

Augustana College
Chapel of Reconciliation

Ethics and Biology

Paul Eglund
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I would like to start by thanking Rich Bowman for the invitation to speak today and by thanking all of you for coming to hear some thoughts on ethics and biology.

In thinking about a specific topic for today, it occurred to me that there are several ethical issues in biology that carry a lot of emotion. As the study of living things, biology is involved in the definition of life and the treatment of the aged and the unborn. As biologists, we are rightfully charged with consideration and protection of our study subjects, which are living things or parts of living things, and the ethical issues can get be very emotional and sometimes polarizing. As a microbiologist, I can kill billions of bacteria without guilt or judgment by animal rights activists; but there are layers of protection whenever human or other animal subjects are involved. Even rodents that are generally considered undesirable carriers of disease are afforded protection when they are part of a biologist's experiment.

I had quite a choice in picking a message on ethics in biology that can be informative and delivered in 12-15 minutes. One of my friends said, "There is the obvious issue, the big one, evolution." At first that came as a bit of a surprise to me because as a biologist, I actually forget that evolution is an ethical issue for some people. She said, "I know, we don't think of it as an ethical issue, but some people do." It's true, within my first couple years of teaching here, I had a teary-eyed freshmen in my office telling me that she had "thought this was a nice Christian school" and she was surprised

that she “would have to sit and listen to a professor at Augustana talk about evolution”. Last fall, I was asked directly by a prospective student and her mother if, we teach about evolution here and if, as a biology major at Augustana, she would “have to learn about Evolution”.

What may amount to an ethical issue to some is really based on misunderstanding- misunderstanding over what the creation story in Genesis actual tells us, and misunderstanding about what the Bible actual is. There is also misunderstanding over the biological meaning of evolution by natural selection. The Bible isn't meant to tell us **how** we got here, nor is biology telling us **why** we are here. So, if you feel that evolution is an ethical issue, talk to your religion professors about the **meaning** of the creation story, and know that you can be good a Christian and study and understand and accept evolution as a biological process.

The topic related to ethics in biology that I would like to talk to you about today is actually a developing ethical issue related to field of human genomics. Genomics is generally defined as a branch of molecular biology that deals with the structure and function of all of the DNA in a particular organism, that is, the structure and function of its genome. Genomics is distinct from genetics in that while genetics deals with the effects of a particular gene, genomics considers all of the genes in an organism and also the DNA that does not actually compose genes. The field of genomics necessarily includes determining the sequence of the genome, or DNA of an organism. In humans, the genome is composed of approx 3.2 billion chemical nucleotide bases (A, T, G and C) that serve as the alphabet used to spell our 25,000 genes. Only about 2% of our DNA is

actually used to encode our genes. Scientists are still determining the function of the rest that DNA.

In the science of biology, the field of human genomics is new and is the result of the successes of the federally supported initiative called the Human Genome Project. The project was formally started in 1990 as a joint initiative between the NIH and the Department of Energy. The goal of the project was not only to sequence the human genome, but also several model organisms including a bacterium, yeast, a worm and the fruit fly. Another critical goal was to develop new technologies to determine the sequences and to do the functional analysis of the data once it was collected. These goals were to be completed within 15 years using a budget of \$200 million per year (1).

As sequence data was accumulated over several years, it was released to the public domain immediately for use by all scientists. The actual completion of the genome was celebrated several times between 2000 and 2003. Many of you can remember the celebration at the White House at which competitors Francis Collins and Craig Venter were congratulated by President Clinton and Prime Minister Tony Blair for their accomplishment of the first draft of the human genome. In 2003, scientists celebrated the completion of the genome at the National Institutes of Health on the 50th anniversary of the publishing of the structure of DNA by James Watson and Francis Crick. My wife and I were post-docs at the NIH at the time, and we'll never forget the excitement in that huge scientific community the day that James Watson himself was there on campus to help unveil the sequence of the human genome. Many of us wondered whether Watson and Crick ever dreamed when they published the structure of the double helix, that one day the sequence of the entire human genome would be known.

With respect to ethics, the HGP is an example of success in intentionally striving for high ethical standards. In fact, the project has stimulated policy change that will provide Americans with new legal protection. It was the first large-scale scientific initiative to intentionally include a budget line for considerations of ethical issues. The Ethical Legal and Social Implications Program (ELSI) was created as part of the HGP to study how the knowledge obtained would affect society. In fact, 3-5% of the total budget of the project was dedicated to ethical studies (1). The funding supported grants for consideration of ethical issues, development of model language that was used in non-discrimination bills and for training courtroom judges in the fundamentals of genetics. Furthermore, the genomics era has prompted, after 13 years of congressional debate, the passage of the Genetic Information Nondiscrimination Act of 2008. The new law is described as an act “To prohibit discrimination on the basis of genetic information with respect to health insurance and employment.” This dedication to ethical considerations was certainly warranted, as there was a high level of public concern about the project. A CNN-Time Magazine poll taken as late into the project as June of 2000 showed that 41% of Americans believed that sequencing the human genome was “morally wrong” and that 46% expected “harmful results”. Concerns included ownership of the data and access to the data by employers and insurance companies.

Why should there be renewed concern over the human genome and ethical issues? It comes down to availability. When the HGP was started, it had an estimated cost of \$3 billion dollars. We can't really think of that \$3 billion as a purchase price for a product, however. The funding for the project contributed to technology, basic research and research on specific human diseases. We can actually think of the sequencing of the

genome as a result of many more focused research programs. The HGP resulted in acquisition of collateral knowledge and development of technology, in addition to the raw data of the genome sequence. The sequence itself is estimated to have cost only a few hundred million dollars. This first genome sequence was actually a composite of DNA from many de-identified humans, and although it serves as a valuable reference, it is not the sequence of any one person's genome. However, in October of 2007, we had the complete genome of one individual, Craig Venter. Venter was the major player in the private sector race to complete the genome (2). By April of 2008, the genome of a second individual, James Watson, was published and was reported to have cost less than \$1 million (3). Within 7 months, two more complete genomes were published. This time, they were the genomes of an Eastern Asian individual whose genome represents a population that accounts for nearly 30% of the human population (4), and an individual of West African descent (5). The cost of sequencing each of these genomes was under \$500,000; and it is now possible to determine the sequences in only 1-2 months. At about the same time last year, a start-up company called Complete Genomics claimed that starting in 2009, it would begin sequencing individual genomes for \$5000 each (6). Furthermore, the National Human Genome Research Institute (NHGRI) has announced intentional programs to produce high quality human genome sequences cheaply. It is currently funding grants aimed at the development of break-through technologies that will result in the ability to sequence an entire human genome for \$1000 (7). To compare this to what a test to sequence a single gene costs, in 2008, the sequencing of the BRCA1 gene that is associated with increased risk of breast cancer cost about \$3000 per patient.

In terms of current availability of personal access to partial genomic data, a new home DNA test kit, 23andMe, is now commercially available (8). This test, which was co-created by Augustana graduate Linda Avey, was one of Time Magazine's inventions of the year in 2007. 23andMe is currently available online for \$399 (there's a \$50 discount if you order two kits before the end of this month). The kit offers personalized information about a customer's genetic predisposition to 26 genetic conditions for which there is data supported by multiple peer-reviewed studies. Examples include cystic fibrosis, sickle cell anemia and prostate cancer. In addition, the kit offers information on 75 other traits that the producers admit have not yet gained the same level of scientific scrutiny. These include genetic factors associated with memory, intelligence and back-pain (8).

The availability of large-scale personal genomic data is leading us to the era of personalized medicine. Understanding genetic variation among individuals will allow tailored healthcare based on the individual as opposed to population statistics. For example, when treating a person with breast cancer, treatment options are currently determined based on population studies and statistics. Personalized medicine will make treatment decisions based on how an individual is predicted to respond based on the genetic make-up of the individual case.

This technology and the information it will deliver will result in new ethical questions. As the cost of whole genome sequencing continues to drop, there will be questions about whether this technology should be available and part of general preventative health care. Although the Genetic Information Nondiscrimination Act is intended to protect us from discrimination by insurance companies, could an insurance

company require us to have our genome sequence determined? Knowing that our genetic make-up predicted an increased chance of an early death from heart disease or cancer, for example, would certainly change the way that we live. Hopefully that would result in prevention of disease, saving money that would otherwise be spent on treatment. We will also need oversight on how genomic information is delivered to the patient. While home DNA test kits are convenient and have the potential to offer valuable personal information, the delivery of the results is impersonal and lacks the counseling and education that must come with such information.

While there are certainly genetic risk factors that correlate to disease, there is more to disease than genetics. Our environment and personal choices have an effect on our health as well. Access to personal genome data, whether scientifically validated or not, will cause us to consider the choices we make in our lifetimes more carefully. With cheap access to our genome sequences and the data correlating the sequences to particular traits, discussion about genomics will be commonplace among the general public. How will we prepare ourselves for this? One thing that we can do at Augustana is start by planning a capstone course called, “Your Genome Sequence Revealed, How Then Shall You Live?” Students would consider the potential ramifications of their own genome sequences and discuss the validity and rigor with which claims about associations of DNA sequences with traits were made. They would consider how the possibility of certain genetic fates would affect their future decisions and obligations. While the benefits of personal genomics and personalized medicine will be available to us in the coming years, this will contribute to the disparity that we already see across the human population with respect to health care. How much should we invest in the prediction of

potential health problems in the richest nations, while people in poorest nations still suffer from diseases associated with hunger and the lack of clean drinking water?

We will soon be living in a different world of technology with respect to understanding of our genomes and how the sequences relate to our health. We need to begin to prepare ourselves for how this technology will change our future.

References

1. Collins, F.S., M. Morgan and A. Patrinos. 2003. The Human Genome Project: Lessons from Large-Scale Biology. *Science* **300**:286-290.
2. Levy, et al. The Diploid Genome Sequence of an Individual. 2007. *PLoS Biology* **10**:2113-2144
3. Wheeler, D.A., et al. 2007. The Complete Genome of an Individual by Massively Parallel DNA Sequencing. *Nature* **452**, 872-876
4. Wang, J. et al. 2007. The Diploid Genome Sequence of an Asian Individual. *Nature* **456**: 60-65.
5. Bentley, D.R., et al. 2008. Accurate Whole Human Genome Sequencing Using Reversible Terminator Chemistry. *Nature*. **456**:53-59
6. Pollack, A. Dawn of Low-Price Mapping Could Broaden DNA Uses. *New York Times*. Oct 6 2008. www.nytimes.com/2008/10/06/business/06gene.html. Accessed Feb. 14, 2009.
7. NIH News Release: NHGRI Seeks DNA Sequencing Technologies Fit for Routine Laboratory and Medical Use. August 20, 2008. www.genome.gov/27527585
8. 23andMe- Genetics Just Got Personal. www.23andMe. Accessed Feb 10, 2009.

MORNING WORSHIP
Monday, February 16, 2009

Prelude *“God, Who Stretched the Spangled Heaven”* Dale Wood

Welcome/announcements

Invocation

Gospel Genesis 1: 26-31

Hymn *“God Who Stretched the Spangled Heavens”* ELW #771

Message *“Ethics in the Academic Disciplines: Biology”* Paul Egland

Lord’s Prayer

Benediction

Postlude *“God, Who Stretched the Spangled Heaven”*
Sam Batt Owens

CAMPUS MINISTRY ANNOUNCEMENTS

SEMINARY REPRESENTATIVES - Tuesday, February 17th
representatives from all eight ELCA seminaries will be at Augustana.
At 10 am you may hear the distinctive programs of study at each.
Individual appointments for exploration and discernment are available
throughout the day. **Contact Carol, 274-5403, to make appointments.**

SERVING THE BANQUET - On Mon., March 2nd, we again have
the privilege of serving the Banquet (the local downtown soup kitchen.)
There will be two shifts - one for food prep, and one for serving. The
afternoon shift runs from about 2-4 pm, and the serving shift starts
about 5:15 pm. There is a sign-up sheet on the Narthex table.

CHAIR OF MORAL VALUES SERIES - "*Ethics in the Academic Disciplines*" series begins on Feb. 9th and continues on Mondays through Mar. 16th. The preachers will represent various departments on campus. There will be a panel discussion to wrap up this series on Mar. 19th.

SPRING BREAK SERVICE TRIP - Registration is beginning for the spring break service trip to flood-plagued parts of Iowa. Please see Carol in the chapel office for details.

CHAPEL SCHEDULE

Tuesday (17 th)	Koinonia, 10 am - Seminary Reps. - see Carol for appts.
Wednesday (18 th)	Holy Communion, 10 am - Karla Wildberger, '89, Wartburg Seminary; Senior Academy
Friday (20 th)	Worship, 10 am - Lisa Bengston, Sr. Spkr.
Sunday (22 nd)	Worship, 11 am - Pr. Paul
Monday (23 rd)	Worship, 10 am - CMV Series, Pr. Paul
Wednesday (25 th)	ASH WEDNESDAY Holy Communion, 10 am - Pr. Paul; imposition of ashes