

the  for Ethics
in Science & Technology

Message from the Director

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In the past few months, some of the most important news stories have involved science and technology questions that have been the focus of our Exploring Ethics programs.

The **cell phone hacking** scandal in Britain has been a reminder that the benefits of cell phone technology are accompanied by privacy risks. The latest judicial ruling allowing for federal funding of **human embryonic stem cell research** is clearly part of an ongoing debate about not only whether such research should be permitted, but how it should be regulated if it is permitted. The science is advancing rapidly for improved **profiling of cancers**, which could then allow for more targeted treatment; however, this is contrasted with a cautionary July story from Gina Kolata in the New York Times. In late June, the U.S. Defense Advanced Research Projects Agency (DARPA) announced plans to spend \$30 million on **synthetic biology** to advance our ability to in effect use cells and their genetic machinery as building blocks. These topics were the focus of our Exploring Ethics programs in May, June, July, and August, respectively. All are featured in this Ethics Center report.

Beginning in September, our Exploring Ethics forum will be embark in a new direction. As noted in our previous newsletter, we have constructed our programming for the full academic year (September 2011 – May 2012) around a common theme, Rebecca Skloot's bestselling book, *The Immortal Life of Henrietta Lacks*. This series of programs, now titled *The Henrietta Lacks Series*, is the core of a community wide collection of programs and activities: *The Henrietta Lacks Project*. More information about the *Series* and the *Project* can be found in this report.

Finally, before closing, I should mention that we announced this year's winner of the Ethics in Science awards at our June Exploring Ethics program. These students deserve our praise for their interest and success in addressing the ethical dimensions of their scientific interests. The award winners are featured in this report as well.

We will have more exciting news to share in the coming months. As always, we look forward to your continued participation in our programs and your perspectives on ethical challenges in science and technology.

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

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May: “Who Owns Your Cell Phone?”

Marshall Clow began his **May 4 “Exploring Ethics”** presentation on cell phones and privacy issues by delivering good news – “You own your cell phone” – and not-so-good news – “but it’s a little more complicated than that.”

Clow, Principal Engineer in the Office of the Chief Scientist at QUALCOMM, discussed challenges that confront cell phone users who, increasingly, must choose between easy network access and personal security. The same technology that allows anyone to call anywhere anytime also opens the door to surveillance, hacking, and theft.



Marshall Clow

“Every cell phone is a cellular eavesdropping device,” Clow told the audience. “It is designed to decode cellular transmissions, and it has a list of the people you’ve called recently.”

Thanks to wireless networks, each call made or received on a mobile phone creates an indelible electronic footprint. “The location of the cell phone tower that a user connects with is a proxy for the location of the user,” Clow said. “The data can produce a record of everywhere the user has been for the past six months, and other people can have access to that information.”

“We’re used to the idea that when we go out in public, we’re anonymous,” he added. “When you carry a locating device, you’re no longer anonymous.”

Among “the players” Clow identified in the cell phone data industry are manufacturers, providers of services, content, data and applications; and advertisers. “Your phone does not live all by itself,” he said. “There are a lot of services and infrastructure behind it that you need to make your cell phone work. ... You give away ownership when you click on the license agreement.”

Clow presented an array of instances where cell phone users have sacrificed privacy and security:

- Schools around the country routinely look at the content of phones confiscated from students.
- A Michigan court has ruled that police can search a driver’s cell phone during a traffic stop.
- U.S. Customs officials can search the cell phones of people who cross international borders.

Advertisers constantly trawl for data from online activity. “The more they know about you,” Clow said, “the better they can sell stuff to you.” Thieves can hack into phones without ever touching them by convincing users to download applications or by finding bugs in software and exploiting them.

During the Q&A session, audience members debated the real risks of cyber-surveillance by law enforcement. Some felt that cell phone users who are not committing crimes have nothing to fear. Others voiced concerns about misuse of information for political or social harassment.

Throughout the forum, Clow offered the audience tips for reducing the risk of privacy violations, including:

- Putting a pass code on a cell phone can prevent theft of the phone and gratuitous use of all the data on it. The website <http://whocalled.us> offers help in identifying strange calls that may be from scam artists.
- The trade-off between connectivity and security comes down to what Clow called “choices that are pretty stark,” including “one easy choice: don’t carry a device.”

“These kinds of devices have become not only ubiquitous but also indispensable,” he concluded. “It’s neither an unalloyed boon nor an unalloyed menace, and that’s what makes it hard.”

“Every cell phone is a cellular eavesdropping device. It is designed to decode cellular transmissions, and it has a list of the people you’ve called recently.”

June: “Stem Cells and Informed Consent: Right Balance?”

Like all human research subjects, couples who donated embryos for early stem cell studies signed “informed consent” documents that sometimes noted very specific research goals. In the years since, as stem cell science has advanced, new opportunities have arisen to pursue new research goals using federally-registered stem cell lines. But the donors did not, and could not, have agreed to those goals. Is it time to revisit the concept of strict adherence to old “informed consent” documents?

That question was put to participants in the **June 1 “Exploring Ethics”** forum on “Stem Cells and Informed Consent: What’s the Right Balance?” Led by Ethics Center Director Michael Kalichman, the forum introduced a new model for the 3-year-old “Exploring Ethics” series. After hearing a background presentation, the audience divided into groups, analyzed the pros and cons of this ethical challenge, and delivered recommendations for policy development.

The presentation focused on what Kalichman termed “a fascinating problem that most people aren’t aware of”: the 91 existing stem cell lines eligible for federal research funding are restricted to areas delineated in years-old donor “informed consent” documents. The donors may have wanted to contribute to medical research in general, but the wording of the consent documents potentially limits the use of their cells in perpetuity.

As an example, he cited Harvard University Embryonic Stem (HUES) cell lines. These lines, listed on the National Institutes of Health registry, are valuable in an array of medical research fields. But the original goal of the Harvard study was, as stated in the consent document, “to study the embryonic development of endoderm with a focus on pancreatic formation.” Because the donors had only explicitly agreed to that goal, “you can use federal money for these stem cells,” Kalichman said, “but only if you’re going to do research that involves the pancreas or diabetes.”



June Forum Discussion Group

Eight audience discussion groups were given two options for handling the HUES cell line dilemma: “protect the donors by limiting research to only those purposes specifically named in the consent document, or protect the interests of the donors by allowing research for purposes not specifically excluded in the consent document.” But Kalichman also advised the audience, “You aren’t limited to one black-and-white answer. There may be some thinking out of the box that will provide a solution.”

Two groups chose the first option of adhering to the restriction. In selecting the second option to lift the restriction, six groups took Kalichman’s advice to heart by issuing nuanced recommendations that included:

- Allow studies of the embryonic development of endoderm but widen the focus to include non-pancreatic research.
- Since obesity has its roots in pancreatic activity, and it has reached epidemic levels in the U.S. population, allow unfettered use of the cell lines.
- Recognized that adherence to language in old consent documents may now cause great harm to a growing number of people.

Kalichman put a final question to the general audience: “If it had been you who had signed that informed consent document, how many of you would be offended if the research community couldn’t use your cells for anything other than diabetes research?” After a sizable majority of audience members raised their hands, Kalichman commented, “You are now much more informed potential participants in research, and you can ask, as part of an informed consent process, what’s going to happen” with donated material.

July: “Navigating Cancer Treatment”

Medical science has made great strides forward in cancer treatment in recent decades. But some cancers remain resistant to available therapies. For those diseases, scientists have been investigating how molecular profiles of individual tumors could identify genetic defects and pinpoint optimal treatment approaches.

Laura Shawver, a cancer researcher and a cancer survivor, has emerged as a national leader in advocacy for diagnostic tumor profiling. In her **July 19 “Exploring Ethics”** presentation, “Navigating Cancer Treatment in the New Era of Personalized Medicine,” she argued for increased use of profiling, and she described the personal journey that led her to establish [the Clarity Foundation](#) for ovarian cancer patients.



Laura Shawver

The July forum was unusual on two counts. First, a Balboa Park power outage forced a rescheduling of the event from July 6 to July 19. Then, the day after the originally scheduled event, a *New York Times* article, “[How Bright Promise in Cancer Testing Fell Apart](#),” raised doubts about profiling because it “has yet to yield many reliable methods for diagnosing cancer or identifying the best treatment.”

Shawver began her talk by saying, “Thank goodness for the cancellation. If I had spoken and then this article came out, you’d have thought that I was a quack.” Taking issue with the *Times* reporting, she said, “The promise is very bright. All of us should be aware that there are ways to match treatments to particular types of cancer.”

In 2006, while Shawver was enjoying a successful career as a biotech entrepreneur and executive, she was diagnosed with ovarian cancer, a disease that recurs in 75 percent of patients and kills more than 90 percent of them. As a medical professional, Shawver was able to arrange a molecular profile of her tumor. But, she said, “As a Jane Doe off the street, it wouldn’t have happened.” In the five years since she underwent chemotherapy based on her profile, she has been cancer-free.

In 2007, Shawver founded the Clarity Foundation to help other ovarian cancer patients obtain tumor profiling. Without such testing, she said, “it’s often ‘let’s pick a treatment out of a hat.’ ... It’s unacceptable for patients to receive toxicity without benefit. We need to eliminate those drugs with a low probability of working and prioritize those drugs with a high probability of working.”

In response to the *Times* article, and also to challenges from health care professionals in the audience, Shawver agreed that tumor profiling is still considered “controversial ... Otherwise, it would be commonly accepted and everybody would be doing it.” But she did not agree that evidence of profiling effectiveness is too sparse to warrant health care coverage.

In an unusually compelling audience discussion period, cancer survivors and patient advocates shared their frustrations with the harsh realities of oncology care. Points of consensus included the benefits of entering clinical trials in early disease stages and the tensions that exist between trying to save patients today and searching for cures for future patients.

As an example, Shawver cited the “big dilemma” of double-blind clinical studies. “I wear two hats,” she said. “As a drug developer for more than 20 years, I know that that’s how you get drugs approved. But as a patient advocate, I tell people to stay away from them. Cancer patients who are struggling for their lives want the latest and greatest treatments.”

“We need to eliminate those [cancer] drugs with a low probability of working and prioritize those drugs with a high probability of working.”

August: “Genetically Manipulated Organisms: Are We Ready?”

As science contends with a growing torrent of new data from DNA synthesis, the international community of genomics researchers, both academic and commercial, is joining forces to ensure that such data are used safely and responsibly.

Kevin Clancy discussed that effort and the challenges faced by Life Technologies at the **August 3 “Exploring Ethics”** forum, “Engineering Genetically Manipulated Organisms in a Global Market: Are We Ready?”

Clancy is Senior Staff Scientist for Synthetic Biology at Life Technologies, a Carlsbad-based biotech manufacturer of research instruments and materials. Because the company dominates the market for synthetic biology products – “We penetrate every biological research laboratory ... and we are involved in every aspect of the biological arena,” Clancy said – Life Technologies has been thrust into a leadership role in considering ethical uses of its own innovations.

Calling himself a “bioinformaticist,” Clancy delved into the complexities of applying new knowledge about the human genome’s 28,000 genes. “Our ability to synthesize genes is remarkable,” he said. “The major problem is not generating data. It’s analyzing and understanding the data.”

Acquiring the tools needed to engineer genes is fairly easy; as Clancy observed, “Just go to eBay and type in ‘DNA synthesizer.’” But “the limiting factor,” he added, “is the biochemicals” required to use the tools. “Biological research is not cheap,” he said. “You have to start buying stuff, and you have to go to the companies that make it.”

In the absence of formal restraints on genomics trade, informal monitoring is carried out by two international alliances: [The Australia Group](#), a 41-nation forum that seeks to halt production of chemical and biological weapons, and the [International Gene Synthesis Consortium](#), founded in 2009 by five member companies that represent 80 percent of global gene synthesis capacity.

The two groups have developed principles for export controls that include, as Clancy phrased it, “never synthesize anything from an unknown actor.” But the industry has equal concerns about biosecurity lapses by benevolent researchers. “It would be an error,” Clancy said, “to think that we only need to worry about nefarious individuals as opposed to scientists with NIH grants who have accidents.”

During the Q&A period, audience members raised the idea of greater regulation of genomics research. As one person noted, “You have to have a license to be a physician, and you have to pass the bar to be a lawyer, so maybe you should need some kind of license more than just the academic credential” to work in synthetic biology.

Audience members also questioned whether the profit motive might induce genomics corporations to behave unethically. And, citing contamination by genetically-engineered organisms in food production, members asked how synthetic biology can avoid a “tipping point” where advances outpace ethical constraints.

Clancy emphasized that for-profit companies are driven to protect their own workforces and thus “move toward safer, more sustainable, less toxic ways to do experiments.” And, as the science of genomics advances, he said, “we will be able to sequence the organism, understand what it’s going to do before we release it, and anticipate what will happen in its environment.”

Asked to name potential benefits of synthetic biology, Clancy cited two: new sources of energy production and new methods of treating disorders such as Crohn’s disease by transforming unhealthy bacteria into healthy bacteria.

“Most of the organisms in your body are bacteria and viruses,” he said. “Only 10 percent of you is human; the rest of you has been colonized.”



Kevin Clancy

The 2011-2012 Henrietta Lacks Series: A Community

San Diego Alliance Launches “Lacks Project”

A San Diego science and education alliance has launched “The Henrietta Lacks Project: A Community Exploration of Science, Ethics and Diversity.” This unprecedented regional series of events will examine research ethics and diversity issues through the platform of the bestselling book *The Immortal Life of Henrietta Lacks* by Rebecca Skloot.

Spanning the 2011-2012 academic year from September through June, “The Henrietta Lacks Project” will involve six universities and colleges – San Diego State University, the University of San Diego, CSU San Marcos, Point Loma Nazarene University, Grossmont College, and UC San Diego – in leading a public discussion of the riveting story of Lacks, an African-American cancer patient whose cells were used for research without her knowledge.

The coalition includes the Reuben H. Fleet Science Center, the Ethics Center, and SDSU’s Initiative for Moral Courage. Educators

“San Diego is the perfect place to stage such an ambitious series, and the story of Henrietta Lacks is the ideal catalyst for it.”

from the San Diego Unified School District will offer special curricular programs, and area K-12 students will be invited to participate in activities throughout the county.

All participating institutions will stage multiple satellite events. As one example, the Ethics Center will devote nine of its monthly “Exploring Ethics” public forums at the Fleet Center to a special “Henrietta Lacks Series.” A high point of the series, which is coordinated with CONNECT, will be a November 2 lecture at the Fleet by Skloot.

The Immortal Life of Henrietta Lacks chronicles the true story of how cervical cancer cells taken from Lacks were used without her permission to produce a human cell line for research purposes. Officially labeled “HeLa” cells, Lacks’ cell line was so resilient and bountiful that it is still being used for medical research 60 years after her death in 1951. HeLa cells have been instrumental in studying cancer, polio, radiation sickness, gene mapping, and a range of other areas.

The book, Skloot’s first, has won widespread acclaim and numerous awards, including the Wellcome Trust Book Prize and the Heartland Prize. It was ranked among the “Top 10 Books of 2010” by *Publisher’s Weekly* and among the “100 Notable Books of the Year” by *The New York Times*.

“We are tremendously excited about this first-of-a-kind series and the opportunities it presents for dynamic public engagement about science,” said Ethics Center Director Michael Kalichman, who also directs the UC San Diego Research Ethics Program. “San Diego is the perfect place to stage such an ambitious series, and the story of Henrietta Lacks is the ideal catalyst for it.”



Exploration of Science, Ethics, and Diversity

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

September 7

HeLa: Immortal Cells and Enduring Questions

Laura Rivard, Ph.D., University of San Diego

The resilient HeLa cells taken from Henrietta Lacks in the 1950s without her permission are still being used in medical research — and her story still resonates with ethical issues surrounding informed consent and tissue ownership.



October 5

The Politics of Race, Class, Gender, and HIV/AIDS in S. Africa

Jamie Gates, Ph.D., Point Loma Nazarene University

The HIV/AIDS crisis in South Africa, like the Henrietta Lacks story, is a controversial chapter in modern health care that raises ethical questions about science, race, gender and inequality.

November 2

Rebecca Skloot, Author, *The Immortal Life of Henrietta Lacks*

Jamie Gates, Ph.D., Point Loma Nazarene University

Skloot will discuss her award-winning book, and how its themes of research ethics and diversity have attracted global attention and sparked ongoing public debate.

NOTE: Venue seating will be limited but satellite viewing will be available.



December 7

Barriers to Clinical Trial Recruitment

Georgia Sadler, MBA, Ph.D., UC San Diego

Clinical trials are indispensable to advances in medical treatment, but their value depends on recruiting participants who are diverse in race, ethnicity, and age.

January 4

Science Literacy and Underserved Populations

Tate Hurvitz, Ph.D., 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.





Thomas Scott, Ph.D.

Vice President for Research and Dean of Graduate Affairs, SDSU
Member, Board of Advisors, the Center for Ethics in Science and Technology

Thomas R. Scott, a neuroscientist specializing in sensory processes, has been a member of the Ethics Center's Board of Advisors since 2004. Dr. Scott joined SDSU in 2000 as Dean of Sciences and began serving as Vice President for Research and Dean of Graduate Affairs in 2005. In 2006, he was named interim Chief Executive Officer of the SDSU Research Foundation, a \$200-million non-profit foundation that manages SDSU's contract and grant activity. Dr. Scott has published 125 papers, and he has been elected President of two national organizations: The

Association for Chemoreception Sciences (1997-98) and the Society for the Study of Ingestive Behavior (2000-2001).

How and why did you become involved with the Ethics Center?

Mike Kalichman, Larry Hinman and Mark Trotter approached then-President Stephen Weber and me seven years ago with the idea of creating a Center for Ethics in Science and Technology. Ethical issues were prominent in the public domain: the falsification of data by a Korean scientist, the right of Terri Schiavo's parents to end her mechanically-sustained life, the passage of Proposition 71 in California to bypass the ban on federal funding for stem cell research imposed because of ethical concerns. Locally, San Diego was newly rich in science, and as our young companies matured, a moral compass would be a valuable guide to their growth. The timing was propitious; President Weber responded positively to the request for support; I eagerly agreed to represent the University.

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

The Center brings to the public an unbiased ethical consideration of important scientific issues. It has done so both through formal professional meetings with published proceedings and through monthly forums at the Fleet Museum. Mike Kalichman has led these gatherings, and he is scrupulous about informing, but not persuading, the audience. Thousands of San Diegans have been introduced to profound moral issues through these events.

What should be the Center's priorities over the next 5 years?

Foremost, establishing a firm financial base. The Center's needs are modest, but real. Institutions that provided the initial support (Legler-Benbough, UCSD, USD, SDSU, et al.) have suffered directly, or through loss of state funding, from the recession. Surveys of the community reveal that our citizens and institutions appreciate the Center's activities, but matters of ethics are not the highest priority for those enduring financial pressures. Recently, the Center joined with CONNECT to create a coalition that will offer both an added dimension to CONNECT's already formidable services and the prospect of more reliable resources for the Center.

What ethical issues have special traction in San Diego?

San Diego is justly renowned for scientific research in wireless communications, biotechnology, and now renewable energy. Ethical considerations pervade all three: issues of privacy, of whether genes should be patentable, of human embryonic stem cell use, of the debasement by one species of an environment shared by millions. But these industries are young, still discovering not just technologies, but their own corporate values. Ethics has a firm role in that process, and so in defining the nature of the community San Diego will become.

You leave your administrative positions this month to return to the faculty. What are your plans?

One appealing aspect of a university's system of shared governance is that faculty may move into administrative roles without becoming professional administrators. When a task is complete, or the time is right, he or she may comfortably return to the faculty. After 25 years of being a faculty-administrator, the time is right for me. I was drawn to this profession not for the prospect of setting research policies or overseeing graduate programs, though these are essential to a well-managed institution and carry their own rewards. Rather, I was attracted by the opportunities to teach and to conduct scientific research. The appeal of those activities has not faded through four decades and I will enjoy reengaging them full time in the fall.

SD Science Fair Students Win “Ethics In Science” Awards

The June “Exploring Ethics” Forum featured a presentation ceremony for special “Ethics in Science” awards given to student participants in the 2011 Greater San Diego Science and Engineering Fair. Award recipients were chosen for the quality of their essays that explored societal and ethical issues related to their Science Fair Projects. The “Ethics in Science” program is part of the Ethics Center’s ongoing K-12 educational outreach efforts. As program coordinator David Higgins explained, “We want to encourage the next generation of scientists to see ethics as part of their research and not as a question to be handled only by others.”



“Ethics in Science” award winners gathered at the Fleet Center for the June 1 ceremony. Left to right: David Higgins, awards coordinator; Sharona Silverstein, 3rd place; Alyssa Chan, 2nd place; Mark Matten, 1st place; Yichen Song and Sophia Wang, 3rd place; Michael Kalichman, Ethics Center Director. Not pictured: Russyan Mabeza, 3rd

Excerpts from award-winning “Ethics in Science” student essays

“After reflecting on our robot’s capabilities, I realized the importance of asking deeper questions ... The questions went beyond the initial ‘How can this technology be used in the future?’ but rather, ‘Is it *right* to use this technology?’ In addition, ‘Is the use of autonomous robots justified, what are the concerns, and what are the consequences?’”

Mark Matten, “Out of Harm’s Way: Ethical Challenges of Autonomous Military Robots” (1st place, \$500 prize)

“Scientists must carefully evaluate the possible ramifications of their work and be aware of both the positive and negative implications. While scientific research is first and foremost an intellectual endeavor, its moral component, while often overlooked, is also important.”

Alyssa Chan, “Ethical Ramifications of the Widespread Use of Porous Silicon-Based Chemical Sensors” (2nd place, \$200 prize)

“Early school start times for teenagers put three ethical principles at stake [including] respect for autonomy or the idea of self-determination and allowing individuals to make their own choices.”

Sharona Silverstein, “Sleep Patterns and Psychological Health: Implications for Resolving the Ethical Challenges Posed by Early School Start Times” (3rd place, \$200 prize)

“There are questions, especially in the biological field, that cannot be objectively answered by science. ... As humans, we also have the ability to judge what we think is right or wrong.”

Yichen Song and Sophia Wang, “Ethical Issues Involved in Animal Research for Treatment of Human Disease and Possible Solutions.” (3rd place, \$100 prize)

“We have progressed a lot as a nation, and our industrializing powers have truly expanded. However, we have forgotten certain issues and consequences that come with it.”

Russyan Mabeza, “An Inspired Innovation” (3rd place, \$100 prize)

the **Center**  for **Ethics**
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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

Visit us on the web:

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Ethics Center in the News

“Bishop’s Student Gets Science Ethics Award” La Jolla Light, July 22, 2011

“The Center for Ethics in Science and Technology was founded in 2004 to foster science in the public interest by promoting awareness, understanding and discussion of the ethical implications of new developments in science and technology.” (Read more: see <http://www.lajollalight.com/2011/07/22/news-and-notes-on-la-jolla-students-and-grads>)

“A Scientist’s Life: 10 Things USD’s Lawrence Hinman Has Done” San Diego Union-Tribune, August 15, 2011

“Meet Lawrence Hinman, the philosophy professor who co-founded and helped to direct the Center for Ethics in Science and Technology.” (Read more: see <http://www.signonsandiego.com/news/2011/jul/24/voices-new-era-meet-community-editorial-board>)

Editor’s note: Larry Hinman will be the moderator for the opening forum in “The Henrietta Lacks Series” on September 7 featuring a presentation by his colleague, USD biologist Laura Rivard (see article on pages 6-7).

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