INTRODUCTION. This syllabus is adapted from a course on science and human rights first offered under the auspices of the Council on Science and Technology at Princeton University (1996). This up-dated syllabus is designed as an advanced undergraduate seminar, organized roundtable-style, thereby depending upon full participation in the discussion of complex and controversial topics. It is also intended to enhance understanding of the international politics and law related to global human rights issues, and to explore some of the ways in which human rights impinge on the applied sciences and the fields of technology and public health.

Required and recommended readings for the class will be drawn from three paperback books. (1) Richard Pierre Claude, SCIENCE IN THE SERVICE OF HUMAN RIGHTS, (University of Pennsylvania Press, 2002); (2) George J. ANNAS and Michael. A. Grodin, NAZI DOCTORS & THE NUREMBERG CODE (Oxford University Press, 1992); (3) Robert Drinan, THE MOBILIZATION OF SHAME; A WORLDVIEW OF HUMAN RIGHTS (Yale University Press, 2001). Additional readings are drawn from the selected bibliography titles set out below and corresponding to each of the ten chapters in SCIENCE IN THE SERVICE OF HUMAN RIGHTS.

Among the provisions of the Universal Declaration that are of central importance to science are the following:

Article 19. Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 20. Everyone has the right to freedom of peaceful assembly and association. No one may be compelled to belong to an association.

Article 27. (i) Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits. (ii) Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he [or she] is the author.

These safeguards are clustered at the core of the right to scientific freedom and everyone’s right to the benefits of science because free speech, assembly and participation as well as rights to intellectual property are tied so centrally to the conditions that must be met for scientists to pursue their professional work effectively and because these rights bear on the public’s prospects to enjoy the applications of science.

The Preamble to the Universal Declaration of Human Rights says that it was formulated for many reasons, including humankind’s “outraged conscience” over “barbarous acts” resulting from “disregard and contempt for human rights.” For example, the Nuremberg "Doctors' Trials" in 1946
presented ghastly images of physicians trained in the pseudo-science of eugenics and undertaking concentration camp experiments on unwilling prisoners. According to René Cassin, the influential French member of the Declaration drafting committee, Nuremberg influenced the debate on how or whether to connect human rights and science in the Universal Declaration. Moreover, those who drafted the Universal Declaration were mindful of the importance of scientific freedom in light of Soviet experience in the mid-1930's when one of Stalin's political favorites was the biologist, Trofim Lysenko. He controlled scientific research, bending laboratory results to suit ideological expectations and coercing biologists to reject modern genetics. Referring, inter alia, to the victims of Lysenkoism among Soviet scientists, the historian Paul P. Josephson wrote:

More biologists may have suffered from ... [banishment and imprisonment] than any other scientific specialists. In Nazi Germany, one in ten senior research biologists and professors lost their jobs and were forced to emigrate.... The Nazi diaspora and Soviet imprisonments were quite different, with one mainly racial and the other political in its roots. But in both systems, as in all countries where it has existed, totalitarian rule has had profound and similar implications for scientific research and engineering.  

The post-World War II period is marked by enlarged notions of scientific freedom and responsibility, newly informed by the Universal Declaration of Human Rights. For example, scientists contributed to debate over the need for such a Declaration in 1948, and have ever increasingly come to rely on its protection, as seen by contemporary examples of scientists and science associations in one country invoking human rights norms to protest political repression of scientists in other countries. More recently, technological and cultural changes have gone beyond prompting scientists to defend abused colleagues overseas but more positively to employ their technical expertise in the service of human rights of people everywhere. This thematic point is nicely encapsulated in physicist Andrei Sakharov’s memorable statement: “It is now both morally and technologically true that we can no longer ignore the way people are treated in their human rights from one country to another.”

The size of the class should be limited to that of a seminar, or if a lecture class, discussion sessions are necessary and attendance is critically important. The class should make use of a mix of lectures, discussion of seven case studies (set out below), student written reports subjected to

critical student review, outside speakers, and the final production of a research paper with an oral and written report thereon at the end of the semester.

Our topic requires discussion and analysis because it is both complex and charged with ethical and normative issues and dilemmas. Global human rights issues seem to arise in public affairs on a daily basis: Chinese denials of organ harvesting without informed consent and overseas sale of kidneys and other live human organs; Kurdish testimony about poisoned gas attacks from Iraqi bombing of civilians; Bosnian Muslim physicians locked out of their hospital by Serbian policies of “ethnic cleansing”; Burmese (Myanmar) evidence of military use of civilians to clear dangerous mine fields and slave labor in the construction of gas pipelines designed by American engineers; United States prohibition of American mathematicians traveling to a conference of the International Mathematical Union in Havana. These and myriad other such issues require analysis in the context of the newly emerging field of the international law of human rights and fundamental freedoms and of international action in support of United Nations objectives of preserving global security and promoting human rights. The underlying importance of these concerns was articulated by President John Kennedy in 1963, asking a group of Washington, D.C. college students: “Is not peace, in the last analysis, a matter of human rights?” Given the importance of human rights in terms of international peace, and in view of the interest heightened in the subject by the Nobel Peace Prize awarded to Amnesty International, and the liveliness of debate over the role of human rights in U.S. foreign policy, college level courses on the subject have become commonplace. This growing field, characterized by documentary and historical richness, is very broad—involving domestic, comparative and international issues and institutions. Missing, heretofore, has been the infusion of human rights ideas into education in the sciences and related fields.

In 1974, the United Nations Educational, Scientific and Cultural Organization (UNESCO) defined science as an enterprise whereby humankind, “acting individually or in small or large groups, makes an organized attempt, by means of the objective study of observed phenomena, to discover and master the chain of causalities; brings together in a coordinated form the resultant sub-systems of knowledge by means of systematic reflection and conceptualization, often largely expressed in the symbols of mathematics; and thereby furnishes itself with the opportunity of using, to its own advantage, understanding of the processes and phenomena occurring in nature and society.” This definition, complete as far as it goes, obviously leaves out consideration of the scientist as a human being. This course concentrates not so much on science as a discipline as on scientists as carriers of human rights and responsibilities, as people capable of bringing science into the service of human rights, and as the custodians and trustees of everyone’s right to enjoy and share the benefits of science and its applications.

**TOPICS FOR READINGS AND DISCUSSION**

Consistent with the organization of SCIENCE IN THE SERVICE OF HUMAN RIGHTS, class, lectures and class discussion will focus on these ten topics:
I. INTERNATIONAL STANDARDS

1. Links between Science and Human Rights

2. Science in the Universal Declaration of Human Rights
   Document: *Universal Declaration of Human Rights*
   Discussion of Case # 1: Dr. Filartiga and Customary International Law

3. Science in the ESC Covenant
   Document: *International Covenant on Social, Economic and Cultural Rights (ESC)*
   Discussion of Case # 2: Scientific Freedom and Fernandez Case

4. State Responsibilities in the ESC Covenant
   Document: *International Covenant on Social, Economic and Cultural Rights*
   Discussion of Case #3: The Rationale for the Pugwash Conferences

II. ISSUES

Introduction to Part II

5. Health and Medical Ethics
   Document: *International Code of Medical Ethics*
   Discussion of Case # 4: the Turkish Torture Case

6. Information Technology and Statistics

III. POLITICS

Introduction to Part III

7. Scientists as Human Rights Activists
   Discussion of Case # 5: the AAAS Case and Scientific Responsibility

8. NGO Activism in Issues of Science, Technology and Health
   Discussion of Case # 6: MSF’s Forensic Work in Bosnia

9. Grassroots Activism in Issues of Science, Technology and Health
   Document: *Universal Declaration on Human Rights and the Human Genome*
   Discussion of Case # 7: Wendy Watson versus Myriad Genetics Company

10. Emerging Governance among Transnational Organizations
    Document: *Draft Declaration of Principles on Human Rights and the Environment*
SIX CASE STUDIES WITH DISCUSSION QUESTIONS

1. The Case of Joélito Filártiga (Paraguay, 1984)

In the small landlocked country of Paraguay in South America, Dr. Joel Filártiga runs a clinic for the 50,000 impoverished people in the Ybycuí Valley. He publicly spoke with admiration of Article 25 of the UDHR that “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care....”

In a tragic incident involving the Filártiga family, ironically it was the doctor’s innocent teenage son who suffered most at the hands of General Alfredo Stroessner’s dictatorship. Because Dr. Filártiga was an outspoken critic of the government’s derelict public health policy and gave free medical care to the campesinos, the right-wing dictatorship’s police suspected him of subversive activities. In 1976, young Joélito was abducted by police Inspector Américo Peña, who assumed the boy could be forced to betray his father. Instead, he died of cardiac arrest during the hideous torture interrogation. Thereafter, Dr. Filártiga and his family cooperated with Amnesty International (A.I.) human rights workers in Paraguay. Dr. Richard Alan White, an historian then visiting from the University of California, Los Angeles documented the case in Asunción, and he, in turn, transmitted information about the politically motivated torture-murder to A.I.’s research headquarters in London. The Amnesty Secretariat and its medical officer took an interest in the murdered boy’s case because A.I. is dedicated to acting on behalf of those prisoners of conscience who suffer torture in violation of the Universal Declaration of Human Rights.

Amnesty International double checked the facts, making sure that the Filártigas were not advocates of violence, that the boy was taken as a prisoner of conscience and tortured for political reasons. They organized a worldwide campaign, issuing urgent action memos calling on members to pressure the Paraguayan and other governments to take action. Soon afterwards, the dictator buckled under the intense international outcry and suspended Peña. While visiting the United States, Dr. Filártiga and his daughter Dolly traced the policeman responsible for the murder of his son to New York where he was apprehended by Immigration authorities. Thereafter, Dolly Filártiga and her father filed a wrongful death action in federal district court under “The Alien Tort Statute” (1789), alleging that in 1976 Peña-Irala kidnapped and tortured to death Joélito Filártiga, the physician’s seventeen-year-old son. The district court dismissed the Filártigas’ complaint.

The court of appeals reversed, recognizing the emergence of universal consensus that international law places limits on a state's treatment of its citizens. From these circumstances,

the landmark case of *Filártiga v. Peña* emerged, marking for the first time a U.S. Federal Court accepting jurisdiction in a civil suit against torture committed in a foreign country. Péña’s responsibility for the human rights offense was the basis for the ruling that officially sanctioned torture is a violation of international law. The Court said: “Like the pirate and slave trader before him, the torturer has become the enemy of all mankind.” In considering the award of damages in the Filártiga’s civil suit against Peña, four medical specialists — physicians and psychiatrists — presented expert testimony on the effects of torture on family survivors. In 1984, Judge Eugene Nickerson announced a total judgment against the defendant amounting to $10,385 million.

**Discussion Questions for the Filartiga Case.** Does this case suggest that the prospects for realizing the right to health are better off in a democracy than in a police state like Paraguay? What does the case tell you about the importance and work of Amnesty International? What does the legal decision in the USA tell you about the protection and enforcement of human rights? Why was the court’s decision based on “customary international law,” instead of the International Covenant on Civil and Political Rights? If you were a health professional treating the Filártiga family survivors, might seeking justice contribute to improving their health? Why is the USA fertile ground for Alien Tort cases as interpreted by *Filártiga v. Peña*?

2. The Case of Irene Fernandez (Malaysia, 1996)

The case of Irene Fernandez involves a sad story of a state suppressing publication of an epidemiological study, with consequent risks to health, life and denial of people enjoying the benefits of science. In Malaysia monitoring the health and welfare of female migrant laborers has been done for years by Tenaganita, a women’s human rights NGO. It sponsors drop-in counseling centers, special programs on women and AIDS, and a halfway house for health recovery including help for HIV-positive women. In 1995, the group’s founder, Irene Fernandez, released her "Memorandum on Abuse, Torture, Dehumanized Treatment and Deaths of Migrant Workers at Detention Camps." The focus was on eleven secret detention camps throughout Malaysia holding ten thousand overseas workers who were undocumented or whose labor permits were lost, often arbitrarily confiscated by their employers. Add to this, the predicament that those held in the camps of the Southeast Asian country had no procedural rights to contest their detention. With advice from epidemiological experts and using World Health Organization guidelines, Tenaganita interviewed detainees and revealed they did not get any medical attention even when they were sick, had a high fever or diarrhea. The report said: "The denial of proper food, water and medical care led to migrants suffering from severe malnutrition, dehydration and diseases. To allow immigrant detainees to die of beri beri, a highly treatable disease, involves serious government negligence," — a failure to fulfill its duties to advance people’s human rights to the benefits of science by providing elementary health care for detained overseas laborers.

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In March, 1996, Fernandez was charged with “maliciously maligning the good name of Malaysia in the eyes of the world.” According to the judge, the truth of published statements is not a sufficient defense if carelessness or malicious intent are involved. The NGO’s work focusing on improving health conditions for overseas laborers seeks to ensure that everyone, not just Malaysian citizens, enjoys the benefits of health care and scientific advances. Malaysia claims that conditions have improved since 1996, it denied Fernandez’ right to disseminate the results of her research.

The environment for the free exercise of human rights in the Fernandez case violates the International Convention on the Protection of the Rights of all Migrant Workers and Members of Their Families. Referring to some of the world’s most vulnerable people, it says: “Migrant workers and their families shall have the right to receive any medical care that is urgently required for the preservation of their life or the avoidance of irreparable harm to their health on the basis of equality of treatment with nationals of the State concerned.” (Article 28). The issue of whether people actually enjoy the benefits of scientific progress and its applications depends upon related basic rights, essentially tied to free speech, access to information, participation, assembly and association. An example from Malaysia shows the harm done to everyone’s rights in this area by virtue of the suppression of a health study said to embarrass the government.

**Discussion Questions for the Fernandez Case.** Can you name some of the rights violations in the Fernandez case and explain each one’s respective relation to the right to health? Imagine you were a teacher wanting to show students the interconnectedness of rights, how, if one right is undermined others are as well. Does this case help clarify that idea, e.g., the connections between civil rights and economic and social rights? Why is it important to see the interconnectedness of rights, to see human rights in a holistic fashion? Or isn’t it important?

**3. The Pugwash Conferences on Science and World Affairs**

Bringing people of diverse backgrounds together to discuss serious policy issues relating to international peace and security is the objective of the Pugwash Conferences on Science and World Affairs, as envisioned by its creators Albert Einstein and Bertrand Russell. Noting that there exists no universal code of ethics for scientists, they sought to address this ethical void in 1955 by outlining the risks of thermonuclear war. This led to the Pugwash Movement, financed by Cleveland industrialist Cyrus Eaton, to provide a forum for scientists and others to analyze and promote the cause of international peace.

Pugwash meetings were organized convening scientists and non-scientists to share views

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in the spirit of the framers of Article 15 (of the ESC Covenant) who promoted inclusiveness for popular participation. Every few years, Pugwash participants assemble from around the world: young science and non-science students and scholars as well as public figures concerned with reducing the danger of armed conflict and seeking cooperative solutions for global problems.

While non-governmental in makeup, Pugwash Conferences have occasionally relied on inter-governmental dissemination. Meeting in private as individuals, rather than as representatives of governments or institutions, Pugwash participants exchange views and explore such topics as alternative approaches to arms control and global tension-reduction with a combination of candor and flexibility seldom attained in official East-West or North-South discussions and negotiations. Yet, because of the stature of the participants insights from Pugwash discussions often disseminate to the appropriate levels of official policy-making.

The first twenty years of Pugwash’s history coincided with some of the most frigid years of the Cold War, marked by the Berlin Crisis, the Cuban Missile Crisis, the invasion of Czechoslovakia, and the Vietnam War. In this period of strained official relations and few unofficial channels, the forums and lines of communication it provided played useful background roles in helping lay the groundwork for the Partial Test Ban Treaty of 1963, the Non-Proliferation Treaty of 1968, the Anti-Ballistic Missile Treaty of 1972, the Biological Weapons Convention of 1972, and the Chemical Weapons Convention of 1993. In 1995, the Pugwash Conferences on Science and World Affairs was awarded the Nobel Peace Prize.

**Discussion Questions on Pugwash.** In discussing the links between human rights and society’s need for scientific advancement based on scientific freedom, the framers of the ESC Covenant’s Article 15 deliberately turned away from stipulating a right to international contacts exclusive to scientists. The Pugwash founders, Albert Einstein and Bertrand Russell, saw no threat to the integrity of science or to the role of scientists by including non-professionals. Playing the roles of Einstein and Russell in conversation, construct the arguments that support their view, acknowledging objections and obstacles to popular participation in the discussion of science policy.

4. **The Case of the Adana Rehabilitation Center (Turkey, 1996)**

In 1996, the International Council for Rehabilitation of Torture Victims (ICRT, Copenhagen) complained of Turkey’s record of torture by police. The country’s dreadful human rights record was propped up by an Anti-Terror Law permitting persons arrested under it to be held in solitary confinement for as long as 30 days, leaving ample opportunity for abuse of detainees. The same

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year, the Council of Europe’s Committee for the Prevention of Torture found evidence of torture by law enforcement officers in Turkey, even uncovering torture instruments during their inspection tour of prisons and detention centers. According to the ICRT, the country’s Foreign Ministry was stung by the European report. Taking a “kill the messenger” approach, they convened a meeting to decide on shutting down the ICRT affiliate clinic, the Human Rights Foundation of Turkey (HRFT). By 1996, HRFT had established four treatment and rehabilitation centers where eight doctors, three psychiatrists, and three social workers had treated some 3000 torture survivors. Fearing exposure, the ministers suspected that the HRFT regularly reported torture cases to international organizations, thereby drawing criticism from NGOs as well as European and NATO officials.

Having tolerated the existence of these centers for six years, the Turkish Ministry of Justice convened a criminal trial disingenuously invoking two propositions: (1), torture is a crime in Turkey, and (2), it is a crime not to report a crime. Using these norms as a legal trap, Turkish prosecutors began a harassing practice in 1996 of filing criminal charges against HRFT personnel, charging them with “disobedience to the orders of officials authorities” and “negligence in denouncing the crime of torture.” The “disobedience” alluded to was the justifiable refusal of administrators and health professionals to let authorities look into medical records of persons who were treated at the HRFT’s Adana Rehabilitation Center. The police demanded detailed information on the patients and their medical records which presumably contained information about police torturers. Over time, Turkey brought to trial many of the founding members of the HRFT and physicians from Istanbul and Adana branches, accusing them of operating illegal medical facilities, all the while continuing state approved torture to prop up a shaky regime.

The Turkish trials continuing through 2000, were a source of international embarrassment, among other reasons because numerous NGO’s sent trial observers, including the Center for Victims of Torture (Minneapolis), International Rehabilitation Council for Torture Victims (Copenhagen), the Danish Amnesty International Medical Group, as well as the International Federation of Health and Human Rights Organizations.

Discussion Questions for the Adana Case. Why were Turkish officials eager to review the Center’s medical records? Why do physicians need confidentiality? What about patients? What is “medical neutrality”? Does it mean health professionals are neutral in their opinions about the parties and issues in any given field of conflict and armed hostility? The principles of medical neutrality derive from an amalgam of professional ethics, human rights standards, and humanitarian law. What are some of the ways the latter two differ? Were the overseas medical groups who sat in on the criminal trials of the Turkish doctors inappropriately interfering in the internal affairs of a sovereign state? What was the role of the NGOs in this case?

5. The Case of the AAAS Debate over Scientific Responsibility (Washington, 1977)

In professional circles, polemics about scientists actively promoting human rights involve no tea party banter but heated disputations reflecting fear about science being undermined by
politics. For example, in 1977, Sir Andrew Huxley tried to dissuade the British Association for the Advancement of Science from passing a resolution condemning the persecution of scientists in various dictatorships in Latin America and Asia. Thus, Roger Posadas, then the Philippines' only nuclear physicist was jailed by the Marcos regime for public criticism of its excesses; likewise, Dr. Joel Filártiga was harassed in Paraguay for giving free medical care to the rural poor; and other scientists in the Southern Cone of Latin America paid for openly faulting dictators by being locked out of their laboratories, dismissed from academic posts, and sometimes joining the ranks of the disappeared. Huxley said of Soviet dissidents like the mathematician Yuri Orlov and scientists in detention without charges in Latin America and the Philippines that these are people "suffering not for their scientific opinions but for political acts unrelated to the fact that they are scientists." He said scientists who were concerned should join Amnesty International, but should not commandeर the science academy to undertake political work.

Dr. John Edsall, Harvard biologist and founder of the Committee on Scientific Freedom and Responsibility of the American Association for the Advancement of Science, responded to Andrew Huxley by insisting that "Bodies such as the British Royal Society or the United States National Academy of Sciences, have not only a right but a responsibility to concern themselves with the defense of human rights of scientists." Professor Edsall's view has become the accepted standard. He reasoned that when scientists overseas are deprived of their jobs because authorities dislike their social commentary or are denied access to scientific literature for political reasons, etc., then "it is wrong to pretend that all of this is none of our business as scientists." In his appeal for solidarity with persecuted scientists, Dr. Edsall pointed to the compelling case of Andrei Sakharov.

In the late 1950's Andrei Sakharov boldly called for a unilateral ban on nuclear testing. Because the Soviet Union’s premier nuclear physicist was also father of their hydrogen bomb, his views commanded global attention. He urged scientists and statesmen to do whatever they could to terminate the dangerous arms race, arguing for peaceful coexistence with the West to avoid destruction of civilization. Sakharov explained that after Nikita Khrushchev exposed the human costs of Stalin's totalitarian rule, he began to give critical thought to his own links to the Soviet military industrial structure. The great physicist insisted his work as a scientist and human rights activist were connected: “My views were formed during the years I spent on nuclear weapons, my struggle against testing of these weapons in the atmosphere, underwater, or in space; in my civic activity and writing; in the human rights movements.”

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6 Editor’s Page, “Andrew Huxley on Science and Politics,” Address to the British Association for the Advancement of Science, Chemical and Engineering News (26 September 1977), p.5.


**Discussion Questions for The Science Association Case.** Let’s say, for the sake of argument, that you think Sir Andrew Huxley’s argument is prudent and valid. How would you flesh it out, elaborate or add to his argument? How could you strengthen Dr. Edsall’s contrary views? Which of the two is correct, or do you see an alternative position? As Huxley and Edsall were focusing on the mix of science and politics, do you think different considerations apply to health professionals? Is there anything in the Declaration of Geneva suggesting a professional duty for solidarity among health providers? [”My colleagues will be my sisters and my brothers.” Meaning?]

6. **The Case of MSF’s Forensic Work (Bosnia, 2000)**

The Balkan Wars of the 1990s brought terrible suffering to East Central Europe, causing enormous human carnage and dislocations. With the sudden exodus in 1999 of more than 800,000 Kosovars to neighboring regions and countries, *Médecins sans frontiers / Doctors Without Borders (MSF)* focused on caring for the refugees and displaced persons in Albania, Macedonia and Montenegro, providing both medical and mental health care in the refugee camps, building housing as well as water and sanitation systems. The French doctors’ group also helped refugees as they returned home by initiating mental health training programs, disinfecting thousands of contaminated wells, and bringing mobile clinics to the Roma (Gypsies) and the villages of isolated Serbs.

Medical work done to assist legal investigation, that is, forensic medicine, is a uniquely pertinent humanitarian service proving valuable in human rights cases. In the aftermath of hostilities in the former Yugoslavia, forensic work was critically important. War, ethnic cleansing, persecution of minorities, indiscriminate attacks on civilians, lack of respect for humanitarian principles and deliberate targeting of aid workers were some of the trademarks of the conflict in Bosnia in the early 1990s. That catastrophe exacted a substantial cost in lives and human health, and the Muslim enclave of Srebenica, perhaps its most tragic example of genocidal policies as prohibited by international law.

For almost the entire month of April, 1993, Serbian forces surrounding Srebenica obstructed all convoys of humanitarian supplies. Serbian forces also kept out doctors, including physicians from *Médecins sans frontiers*. As a result Srebenica was left with a single doctor for over 40,000, of whom some 30,000 were refugees.

During the siege of Srebenica, denial of humanitarian assistance meant the death of thousands of civilians. As Dr. Majkanovic said, “At least half of the wounded brought to our hospital would have survived if we had the medicines and supplies we needed.” In the years that followed, the surviving women of Srebrenica joined together to find out what happened to their families. In 2000,

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at a new morgue facility in the northern Bosnian town of Tuzla, investigators tried to uncover the answer.\footnote{David J. Lynch, “‘One of the Worst Places on Earth,’ DNA Identifies the Victims of Bosnian Slaughter at Srebrenica in July 1995, Europe’s Worst Massacre Since the Nazi Era,” \textit{USA Today} (November 17, 2000), 19A, 20A} Dozens of international experts worked for months, digging up 2,028 bodies and finding another 2,500, spread over more than a score of sites. In their cold storage facilities, they assembled the disinterred remains.

The International Commission for Missing Persons in coordination with Physicians for Human Rights (USA) provided state of the art technology for the forensic pathologists identifying the remains. The mitochondrial DNA sequencers donated by the California-based “PE Biosystems,” in fact, made possible matching DNA from the victims’ bones with blood samples from a relative. Appropriately, the fit served two purposes. Through this process, the surviving families learned the fate of their missing loved ones. Further, the process built evidence useful in proceedings at the International Criminal Tribunal for the former Yugoslavia in the Hague. That court crossed an historic threshold, because such evidence was not produced during the trials in Tokyo and Nuremberg following World War II but was used to a lesser extent in the trials in Rwanda dealing with massacres there in 1994.
On August 2, 2001, the Tribunal in the Hague found former general Radislav Krstic guilty of genocide for his role in the systematic execution of more than 7,000 unarmed Muslim men and boys near Srebrenica in 1995. He was sentenced to 46 years imprisonment. Prosecutors said that the Krstic’s trial was the first international trial where forensic evidence played such a crucial role. Presiding Judge Almiro Rodriques said: “By deciding to kill all the men of fighting age, a decision was taken to make it impossible for the Muslim people of Srebrenica to survive.” He concluded, “what was ethnic cleansing became genocide.”

Bringing humanitarian aid as well as some promise of justice to the victims of Srebrenica encompassed the work of many organizations.

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Marlise Simons, “Tribunal in Hague Finds Bosnia Serb Guilty of Genocide,” *New York Times* (August 3, 2001), pp. 1, 8. The Convention on the Prevention and Punishment of the Crime of Genocide says that in Article 1 that genocide is a crime under international law, and in Article 2 says: In the present Convention, genocide means any of the following acts committed with intent to destroy, in whole or in part, a national, ethnical, racial or religious group, as such: (a) killing members of the groups; (b) causing serious bodily or mental harm to members of the group; (c) deliberately inflicting on the group conditions of life calculate to bring about its physical destruction in whole or in part; (d) imposing measures intended to prevent births within the group; (e) forcibly transferring children of the group to another group.
Discussion Questions for the Case of MSF in Bosnia. What is genocide? What are some of the ways that scientists and health professionals can respond to it? Some of the purposes and effects of medico-legal investigations as suggested by the work of Médecins sans frontier (MSF) are to: (1) Identify the deceased and cause and manner of death. But why? (2) Identify those responsible. Why? (3) Bring relief and closure to survivors. Why? Why do you think the Krstic prosecutor said the work of medico-legal forensic investigation was crucial to justice in this case?

7. The Case of Wendy Watson and Myriad Genetics, Inc. (UK, 2000)

Wendy Watson has a genetic pre-disposition to breast cancer. Without any formal training, she learned from experience that microbiology and biogenetic science have made great medical strides. Through genetic testing, she grasped the fact that gene activity inside cells can give up important secrets concerning which type of breast cancer a woman has. This technology enables doctors to choose the most promising treatment with the fewest side effects, and to determine which women face a high risk of recurrence and need close follow-up. For example, examining the activity of 51 genes --whether they are turned on, and thus making proteins, or turned off --enables doctors to distinguish among three types of breast cancer: the non-inherited forms or the inherited forms caused by either the BRAC1 or BRAC2 gene. Fewer than one in ten women with breast cancer have the hereditary form, but those with a mutation on the BRAC1 or BRAC2 gene have a four out of five greater lifetime risk than others of contracting breast cancer.

Research on breast cancer took on political salience in Great Britain in the late 1990's when Watson participated in a worldwide research project that helped to identify the "BRAC1 predisposition gene." The work leading to the discovery was largely publicly funded. When Watson learned that the Myriad Genetics Company (USA) attempted to patent two genes, she organized with other British women to establish the Hereditary Breast Cancer Foundation (HBCF). The patent would cover diagnostic tests and therapeutic treatments which are estimated to cost minimally $2,500. Watson, lobbied for protective international guidelines, arguing before the European Parliament that, "They cannot patent a gene which was only found with the help of people like me where there was evidence of hereditary cancer --nine people in my case. No company should benefit commercially from that kind of research."[13]

Watson’s arguments and those of her NGO touched off vigorous debate over the “commodification” of genetic research in the European Parliament. Bolstering the HBCF’s

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representations is the *Universal Declaration on the Human Genome and Human Rights (1995)* which states in Article 4 that, “The human genome in its natural state shall not give rise to financial gains.” Watson’s claims point up the tension sometimes seen in such cases and for which the World Intellectual Property Organization (WIPO) provides a forum to discuss needed new remedial standards and procedures.

Watson’s group insisted that human rights claims favoring the women tissue donors should prevail over patent rights of the Myriad Genetics Company. Their view was that the claims on behalf of intellectual property are becoming more and more commercial thereby linking them with the powerful forces of pharmaceutical corporations and placing them on uneven par with the human rights claims of isolated individuals. HBCF sympathizers asserted that to grant monopoly patents would be to discourage the open exchange of vital information and impede cooperation in advancing scientific research in developing genetic diagnostic tools, in finding cures for diseases, and in developing new medical treatments. The women tested along with Watson said that, but for their contribution, the diagnostic tests would not have been developed. This kind of innovation is protected by the first part of Article 15 of the International Covenant on Economic, Social and Cultural Rights saying everyone has the right “to enjoy the benefits of scientific progress and its applications.”

The patent holders relied on the second part of Article 15 saying everyone has a right to “benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which [s]he is the author.” An American corporate spokesman said, “The gene would probably not have been discovered but for the potential of patenting. Without the protection that the patent affords, a company could not invest hundreds of millions of dollars in getting it to the market place.” Undergirding their argument was the fact that the commercialization of genetics has become a multi-billion dollar industry which many governments see as a vital part of the economy. Broad human rights norms lacking the precision of regulatory standards can easily prove fragile under the attack of corporate lawyers. *The Cancer Journal* editorialized that the conflict could be described as “gene hunters” at play in a field of “wild west law.”

**Discussion Questions for Watson’s Case against Myriad Genetics.** Can you reconstruct Wendy Watson’s argument from the point of view of everyone’s right to enjoy the benefits of the advancement of science? And add to it from the point of view of the right to health? What about Myriad Genetics, Inc.? They also had a human rights argument based on the provisions of the UDHR (Article 27 on intellectual property) and the ESC Covenant (Article 15). Could they draw on the right to health and medical care to shore up their position favoring the commodification of genetic material? Doesn’t Myriad Genetics, Inc. deserve to profit from its contribution to medical science?

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How can we settle a clash of rights like this, with both standards entrenched in the same human rights documents?

A NOTE ON RESEARCH RESOURCES

For students conducting research and writing term papers, David Forsythe's THE INTERNATIONALIZATION OF HUMAN RIGHTS (Lexington Books, 1991) provides a useful primer on primary sources, "Researching Basic Sources on Human Rights," and the text by Claude and Weston ends each of six chapters with lengthy annotated bibliographies of secondary sources, or scholarly books of commentary. Especially useful is Jack Tobin and Jennifer, Green, eds., GUIDE TO HUMAN RIGHTS RESEARCH (Human Rights Program, Harvard Law School, 1994). Secondary sources usually constitute analysis and commentary on public affairs by various experts, but not necessarily those responsible for finding and reporting the information relied upon. Among the NGOs and IGOs directly concerned with issues of science and human rights are: The Science and Human Rights Program of the American Association for the Advancement of Science, The International Affairs Committee of the National Academy of Science, The Lawyers Committee for Human Rights, Amnesty International, USA, Watch Committees, The Helsinki Commission, and the Bureau of Human Rights and Humanitarian Affairs of the United States Department of State.

Numerous research tools now exist on the Internet. A good beginning is the AAAS Directory of Human Rights Resources on the Internet <http://shr.aaas.org/dhr.htm>. It lists and profiles human rights Internet sites arranged alphabetically by name. Contact information is supplied along with a profile of each organization. Another resource available from the AAAS is GETTING ONLINE FOR HUMAN RIGHTS, FREQUENTLY ASKED QUESTIONS AND ANSWERS ABOUT USING THE INTERNET IN HUMAN RIGHTS WORK, by Stephen A. Hansen.

Students should be aware of various scholarly journals and other resources available in most libraries. These include HUMAN RIGHTS QUARTERLY, a comparative and international journal of the humanities, social sciences and law; The HARVARD HUMAN RIGHTS JOURNAL; HEALTH AND HUMAN RIGHTS (Harvard); THE NETHERLANDS QUARTERLY ON HUMAN RIGHTS, THE HUMAN RIGHTS LAW JOURNAL (mostly concentrating on European regional developments); THE HUMAN RIGHTS TRIBUNE, and the HUMAN RIGHTS INTERNET REPORTER (published until 1991 in Canada to report on the activities of human rights organizations, especially non-governmental organizations or "NGOs"). Other related magazines and journals are: the INDEX ON CENSORSHIP, FREEDOM AT ISSUE, THE AMERICAN JOURNAL OF INTERNATIONAL LAW, and the INTERNATIONAL AND COMPARATIVE LAW JOURNAL. To look up periodical literature on human rights there are various research tools. They include: the INDEX TO LEGAL PERIODICALS, the SOCIAL SCIENCE INDEX, THE INDEX TO FOREIGN LEGAL PERIODICALS, etc. Human rights legal documents such as the U.S. Department of State COUNTRY REPORTS ON HUMAN RIGHTS PRACTICES are available in the Government Documents collections of most libraries, as are United Nations documents and reports. Human rights treaties and other sources of international law are available in a convenient single volume edited by

Of special interest for interdisciplinary work is the GUIDE TO HUMAN RIGHTS RESEARCH, edited by Jack Tobin and Jennifer Green, for the Human Rights Program of the Harvard Law School. Persons interested in measurement issues associated with human rights policy should consult: A "GUIDE TO HUMAN RIGHTS DATA SOURCES" and quantitative indicators available in HUMAN RIGHTS AND STATISTICS; GETTING THE RECORD STRAIGHT, Jabine and Claude, editors, (University of Pennsylvania Press, 1991), 392-342. Also see, Herbert F. Spirer and Louise Spirer, DATA ANALYSIS FOR MONITORING HUMAN RIGHTS (American Association for the Advancement of Science, 1997).

SELECTED BIBLIOGRAPHY

1. Links between Science and Human Rights


Wells, H.G. *The Rights of Man or What Are We Fighting For?* Harmondsworth: Penguin Books, 1940.
2. Science in the Universal Declaration of Human Rights


3. Science in the ESC Covenant


4. State Responsibilities in the ESC Covenant


5. Health and Medical Ethics


6. Information Technology and Statistics


7. Scientists as Human Rights Activists


8. NGO Activism in Issues of Science, Technology and Health


9. Grassroots Activism in Issues of Science, Technology and Health


10. Emerging Governance among Transnational Organizations


