

Where the Issues of Science and Society Meet

The Center for Society and Genetics
brings together the biological
and social questions that are emerging in
an age of expanding genetic discoveries.

By Robin Heffler

Medical researcher Eric Vilain works with children whose anatomy is not fully determined as either male or female, making their gender uncertain. Vilain, an associate professor of human genetics, pediatrics and urology, sees children with this condition, known as intersexuality, in a clinic where he helps anxious parents understand what has caused the condition and to determine a gender for their offspring.

In these cases, should the children be altered so they conform to society's definition of what's normal? Or can society be educated to try to be more accepting of these children as they are?

Such complex questions occupy Vilain and other researchers who are working together across disciplines in the UCLA Center for Society and Genetics. Launched in 2001, the center seeks to go beyond simply examining difficult social and medical issues. A multidisciplinary center in the College, the center's bold aim is to give direction to the many—and increasingly complex—ethical questions involved in genetic research, and to bring clarity to the “co-evolution” of science and humanity. In so doing, the center confronts the most basic questions about who we are.

Coevolution of Society and Genetics

“Some people think of genetic discoveries in terms of reducing ourselves to our genes, but there is a deep, intimate relationship between our genetic being and our social being,” said M. Norton Wise, a professor of history who co-directs the center along with Edward R.B. McCabe, executive chair of the pediatrics department and physician-in-chief of the Mattel Children's Hospital at UCLA.

“From our food and medicine to our sexuality and emotions, the flood of new findings in genetics is requiring all of us to rethink our views about what it means to be human, to form social bonds, and to live in society,” Wise said. “The Center for Society and Genetics focuses attention on both the opportunities and the challenges that these issues bring to our world. The questions we face cannot be separated into biological and social components; they move together, or coevolve—society and genetics shaping each other in a dynamic relationship.”

One example of the coevolution of genetics and society that Wise cites is lactose tolerance.

“Lactose tolerance is often said to be caused by a simple genetic mutation,” Wise said, “which makes it seem purely a matter of biology. But the mutation would be meaningless if it did not arise in a society that was domesticating cattle for milk consumption; otherwise, it would disappear.”

In this sense, the cause of lactose tolerance in a population might equally be said to be their dairying practices. Indeed, researchers have found that



M. Norton Wise, professor of history

this story has been repeated at least three times, with lactose tolerance arising in different populations at different times in association with different DNA changes. A full understanding of lactose tolerance, then, must simultaneously stem from the biological, social and historical dimensions of its emergence and persistence.

“Many other issues in science, medicine and human development can only be explored adequately by linking the findings of genetic researchers with those of scholars in social and cultural fields,” Wise said. “And findings about social and cultural developments must be reappraised once researchers are aware of the role that genetics plays in what they are examining.”

A case in point, Wise said, is the recent discovery that the several British peoples all have a common genetic heritage dating to Spain 12,000 years ago, compelling historians who study British heritage to rethink previous conclusions about the origins, and arguably the identities, of the Scots, Welsh, Irish and English.

New Faculty, New Research in New Fields

At the center, faculty and students come together from 26 departments, nine schools and three divisions of the College for research, teaching and public events exploring the dynamic intersection of genetics and society.

“The breadth of disciplines represented in the center is phenomenal,” said McCabe, “and is testimony to the fact that the problems of the 21st century occur at the intersection of many disciplines, not within the strictly defined academic fields that developed at universities 200 years ago.”

The center attracts faculty members from around campus who want to cross these intellectual boundaries in their work. Christina Palmer, an associate professor-in-residence in psychiatry and biobehavioral sciences at the Neuropsychiatric Institute, is examining genetic testing for deafness, while also exploring the perspectives of those in the deaf community who don’t see the condition as a disability and therefore question the necessity of testing and

treatment. And, Professors of Law Russell Korobkin and Stephen Munzer study and write extensively about legal and philosophical issues raised by stem cell research. Their work for example, explores potential problems with creating markets for human eggs and creating human-non-human chimeras—issues that require us once more to examine fundamental questions about our humanity.

Basic questions and choices about human health and well-being arise in other areas as well, again typically at the intersection of traditional academic disciplines. McCabe and his wife, Linda, an adjunct associate professor in genetics, have personal experience with crossing disciplines—their lifelong work to develop newborn genetic screenings for more than 50 diseases involves them not only in exertions at the lab bench but also in debates about ethics and public policy.

“There are many policy issues that focus on when babies should be tested,” said McCabe, who chaired an advisory committee on genetic testing for Presidents Clinton and Bush. “For example, early discharge from the hospital interferes with some testing and each state tests for a different number of diseases. We’ve been active in trying to get a national standard policy.”

Working with Sean McGhee, a UCLA pediatric allergist and immunologist, the McCabes are currently trying to develop new screenings for severe combined immunodeficiency (SCID), popularly known as the “boy-in-the-bubble” disease. “Early diagnosis is critical,” said Ed McCabe, “because we know that with early bone marrow transplantation, we can cure SCID in greater than 90 percent of cases. Without it, these children will die by age two.”

A segment of the population that they are especially eager to test for SCID is Native Americans, who are 25 times more likely to have the disease than the general population. However, some Native American tribes are reluctant to undergo testing because of their claims that genetic material

Soroya de Chadarevian, professor of history



previously gathered by other researchers was used without their consent, and because genetic information about their origins may run counter to their oral history and beliefs.

“Genetic research has to be culturally sensitive,” said McCabe, since it can challenge the self-understandings and practices of individuals and groups. “Laura Foster, a UCLA women’s studies graduate student who is also a graduate student fellow at the center and a lawyer, brings to the center a familiarity with indigenous peoples around the world and a concern for how to involve them as participants in the research. She hopes to ensure that university investigators show proper respect for indigenous people, and she hopes to broker relationships between indigenous people and the researchers.”

The notion that science simultaneously shapes and is shaped by society is an insight that informs the Center’s approach to ethics education in general, since it underscores how ethical problems and possibilities are integral parts of the science itself.

“We want to promote a way of thinking about the ethical dimensions of an issue so scientists see ethics not as an unfortunate obstacle, but as a dimension of their work that has value and significance to them,” said Sally Gibbons, associate director of the center and an adjunct assistant professor of philosophy.

Historical Context of Genetic Developments

Hired in 2006, Professor of History Soraya de Chadarevian holds the distinction of being the first faculty member to have a joint appointment in the center and her department. Her research focuses on the historical context of modern scientific developments, including the development



Edward R. B. McCabe, executive chair of pediatrics

As part of this effort, researchers developed new techniques to visualize human chromosomes and study mutations on the chromosomal level. This research, she said, led to the understanding that humans have 46 instead of 48 chromosomes, as previously believed, and to the discovery of unusual chromosome forms or numbers, as in the case of Down syndrome. These findings, in turn, led to the development of new diagnostic techniques.

Giving Undergraduates and the Public Food for Thought

With Gibbons, de Chadarevian has taught one of the center’s upper division core courses, which explores historical and philosophical perspectives regarding genetics. She is also teaching a graduate seminar on the history of

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of molecular biology and, more recently, genetics.

“Studying this history is useful because it sharpens our understanding of the present,” de Chadarevian said. “It helps us understand why genetics became so important in the late 20th century, why certain questions are asked, why certain practices and institutions are in place, what alternatives existed, and why they weren’t chosen.”

She has traced the development of genetics in the context of research on radiation biology in the 1940s–60s.

“After World War II and the development of atomic energy for military and peaceful uses, there were concerns about the effects of radiation on workers in the field and, later, the general population,” de Chadarevian said. “The biggest worries were cancer and long-term genetic effects, so a lot of money went into investigating the biological effects of radiation.”

science and commercialization. This year, Vilain and three other faculty members in the biological and social sciences launched a year-long general education cluster course for freshmen. Titled “Sex: From Biology to Gendered Society,” the popular course encouraged students to think and write critically about the interaction of the biological, psychological and social factors that influence our behavior and experiences as human beings.

In addition to the cluster, the center is also planning to offer undergraduates a minor in society and genetics, as well as a major in biology and society. And the center reaches out to the community by presenting a public symposium each year.

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