Professional Ethics Report

Current Issue — PER Main Page — SFRCL Main Page

Volume XIII, Number 4, Fall 2000

Publication of the AAAS Scientific Freedom, Responsibility and Law Program, in collaboration with the Committee on Scientific Freedom and Responsibility and the Professional Society Ethics Group

ISSN: 1045-8808URL: http://www.aaas.org/spp/sfrl/sfrl.htm

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The Public Perceptions of the Rewards and Risks of Genetic Research: The Oregon Story

by Gregory Fowler and Barry Anderson

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The genomics revolution rolls on, promising tremendous improvements in our ability to secure a new level of physical well-being, yet, at the same time, creating a sense of unease about some of its possible consequences. With the growing power to obtain accurate genetic information about individuals the question we need to ask ourselves is: Who should have access to this information? And under what conditions?

Genetic privacy and research have been considered in every legislative session in Oregon since 1993. The issues are technical and complex and the ramifications are wide ranging.

Does such a landscape call for a new level of public education and public dialogue about the scientific, ethical and

social issues raised by genome science? Based on a survey of lay citizens, a gubinatorially-appointed legislative body of experts in Oregon thinks so.

For the past year, the Genetic Research Advisory Committee (GRAC), a group of health care professionals, business and industry leaders, and policy makers, has been deliberating on the use and disclosure of genetic information, that is, knowledge about an individual or family obtained through DNA testing of tissue samples. Oregon's 1995 genetic privacy act, the first in the nation, says that a person's DNA is his or her own personal property and cannot be used for any purpose, including research, without that person's informed consent.

Throughout its deliberations, the GRAC had the benefit of input from Oregonians around the state generated from focus groups and an Internet Web site (http://www.geneforum.org) organized by Geneforum.org, a Portland based nonprofit, nonpartisan organization seeking to educate and inform citizens about the societal implications stemming from the new genetics.

The input we received reflects a citizenry generally supportive of genetic research but equally concerned about the protection of their privacy. In addition, Geneforum.org's preliminary findings show that Oregonians share with citizens throughout the country a high degree of confusion, misunderstanding and misinformation about all aspects of genetic research and genetic privacy.

The Method

An interactive scenario, "The Office Visit," was used by Geneforum.org to elicit citizen response. It begins with the following Web site instructions (the italicized words are defined in linked hypertext):

You go to your doctor's office for a routine check-up. Your doctor suspects that you might be at risk of *colon cancer* and wants you to have a *sigmoidoscopy*. In the course of that procedure, the physician is likely to take a *biopsy* of any suspicious *polyps*.

When you go for the test, you are given a form that asks you to decide how your tissue may be used in the future.

Check the choice(s) you are most comfortable with.

Respondents were asked to make several choices. Hypertext descriptions of benefits and risks were provided at each choice point in an attempt to ensure that choice was fully informed. Respondents were asked for the reasons for their choices.

In addition, four offline focus group discussions were convened around the state. Participants in each group were presented the office visit scenario from the Web site and then asked a series of questions to probe their views in greater depth.

Following is a categorization of the views that were expressed. Redundant quotations have been eliminated. The analysis is strictly qualitative, since the methodology provides little reason to believe that any frequency counts would be representative. What is presented below is classification of the most articulate statements of the various points of view expressed at the Web site and in the focus groups.

The Responses

Releasing Tissue

Tissue can be considered as material or as information. The following statements comment on *tissue as material:*

"Common law requires consideration be paid in order for any object to become one's property. Consideration was paid by us or someone else for the tissue(s) by supplying the body with food. Therefore, it is perfectly legal to sell your blood."

"Although I'd like to profit from the results, I think that it would be an administrative nightmare and would limit research."

Tissue as information is information about the donor's body (e.g., what diseases the donor may be prone to) or about the human body, in general, and not information about the donor's identity (*e.g.*, the donor's name and Social Security number).

"The DNA that defines and shapes me floats on a slow-moving stream of life. The "I" that takes shape with this DNA is a wonderful gift. I don't think I own it. It came as a gift, a wonderful surprise…. The secrets of DNA just seem to belong to all of us."

"Common law requires consideration be paid in order for any object to become one's property. None of us paid for the information encoded by our DNA… The information contained in the cells…is public domain." "I wouldn't want to profit from the research, but…if they found something that could save lives…I would want it to be common knowledge for anyone who needs it."

"I would want to know if risks are present in future family offspring."

"I would want to know if there are reasons not to have children."

"Some women will abort a fetus based on their genetic test. This is a very disturbing scenario for me."

"Just as if a limb were to be amputated, any and all uses of that limb by the hospital would be my choice. This is no different."

"I feel that I own my DNA, and I am not comfortable that it could 'take on a life of its own' outside of my knowledge and control."

"I really wouldn't someone making another me without my knowing it."

"First, let's look at the ethical issue and develop a standard of where this is going to go."

"The assurance by the researchers of what the tissue will be used for [is necessary] so that there is no conflict with the donor's ethics."

Releasing Information about One's Identity

A person can give up tissue with or without information about his or her identity. There are both benefits and risks associated with letting others know what tissue is yours. Coding systems have been devised in an attempt to secure the benefits without incurring the risks. Benefits relate to the coordination of data for research purposes. Risks focus on the misuse of information about the donor by HMOs, insurance companies, employers, and data brokers.

"Genetic diseases…are the product of random processes over which the individual has no control. Legislatures will eventually pass laws against such discrimination…. Until they do, I want my identity kept confidential."

"I feel, perhaps naively, that the safeguards outlined in the scenario would guarantee sufficient, protection from misuse."

"I would prefer that no identifying data was forwarded with the sample but rather that information was kept for the pool of individuals who donated who would then be compensated as a group if any profit was made from their tissue sample."

As for the benefits of maintaining at least a coded link from the tissue to the identity of the donor,

"Raw genetic data by itself without any knowledge of the other health or physiological condition of the donor is not nearly as useful as when that information is linked to it.

"There isn't a safe way to ensure privacy of genetic privacy, even with codes."

Concerns were voiced on the risks of genetic information being linked to the donor and getting to the donor's HMO, insurance company, employers or data brokers:

"I would not want anyone else to know the results because of the possibility, nay the certainty, that certain insurance companies/HMOs would use this as discriminating and incriminating reasons for rejection."

"I wouldn't want any employer being able to find out any possible defects about myself."

Research and Profit

The two reasons people want tissue are for research and for profit. The following statements comment on the research motive:

"I want to support research."

"I believe that the study of genetics is terrific…especially in the fight and prevention of many diseases. However, I do not see the need to clone a human being…. I just don't think that we should be [messing] up the human gene pool. It's great that we are making better vegetables, but let's keep genetic mutations to food only and not people."

"I choose for my tissue to be used for other research, not genetic."

"There is no guarantee as to what purpose this will be used."

The following statements comment on the profit motive:

"Decreasing the potential for monetary gain will decrease the amount of research in the future."

"I believe that the profit motive and the free market need to be regulated…. I look to legislative and other public bodies (such as the FDA) to be the vehicles (with public input) for regulations that constrain the profit motive to contribute to the general well being of society…. I am greatly concerned that this DNA-focused research will lose sight of the human condition generally and collapse into a costly focus on the wealthy elite…."

"I think the BIG problem with the power of genetics in biomedicine and ag[riculture]is fear over what corporations will do with this power, given their penchant for [putting their own] profits above all other considerations. With our patent and regulatory laws virtually restricting the commercial domain to multinationals who can afford the horrendous expenses and risks of working in this area, it means what happens with the technology will be determined by a very few, very large global corporations. Until these corporations can demonstrate that they are far better global citizens than they have, as a community, so far—or that government regulatory bodies are truly competent and in control—people will be very hesitant to allow genetic technology to be widely employed."

The Significance

Observations from the Geneforum.org Web site and the statewide focus groups present a consistent qualitative picture of the values and beliefs of a sample of Oregonians regarding the decision to allow their tissue to be used in genetic research. On the one hand, there appears to be considerable willingness to support genetic research by donating tissue. On the other, Oregonians have concerns about confidentiality and informed consent. In general, then, responses suggest more willingness to release tissue than to release information about personal identity.

Even from these early attempts by Geneforum.org to assess public values and beliefs among Oregonians, it is clear that much needs to be done in the way of informing and educating the public about the realities and possibilities of genetic research.

GRAC agrees. In its final report to the state legislature the committee recommends the creation of a new, and ongoing, advisory committee established to monitor genetic research and privacy in the state. The following statutory language reflects the proposed role of the public in that process:

As part of its regular activities, the Advisory Committee on Genetic Privacy and Research shall create opportunities for public education on the scientific, legal, and ethical development within the fields of genetic privacy and research.

The committee shall also elicit public input on these matters. The committee's recommendations shall take into consideration public concerns and values related to these matters. The committee should make reasonable efforts to insure that this public input is representative of the diversity of opinion in the Oregon population.

So, where do we go from here? The fact that the GRAC committee recognizes the importance of public perspectives on genetic research is no guarantee that the Oregon legislature will feel the same way. However, the perception that informed public opinion is an endangered species has been seriously challenged by the activities of Geneforum.org reported here. The upcoming challenge is to create more opportunities for public education and intelligent public opinion polling. In 2001, Geneforum.org will continue its effort toward this end by administering a statewide survey on genetic privacy designed to collect perspectives from a broad spectrum of Oregon stakeholders and the general public.

The use of human biological material by researchers is vital to the advancement of human health, but the rights and welfare of those who provide the specimens should never be compromised.

IN THE NEWS

RESEARCH MISCONDUCT POLICY FINALIZED

Since the 1980's, with the disclosure of four cases of research misconduct at major research institutions, research misconduct and its prevention have piqued the interest of the US public and the scientific community. After public comment and deliberation, the US Office of Science and Technology Policy (OSTP) released the revised "Federal Policy On Research Misconduct"*(1)* on December 6, 2000.

The policy establishes the scope of the federal government's interest in the accuracy and reliability of the research record and the process involved in its development. It consists of a definition of research misconduct and basic guidelines for the response of federal agencies and research institutions to allegations of research misconduct. It communicates to scientists, engineers, and the public those behaviors that constitute research misconduct and how to take action when research misconduct is alleged or found to have occurred.

The policy applies to all federally funded research and research proposals submitted to federal agencies for research funding. Thus, it includes research conducted by federal agencies, conducted or managed for the federal government by contractors, or supported by the federal government and performed at research institutions, including universities and industry.

Agencies will have one year to implement the new policy. Once implemented, it will establish uniformity among the federal agencies' definition of research misconduct. In order to meet this deadline, an interagency research misconduct policy implementation group has been established through the National Science and Technology Council. In some cases, agencies will be required to amend or replace their existing regulations addressing research misconduct, or put new regulations in place.

Government or institutional policies and procedures for addressing other forms of misconduct, such as the unethical treatment of human subjects or mistreatment of laboratory animals used in research are not superseded by the policy, nor does this policy supersede criminal or other civil law. More information on the new federal-wide policy can be found at http://www.ostp.gov/html/mis-conduct.html.

1 The comments that resulted in modification of the policy along with the final policy notification are in the *Federal Register* [December 6, 2000 (Volume 65, Number 235) pages 76260 - 76264]. RJG

GENETIC TESTS TO DETERMINE LIFE INSURANCE PREMIUMS

In October, the British Department of Health's Genetics and Insurance Committee (GAIC) gave insurers the go ahead

to use the results of genetic test results for Huntington's disease to assess life insurance premiums.

The Association of British Insurers (ABI) asked GAIC to assess the reliability and accuracy of several genetic screening tests for use as a risk assessment tool by insurers. In response, GAIC announced that it considers current tests for Huntington's disease as a sufficiently reliable determinant and that correlation exists between the possession of an abnormal Huntington's disease gene and mortality. GAIC Chairman, John Durant, said that this "decision does not mean that individuals will be asked to have a genetic test for Huntington's disease before obtaining insurance," but in cases "where individuals have already been tested as part of their medical care, there is nothing to prevent insurance companies [from] asking for that information." The announcement also states that those individuals with a family history of Huntington's disease, but who test negative, do not have to pay higher premiums for life insurance. In the past, insurers often declined to insure individuals with a family history of the disease or charge high premiums.

GAIC has only released a decision on genetic screening tests for Huntington's disease. ABI awaits the decision on six other screening tests and has agreed to adhere to GAIC's determinations. If GAIC decides that "evidence on the reliability and relevance of a particular test is insufficient to justify its use," the insurance industry will "stop using them and retrospectively reassess affected individuals insurance premiums." Britain's National Consumer Council fears that

GAIC's announcement on the use of tests, for Huntington's disease could dissuade individuals from taking genetic tests, especially since the results may lead some to be denied life insurance or charged high premiums. GAIC's announcement regarding Hunting-ton's disease in assessing life insurance premiums and background information can be found on its Web site at http://www.doh.gov.uk/genetics/gaic.htm. The broader social and ethical issues surrounding the use of genetic tests in insurance and employment have been referred to the Human Genetics Advisory Commission (HGAC), which was developed to provide independent advice on issues arising from developments in human genetics. Further information on HGAC can be found on at http://www.dti.gov.uk/hgac/. -RJG

NEW WHISTLEBLOWER REGULATIONS

In November 2000, the U.S. Department of Health and Human Services (DHHS) proposed new regulations protecting research misconduct whistleblowers from retaliation. The new regulations mandate that universities receiving funds from the agency must establish written procedures for handling misconduct retaliation allegations, and that these procedures must meet certain minimum standards. The regulations are the result of a 1993 law passed by Congress that required the agency to establish such protections. Following a 60-day public comment period ending January 29, 2001, DHHS will consider the comments and issue the final version of the regulations.

The new regulations would require universities to follow certain procedures when individuals making good-faith allegations of research misconduct claim that they have suffered from retaliation because of their allegations. Universities must designate an official to handle retaliation allegations. The official would attempt to mediate an agreement settling the charges in cases of complaint. If no settlement can be reached, the whistle-blower must be offered the option of an administrative hearing. At the hearing, whistleblowers would be allowed representation by counsel and cross-examination of witnesses. Hearings would be overseen by an independent "decision-maker" who would rule on the allegations based on the standard of a preponderance of evidence. Whistleblowers could pursue their complaints through other legal channels. The new rules also cover individuals alleging retaliation who cooperated with misconduct investigations.

The Office of Research Integrity (ORI) is responsible for monitoring compliance with the new regulations. If a university is found to not have followed the regulations, ORI has the authority to suspend DHHS grants to the institution or take other actions.

The proposed PHS Standards for Protection of Research Misconduct Whis-tleblowers were published on November 28, 2000 (65 *Federal Register* 70830-70841), and can also be found on the ORI website: http://ori.hhs.gov. -MI

GELSINGER FAMILY BRINGS SUIT, THEN SETTLES

The family of Jesse Gelsinger, the eighteen-year-old who died after receiving an experimental gene transfer treatment

on September 17, 1999, settled their suit against the University of Pennsylvania and several individuals for an undisclosed sum in early November. Jesse had suffered from a mild form of ornithine trans-carbamylase deficiency (OTC), a rare disorder that prevented his body from breaking down and excreting ammonia. Throughout his life he had been able to control the disorder with a low-protein diet and medication.

According to the complaint, Jesse volunteered to participate in the experiment, even though he knew it would not help his condition, because he was told that the experiment would involve little risk and would benefit future generations of children born with OTC. In the course of the experiment, Jesse was injected with an adenovirus vector that caused him to slip into a coma and die within four days of being given the treatment.

The suit named as defendants the University of Pennsylvania, several doctors involved in the treatment, the dean of the medical school, and bioethicist Arthur Caplan. The suit alleged that Jesse and his family were not adequately informed of numerous dangers involved in the experiment, including: the possible toxicity of the injection; the fact that monkeys who had been given the injection had become ill and/or died; the fact that patients who had previously participated in the trial had suffered serious adverse effects; the Institute for Human Gene Therapy's (IHGT) misrepresentation that it had "achieved certain efficacy with respect to the treatment of OTC"; and the fact that Dr. Wilson, one of the participating physicians, and the University of Pennsylvania stood to gain financially from the gene transfer experiment. -MS

OF RATS, MICE, BIRDS AND MAN

An amendment added by Senator Thad Cochran (R-Miss.) to an agriculture appropriations bill two months ago prohibits USDA from spending money during the 2001 fiscal year on a rulemaking process that would extend laboratory animal regulations to rats, mice and birds, the country's most widely used experimental animals.

The U.S. Department of Agriculture (USDA), which is charged with implementing the 1972 Animal Welfare Act (AWA), has never included rats, mice and birds in its coverage. The AWA addresses a broad variety of issues associated with animal experimentation including annual facility inspections, cage sizes and the requirement to search for alternatives when designing experiments. Over a year ago, the Alternatives Research and Development Foundation (ARDF) sued the USDA on behalf of an undergraduate student who claimed she suffered emotional and aesthetic harm from participating in rat experimentation in a college psychology lab. ARDF is affiliated with the American Antivivisection Society, which is opposed to any use of animals in research. An out-of-court pact settled the pending lawsuit, with the USDA agreeing to take the first steps in the beginning the rulemaking process.

Biomedical research organizations such as the National Association for Biomedical Research (NABR) are using the one-year moratorium to urge a review of all laboratory animal regulations. They point out that any facility accepting Public Health Service money must sign an assurance regarding their animal care programs. They note that government assurance programs and other voluntary programs, such as that of the Association for Assessment and Accreditation of Laboratory Animal Care International (AAALAC), are sufficient for the protection of all animals, including rats, mice and birds. Further regulations will only drive up animal-care costs, dooming animal use in smaller labs, and encumber researchers with additional paperwork without improving animal care. The USDA says the new regulatory duties could compromise their financially limited enforcement program, thereby reducing its ability to oversee care of all animals.

Animal rights advocates believe that these concerns are exaggerated. They claim that inclusion of rats, mice and birds will primarily affect the facilities with substandard animal care and use programs. However, the research community points out that every animal laboratory facility will have to shoulder the additional paperwork. Animal rights groups also claim that inclusion of rats, mice, and birds in USDA reports will allow for reliable accounting of these animals in order to monitor the number of animals used in research. The research community counters by pointing out that the USDA is not charged with monitoring the numbers of animals used. USDA's charge is only to address issues of care. -MH and DCR

HUMAN SUBJECTS PROTECTED IN INTERNATIONAL RESEARCH AND DRUG TRIALS On September 29, 2000, the U.S. National Bioethics Advisory Commission (NBAC) issued guidelines designed to ensure that anysuccessful treatments resulting from research done in a third world country will be made available to that entire country. Before their research plan is approved, researchers must design a plan for making a potentially successful

treatment available to all. Previously, treatments had only been given to study participants.

Other guidelines issued in NBAC's report cover administering standard treatments and obtaining consent. If a researcher can explain that providing established treatments to all participants would make the trial irrelevant to the country, a placebo trial may be acceptable. Otherwise, researchers must provide the same standard of care as would be provided in the U.S. Standards for informed consent, which is required for all trials, will be more flexible than in the United States. Verbal consent may be obtained in place of written consent, but only in cases where participants are illiterate and therefore unable to read and sign standard consent documents. Although its guidelines may be influential, NBAC does not have the authority to monitor trials. -MT

TWO ANTHROPOLOGISTS ACCUSED OF RESEARCH MISCONDUCT

A book published in November 2000 alleges that two well-known researchers, anthropologist Napoleon Chagnon and geneticist James Neal (recently deceased), violated important principles of research ethics and harmed members of the Yanomami, a native people of the Amazon River basin the researchers studied for several decades. The accusations, made by investigative journalist Patrick Tierney in *Darkness in El Dorado: How Scientists and Journalists Devastated the Amazon* (W.W. Norton & Company), have led several institutions to publicly denounce the book's conclusions. The American Anthropological Association (AAA) is currently considering whether to conduct an investigation of the accusations against Chagnon and Neal.

Tierney alleges in his book that Chagnon, Neal, and other researchers harmed the Yanomamo on numerous occasions. According to Tierney, an epidemic of measles among the Yanomamo in 1968 was either caused or exacerbated by a measles vaccine used by the researchers. Tierney contends that the vaccine caused some vaccinated individuals to develop measles and to pass it on to non-vaccinated people, and that the researchers failed to provide medical assistance to those infected. The researchers are also accused of many other types of research misconduct, including the failure to obtain informed consent for experiments. Chagnon, who studied aggression and war among the Yanomami, is accused of manipulating situations and starting fights in order to produce data supporting his anthropological theories. Chagnon has denied all the allegations.

Several institutions have attacked the book and have spoken out in support of Chagnon and/or Neal. The University of Michigan, where both researchers worked at the time of their joint research, issued a statement in September (before the book's publication) strongly supporting Chagnon and Neal and stated that their own investigation of the accusations showed Tierney's allegations to be baseless. The National Academies of Science (NAS), where Neal was a Fellow, cited many factual errors in the book in a statement issued in November. And although it has not made an official statement on the allegations, the University of California at Santa Barbara, where Chagnon later moved to and is now a professor emeritus, has allowed Chagnon and his supporters to create a website refuting the charges.

At the AAA Annual Meeting in November, the Executive Board considered the allegations and passed three resolutions. A Special Ad Hoc Task Force was appointed to consider whether the association should conduct an investigation of the allegations, and will report its recommendations to the Board at their February meeting. The AAA Committee on Ethics was charged with augmenting the AAA ethics code in order to provide more guidance to anthropologists working in the field—addressing topics like the appropriate remuneration of subjects, responsibilities to subjects experiencing health emergencies, and informed consent. And another Ad Hoc Task Force was established to study the current state of native populations and recommend how the AAA can help strengthen regulations, standards and guidelines protecting them in their contacts with researchers.

The AAA Board Resolution can be found at http://www.aaanet.org/presseldorado.htm. Response of Chagnon and links to the NAS and University of Michigan statement http://www.anth.ucsb.edu/chagnon.html -MI

NEW HELSKINKI DECLARATION STAND ON PLACEBOS SPARKS DEBATE

Participants at a conference aimed at discussing the science of the "placebo effect" in late November at the National Institutes of Health instead debated the use of placebos in trials for new drugs. The debate was sparked by changes made to the Declaration of Helsinki (www.wma. net/), an international medical document, which states that experimental treatments should always be tested against the "best current" treatments. The document also states that placebos should only be used when no other treatment exists.

Opponents to the use of placebos say that withholding treatment from study participants puts them at risk for "death or lasting disability," although placebos are rarely used to test antibiotics, cancer chemotherapy drugs, and diabetes treatments, for example. Opponents also say that the interests of the patient should always come before the study and that available treatments should never be withheld. -MT

PATIENT SAFETY FOUNDATION ISSUES STATEMENT ON MEDICAL ERROR DISCLOSURE

Acknowledging that health care providers are ethically obligated to inform patients and their families of all errors occurring during treatment, the National Patient Safety Foundation adopted a *Statement of Principle* at its Board of Director's meeting on November 14, 2000. An excerpt appears below; the full Statement can be found on the Web at http://www.npsf.org.

When a health care injury occurs, the patient and the family or representative are entitled to a prompt explanation of how the injury occurred and its short and long-term effects. When an error contributed to the injury, the patient and the family or representative should receive a truthful and compassionate explanation about the error and the remedies available to the patient.…Health care professionals and institutions that accept this responsibility are acknowledging their ethical obligation to be forthcoming about health care injuries and errors. -MSF

SPECIAL CONTRIBUTION

The Practice of Science at the Edge of Knowledge

By Frederick Grinnell

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In recent decades, postmodernists and sociologists of science have argued that science is just one of many human activities with social and political aims — comparable to, say, religion or art. They have questioned the objectivity of science, and whether it has any unique ability to find the truth. Not surprisingly, such claims have evoked a negative response from proponents of the traditional view of science; the debate between the two sides has been called the science wars. In the debate, scientists have made few attempts to meet the postmodern critique on its own grounds, through serious reflection on the everyday practice of science. Yet that is the only way to understand the nature of science and the features that distinguish science from other activities.

The behavior of baseball umpires helps define the issues. There are three types of umpires. The first type says: "I call balls and strikes as they are." The second says: "I call them as I see them." And the third says: "What I call them is what they become."

What distinguishes the types of umpires is not the situations in which they find themselves, but the attitudes that they bring to their work. As a result of those attitudes, they practice umpiring differently. The first type claims truth; the second, perspective; and the third, power.

Philosophers might identify the umpires' different claims as realism, contextualism, and social constructivism. Realism corresponds to the traditional view of science that links reality directly to observation. Contextualism suggests that how one looks at things will determine, to some extent, what one sees. Social constructivism corresponds to the postmodern view, linking reality with power. To determine which view most accurately reflects what scientists do, let us consider the two central features of scientific practice: discovery and credibility.

Discovery begins within the context of prevailing scientific beliefs. At the same time, the goals of discovery assume

that previous knowledge is incomplete or wrong. Discovery takes place at the edge of knowledge, an ambiguous place where no one has been before. At the edge, one must make risky choices and address hard questions: What should be done first? How does one recognize data, especially when one is searching for something never seen before? And when experimental results do not meet one's expectations, is it because one's original idea was wrong, or because the methods used to test the idea were wrong? Scientists have a saying: Don't give up a good idea just because the data don't fit. That description of research contrasts sharply with the traditional idea that in science, one proceeds from hypothesis to discovery in a linear fashion, guided by method and logic. Of course, some science does conform to that traditional model. An example would be a clinical drug trial approved by the Food and Drug Administration, in which researchers agree in advance on what will count as data, how many patients will be necessary for the data to be meaningful, and what will constitute a positive or negative outcome.

At the edge of knowledge, however, method and logic are insufficient. Intuition and creative insight become just as important. Moreover, researchers frequently find themselves taking unplanned journeys to unexpected places, realizing only later just what it is that they have discovered. Because experimental conditions cannot be controlled completely, unexpected and important results sometimes occur, an aspect of research that Max Delbruck often called the principle of limited sloppiness.

Discovery begins as protoscience. For it to become science, the researcher must focus next on credibility — convincing his or her peers that the new findings are correct. The researcher presents the work in highly stylized research publications. In those scientific short stories, which use the linear scientific method as plot, ambiguity and error disappear. The publication becomes the discovery. Because the linear model is the primary way in which scientists communicate, the public has come to believe that science works in a linear fashion, a misunderstanding of the nature of science and a source of disappointment when the results of research do not meet expectations. When high-school science teachers spend a summer working in my laboratory, they are amazed at how frequently experiments fail to work out as planned.

Professional scientists usually respond to new findings with a profound skepticism that goes beyond the specifics of the research. When first confronted with new work, gatekeepers judge it according to how well it fits with prevailing beliefs. Therefore, the more novel and unexpected a discovery, the more likely that other scientists will reject it — precisely because it contradicts current understanding. When they were initially proposed, ribozymes, prions, and cold fusion all looked like long shots.

Faced with rejection, the researcher experiences a deep sense of insecurity. Error often accompanies the ambiguity of discovery, and in science, being wrong is almost as bad as being ignored. On the other hand, as another saying puts it: Don't give up a good idea just because others don't understand it. To succeed in science, researchers have to confront rejection by becoming advocates for their new findings.

Indeed, at every step of the process, researchers continually reshape their work to anticipate and respond to the criticisms that they expect to receive from their peers. Only when others validate the observations — often modifying them at the same time — will the new work become widely accepted. Objectivity is embedded in the group, not the individual. Ribozymes and prions made it; cold fusion did not.

Returning to the analogy of the baseball umpire, it should now be clear that in the everyday practice of science, individual researchers call things as they see them. Calling things as they are is reserved for scientists acting collectively, and even those calls are tentative. That is, scientists are satisfied with credibility in the present, deferring truth to the future. In fact, unchangeable truth cannot be part of science. Last year's discoveries become this year's instruments of discovery. Moreover, the emergence of truth occurs not through power, as postmodernists assume, but as what the philosopher Annette Baier refers to as the commons of the mind, in her book of that name: "We reason together, challenge, revise, and complete each other's reasoning and each other's conceptions of reason."

The everyday practice of science is neither realism nor social constructivism, but rather balances on a contextual ledge in between.

As an aside, science obviously involves uncertainty, as it remains open to new possibilities. That uncertainty typically produces optimism in scientists about the future, while those watching from the sidelines often are concerned about

unanticipated consequences of discoveries. History teaches us that we should not minimize such unanticipated consequences, which can have a significant impact on society. An example would be the negative effects of technology on the environment. The increasing power of science requires an increasing commitment to social responsibility.

Postmodernists are right that the everyday practice of science is a social and political activity. But that does not mean that science is indistinguishable from other social and political activities. Just as different attitudes result in different practices for baseball umpires, the scientific attitude is only one way to practice exploration of the world, and not everything that one finds during exploration can be accommodated by science.

Besides mapping new territory, exploration offers us opportunities to learn how the world feels, and what it appears to mean. But those latter experiences typically depend too much on the individual's unique background and beliefs for others to verify them. Establishing credibility in science means trying to extract from experience just those aspects of the world that are common to other people, in other places and at other times. In an ideal world, credible science would be done by anonymous researchers.

In contrast, the individual is central in religion and art. In the religious attitude, knowledge of the world becomes absolute as the content of an individual's experience disappears in pure encounter — ineffable spiritual union. Rather than looking for truth in the future, religion is oriented toward the past, where the sources of unchanging truth typically are located: revelation, prophecy, enlightenment. As a result, the aim is rediscovery rather than discovery. In corresponding fashion, credibility functions as a means of reaffirming the past and as a criterion for membership.

In the artistic attitude, on the other hand, knowledge of the world becomes personal through an individual's momentary vision. As in science, the artist tries to go where nobody has gone before, but what the artist discovers is an inner truth. That truth may have revelatory impact on others, and the quality of the artistic expression will always be open to critical evaluation, but those features are separate from the truth of the vision. Moreover, as the reflection of a particular historical moment, each artistic work has the potential to stand on its own, independent of past or future works.

In short, we can practice the world as science, religion, or art, depending upon the attitude that we bring to the project. If postmodernists think that the boundaries between science and those other practices have been blurred, it is because they focus on power, or the view of the third type of baseball umpire: "What I call them is what they become."

Eventually, however, technology will come to baseball. Instant replays will allow anyone who is interested to see — in slow motion and from multiple angles — the position of the baseball as it crosses the plate, and to judge the accuracy of the call. Then all umpires will be calling them as they see them, and those who call them wrong too often will be looking for new work.

Some postmodernists also critique scientific facts as mere social constructs, instead of reality. From the point of view of everyday practice, scientific facts are neither. Instead, they have become credible through verification by others, and powerful through development into technology. Unfortunately, the origin of scientific facts in everyday practice is usually obscured by modern science education. We teach our students only the linear model of discovery, in which ambiguity disappears, along with intuition and creative insight, and in which research becomes equivalent to critical thinking, logic, and problem solving. We leave students with the expectation that the hypothesis must come first, never last.

Critical thinking, logic, and problem solving are certainly important for managing life in a complex world, but what we give our students is an alienated view of science, with sterility and anonymity replacing adventure and excitement. Sir Peter Medawar used to criticize the traditional scientific paper because it omitted the "flights of imagination" that led researchers to their discoveries. The same can be said of science education. An understanding of the everyday practice of science is just as important for science literacy as the mastery of scientific facts. We need to teach both.

ANNOUNCEMENTS

A new website (http://rcr.ucsd.edu) offering resource materials for fulfilling the new **Responsible Conduct of Research (RCR)** requirements was released for public use on November 1, 2000. The site is intended to provide individuals and institutions with the tools and resources to refine existing programs or develop new programs to foster the responsible conduct of research. Included are a list of suggested RCR topics, formats for RCR instruction, tools for RCR instructors, and evaluation methods for RCR programs. t The National Institute on Drug Abuse (NIDA) at the National Institutes of Health is soliciting grant applications on the ethical, legal, and social implications of discovering gene variants that confer vulnerability to addiction. The deadlines for submission are February 1, and June 1, 2001. Contact Jonathan D. Pollock, Cell Biology and Genetics, National Institute on Drug Abuse, (301)435-1309, Fax (301)594-6043, Email jp183r@nih.gov. http://www.nhgri.nih.gov/ELSI/ELSI_R01_ PA.html.

The **North Carolina Association for Biomedical Research (NCABR)** has developed a video series, "Debates in Biomedicine," that explores the ethics of human cloning and xenotransplantation. The videos aim to foster debate and discussion about bioethical issues for staff development programs, professional societies, civic and religious groups, and high school and college classes. Each 20 minute long tape is accompanied by a discussion guide. http://www.ncabr.org/ncabr.nsf/web/debates+orders+forms.

The Ethics Institute at Dartmouth College will offer an intensive two-week summer program on **Teaching the Ethical, Legal, and Social Implications of the Human Genome Project**, on July 17-29, 2001, at Dartmouth College. The program will train faculty to teach genetic literacy and provide an introduction to key ethical, legal, and social implications of genome research to college students. Participants in the Faculty Summer Institute will be competitively selected from a pool of applicants from liberal arts colleges and universities who demonstrate a commitment to teaching with a multidisciplinary approach. Applications are being solicited from two-person interdisciplinary teams and individual faculty. The deadline for applications is March 15, 2001. Contact Barbara J. Hillinger, (603)646-1263, Fax (603)646-2652, Email barbara.hillinger@dartmouth.edu. http://www.dartmouth. edu/artsci/ethics-inst/elsi_index.html.

The **Sixth Annual Ethics and Technology Conference** will be held April 27-28, 2001, at Santa Clara University in Santa Clara, California. The two-day conference will focus on the theme "The technology of the future and how we will deal with it ethically," and will feature papers, keynote speakers, panel presentations, and other demonstrations. The conference is co-sponsored by the Markkula Center for Applied Ethics and the Center for Science, Technology, and Society at Santa Clara University, Boston College, and Loyola University of Chicago. Contact Neil R. Quinn, Jr., (408)554-5723, Fax (408)554-2373, Email nquinn@scu.edu. http://www.scu.edu/SCU/Centers/Ethics.