. 58, 64.

⁴⁵ See <http://www.business-humanrights.org>, <http://www.ashoka.org/home/index.cfm> and <http://www.blihr.org/human.htm>.

compulsory licenses by pharmaceutical companies themselves.⁴⁶

Another development can be found in jurisprudence on corporate law, in so far, that the codes of conduct, although voluntary, are often used as a frame of reference for judgements about good governance and in the broader interpretation of reasonableness, fairness and competition.⁴⁷ I refer to the case of *Abdullahi versus Pfizer* of the US Court of Appeal, which concerned the testing of an experimental drug for children suffering from bacterial meningitis in Nigeria.⁴⁸ Although the case was dismissed on the basis of *forum non conveniens*, it showed that compliance with the international guidelines might be relevant for determining liability for injuries caused by companies.

Furthermore, we see that more attention is paid to the responsibilities corporations have in civil law. Also, more recent, the *Fortis Bank versus Stichting Volendam* case of the Supreme Court of the Netherlands.⁴⁹ In this case, the Supreme Court stated that companies with a social position in society within their business activities not only have to take into account the interests of their counterparts to avoid accountability, but also those of third parties who are affected by the activities the companies undertake. A similar development can be found in EU law. Although corporations are granted patent rights, this does not mean that they can use these rights without any limitation. Since corporations have responsibilities regarding the realisation of human rights, misuse or abuse of a patent right could under certain circumstances be seen as an infringement of those human rights.⁵⁰

Finally, with regard to the responsibilities of pharmaceutical companies, one can draw a parallel with the ethical and moral "natural obligations" in civil law.⁵¹ These obligations are not enforceable, but once a corporation has taken up a moral obligation, it can become judicial relevant since it can be seen as a compliance with an acquirement of a third party. In this context, when corporations refer to international guidelines, these can be seen as natural obligations they have accepted.

Conclusion

Globalisation has led to the thought that not only States, but also other actors can play an important role with regard to the promotion and protection of human rights. In this setting, pharmaceutical companies have become more socially conscious and have started to develop internal non-binding guidelines. Also at the international level CSR got more attention and several international guidelines and standards were drafted. In this regard, the Norms on Responsibilities of Transnational Corporations and Other Business Enterprises with regard to Human Rights, although not binding, are the most important and set out a trend towards more human rights responsibilities for corporations. The analyses of three

pharmaceutical companies show how they have implemented CSR in their policy. In general, they are more focused on the traditional human rights. Although, we do see some development, their business policy lacks a clear and more fundamental view with regard to access to aids-medicines. There is still the impression that their policy is based on philanthropy. Corporations have to respect human rights and States have to ensure that they do not violate these rights. This already is a difficult task.⁵²

From an *international* perspective, the extent of the *positive* obligations of pharmaceutical companies to protect and to fulfil human rights is still diffuse, since they only have responsibilities. Yet, there are developments at a domestic level as we see a positive trend in corporate and civil law towards a further extension and elaboration of responsibilities of corporations. Though, it is not easy to oblige corporations from a legal point of view, ethically there is no way out.

Further reading list:

Books:

- Hamers J.J.A., Schwarz C.A. and Stein Bisschops B.T.M. (eds.), *Maatschappelijk Verantwoord Ondernemen: Corporate Social Responsibility in a Transnational Perspective*, Antwerp/Oxford/New York, Intersentia, 2005.
- Jägers N.M.C.P., *Corporate human rights obligations: in search of accountability*, School of Human Rights Research Vol. 17, Antwerp/Oxford/New York: Intersentia, 2002.
- Leipzig D., *The corporate responsibility code book*, Greenleaf Publishing Limited, Sheffield (2003).
- Toebes B.C.A., *The right to health as a human right in International Law*, School of Human Rights Research Series Vol. 1, Antwerpen/Groningen/Oxford, 1999.

Articles:

- Chirwa D.M., 'The right to health in international law: its implications for the obligations of state and non-state actors in ensuring access to essential medicines', *19 SAJHR* (2003), pp. 541-566.
- Coomans A.P.M. and Vlemminx F., 'Als men de vos niet vangen wil, kan men geen honden vinden: de mensenrechtelijke aspecten van de zaak Vos BV', in: *Niet-statelijke actoren en de rechten van de mens: gevestigde waarden, nieuwe wegen*, C. Flinterman, W. Van Genugten, Schoordijk Instituut, Onderzoekschool Rechten van de Mens, Den Haag (2003), pp. 51-65.
- Davies C.R., 'Glaxo Group Ltd v Dowellhurst and Taylor: What future for altruism in the pharmaceutical industry?', *EIPR issue 10*, Sweet & Maxwell limited.
- Ferreira L., 'Access to affordable HIV/Aids drugs: the human rights obligations of multinational pharmaceutical corporations', *Fordham Law review* 1133, (December 2002), pp. 1133-1179.
- Hermans K., 'Enforcement of corporate governance', in: *Maatschappelijk Verantwoord Ondernemen: Corporate Social Responsibility in a transnational perspective*, J.J.A. Hamers, C.A. Schwarz and B.T.M. Steins Bisschop, Intersentia 2005, pp. 41-51.
- H.V. Hogerzeil, 'Essential medicines and human rights: what can they learn from each other?', in *Bulletin of the World Health Organization*, 84 (5), (May 2006), pp. 371-375.
- Joseph S., 'Pharmaceutical Corporations and access to drugs: The fourth wave of corporate human rights scrutiny', *25 Human Rights Quarterly* 425 (2003), pp. 425-452.
- Lambooy T.E., 'De problematiek van het maatschappelijk verantwoord ondernemen en corporate governance', in *Maatschappelijk Verantwoord Ondernemen: Corporate Social Responsibility in a transnational perspective*, J.J.A. Hamers, C.A. Schwarz and B.T.M. Steins Bisschop, Intersentia 2005, pp. 53-103.
- Lefebvre F., 'The World Intellectual Property Organization and the developing world', *The Courier* nr. 201 (Nov-Dec 2003), pp. 24-25.
- Love J., 'CPT Comment on South Africa's pharmaceutical legislation, Discusses parallel imports and health registration data, 6 October 1997, available at <http://www.cptech.org/pharm/sa/sa-10-97.html>.
- Medicines Sans Frontiers, 'Sources and prices of selected medicines and diagnostics for people living with HIV/Aids', A joint UNICEF, UNAIDS, WHO and MSF project, (June 2005).
- Treatment Action Campaign, 'An explanation of the Medicines Act and the implications of the Court Victory', 24 April 2001, available at

⁴⁶ *The pharmaceutical Manufacturers' Association of South Africa v the President of the Republic of South Africa, Mr. N.R. Mandela*, the High Court of South Africa, Case no. 4183/98. Also see, BBC News, *Aids Court Battle*: joint statement, 19 April 2001, available at <http://news.bbc.co.uk/1/hi/world/africa/1285645.stm>.

⁴⁷ Lambooy, p. 83-85.

⁴⁸ *Abdullahi versus Pfizer Inc.*, US Appeal, Case No. 01 Civ. 8118 (S.D.N.Y. 2002). Also see D. Weissbrodt, *Current developments: Norms on Responsibilities of transnational corporations and other business enterprises with regard to Human Rights*, *97 American Journal of International Law* 901, Vol. 97 (2003), p. 921.

⁴⁹ *Fortis Bank vs. Stichting Volendam*, The Supreme Court of the Netherlands, 23 December 2005, NJ 2006/289, see in particular the note of M.R. Mok.

⁵⁰ *Syfait and others v. GlaxoSmithKline*, Court of Justice of the EU, 31 May 2005, NJ 2006/252, nr. C-53/03, see in particular the note of M.R. Mok. Although the court finally decided that it was not competent, nevertheless the case also dealt with the pricing policy of GSK and the abuse of their monopoly position against others.

⁵¹ Art. 6:3 BW, Dutch Civil Code.

⁵² General Comment No. 14, paragraph 35, 39.

http://www.globaltreatmentaccess.org/content/press_releases/01/042401_TAC_S_lawsuitwin.html.

Weissbrodt D. and Kruger M., Current developments: Norms on Responsibilities of transnational corporations and other business enterprises with regard to Human Rights, *97 American Journal of International Law* 901, Vol. 97 (2003), pp. 901-922.

Wesson M., 'Grootboom and beyond: reassessing the socio-economic jurisprudence of the South African Constitutional Court', *20 SAJHR* (2004), pp. 284-308.

Yamin A.E., 'Not just a tragedy: access to medications as a right under international law', *Boston University International Law Journal* (2003), pp. 325-371.

Reports:

Annual Report Pfizer 2005, published 23 February 2006, available at http://www.pfizer.com/pfizer/are/investors_reports/index.jsp.

Annual Report GSK 2005, published 3 March 2006, available at http://www.gsk.com/responsibility/cr_report_2005/index.htm.

Pfizer Corporate Citizenship Report 2005, available at http://www.pfizer.com/corporate/subsites/corporate_citizenship/report/c_report_2005.pdf.

Annual Report Boehringer-Ingelheim 2005, published 15 February 2006, available at http://www.boehringer-ingelheim.com/corporate/news/publication_download.htm.

BBC News, Aids Court Battle: joint statement, 19 April 2001.

Convention on the Right of the Child, 20 November 1989, G.A. Res 44/25, U.N. GAOR, 44th Session, Supp. No. 49, at 167, U.N. Doc. A/44/49 (1989).

General Assembly of the United Nations, Declaration of Commitment on HIV/Aids ('Global Crisis – Global Action'), resolution A/RES/S – 26/2 (27 June 2001).

General Assembly of the United Nations, Follow-up to the outcome of the twenty-sixth special session: implementation of the Declaration of Commitment on HIV/AIDS, A/60/737, 24 March 2006.

General Assembly of the United Nations, Universal Declaration of Human Rights, resolution 217 A (III) of 10 December 1948.

CESCR, General Comment No. 3 (1990), The nature of State parties obligations, 5th Session, 14 December 1990.

CESCR, General Comment No.4 (1991), The right to adequate housing, 6th Session, 13 December 1991.

CCPR, General Comment No. 6, The right to life, 16th Session, 30 March 1982.

CESCR, General Comment No. 14 (2000), The highest attainable standard of health, 20th Session, UN Doc. E/C.12/2000/4.

2006 High-level Meeting on Aids, uniting the world against aids, UN New York, 31 May-2 June, available at <http://www.un.org/ga/aidsmeeting2006/>.

International Bill of Human Rights, adopted and proclaimed by General Assembly resolution 217 A (III) of 10 December 1948.

International Guidelines on HIV/Aids and Human Rights, U.N. Doc. E/CN.4/1997/150 (1997), UNCHR res. 1997/33.

Office of the United Nations High Commissioner for Human Rights & Joint United Nations Programme on HIV/AIDS, 'HIV/AIDS and Human Rights: International Guidelines: Third International Consultation on HIV/AIDS and Human Rights', Geneva (2002).

Preliminary report of the Secretary-General of the United Nations, *Globalisation and its impact on the full enjoyment of all human right*, UN Doc.A/55/342, 31 august 2000.

Press Release, SG/SM/6881, Speech made by the UN Secretary-General, Kofi Annan, at the World Economic Forum in Davos, Switzerland, 31 January 1999.

Sub-Commission on the Promotion and Protection of Human Rights, Norms on Responsibilities of Transnational Corporations and Other Business Enterprises with regard to Human Rights, UN Doc.E/CN.4/Sub.2/2003/12/Rev.2 (2003).

Sub-Commission on the Promotion and Protection of Human Rights, Responsibilities of Transnational Corporations and Other Business Enterprises with regard to Human Rights, Resolution 2003/16, UN Doc.E/CN.4/Sub.2/2003/L.11 (2003).

Volkskrant, 'Apple in verlegenheid door iPod-fabrieken in China', 16 June 2006.

Volkskrant, 'Aids maakt ook je markt kapot, Bierconcern Heineken geldt als voorbeeld voor bedrijven in strijd tegen aids', 16 August 2006.

Case law:

Abdullahi versus Pfizer Inc., US Appeal, Case No. 01 Civ. 8118 (S.D.N.Y. 2002).

Fortis Bank vs. Stichting Volendam, The Supreme Court of the Netherlands, 23 December 2005, NJ 2006/289.

Government of the Republic of South Africa v. Grootboom, 2001 (1) SA 46 (CC).

Minister of Health and others (the Government) v. Treatment Action Campaign (TAC) and others, 2002 (5) SA 721 (CC).

Syfait and others v. GlaxoSmithKline, Court of Justice of the EU, 31 May 2005, NJ 2006/252, nr. C-53/03.

The pharmaceutical Manufacturers' Association of South Africa v the President of the Republic of South Africa, Mr. N.R. Mandela, the High Court of South Africa, Case no. 4183/98.

The Social and Economic Rights Action Center for Economic and Social Rights v. Nigeria, African Commission on Human and Peoples' Rights, Communication No. 155/96, October 2001.

Treatment Action Campaign (TAC) and others v. Minister of Health and others (the Government), South African Pretoria High Court, Case No. 21182/2001, 14 December 2001.

Websites:

<http://news.bbc.co.uk/1/hi/world/africa/826742.stm>

<http://www.business-humanrights.org>

<http://www.ashoka.org>

<http://www.blihr.org>

<http://www.hrw.org>

<http://www.unglobalcompact.org>

<http://www.udhr.org>

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IAB Genetics & Bioethics Network: On-line

The complete address list is updated on the Internet. Send all changes to Darryl Macer.

UNESCO Asia-Pacific School of Ethics

<http://www.unescobkk.org/index.php?id=4913>

EJAIB Editor: Darryl Macer

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Asian Bioethics Association (ABA)

The website for ABA is <eubios.info/ABA.htm>

ABA Membership for China (updated list from ABA Vice-President for China, Prof. Yanguang WANG)

Prof CHEN, Yuanfang,
Department of Medicine, Peking Union
Medical College Hospital, PUMC,
Beijing, PRC; Shuaifuyuan Hutong,
Dongchang District, Beijing 100730,
PRC
Email: chenyfPUMCH@hotmail.com

Prof CAO, Yongfu
Department of Medical Ethics, School of
Medicine, Shandong University, 44
Wenhua West Road, Jinan 250012,
Shandong Province, PRC
Email: cyongfu@sdu.edu.cn

Prof CHEN, Xiaoyang
School of Medicine, Shandong
University, 44 Wenhua Xi Road,
Jinan City, 250012, PRC
Email: chenxy@sdu.edu.cn

Dr CHENG, Xinyu
Institute of Medical Humanities,
Department of Social Science, Tongji
Medical College, 13 Hangkong Road,
Wuhan, 430030, PRC
Email: rosecheng22@hotmail.com

Prof CHEN, Yong
Tianjin Academy of Social Sciences, 7
YingShui Road, Nan Kai District, TianJin
300191, PRC.
Email: yongch12345@yahoo.com.cn

DENG, Rui
Department of the Humanities, Shanxi
Medical University
Shanxi Medical University, Taiyuan City
030001, Shanxi Province, PRC
Email: telefriendme@msn.com

Prof DONG, Yuzheng
Journal of Renzhichu, 2# Huanshidong,
Shuiyin Road, Guangzhou City 510075,
Guangdong Province, PRC
Email: dongyuzheng88@hotmail.com

DONG, Junmei
Department of Social Sciences,
Changzhi Medical College, Shanxi
Province, PRC; 46# Yanan South Road
Changzhi, Shanxi 046000, PRC
Email: dongjunmei6666@126.com

Dr. HAN, Yuehong
School of Law, Kunming University of
Science & Technology
256 Postbox Xinying Campus, Kunming
University of Science and Technology,
Kunming, Yunnan, 650051, CHINA
Email: hanyhong@public.km.yn.cn

HE, Jun
Beijing S & P Law Firm, Postbox 84-014,
Haidian District, Beijing 100084, PRC
Email: junehe_bj@hotmail.com

KE, Binzheng
Medical Association of Xicheng District,
Beijing, PRC
7. Xin Wenhua Street, Beijing 100031,
PRC
Email: kebinzheng0705@sina.com

Dr. LEI, Rui-Peng
Center for Bioethics, Department of
Philosophy, Huazhong University of
Science & Technology, 1037 Luoyu
Road, Wuhan, Hubei 430074, PRC
Email: lxp73615@163.com;
rlai@hsph.harvard.edu

Prof LI, Dun
Center for Contemporary China, Tsing
Hua University, Beijing, PRC; Room
0406, A1, Anxiang Road, Chaoyang
District, Beijing 100084, PRC
Email: lidun@vip.sina.com

Prof LI, Haiyan
Center for Bioethics, School of Political
Science and Public Administration,
Wuhan University, 430072, PRC
Email: LHY1111@126.com

Prof LEI, Jincheng
Department of Social Science,
Jiangxi Medical College,
603 Bayi Road, Nanchang City 330006,
PRC
Email: Leijincheng@Jxmu.edu.cn

Prof LI, Jining
Guangxi College of Public
Administration, Nanning, Guangxi
Province, PRC; 37# Taoyuan Road,
Nanning City, Guangxi Province, PRC
Email: ljn8494@sohu.com

Prof LI, Ruifeng
School of Liberal Arts, Law and
Economics, Wuhan University of
Science and Technology; 947# Heping
Avenue, Qingshan District, Wuhan,
Hubei Province, 430081, PRC
Email: ruiheng_li@sohu.com

LI, Zhonglin
Medical School, Zhengzhou University,
11, Building 8, Medical School
Apartments, No.40 Daxue Road,
Zhengzhou 450052, PRC
Email: lzh@zzu.edu.cn

LIANG, Li
Department of Social Science, Chengde
Medical College
6# Cuiqiao Road, Chengde City 067000,
Hebei Province, PRC
Email: liangli903@tom.com

LIANG, Lizhi
Faculty of Medical Humanities School of
Health, Administration and Education,
Capital Medical University
No.10 Xitoutiao, You An Men Beijing
100069, PRC
Email: lucyllz@163.com

Prof LIU, Xueli
Department of Social Sciences, Fudan
University
Handan Road, Shanghai 200433, PRC
Email: liuxueli@eastday.com

Shen Zhuang
School of Journalism, Fudan University,
220, Handan Road, Shanghai 200433,
PRC

Email: shenzhuangfd@hotmail.com

Prof LIU, Junrong
Division of Social Sciences, Guangzhou
Medical College
195 Dongfeng West Road, Guangzhou
510182, PRC
Email: jrliu229@sina.com

Prof LIU, Yingliang
Faculty of Civil Commercial Law,
Chinese University of Politics and Law,
Room 905, National Investment Building,
7 Fuchengmen Wai Street, Beijing
100037, PRC
Email: yinliangliu@hotmail.com

Dr MAO, Xinzhi
Center for Bioethics, Huazhong
University of Science and Technology,
Yujiashan, Wuhan 430074, PRC
Email: mxz835@sohu.com

Ng, Wai I (Milly)
Kiang Wu Nursing College of Macau
Rua Coelho Amaral, Hospital Kiang Wu,
Macau
Email: nwi@kwnc.edu.mo

QU, Xiaomin
Department of Social Sciences, Fudan
University
138#, Yixueyuan Road, Shanghai
200400, PRC
Tel: 86 21 64041900-2068

Prof. QIU, Ren-Zong
#2121, Building 9, Caoqiao Xinyuan 3
Qu, Beijing 100054, China
Email: rzq@chinaphs.org,
renzongqiu@sohu.com

Prof SHEN, Mingxian
Institute of Philosophy, Shanghai
Academy of Social Sciences
1610 West Zhongshan Road, Shanghai
200233, PRC
Email: Portia_shen@ccgate.asl.com

SHI, Xiaoya
Department of Social Sciences, Chinese
PLA General Hospital / Chinese PLA
Postgraduate Medical School; 28#
Fuxing Road, Beijing 100853, PRC
Email: shixybj2@sina.com

Prof SHI, Weixing
School of Medicine, Zhejiang University
353# Yan'an Road, Hangzhou City,
Zhejiang Province, PRC
Email: swx@zju.edu.cn

Ms. SUI, Suli
Center for Bioethics, Peking Union
Medical College, 5 Dongdan San Tiao,
Beijing 100005, PRC
Email: suisuli@hotmail.com

SUN, Lihong
Division of Social Science, Cheng De
Medical College, 6 Cui Qiao Road,
Cheng De City 067000, Hebei Province
PRC
Email: sunlihong120@sohu.com

Prof. WANG, Yanguang
Center for Applied Ethics, Chinese
Academy of Social Sciences, 5
Jianguomennei Avenue, Beijing 100732,
PRC
Email: ameliaw2002@hotmail.com;
ameliawyg@sohu.com

Prof WANG, Yuankun
Division of Social Sciences, Kunming
Medical College
191 Western Renmin Road, Kunming
650031, Yunman Province, PRC
Email: kathykmwyk@hotmail.com

Prof WANG, Zhijie
Organizing Department, Jinzhou Medical
College
No.40, Section 3, Songpo Road, Linghe
District, Jinzhou City 121001, Liaoning
Province, PRC
Email: zzxx2000@mail.PRC.com
wzhijie4158@mail.PRC.com

Prof WANG, Hongjie
School of the Humanities, Shanxi
Medical University, Taiyuan City 030001,
Shanxi Province, PRC
Email: xianline@public.ty.sx.cn;
telefriendme@msn.com

Dr. ZHOU, Hong
Apartment 102, Door 5, Building 8,
Anyuan dongli Area 1, Chaoyang
District, Beijing 100029, CHINA
Email zhouhong86@hotmail.com

Prof WANG, Liyu
Division of Social Science, PRC
Medical University
92# Bei Er Road, Heping District,
Shenyang City 110001, Liaoning
Province, PRC
Email: wangliyu072@yahoo.com.cn

Prof WENG, Zongyi
Guang Zhou Medical College, Center for
Medical Ethics of Guangdong Province,
195# Dongfeng Xi Road, Guangzhou
510182, PRC
Email: zongyiweng@msn.com

Prof WU, Tianzhang
Guangzhou Medical College, 195#
Dongfeng Xi Road, Guangzhou City
510182, Guangdong Province, PRC
Email: wutianzhang8134@sina.com

Prof. (Ms.) XIA, Guomei
Institute of Sociology, Shanghai
Academy of Social Sciences, 7 622
Lane, Huaihai Road(M), Shanghai
200020, PRC
Email: xiagm@online.sh.cn

Prof. (Ms.) XIAO, Wei
School of Humanities & Social Sciences,
Tsinghua University
Beijing 100084, CHINA
Email: xiaowei@mail.tsinghua.edu.cn

SUN, Yingmei
Department of Social Sciences,
Shenyang Academy of Medical
Sciences, Mail box 119, Wucaicincun, 14#
Baishanlu, Huangheng Bei Dajie,
Shenyang City 110034, Liaoning
Province, PRC
Email: symhappy2005@163.com

Prof YIN, Yiqiao
Kiang Wu Nursing College of Macau
KWNC; Rua Coelho Amaral, Hospital
"Kiang Wu" Macau
Email: van@kwnc.edu.mo

Dr. Zhai, Xiaomei,
Dept. of Social Sciences, Peking Union
Medical College & Chinese Academy of
Medical Sciences, Dong dan san tiao
No.5, Beijing 100005, PRC
Email: xmzhai@hotmail.com

Prof ZHANG, Hui
School of Social Science and
Humanities, Jinzhou Medical College, 40
Song Po Lu Sanduan, Jinzhou 121001,
PRC
Email: jzqbdsubs@vip.163.com

Prof ZHANG, Fuming
Jindongnan Normal College, No.73
Chengbei Road, Changzhi, Shanxi
046011, PRC
Email: fmjohn@sohu.com

Dr ZHU Wei
Department of Social Sciences, Fudan
University
Handan Road, Shanghai 200433, PRC
Email: wzhu@hsph.harvard.edu

Dr ZHANG, Xinqing
Center for Bioethics, Peking Union
Medical College
5 Dongdan San Tiao, Beijing 100005,
PRC
Email: zxqclx@vip.sina.com

ZHOU, Xiangtao
School of the Humanities and Social
Science, Jinzhou Medical College, 40
Song Po Road, Sanduan,
Jinzhou 121001, PRC
Email: zhouxt0622@sina.com

ZHOU, Yiman
Center for Bioethics, Peking Union
Medical College, 5 Dongdan San Tiao,
Beijing 100005, PRC
Email: ymzhou1207@2911.net,
ym.zhou@sohu.com

LI, Xiaoping
Department of Social Science, Guangxi
Medical University,
Nanning, Guangxi Province 530023
China
Email: lixiaoping2@mail.PRC.com

WANG, Yunfeng
Nursing College, Peking Union Medical
College, Room 502, Building 8, Ba Jiao
Nan Li Road, Shijingshan District, Beijing
100040, PRC
Tel: 86 10 88961406
Email: wtoou.cn@yahoo.com

LIU, Jian
Department of Humanities and Social
Sciences Xinjiang Medical University,
Xinjiang Uygur Autonomous Region
830054, PRC
Email: liujianpeizhen@sohu.com

LI, Yong
Medical Administration College, Nanjing
Medical University,
Nanjing City 210029, Jiangsu Province,
PRC
Email: ly819@263.net

ZHONG, Xiaohu
Teaching and Research Center for
Marxism, Jilin University, (Nan Hu
Campus), Changchun City 130012, Jilin
Province, PRC
Email: tg2100@yeah.net

SHEN, Ying
Beijing Children's Hospital, 56# Nan Li
Shi Lu Road, Xicheng District, Beijing
100045, PRC; Room 1401, Building
No.12, A1 Fu Xing Road, Beijing
100038, PRC
Email: ying_116sh@sohu.com

WANG, Pu
Zhejiang University Publishing House,
Hangzhou City, Zhejiang Province, PRC
Tel: 86 571 88273010(O), 86 571
87990282(H)

LI, Xiaoni
Faculty of Health Law, Division of
General Education, Health Science
Center, Peking University
38# Xueyuan Road, Haidian District,
Beijing 100083, PRC; Building 24-4-2,
38# Xueyuan Road, Haidian District,
Beijing 100083, PRC
Email: sunnyxiaoni@sohu.com

LI, Xiaonong
Faculty of Health Law, Division of
General Education, Health Science
Center, Peking University, Beijing
100083, China
Email: ninong_li@163.com

HU, Yiyun
Scientific Research Division, Beijing
Children's Hospital, Beijing 100045, PRC
Email: yiyunhu@btamail.net.cn;
yiyunhu@yahoo.com

LU, Yuhong
Department of Medical Humanities,
Tianjin Medical University,
Tianjin City 300070, PRC
Email: kingkoo01@sohu.com

WANG, Ping
Department of Social Sciences, Jiangxi
Medical College
Nanchang City 330006, Jiangxi
Province, PRC
Tel: 86 791 8606632(O), 86 795
7334835
Mobile: 13077908182
Email: yh0125@sina.com

LI, Beiyong
Department of Social Sciences,
Chongqing Medical University;
Chongqing City 400016, Sichuan
Province, PRC
Tel: 86 023 67610086(H)
Email: jacklinlee@yahoo.com

LI, Song
No. 4 Army Medical University, Xian,
Shaanxi Province, 710032, PRC
Email: lisong@fmmu.edu.cn

CHENG, Guobin
Center for Medicine and Humanities,
Southeast University,
Nanjing City 210009, Jiangsu Province,
PRC
Email: cgb1994@163.com

Prof. DA, Qingdong
Yi Xue Yuan Road 138 # , Department of
Social Sciences and Humanities,
Shanghai University of Medical
Sciences, Shanghai 200032 PRC

Prof XU, Zhongliang
Department of Social Sciences,
Fudan University
Handan Road, Shanghai 200433, PRC

Prof. DU, Zhizheng
Press of the Journal of Medicine and
Philosophy, Box of Medical and
Philosophy in Dalian Medical University,
465 Zhongshan Road, Sha Hekou
District, Dalian116027, PRC
Email:duzhi@mail.dlptt.ln.cn

Prof. LI, Benfu
Division of Medical Ethics,
Health Science Center, Peking
University,
Beijing 100083, PRC
Email:ethics@hsc.pku.edu.cn

Prof. SUN, Muyi
Center for Medicine and Humanities,
Southeast University,
Nanjing City 210009, Jiangsu Province,
PRC
Email:sunmy@sina.com

Prof. (Ms.) CONG, Yali
Division of Medical Ethics, Health
Science Center, Peking University,
Beijing 100083, PRC
Email:congyali@sohu.com

Prof. ZHANG, Daqing
Center of History of Medicine, Health
Science Center, Peking University,
Beijing 100083, PRC
Email:zhangdq@hsc.pku.edu.cn

HU, LinYing
Division of Medical Ethics, Health
Science Center, Peking University,
Beijing 100083, PRC
Email:hlying51@sohu.com

Ms. FU, Jinhua
The High School Affiliated to Beijing
Normal University
No 18 Nanxinhua Street Xuanwu District
Beijing 100052, PRC
Email:xinyue2468@sina.com

LI, Jianhui
Beijing Normal University, Department of
Philosophy
19 Xijiekouwai Avenue, Beijing 100875,
PRC
Email:ljh@bnu.edu.cn

Dr XU, Jin
Beijing Hospital, No 1, Da Hua Road,
Dong Dan, Beijing 100730, PRC
Email:xujin136@163.com

FAN, Chunliang
Institute of Policy and Management
Chinese Academy of Sciences, No. 55
Zhongguancun Donglu Beijing 100080,
PRC
Email:fcl@mail.casipm.ac.cn

Mr. Zhao, Mingjie
Press of the Journal of Medicine and
Philosophy, Box of Medical and
Philosophy in Dalian Medical University,
465 Zhongshan Road, Sha Hekou
District, Dalian116027, PRC
Email:yizhe@yizhe.org

Prof TONG, Zilin
Heilongjiang Chinese Traditional Medical
University
24, Hepinglu, Harbin, 150040, PRC
Email:success_tong@163.com

CHEN, Huizhen
Center for Applied Ethics, Chinese
Academy of Social Sciences, 5
Jianguomennei Avenue, Beijing 100732,
PRC
Email:chz1165@163.com

LI, Enchang
Chinese Medical ethics, Medical School
of Xian Jiaotong University, Xian,
710061, PRC
Email:zgexllx@mail.xjtu.edu.cn

GAI, Yu
Press of Science, 16,
Donghuangchenggenbeijie, Beijing
100717, PRC
Email:yugai_2000@yahoo.com

YANG, Kai
Law School, Huanan Institute of
Technology,
382, Guangzhoudaxuewaihuandonglu,
Guangzhou 510006, PRC
Email:yangkai_6363@163.com,

YIN, Xiuyun
Division of Medical Ethics, Health
Science Center, Peking University,
Beijing 100083, PRC
Email:yinxiuyun@bjmu.edu.cn,
ethics@hsc.pku.edu.cn

Prof MENG, Guoxiang
Medical Administration College, Nanjing
Medical University,
Nanjing City 210029, Jiangsu Province,
PRC
Email:gxiangmeng@163.com

Prof HU, Xinhe
College of Humanities, Graduate School of
the Chinese Academy of Sciences, No.19A
YuQuan Rd, Beijing 100039, PRC
Email:huxinhe@gscas.ac.cn

Prof LIU, Xiaoting
Beijing Normal University, Department of
Philosophy
No19 Xijiekouwai Avenue, Beijing
100875, PRC
Email:xiao-tingliu@263.net

LI, Ying
Capital Medical University, No.10
Xitoutiao, You An Men Beijing 100069,
PRC
Email:liyiting@cpums.edu.cn

Prof WANG, Xiaoyan
School of Health Administration and
Education Capital Medical University,
No.10 Xitoutiao, You An Men Beijing
100069, PRC
Email:wxy@ccmu.edu.cn

LI Yun
Department of Social Sciences, Shanxi
Yuncheng College, Shanxi 044000, PRC
Email:liyuncass@sohu.com,

Miao Jia
Institute of Sociology, Shanghai
Academy of Social Sciences
7 622 Lane, Huaihai Road(M), Shanghai
200020, PRC
Email:applesass@126.com

Conferences

A bioethics conference calendar website is:
<http://www.who.int/ethics/events/en/>

For a list of some ethics meetings in Asia and Pacific:
http://www.unescobkk.org/index.php?id=current_and_future_events

UNESCO Conference Ethics of Energy Technologies in Asia and the Pacific 26-28 September, 2007
Imperial Tara Hotel, Bangkok, Thailand
Contact: Dr. Darryl Macer

20th Annual Congress of the European Society of Intensive Care Medicine, 7-10 October 2007, Berlin, Germany
<http://www.esicm.org> Email: public@esicm.org

UNESCO Pacific Regional Bioethics Workshop (in cooperation with the National Commission to UNESCO of New Zealand), 13-15 November, Apia, Samoa.

Contact: Dr. Susan Vize, Email: susan@unesco.org.ws

UNESCO-University of Kumamoto Joint Bioethics Roundtable: Self-Determination in Asia

15-16 December, 2007 University of Kumamoto, Japan

Contact: Dr. Darryl Macer, Prof. Takao Takahashi

22nd International Conference of the European Society for Philosophy of medicine and Healthcare: European Bioethics in Global Context, 20-23 August, 2008, Tartu, Estonia.

Contact: Dr. Bert Gordijn, b.gordijn@efg.umcn.nl

Ninth Asian Bioethics Conference (ABC9): Healthy and Productive Life in Harmony with Nature, 3-7 November, 2008, Jogjakarta, Indonesia. Hosts: Indonesian National Bioethics Commission.

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