

## *Message from the Director*

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Recent headlines have underscored the profound impact of new developments in science and technology. Cell phones and the Internet brought worldwide attention to civil unrest in Middle East countries. New scientific reports have further elucidated stem cell use. Effects of human climate change have sparked growing concern. Each of these topics raises multiple ethical challenges, and as summarized in this newsletter, all were discussed at our latest Exploring Ethics forums.

The goal of our Exploring Ethics series at the Reuben H. Fleet Science Center is to address provocative ethical issues in science and technology. To best meet that goal, we continue to experiment with different programming types and formats. As one example, we have launched an unprecedented partnership throughout the San Diego community. Building from a focus on Rebecca Skloot's bestselling book, *The Immortal Life of Henrietta Lacks*, we are scheduling a series of Exploring Ethics programs from September 2011 through April 2012. These programs involve an alliance of half a dozen colleges and universities in San Diego. Multiple satellite events will take place on their campuses. The main event on November 2nd will feature Skloot as our "Exploring Ethics" speaker in a program hosted by San Diego State University.

Two-way conversations between scientists and the public are the defining reason for the Ethics Center. Such dialogue benefits our community, and it engages the next generation in science as a career path and a public resource. To reach out to that next generation, we are proud of ongoing relationships with the Greater San Diego Science and Engineering Fair since 2008 and the San Diego Science Festival since 2009. Summaries of these partnerships appear in this issue as well.

Finally, we are delighted to report that the Ethics Center has entered into a partnership with CONNECT to assist us in managing events and developing a sustainable approach to the Center's future. Having helped launch over 2,000 companies, CONNECT is highly respected as a catalyst for promoting science and technology innovation in the San Diego community.

We will have more exciting news to share in the coming months. Please keep in touch. 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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## *January: Do Unfertilized Eggs Offer A Better Stem Cell Technology?*

A new stem cell technology that harvests unfertilized eggs may alleviate ethical concerns about harming viable human embryos, but it presents unique ethical challenges about recruiting egg donors here and abroad.

**Jeffrey Janus**, Senior Vice President at International Stem Cell Corporation (ISCO), led the first 2011 “Exploring Ethics” forum on **January 5** with a talk on **“Human Embryonic Stem Cells: Do Unfertilized Human Eggs Offer Another Way?”** An ISCO method derives human stem cells by using only unfertilized human eggs rather than embryos. Through appropriate manipulation of the egg, it can be stimulated to form a parthenote. Janus said this is “a way to create pluripotent stem cells without disruption of a viable embryo.” An additional benefit is that, unlike embryonic or adult stem cells, parthenotes have value for treating diseases with a genetic component.



“If the egg donor has an immune type that’s common in the population, many people can receive those stem cells,” he noted. “We’ve already created one line of cells ... that will match 75 million individuals from different racial groups.” However, because parthenogenesis involves donated human eggs, it raises issues about the ethics of recruiting egg donors, defraying the costs of their in vitro fertilization (IVF) egg extraction, and separating out a few eggs for research. ISCO’s first study took place in Russia, where many donors could not otherwise have afforded an IVF procedure. Despite ISCO’s exhaustive screening and integrity review measures, ethical challenges are still perceived by some. “I talk to people who don’t want this to happen because they are afraid of exploiting women,” said Janus. “I also hear from people who think that, even if a parthenote can’t become a human being, it’s a ‘disabled’ human being, so it’s still a life.”

Janus noted that women in the United States have approached ISCO because “they want to be donors for altruistic reasons, usually because they have relatives with serious illnesses.” He also described the potential use of stem cells derived from parthenote technology as “no different from an organ transplant, it just happens at the cellular level. ... If we could get a cell to make insulin, diabetic patients wouldn’t need to inject themselves with insulin every day. So this has the potential to affect the costs of health care.”

## *February: Giving Patient Mediators a Role in Drug Approval Process*

When federal regulators and pharmaceutical companies reach stalemates over new drug approvals, patient mediators could bring the two sides together and expedite delivery of life-saving medical products.

That was the focus of the **February 2 “Exploring Ethics”** presentation by **Duane Roth** that drew on his newly-published *Hastings Center Report* paper, **[“A Third Seat at the Table: An Insider’s Perspective on Patient Representatives.”](#)**

Roth, CEO of San Diego’s regional CONNECT, wrote the paper to share lessons he has learned as Vice Chairman of the Independent Citizens Oversight Committee of the California Institute for Regenerative Medicine (CIRM). Since its 2005 inception, the 29-member CIRM board has included 10 designated “patient advocates” who represent 10 disease groups with a stake in stem cell science. When he joined the board as an industry representative, Roth recalled, he was skeptical about patient advocates. “I thought, ‘These advocates are all going to fight for their own diseases,’” he said. “I couldn’t have been more wrong.”

Based on his years with CIRM, Roth believes that people who have experienced serious illnesses as patients or caregivers are uniquely qualified to judge the risks and benefits of potential therapies for those illnesses. “Only patients who are affected by the disease can help the FDA and the company make risk-benefit decisions,” Roth told the audience. “In the current system, those patients are told, ‘Sit outside the room while we have our conversation, and wait until we come out and tell you what we’ve said.’”

While critical of the FDA regulatory process, Roth was sympathetic to the agency. When unexpected drug side effects make headlines, “the FDA gets pounded on,” he said. “I would behave like FDA reviewers do if I was part of that agency today. We don’t have a system ready to deal with stem cells and other products of modern medicine.”

The involvement of patient mediators could help make the agency less risk-averse. Should side effects occur, “the patient advocates could say, ‘We knew the risks, we were part of the meeting that took place,’” Roth said. “This would bring a lot more transparency into the process.”



## *March: Is Geoengineering Our Best Hope - or a Hopeless Venture?*

The prospects for mitigating global warming may hinge on a scarce human trait: the ability to set aside self-interest and focus instead on public good.

**Oran Young**, a UC Santa Barbara scholar of international governance and environmental institutions, examined the ramifications of reversing climate change at the **March 2 “Exploring Ethics”** forum on **“Governing Geo-Engineering,”** the last in a three-part series, **“The Ethics of Cooling the Planet Through Geo-Engineering,”** co-sponsored by the Ethics Center and the **Institute for Ethics and Public Affairs** at **San Diego State University**.



Young, the founding chair of the Committee on the Human Dimensions of Global Change of the National Academy of Sciences, explained that geo-engineering options range from pragmatic, like reforestation, to theoretical, like “putting lots of tin foil in the atmosphere” to block solar radiation. While such efforts “may be our last best hope,” he said, unforeseen consequences might entail long-term costs. “Major technologies have a history of producing a lot of side effects,” he observed. And fixes might generate “moral hazards” that bolster irresponsible conduct. “There could be a fundamentally dangerous attitude that ‘we’ll come up with a new technology and invent our way out,’” Young said.

The international community has tried to create a system for global governance of geo-engineering, but “such agreements are hard to put in place,” Young said. “Would they be legally binding? Sanctioning is a sensitive issue, and we don’t have an international police force.” Audience members asked Young to speculate on how economic and social trends exacerbate climate change. “China has seen a massive increase in the middle class,” Young said, “and middle-class people like middle-class lifestyles, which are very consumptive. The challenge of the 21<sup>st</sup> century may be to manage climate change, population increase, and lifestyle changes all at the same time.”

Humankind is “a species that is out of control,” Young said. “We don’t have the capacity, the will, and the knowledge to govern our behavior. But we owe it to the other species and the planet to make a good faith effort.”

## *April: Science for Human Rights: High-Tech Humanitarian Aid*

From earthquakes to massacres, humanitarian crises can now be monitored – and even mitigated – by users who have technology that can access the necessary information. Should such devices be considered a “basic human right” and made available worldwide at no cost to the users?

**Eric Michelsen**, a UC San Diego physicist and a 30-year supporter of Amnesty International, explored this scenario at the **April 6 “Exploring Ethics”** forum on **“Science for Human Rights: Quantitative Methods for Security and Humanitarian Aid.”** A former electrical engineer in data processing systems, Michelsen described how technology has become a powerful tool for upholding the 1948 UN Universal Declaration of Human Rights. Satellite imaging, crowd sourcing, and geospatial mapping can quantify human suffering from natural disasters and tyrannical violence. The proliferation of cell phones, combined with their ability to create networks and transmit data, has spurred “a transference of power from government and big business to individuals,” Michelsen said.



“A team of journalists has maybe a dozen people in it, but there are tens of thousands of cell phones” that can scan human rights abuses, he added. “We can start making truly significant international responses to data we’re getting that are irrefutable.” Audience members wondered about the logistics of universal accessibility to tech tools, and they raised questions about choosing from among legions of catastrophes worldwide. “I believe in doing what you can and not trying to do more,” Michelsen said. “What we need is a concerted Internet effort to address the most severe problems.”

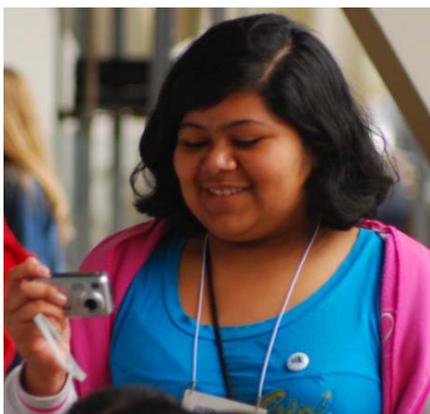
Technology that safeguards human rights can also be manipulated to violate them. At one end of the spectrum, the software platform [Ushahidi](#), developed in Kenya in 2007 to track political persecution, has been used to oversee disaster relief efforts in Haiti, Chile, and Japan. At the other end, a Facebook page promoting a “pro-democracy rally” in Ethiopia was a government ruse that lured hundreds of protestors into prison. Michelsen noted that regional social mores often override universal standards. “Where does culture end and abuse begin in a society that’s monolithic? When we talk about the rights of women, someone we view as a victim of discrimination may herself agree with the practice.”

## *Montgomery Students Learn and Teach Lessons in*

In January 2010, the Ethics Center teamed up with students and teachers at Montgomery Middle School (Monty) to form an after-school club, “Ethics and Science in Montgomery” (eSIM). Its aim was to collaborate on the design and implementation of an ethics and science experiment for the 2010 San Diego County Science Festival at Petco Park. The project was so successful that the eSIM club presented another ambitious experiment at this year’s Science Festival.

It's exciting to work alongside these dedicated teachers of Monty to help make science come alive for these students in ways that make sense to them. To know that they go home and talk about these issues with their parents, and that they are discussing these questions with their classmates, is very rewarding. We hope that active engagement in conversations about science now will lead to active engagement with the practice of science in the future - that's one of the goals of the eSIM club.

— **Dena Plemmons**, *Ethics Center Strategic Planning Group*



**Leslie Mejia**

Our eSIM club explored two issues related to ethics and science: whether scientists should use animals for testing and whether parents should put GPS devices on their children. We developed some questions for a survey that we distributed to students in our school and in the Twin Peaks Middle School in Poway to find out what they think about these two issues. We also gave Montgomery teachers the survey to compare how students and teachers think about animal testing and parents using GPS on children.

Based on our research and survey results, the eSIM club made a poster about animal testing and parents using GPS on children. We presented it at the Science Festival Expo Day, and we gave out the survey to people there.

The eSIM club is the best!

What we learned at Expo Day is that science is a part of life. Science is as important to our lives as math is. Expo Day is a great festival for children to go to.

In one of our experiments, we first put some glue in a cup. Then we poured in food paint and mixed it in well. Then we put it inside a plastic bag with a little water added. In time, the glue hardened and the food paint gave it color, and we were able to take it out and bounce it like a little ball.

Later on, as I was walking through the festival, I saw a lot of people watching something that interested them. I became curious: What were they watching and why was it interesting? I finally got to see what it was: an electronic toy that worked by absorbing energy from the sun.

—**Maria Perez**, 6th Grader



**Jessica Aguilar and Maria Perez**

## *Science Ethics at 2011 San Diego Science Festival*

The eSIM club has proven to be a very inspiring and rewarding after-school experience for my colleague, Will Holsinger, for me, and for the students we work with. For students who join the club, there is candid collaboration and dialogue around science issues and ethics. They engage in healthy but friendly debate in an attempt to develop non-biased surveys designed to give a clear image of what the public thinks about the same issues they are debating. They then conduct the surveys using their school population, including all of the students that are enrolled plus the teachers that are on staff.



*Ray Ruffin and Will Holsinger*

Once the surveys have been disaggregated, the students and teachers evaluate the results to identify trends and/or patterns that might develop between the different populations surveyed.

Trends that have developed over the two years the club has been conducting the surveys have produced very interesting results that seem to indicate that the Montgomery population surveyed tends to reflect public opinion very closely. In fact, during the first year of the survey, Montgomery opinion in the survey directly mirrored public opinion for the same questions that were asked.

These results proved to be very inspiring for the students conducting the survey, and they were a great motivator for the next year's survey.

The club is serving as a recruitment tool for the campus during the 2011 Expo Day. Several parents were interested in their children attending Montgomery after participating in the survey. All of these factors, plus working with a dedicated professional team through UCSD, helps to keep me motivated and looking forward to another year.

I am truly impressed by the caliber of work the Montgomery students continue to produce each year during Expo Day, and I am proud to say I am part of the Montgomery Middle School staff. I look forward to many more years of service as a sponsor of the Montgomery Middle School eSIM club!

## *2011 San Diego Science Fair Ethics Award Applications*



The fourth annual "Ethics in Science" program, sponsored by the Ethics Center in conjunction with the Greater San Diego Science and Engineering Fair, drew many strong applications from among senior division science fair participants. Students submitted ethics projects based on the research they did for their science fair projects. Submissions were judged based on five criteria: significance; ethical principles; stakeholders; solution; and relevant literature.

Awards are: one 1st-place (\$500), one 2nd-place (\$200), and three 3rd-place (\$100). The winners will receive their prizes at the June 1 "Exploring Ethics" forum at the Reuben H. Fleet Science Center, and their names will be published in the next Ethics Center newsletter.

"It is essential that scientists take part in the discussion about how products of their research are used," said David Higgins, "Ethics in Science" coordinator. "This program encourages the next generation of scientists to see ethics as part of their research, and not as a question to be handled only by others."

## Floyd E. Bloom, M.D.

Executive Director, Science Communication, The Scripps Research Institute  
Member, Board of Advisors, the Center for Ethics in Science and Technology



Floyd E. Bloom, a past member of the President's Council on Bioethics, has been elected to the National Academy of Science (1977), The Institute of Medicine (1982), The American Philosophical Society (1989) and the Royal Swedish Academy of Science (1989). He has served as Chairman of the Department of Neuropharmacology at The Scripps Research Institute, Director of Behavioral Neurobiology at the Salk Institute for Biological Studies and Chief of the Laboratory of Neuropharmacology at the National Institute of Mental Health. His numerous awards include the Pasarow Award in Neuropsychiatry, the Hermann van Helmholtz Award, and the Sarnat Award for Mental Health Research. He is past editor-in-chief of *Science* magazine.

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

I believe that senior scientists should give back to the scientific effort by helping train young scientists in principles of research ethics. And we should demonstrate the integrity of the scientific community to the public so that their trust and financial support can be strengthened.

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

The early panel discussions and publications on the uses of embryonic stem cells and on Internet security were cutting edge efforts to reach out with scientific data to the public on these thorny issues. And the meeting on Neuroethics helped bring home to San Diego some of the national debates over the potential for the abuse – or at least the impact on the criminal justice system and society more broadly – of current trends in neuroscience. The Science Fair efforts and the Fleet museum lectures are also laudable.

***“Senior scientists should give back to the scientific effort by helping train young scientists in principles of research ethics.”*** **What should be the Center's priorities over the next 5 years?** The top priority is securing financial sustainability while maintaining continued production of publicly valuable communication-discussion.

### Why have an Ethics Center?

I see the value as instantiating a difficult issue for science and society in a group of visible, active community representatives from public communication, bio-medicine, education, philosophy, business and neuroscience, strengthened by the meetings, lectures, and events. I don't know of a single other city that has one, and it includes a very broad slice of the San Diego scientific, academic and business-religious community.

### What ethical issues have special traction in San Diego?

This being the home of Qualcomm, the ethics of the Internet and wireless communication is #1, and continuing debates over stem cell research and application is #2.

### Is there any topic you would like to see addressed at a future Ethics Center forum?

Hank Greely gave a splendid lecture at the 2010 Society for Neuroscience meeting on neuroethical issues in the current hot topics of neuroscience research. Juan Enriquez posed that if we can implant cochlear devices to restore hearing, can we imagine implants that can hear sounds humans normally cannot? He followed that thought with the proposal that if we could similarly restore vision with optical sensors in the retina, could we create visual abilities that can see in the ultraviolet and infrared — and are these abilities-to-come real enough to be threats to society?

Coming This Fall:

## ***Rebecca Skloot: Henrietta Lacks & Medical Research Ethics***

Starting this fall, a San Diego science and education coalition will launch an unprecedented county-wide series of events that examine research ethics and diversity issues through the platform of the bestseller *The Immortal Life of Henrietta Lacks*.

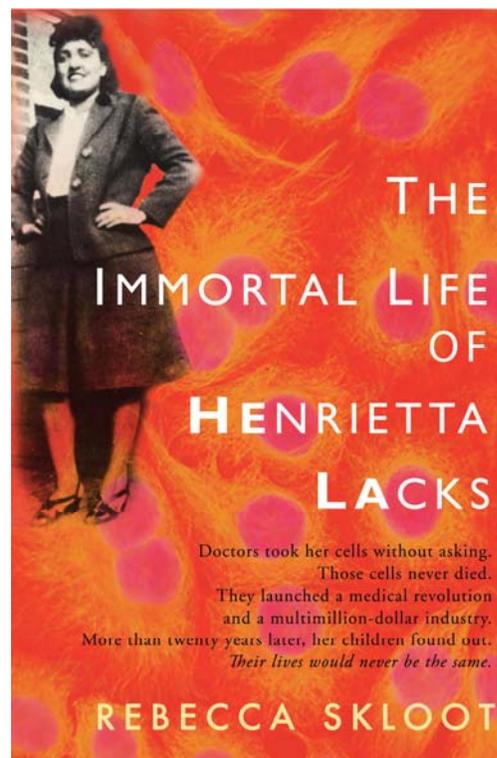
From September 7 through April 2012, the Ethics Center will devote eight of its monthly “Exploring Ethics” forums to different aspects of the riveting story of Lacks, an African-American cancer patient whose cells were used for research without her knowledge or consent. A high point of the series will be a November 2 “Exploring Ethics” lecture by the book’s author, Rebecca Skloot, at the Reuben H. Fleet Science Center.

Other monthly “Exploring” forums will feature expert speakers from UCSD, SDSU, USD, Point Loma University, CSU San Marcos, Grossmont College, and other participating institutions. All of the institutions are planning multiple satellite events ranging from art projects and theatrical productions to common reading experiences.

“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,” 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, which said of the book, “Science writing is often just about ‘the facts.’ Skloot’s book ... is far deeper, braver, and more wonderful.”

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



### ***Save the Date***

Rebecca Skloot will be the guest speaker at the November 2 “Exploring Ethics” monthly forum at the Reuben H. Fleet Science Center, Balboa Park  
5:30—7:00 p.m.

For current information, check [www.ethicscenter.net](http://www.ethicscenter.net)

### ***Other Upcoming Events***

June 1, 2011  
Stem Cells and Informed Consent: What’s the right balance?  
Michael Kalichman, UC San Diego

July 6, 2011  
Navigating Cancer Treatment in the New Era of Personalized Medicine  
Laura Shawver, Clarity Foundation



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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](http://www.ethicscenter.net)**

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## *Ethics Center in the News*

### *“Ethics Center Partners with CONNECT” La Jolla Light, March 13, 2011*

“The Center for Ethics in Science and Technology announced it is joining with CONNECT to expand San Diego’s participation in considering the ethics of new science and technology.” (Read more: see <http://www.lajollalight.com/2011/03/13/ethics-center-partners-with-connect/>)

### *“Aerosols May Change the Nature of Environmentalism” Voice of San Diego, October 4, 2010 Op-Ed by Tate Hurvitz, Ethics Center Fellow*

“For San Diegans the environment is big business. As a city that has emerged as one of the leaders in biofuels research, a potential governor's position on emissions controls will have a large impact on the bio-fuel industry.” (Read more: see [http://www.voiceofsandiego.org/opinion/article\\_00dc6c8e-7512-11e0-a4f2-001cc4c03286.html](http://www.voiceofsandiego.org/opinion/article_00dc6c8e-7512-11e0-a4f2-001cc4c03286.html))

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