

Introduction

I have spent the last 17 years of my life teaching philosophy here at Pacific University. For most of those 17 years I have taught an undergraduate course in biomedical ethics. Genetics has always been a part of that course. I noticed that each year the section on genetics progressively grew from one week to two weeks, then three, then four. Last year I taught a new course exclusively devoted to genetic science and the complex philosophical, theological and policy challenges that this science poses. I am convinced that most of us have not yet grasped our situation vis-à-vis the dramatic advances in genetic technologies we've achieved over the last few decades. This project that you are now a part of grew out of a deep concern that the technology is evolving much faster than our ability to think clearly about it.



When the NIH decided to embark on the Human Genome Project (HGP) it set aside a portion of its research budget to explore the Ethical, Legal and Social Implications (ELSI) of the new knowledge anticipated to emerge from the research. The ELSI program was set up to "...support activities that improve public and professional understanding about genetics, genome technology and the ethical, legal, and social implications of this information and technology." This program is a direct outcome of the ELSI project in genetics.

Having established a relationship with Ecumenical Ministries of Oregon; our vision was to bring the conversation about genetics to regional communities of faith. Having one foot in theology – I have a Masters of Divinity degree from Yale University - and the other in philosophy I have long had an interest in looking at genetic science and technology from both of these angles at once. Here are the words from a speech by Ian Barbour when he accepted his \$1.2 million Templeton Prize on March 10th, 1999: "Most scientists recognize that science itself cannot identify the goals and values toward which the applications of science should be directed. Here religious traditions can have a distinctive role in individual decisions and in public policy." The *Faith Forum on Genetics* program is the product of a common vision of the NIH, Pacific Institute and Ecumenical Ministries of Oregon.

It is a great pleasure for me to welcome you to the program. Many people have spent a great deal of time to make this all possible...from the grant proposal reviewers at the NIH to the community seminar leaders who — I can tell you from personal experience — are prepared, engaged and enthused about our vision. I have put a big link on the first page of our website directly to me as the program director so you can contact me easily at anytime. I am certain that if you commit yourself to doing the readings and coming to the sessions you will be deeply rewarded with new knowledge and insight about our genocentric future.

The Faith Forum on Genetics is about the interface of faith and science. We have made every effort to address, as directly as possible, the theological and spiritual dimension of this debate as well as the ethical and social dimension. We are convinced that communities of faith have a great deal to say about the current debates about genetic testing, pre-implantation diagnosis, the use of embryos in research, cloning, forensics, and the myriad of other controversies created by genetic science. We are also convinced that a basic knowledge of genetic science is necessary for informed discussion to take place about the fundamental ethical questions we must ask if we're to arrive at wise public policy.

Program Objectives

What do we hope to accomplish over the next few months? We have four major objectives:

1. A measurable increase in knowledge about genetic science. You do not need a science background to understand basic genetic science. We are convinced that getting the science right is important if we want to clearly understand the ethical questions and policy decisions we have before us.
2. A measurable increase in knowledge of the complexity of the ethical, theological and policy questions raised by genetic science. This is more difficult because we are not dealing with facts here but concepts. As an educator I have noticed that the first step in real learning is appreciation for complexity. We will not be able to avoid talking about some tough stuff this spring: genetic testing, use of genetic information in medicine, employment, insurance, research on humans and animals, cloning, human embryos, and on and on it goes. An informed appreciation for the complexity of these questions is a prerequisite to wise policy decision-making.
3. Communication of the results of our work to policy makers. We will do this through the drafting of a genetics policy white paper. This will be presented by the community seminar facilitators to the genetics advisory board to the Oregon State Legislature. At that session, in addition to the advisory board members, representatives from the offices of Senator Gordon Smith and Representative David Wu will be present.
4. Development of a flexible, always-up-to-date, adult education program for use in churches throughout the country. We hope, with your help, to develop a program which links live discussion facilitation to a constantly evolving online course specifically designed for communities of faith. Our goal is to make it possible for someone with no scientific background to facilitate a series of discussions which will increase the number of people who are clearly informed and engaged in the public debate about genetics.

Participating Communities of Faith

- *Grace Memorial Episcopal* - Rev. Stephen Schneider, Rev. Esmee Culver¹
- *First Baptist* – Loretta Ganter
- *First Presbyterian* – Merritt McCall
- *Holy Trinity Greek Orthodox* – Dr. John Lingas, Fr. Paul Schroeder
- *Latter Day Saints* - Morris Taylor, Dr. Michael Naillon
- *McMinnville First Baptist* – Kathleen O’Daniels
- *Murray Hills Christian* - Stacy Shelton
- *Peace Church of the Brethren* – Jean Keith-Altemus
- *Saint Philip Neri Catholic Church* – Barbara Harrison
- *Seventh Day Adventist* – Scott LeMert

The Program

The program is funded for a period of two years. The sessions we have developed this winter/spring are part of the second year cycle. Over the next three months you will participate in five conversations on various genetic-related topics we have selected. You will be part of a “community seminar.” You have a community seminar leader. He/she is responsible for setting the dates, times and venue for the sessions. The sessions are labeled and immediately follow this overview. The session is divided into two parts, 1) genetic science, and 2) ethical, theological policy issues. For each of the sessions you will find:

1. An overview of the ethical, theological and policy issues to be discussed
2. Case scenario narratives
3. Questions for discussion
4. A few recommended articles to help illustrate the issues for discussion

The genetic science lesson is only loosely related to the ethical, theological and policy issues. You will find the five lessons under tab seven. Our aim is to provide you with some basic genetic science laid out in five lessons that will familiarize you with terms you might hear about in discussions or read about in the news. Grasping the genetic science provided with each session is not essential for participating in the discussion about the ethical, theological and policy issues. We DO want you to become familiar with the science because we believe that jumping too quickly into the ELSI type questions without adequate knowledge of the science involved can lead to mistakes in judgments or naïve conclusions.

¹ Principal facilitators are listed first. You can contact your facilitator(s) and other participants in your group using the faith forum website at: <http://www.faithforum.net>.

Each community seminar will have its own schedule with respect to the five sessions. Some of you will meet weekly, others more sporadically. The next time we will all come together again will be Saturday May 12th at St. Philip Neri Catholic Church in Portland. At that time we will hear from one or more of our national experts, share experiences, and celebrate our success. Your community seminar leader is the place to look for schedules and questions about the process.

Genetic Science Overview

This program is called the Faith Forum on Genetics. Therefore, we must spend at least some time discussing genetic science. Why is the science important? Geneticists use a lot of specialized vocabulary. In fact, it is been estimated that the average first year biology student learns more new vocabulary words than the average first year foreign language student. While it is clearly not necessary to have an advanced degree in genetics to be able to discuss ethical issues that arise due to modern genetic technologies, it is necessary to understand some of the basic concepts underlying inheritance. It is important to know what is currently possible, what may be possible next week or next year, and what really belongs in the realm of science fiction.



The program will begin with a primer on genetics: Genetics 101. This introduction will explain what the genetic material is, how a gene determines a measurable characteristic and how characteristics are inherited. During each community seminar, additional information pertinent to the discussion will be available.

The first week will address the issue of genes influencing behavior and cognitive functions. We are familiar with the idea that eye color or blood type can be controlled by genes. But what about characteristics such as intelligence and personality? Are human emotions merely the result of chemical reactions? In this section, the current status of behavioral genetics will be examined.

Week two will focus on genetic testing. There are now hundreds of genetic tests available. For some of these tests, the results can be analyzed easily, although decisions based on those results may not be easy. However, more tests are now being developed for traits that are influenced by both genes and the environment. These tests produce results that are not so easily understood. There are tests that can be performed on preimplantation embryos, on fetuses in the womb, on newborns, and on adults. In this section, several examples of tests will be explained.

The third week will cover cloning and transgenic animals, including trying to define what makes a gene “human.” All living organisms have genes composed of DNA. In fact, some organisms, like chimpanzees, share the vast majority of their genes with humans. What does transfer of genes between species indicate about both the concept of species and the importance of genes in defining what it means to be “human.”

In week four, embryonic development and genetic engineering will be covered, as well as a discussion of stem cells. With experimental use of embryonic stem cells in humans underway, it is important to understand exactly what a stem cell is and where it comes from. Manipulation of preimplantation embryos will also be examined.

During the last seminar, the genetic science portion will focus on human genetic diversity and the genetic basis of race. It has been suggested that if aliens from outer space landed on Earth and attempted to analyze the living organisms here by examining their DNA, the aliens would conclude that male humans are more closely related to male chimpanzees than male humans are related to female humans. The amount of genetic information in the Y chromosome (which is found only in males) is greater than the genetic differences between humans and chimpanzees of the same sex. If there is so little genetic difference among humans, how can race be a genetic concept?

To help you understand enough genetic science to have a vigorous discussion, you will access to visual and verbal explanations of concepts for each session. There is also a color-coded glossary of genetic terms. You will have articles from sources such as the New York Times and Discover magazine--articles that address genetic science for the layperson. Finally, I am available to you by e-mail (sardinil@pacificu.edu) and by phone (work-503.352.2729, home-503.985.7199) for any questions you may have.

Consultants

We have a number of nationally and internationally known experts who have agreed to be part of our program. Ted Peters will speak to us at the opening event on January 27th.

Audrey Chapman

Dr. Chapman is a professor in the Department of Community Medicine and Healthcare and I hold the Healey Memorial Chair in the Medical Humanities and Ethics at University of Connecticut Health Center. Until recently, Dr. Chapman was Director of the Science and Human Rights Program of the American Association for the Advancement of Science (AAAS). Along with Ted Peters, Audrey Chapman is our principal consultant on this project.



Ted Peters

Dr. Peters is professor of systematic theology at Pacific Lutheran Theological Seminary and the Graduate Theological Union in Berkeley, California. I knew Ted way back in 1978 when I was a student at the Graduate Theological Union for a year and he was a new professor there. Along with Audrey Chapman, Ted is our principal consultant.

Joseph L. Graves, Jr.

Dr. Graves is Dean of the University Studies program and Professor of Biological Sciences at North Carolina A&T State University.



Ronald M. Green.

Dr. Green is the Eunice and Julian Cohen Professor for the Study of Ethics and Human Values and the Director of Dartmouth's Institute for the Study of Applied and Professional Ethics.



Allen Verhey

Dr. Verhey is Professor of Christian Ethics at Duke Divinity School.



Michael Banner

Michael Banner is Dean and Fellow of Trinity College, Cambridge. He was previously Professor of Public Policy in the Life Sciences in the School of Clinical and Molecular Medicine, Edinburgh University (2004-6), Professor of Moral and Social Theology, King's College, London University (1994-2004, and Dean and Fellow of Peterhouse, Cambridge (1988-94). He was an undergraduate and graduate student of Balliol College, Oxford, from where he holds his doctorate. He chaired a MAFF Committee of Enquiry on the Ethics of Emerging Technologies in the Breeding of Farm Animals, 1993-5; the Department of Health's CJD Incidents Panel, 2000-3; and from 1998-2006 he chaired the Home Office's Animal Procedures Committee. He has been a member of the Royal Commission on Environmental Pollution and of the Agriculture and Environment Biotechnology Commission. He is currently a member of the newly formed Human Tissue Authority. Amongst his publications is a collection of papers entitled Christian Ethics and Contemporary Moral Problems (Cambridge, 1999). He is currently writing a short history of ethics for Blackwells..



Susan Olson

Dr. Olson is Professor of Molecular and Medical Genetics at Oregon Health Sciences University (OHSU) here in Portland. We first met Susan when she was a panelist for one of our town halls on ANDi, the transgenic non-human primate created by the Oregon Primate Center.

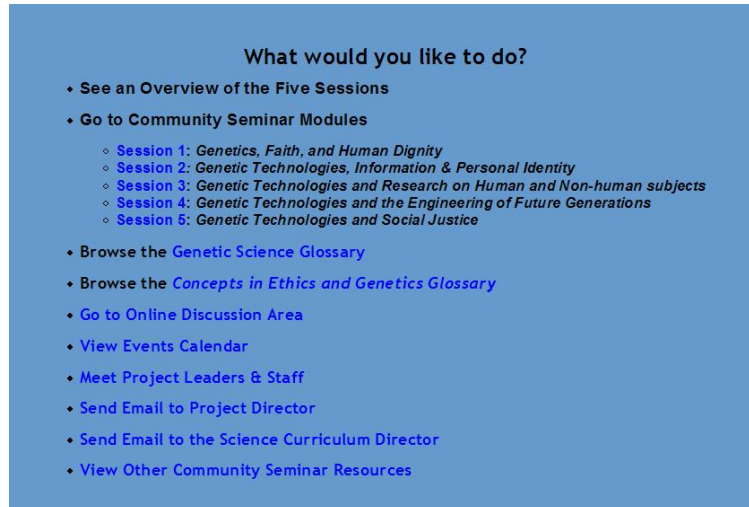
All of our experts have agreed to allow us to post articles of theirs on the faithforum.net website. In addition, they have agreed to field questions that may arise on various topics within your group.

Website

The *Faith Forum on Genetics* website is currently a work in progress. Not all material we want to put on the site is there yet. Not all of the links are working. We continue to test one idea or another. We will be updating the site on a daily basis throughout the project. On this site you will find updated materials, media learning modules, and – most important – online forums for ongoing discussion of our topics.

We have designed the website to be extremely easy to use. No cluttered screens. No techno-jargon. No flashy photos. Just the simple question, “what would you like to do?” This is a “closed” website. That is, it is for participants in the *Faith Forum on Genetics* program only. The first time you go to the website you will enroll in the program. To do this you will need a special enrollment “key.” That key is the word, “**apricot**.” You cannot enroll in the program

without this key. Please do not give this key to anyone outside your community seminar. If you have any trouble with the website you can contact our webmaster, Chris Lane at lanec@pacificu.edu or by calling us at 503.352.2296. The full URL of the website is <http://www.faithforum.net>. As you browse the site please feel free to email us with suggestions on how to make this best work for you.



The image shows a blue rectangular menu box with the title "What would you like to do?". Below the title is a list of options, each preceded by a bullet point. The options are: "See an Overview of the Five Sessions", "Go to Community Seminar Modules" (with sub-options for Session 1: Genetics, Faith, and Human Dignity; Session 2: Genetic Technologies, Information & Personal Identity; Session 3: Genetic Technologies and Research on Human and Non-human subjects; Session 4: Genetic Technologies and the Engineering of Future Generations; Session 5: Genetic Technologies and Social Justice), "Browse the Genetic Science Glossary", "Browse the Concepts in Ethics and Genetics Glossary", "Go to Online Discussion Area", "View Events Calendar", "Meet Project Leaders & Staff", "Send Email to Project Director", "Send Email to the Science Curriculum Director", and "View Other Community Seminar Resources".

Sponsorship

This project was conceived and developed by the *Pacific Institute for Ethics & Social Policy*, a part of Pacific University here in Oregon. We have two important partners: the *National Institute of Health (NIH)* and the *Ecumenical Ministries of Oregon (EMO)*. I’d like to say a word or two about both.

When the *National Institute of Health* decided to embark on the hugely ambitious and expensive human genome project they decided that the 5% of research funds should go to a discussion of the ethical, legal and social implications of genetic science and technology. This decision to fund public outreach was unprecedented in the NIH and a clear testament to the profound questions that this particular kind of science raises. The *Faith Forum on Genetics* program you are now part of is a part of this outreach, commonly known as ELSI, again the Ethical, Legal and Social Implications program. We are very grateful to the NIH, not only for their financial support but for their consistent encouragement.

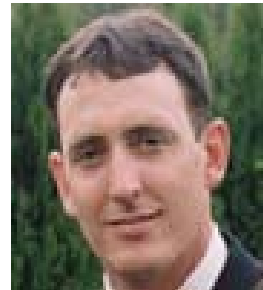
The other partner in this project is *Ecumenical Ministries of Oregon* (EMO) under the leadership of David Leslie has been an invaluable ally in this project. Jan Elfers, EMO's Director of Religious Education, has worked very hard to find community seminar facilitators from different denominational backgrounds willing to guide five sessions and to find at least one hundred people willing to be participants in those sessions this spring. You will see the photos and bios of the facilitators, and indeed everyone connected with the grant on our faithforum.net website.



Staff

Chris Lane

Chris is a lecturer in our Computer Science department here at Pacific University. He is responsible for keeping our servers running and making sure the website looks and acts the way we want it to. He is a long-suffering soul who has spent countless hours working with us to make our web-presence effective.



Bonnie Lynch

Dr. Lynch is Senior Research Associate at RMC Research Corporation. She is working with us on all aspects of program evaluation.

Pacific Institute for Ethics & Social Policy Staff, Interns and Work Study Students

Jean Flory, Program Assistant
Nicole Dickison, Genetics Intern
Heidi Hulsey, Disabilities Intern
Chelsea Hagadone, Work-Study