

the **Center**  for **Ethics**
— in Science & Technology —

Message from the Director

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The Ethics Center addresses ethical challenges for science and technology by convening conversations involving scientists and the public. We help the public learn more about science and technology and the scientific community better understand perspectives and concerns of non-scientists. This year, we have found a new vehicle to meet these goals in the form of *The Henrietta Lacks Series*.

The Series has been an experiment, but one which was even more successful than we had initially hoped. We faced many challenges along the way, but based on feedback, we have generally hit the mark well. One exception is that we are not likely to re-visit a lottery as the solution to an unexpectedly large demand for too few seats!

More importantly, we were delighted to learn based on a post-event survey that over 50% of the respondents agreed or strongly agreed with the statement: "Participating in this program significantly changed my perceptions or understanding." This is an extraordinary response encouraging us that we are on the right path with these programs. With that in mind, we look forward to finding new and better ways to meet our mission for the San Diego community in the coming year.

We have also been rewarded with an outstanding opportunity to further disseminate our remaining programs in the Lacks Series. Thanks to a very generous grant from the Gerald T. and Inez Grant Parker Foundation, we are now scheduled to have all of our programs, December 2011 – May 2012, recorded for broadcast and archiving by UCSD-TV.

Please take some time to read through this issue and learn more about the Lacks Series and its coverage in the local media, our first "Ethics in Science" contest with high school students in the COSMOS program at UC San Diego, and our interview with Dena Plemmons, a leading research ethicist in San Diego.

In closing, we wish you a peaceful and enjoyable holiday season, hope you'll enjoy reading about our most recent activities, and look forward to seeing you at our 2012 programs.

— Michael Kalichman, Director, Center for Ethics in Science & Technology

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September: “HeLa: Immortal Cells, Enduring Questions”

Sixty years after an African-American woman in Baltimore died from a virulent cancer, a community gathering in San Diego learned how her still-thriving cells have opened new windows into the ethical dimensions of research on human subjects.

“The Henrietta Lacks Series” of nine consecutive “Exploring Ethics” forums began on September 7 with a presentation on “HeLa: Immortal Cells and Enduring Questions” by Laura Rivard, Adjunct Professor of Biology at the University of San Diego. Rivard set the stage for the Lacks Series with an overview of *The Immortal Life of Henrietta Lacks*, the best-selling book by Rebecca Skloot.



Laura Rivard

Lacks died on October 4, 1951 without knowing that cells extracted from her cervical cancer tumors were an exceptional vehicle for studying human disease. *The Immortal Life* explores how these scientifically-labeled “HeLa” cells (for “Henrietta Lacks”) helped launch the global biotechnology industry, and the book also tells the haunting story of how Lacks’ impoverished children learned decades later of their mother’s molecular legacy.

“This book shows us that science matters,” Rivard said, “and, perhaps more importantly, that *how* we do science matters.”

In the early 1950s, Johns Hopkins Hospital was one of the few facilities that would treat black patients, and a staff researcher, George Gey, was determined to find a means for culturing human cells. Rivard noted that Gey’s “recipe for cell culture included plasma of chickens, puree of calf liver ... it really was a witch’s brew.” His search ended when a batch of Lacks’ cells survived and grew in his laboratory. “It was a huge scientific breakthrough,” Rivard said, because it paved the way for long-term studies of human disease at the cellular level.

A year after Lacks’ death, her cells helped Jonas Salk formulate a polio vaccine. As demand for them increased, said Rivard, “HeLa cells were traveling by planes, trains, and automobiles” to laboratories around the globe. In the early years, no one profited from the cells. “Johns Hopkins didn’t get any money,” said Rivard, “and George Gey was so excited that he just sent them to anyone for free.”

Today, as then, tissues and cells taken during medical procedures generally do not belong to patients and can be used for research purposes. The rights of patients are safeguarded by the Federal Policy for Protection of Human Subjects, or “The Common Rule,” and patient privacy is shielded by the Health Insurance Portability and Accountability Act. But Rivard emphasized that regulations function as “guidelines, not laws ... [and] much is left to interpretation.”

In the audience discussion period, Rivard presented actual cases involving disputes about ownership of human tissue. Participants in the discussion identified three criteria for settling such disputes: the wishes of the tissue donor, the specific language of the informed consent contract, and the potential benefits of using the tissue for research.

The audience found that different criteria take precedence in different cases. Patients who sued Washington University to have their cells removed from a prostate-cancer bank lost their case when their original contract with the university was upheld. But the Native American Havasupai tribe prevailed over Arizona State University and stopped tribal cells intended for diabetes research from being used in schizophrenia studies.

As Rivard concluded, “Future goals for the use of human tissues in research will balance the needs of the researchers with the needs of the public through open communication.”

“The book shows us that science matters, and, perhaps more importantly, that how we do science matters.”

October: “Race, Gender, and HIV/AIDS in South Africa”

As South Africa struggles with its ongoing HIV/AIDS public health calamity, historic reverberations of racial injustice, government interference, and distrust of science are hindering efforts to treat the disease and prevent the spread of infection.

The second “Exploring Ethics” forum in the “Henrietta Lacks Series” focused on controversies at the heart of the world’s largest HIV epidemic. Led by Jamie Gates of Point Loma Nazarene University (PLNU), the October 5 discussion of “The Politics of Race, Gender, and HIV/AIDS in South Africa” delved into many of the core ethical issues presented in *The Immortal Life of Henrietta Lacks*.

Gates, a professor of cultural anthropology and African studies and director of PLNU’s Center for Justice and Reconciliation, grew up in South Africa, and he spoke movingly of the human dimensions of what he called “a crisis of pandemic proportions ... South Africa has the highest overall population of any country of HIV-infected and AIDS patients,” numbering 5.7 million or more than 10 percent of the nation. And, he noted, “the HIV/AIDS pandemic is heavily skewed toward black South Africans,” whose prevalence rate of the disease is 45 times that of white South Africans.

In thinking of HIV/AIDS in South Africa and the Henrietta Lacks story, Gates said he saw “strong parallels of the growing relationship between science and politics.” Of particular significance, Gates said, is that “complex ethical issues come when you try to address not just the science of HIV/AIDS but the way that science is put into practice and becomes medical care.”

Even after racial apartheid was abolished in South Africa in the mid-1990s, the country has still suffered from political tyranny and dire poverty. High incidences of rape and domestic abuse put women at risk for sexually transmitted diseases. And Thabo Mbeki, elected president in 1999, promoted the theory of “AIDS denialism” questioning the viral nature of the disease. This was readily accepted by a population that, said

“Complex ethical issues come when you try to address the way science is put into practice and becomes medical care.”

Gates, “was leery of decades of European use of science and medicine to the detriment of black South Africans.”

Historically, European science in South Africa was linked to white colonialism and two of its offshoots. The first, said Gates, was “the complicated relationship between scientists and the massive profits that were being made and are still being made in the growing pharmaceutical industry.”

The second, he added, was “a legacy of scientific racism in South Africa.”

Black South Africans were victimized by “medical experimentation that was rampant during the apartheid years,” Gates reported, and ingrained mistrust of the scientific establishment affected black use of health care services for decades.

During the audience discussion, Gates noted that since 2003, AIDS prevention programs have expanded throughout South Africa with considerable support from the international community. But, he added, “one of the big challenges in South Africa is a mostly centralized medical care distribution system where people have to come to hospitals from far away.”

The audience discussion also addressed how impoverished HIV-infected South Africans must sacrifice personal dignity to take part in public health treatment programs. “Poor South Africans have disproportionately less access not only to medical care but to a right to privacy,” Gates said. “In an environment that is so desperate for care of HIV and for the recognition of HIV, how would you protect privacy?”



Jamie Gates

November: “A Conversation With Rebecca Skloot”

Rebecca Skloot began her November 2 “Exploring Ethics” lecture by paying tribute to the unprecedented regional initiative built around and named after her bestselling book, *The Immortal Life of Henrietta Lacks*.

“I feel exceptionally lucky every time I show up to an event and see the number of people who are reading the book and see that it’s part of academic discussions,” Skloot said. “What’s happening here in San Diego is so much more than that. ... Congratulations to San Diego for pulling together what is most definitely so far the most impressive spread of events that I’ve seen of different ways of looking at the issues raised by the book and different ways of starting conversations in different communities. I’m just thrilled to see that.”



Rebecca Skloot and Mike Kalichman

As the keynote speaker for the Ethics Center’s 2011-2012 “Exploring Ethics Henrietta Lacks Series,” Skloot read excerpts from her book and discussed its historical context. She noted that medical researchers in the 1950s were so excited about the discovery of the “immortal” HeLa cells that they did not wonder about the source. “There were so many questions that scientists wanted to answer with cells that were alive that, once the cells grew, they just ran with them,” she said.

In 1974, as HeLa cells had literally spread to research facilities around the world, the family of Henrietta Lacks finally learned about the existence of her cell line. “Her husband, who had a third-grade education and didn’t know what a cell

was, got a phone call one day,” Skloot said. “The way he understood the phone call was, ‘We’ve got your wife, she’s alive in a laboratory, we’ve been doing research on her for the last 25 years, and now we have to test your children to see if they have the cancer that killed her.’ ... For the family, it was absolutely terrifying.”

Today, Henrietta’s surviving relatives “are part of the public discussion of the book,” Skloot said. “The flood of responses they’ve gotten, largely from people who have benefited from the cells, has been pretty therapeutic for the family. Scientists have reached out to them saying, ‘Thank you. Let me tell you about the research I did and why it’s important.’”

During the audience discussion, Skloot said that the Henrietta Lacks story has helped demystify and humanize science. “Science illiteracy is rampant,” she said. “One of the biggest barriers to learning about science is that people just don’t understand why they should care. Telling the stories of science shows you why you should care.

“Everyone has personally benefited from these cells in some way or another,” she added. “[This] shows why cell culture matters to you and how it has actually changed your life.”

Asked about the reaction of scientists to the Lacks story, Skloot said that the scientific community has embraced her book; in fact, she noted, the National Academy of Science awarded *The Immortal Life* its 2011 Best Book Award.

“I wanted to tell all sides of the story,” she said. “There are human beings behind all these biological samples, but there are also human beings behind the scientists, which people tend to forget.”

Skloot expressed hope that conversations sparked by her book “will build public trust” in clinical research. “It’s so important to do the research and to donate the tissues,” she said. “We all depend on the research.”

“One of the biggest barriers to learning about science is that people just don’t understand why they should care. Telling the stories of science shows you why you should care.”

December: “What the Public Needs to Know about Clinical Trials”

In her remarks at the fourth forum of the “Exploring Ethics Henrietta Lacks” series, Georgia Robins Sadler spoke on behalf of the scientific research community when she praised the best-selling book for increasing public awareness of the importance of clinical trials.

Author Rebecca Skloot “has done a wonderful service,” said Sadler. “She has put this question before a national audience. As a result of her efforts, the country is coming forward to ask ‘What are clinical trials?’ and ‘What is research?’”

Sadler, a Clinical Professor of Surgery at UC San Diego, gave a December 7 presentation on “What the Public Needs to Know About Clinical Trials.” In her talk, she emphasized the urgent need for a pool of clinical research participants that is diverse in age, gender, race, and ethnicity. She outlined the challenges recruiters face in achieving that diversity. And she implored members of underrepresented groups to view clinical trials as “opportunities to make a difference.”

“You have a chance to experience a new research discovery before we declare that it works or fails to work,” she said. “A large piece of research is being sure that everybody is represented.”

As Sadler explained, the biggest barrier to rapid scientific progress is not a lack of ideas or even funding. It is “the time it takes to find eligible people ... with narrower and narrower eligibility criteria.” Participation in clinical trials is time consuming, but compensation is prohibited because, she said, “ethically, we cannot make the reward for taking part in a study so positive that you would do something you would not normally do.”

Recruitment efforts also are hampered by confusion and fear surrounding terms like “blind and double blind” studies and especially “placebos.” Sadler emphasized that “the placebo is only given when we really don’t have a better option” because all existing treatments for that patient have proven ineffective.

“We cannot make the reward for taking part in a study so positive that you would do something you would not normally do.”

In recent years, “clinical trial navigators” have begun serving as community ambassadors who help identify and recruit diverse research subjects. Sadler reported that the model has been successful: “Our numbers are now getting better because the community trusts this person. Now the trick is to find the funding mechanism for it [because] inevitably, recruitment gets short shrift in the budget.”

During the audience discussion, Sadler was asked to comment on an ethical dilemma at the heart of the Henrietta Lacks story: when a research breakthrough leads to a profitable new discovery, like HeLa cells, the research subjects who made it possible do not share in the rewards.

“That really has to do with science getting ahead of ethics,” Sadler responded. “We sometimes make discoveries that we never even imagined would be possible, and we don’t have ethical guidelines in place ahead of time.”

Aside from participating in clinical trials, community members also can get involved in the scientific process, and contribute to the development of ethical guidelines, by volunteering to serve on institutional review boards (IRBs) that oversee research conduct.

“Unless we have community involvement, we don’t know what you want, because it’s really your future that we’re talking about,” she said. “IRBs have lay people on their study sections. If you’re interested in becoming more informed about clinical research, it’s very easy to join an IRB. There are many of them around town, and they’re always short of volunteers.”



Georgia Sadler

The 2011-2012 Henrietta Lacks Series: A Community

Lacks “Exploring Ethics” Series in the News

The Henrietta Lacks Series



September 4, 2011, Voice of San Diego

Immortal Cells: Complicated Rights and Responsibilities by Laura Rivard and Margaret Ng Thow Hing

“The availability of human tissue samples for use in experimentation is fundamental to scientific and medical research.” [more](#)

October 1, 2011, Voice of San Diego

Enduring Legacy of Scientific Racism by Kim Faulkner and Jamie Gates

“Exploitation in the name of science in South Africa and the United States have similar ethical implications.” [more](#)

October 18, 2011, San Diego Union-Tribune

Lottery to See Henrietta Lacks Author Ends Today

“Rebecca Skloot, author of the widely acclaimed book “The Immortal Life of Henrietta Lacks” is coming to San Diego for a free lecture Nov. 2, but you’d better hurry if you want to go.” [more](#)

November 2, 2011, San Diego Union-Tribune

Henrietta Lacks Author Sparks Conversation

“When Rebecca Skloot handed in the manuscript for her first book, she thought it was a good story. Good stories don’t always win acclaim, though. They don’t always create change. Hers did both.” [more](#)

November 2, 2011, San Diego Union-Tribune

The Read: Rebecca Skloot

“Rebecca Skloot told a San Diego audience tonight about the 10 years it took her to write “The Immortal Life of Henrietta Lacks”... Her appearance was part of an ambitious Henrietta Lacks project in San Diego.” [more](#)

November 7, 2011, La Jolla Light

Rebecca Skloot Delves into “Cells That Never Died”

“In front of a packed house of about 600 people at University of San Diego’s Shiley Theatre on Wednesday, award-winning science writer Rebecca Skloot discussed her book.” [more](#)

November 26, 2011, La Jolla Light

Grant Enables UCSD-TV to Air Ethics Forums

“The Parker Foundation has awarded a \$30,000 grant to the Center for Ethics in Science and Technology to fund broadcasts and webcasts of the “Exploring Ethics Henrietta Lacks” series over UCSD-TV.” [more](#)

November 30, 2011, Voice of San Diego

Empowering Patients to Participate in Clinical Trials by Georgia Sadler and Alka Malhotra

“It’s important to realize there are benefits for many to participating in clinical trials.” [more](#)

Exploration of Science, Ethics, and Diversity

Lacks “Exploring Ethics” Forums: January 2011 through May 2012

January 4

Science Literacy and Underserved Populations

Tate Hurvitz, Grossmont College

One lesson from the Henrietta Lacks story is the importance of effective teaching of scientific literacy through both science content and strategies for understanding complex information.



February 1

The Conduct of Science in the Information Age

Katherine Kantardjieff, Cal State San Marcos

New digital technologies are creating challenges for access, ownership, quality, and validation of data. As with the discovery and uses of the Henrietta Lacks cell line, scientists can unintentionally mislead the public and themselves. In this information age, we are challenged to ask how we can avoid the risk of misrepresenting scientific data.



March 7

Health Care Disparities: Palliative Power of Understanding Science

Stanley Maloy, San Diego State University

Too often, ethnicity and socioeconomic status affect access to medical services. A lack of scientific knowledge can impede a patient's ability to understand and influence their health care. How can we help a diverse public understand science well enough to make informed health care choices?



April 4

Is Henrietta Lacks Immortal? Religious Perspectives on Life, Death, and Immortality

Panelists:

Michael Lohdahl, Professor of Theology and World Religions, Point Loma Nazarene University

Khaleel Mohammed, Associate Professor of Religion, San Diego State University

Karma Lekshe Somo, Associate Professor of Theology and Religions Studies, University of San Diego

The panel will discuss how some major world religions' views of life, death, and the afterlife intersect with theological and ethical issues that lie at the heart of the Henrietta Lacks story.

May 2

Henrietta Lacks and Human Subject Research: A Look at Past, Present, Future

Speakers: Michael Cheng, Dong Tran, and Nitin Prabhakar of the UCSD Student Society for Medical Ethics
Fifty years after the rights of Henrietta Lacks were ignored, federal law and ethical guidelines now govern the use of human subjects in research. How well do such safeguards work in an era of dwindling privacy and widening socioeconomic gaps?

Dena Plemmons, Ph.D.



Dena Plemmons, a UCSD anthropologist and a long-time member of the Ethics Center's Strategic Planning Group, has been named a 2011 Fellow of the American Association for the Advancement of Science, the nation's largest scientific organization. Plemmons is a research ethicist with the San Diego Research Ethics Consortium who leads seminars and teaches courses to help NIH and NSF grantees meet requirements for training in the responsible conduct of research. Her work in the field of research ethics has ranged from consulting in Ghana, Taiwan and Mexico on ethics curricula in research environments to serving as 2009-2011 Scientist in Residence for ethics and science education at Montgomery Middle School in San Diego.

How did you become involved in the field of research ethics?

I'm an anthropologist who has studied biomedicine as a particular cultural system. I began by studying the practice of forensic psychiatry, and participants in my research represented simultaneously two vulnerable populations, prisoners and mentally ill patients. My next area of research was developmental and behavioral pediatrics which involved yet another vulnerable population. So throughout my anthropology research career, I have had to be aware of the ethical dimensions of working with human research subjects, and I have seen research conducted in ways that are not ethical. As I became more interested in the broader implications of ethical research across all practices of science, not just with human subjects, I was referred to Mike Kalichman. He very generously took me under his wing and invited me to be part of the Research Ethics Program at UC San Diego.

What insights into ethics and science education have you gained from working with middle school students?

Teachers and students alike gain a lot by having conversations during basic science lessons about the ethical dimensions of new breakthroughs in science and technology. And if those students become grown-up scientists later on, they will already have formed the habit of thinking and talking about ethics in the course of doing their science; it will be integrated into science, rather than feeling like an add-on or an afterthought.

As an international consultant in research ethics training, what kind of cultural differences have you seen in the practice of science?

There are some practices and interpretations in science that are culture-specific and others that are universal. Concern by young scientists about getting proper training from their mentors and principal investigators seems universal. A reality across the different environments, disciplines, and cultures in which I've worked is that there must be buy-in from senior faculty before research ethics training can really succeed. In those instances where I've seen that happen, the benefits for the students are immeasurable, which makes sense: when the senior person with whom the student is working most closely engages in conversations about ethics and science, the student sees that those conversations are part of doing science. I've not seen that vary across cultures or disciplines.

What do you think is the Ethics Center's most important achievement to date?

At the "Exploring Ethics" forums on the first Wednesday of every month, the public is not simply invited to be part of a discussion of science and ethics – they are *expected* to sit at the table with scientists, and I think this has been a lasting achievement. The audiences at these forums seem to feel comfortable enough to bring up any side of an argument, including subjects considered highly controversial, like what are the health risks to all children when some children are not vaccinated. What's amazing about this series is that it goes far beyond scientists merely paying lip service to the idea of public engagement. Science happens in a social context. Conversations about science also should happen in a social context, and that is what the "Exploring Ethics" series has done.

COSMOS, Ethics Center Launch Science Essay Contest

A new educational partnership that will promote interdisciplinary excellence in California high schools has been launched by UCSD COSMOS (the California State Summer School for Mathematics and Science) and the Center for Ethics in Science and Technology (Ethics Center).

The inaugural “COSMOS Ethics in Science Essay Contest” has recognized eight COSMOS students in the UCSD Summer 2011 program for outstanding analysis of the ethical dimensions of their own hands-on scientific research. They were chosen out of 140 students who submitted essays.

Jack Takahashi of Lynbrook High School in San Jose received the Grand Prize Award. Other recipients were: James Wang, Westview High School, San Diego; Sunny He, Cupertino High School, Cupertino; Mukta Kelkar, Gretchen Whitney High, Cerritos; Saho Arai, Canyon Crest Academy, San Diego; Brian Hou, Mission San Jose High, Fremont, Arjun Lakshmipathy; Irvington High School, Fremont; and Joyce Zhang, Westlake High, Westlake Village.



Left to right: Frieder Seible, Dean, UCSD Jacobs School of Engineering; James Wang; Sunny He; Muktar Kelkar; Saho Arai; Brian Hou; Arjun Lakshmipathy; Joyce Zhang; Jack Takahashi;; Charles Tu, UCSD COSMOS Director

“The next generation of scientists should be encouraged to see ethics as part of their research and not as a question to be handled solely by others,” said Ethics Center Director Michael Kalichman, who also directs the UC San Diego Research Ethics Program. “That belief has driven our work with students at the Greater San Diego Science and Engineering Fair, and our collaboration with COSMOS is taking that effort to a new level.”

“We are delighted to partner with the Ethics Center to introduce ethics in science at the high school level,” said Charles Tu, Director of UCSD COSMOS, which is run by the Jacobs School of Engineering. “This will support our students in their pursuit of excellence in science and engineering research design.”

The California State Summer School for Mathematics and Science (COSMOS) is a 4-week residential summer program open to entering ninth through exiting twelfth-grade high school students with demonstrated interest and achievement in math and science. Located on four University of California campuses (Davis, Irvine, San Diego and Santa Cruz), COSMOS provides students with a unique opportunity to work side-by-side with outstanding university faculty and researchers, covering topics extending beyond the typical high school curriculum.

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“We are interested in the challenges faced by our society in determining how best to balance the risks and benefits associated with the development and application of the products of science and technology.”

- Dr. Michael Kalichman, Director , Co-Founder

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www.ethicscenter.net

Parker Foundation Funds UCSD-TV Airing of Lacks Ethics Forums

Demand for tickets to the “Exploring Ethics: Henrietta Lacks” forums has out-paced the supply of available seats, and now a guardian angel has come to the rescue.

The Gerald T. and Inez Grant Parker Foundation has awarded a \$30,000 grant to the Ethics Center to fund UCSD-TV broadcasts and webcasts of the December 2011 through May 2012 Lacks Forums.



The Parker Foundation’s stated mission is “the betterment of life for all people of San Diego County.” It was one of the first benefactors to step forward with funding for the 2003 launch of the Ethics Center. Its new gift will make it possible for audiences throughout the county to view the Lacks forums by means of broadcasts on their TV sets or webcasts on their personal computers.

UCSD-TV, a recipient of numerous Emmy awards in its 15-year history, and UCTV, the satellite channel for the entire University of California system, reach more than 22 million homes on satellite and cable. UCSD-TV can be seen on Cox and Time Warner at Channel 135; on AT&T U-verse at Channel 99; and on UHF (no cable) Ch. 35.

For more information about UCSD-TV programming, visit <http://www.ucsd.tv>

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