

Moving Forward with New Momentum

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This has been a remarkable year in the history of the Center for Ethics in Science and Technology. We were privileged to celebrate our fifth anniversary with the support of numerous individuals, including many community leaders.

Following its successful 2008 launch, the monthly Exploring Ethics series at the Reuben H. Fleet Science Center in May 2008 has gained momentum and is now scheduled well into 2010. In conjunction with the Exploring Ethics program, the Ethics Center is regularly featured on the KPBS program *These Days* and frequently included on the CW 6 program *San Diego in the Morning*. And earlier this month, we hosted a special Saturday program at the Fleet Science Center to screen the award-winning documentary *Sound and Fury*. The event was extraordinarily well attended, and the audience engaged in a spirited discussion with the director of the movie, Josh Aronson.

The *Sound and Fury* forum underlined a recurring role for the Center. In discussing the ethics of cochlear implants for deaf children, we were asking:

- Does it work?
- If it works, how should it be used?

These two questions lie at the heart of the Ethics Center's activities

Excellent examples of the first question have been covered throughout our Exploring Ethics series. Does the fMRI technology now being used to detect deception generate a minimum of false positives and false negatives? Do video cameras at busy intersections decrease the risk of traffic accidents? Do drugs taken by students to perform better in school help improve academic performance?

New developments in science and technology, by definition, are not yet known to be both safe and effective. To answer the apparently simple question, "Does it work?", we need to think deeply about many other questions, including: What does that mean "to work"? How would that be tested? Who should conduct the tests? Who should be the research subjects? How can we be sure that subjects understand the risks and benefits of participating in a study? How and when should research results be reported?

The second question, "If it works, how should it be used?", is even more challenging.

If drugs can help an athlete perform better, should athletes be allowed to use them? If it is convenient to share medical and financial information electronically, should we do so? How much information do we need before we decide to allow the clinical use of new stem cell therapies?

The common thread in all of these cases is that no technology can ever be perfect. We cannot expect that something will do exactly what we want, all of the time, and without any negative consequences. Even if the technology works well enough in principle, it isn't always clear that it should be used. And if it is used, how should we best implement it?

There are no easy answers to these questions. But if we don't face these questions, we will not find any answers. The Ethics Center will continue to identify important questions and provide forums for the necessary discussions. We hope you will continue to join us in exploring these issues.

*Michael Kalichman and
Stuart Henry
Co-Directors, Center for Ethics in
Science and Technology*

The Center is co-sponsored by:

University of California, San Diego ~ University of San Diego ~ San Diego State University

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“Exploring Ethics” Upcoming Events

Fact vs. Hype: The Challenges of Reporting Science News

***December 2, 2009, 5:30 - 7:00 p.m.
Reuben H. Fleet Science Center***

Is desalination an effective way to produce drinking water? Which climate change policies deserve support? The public needs reliable information on a range of science topics, and traditional journalism delivers that through objective reporting of verifiable facts, e.g., research findings published in peer-reviewed journals. But science writers face a challenge: coverage of complex science can seem arcane to the lay public, and oversimplified and over-hyped science news can be misleading. What's the best way to convey science news to the public?



Kim McDonald
Director of Science Communications, UC San Diego



David Washburn
Science Editor, *Voice of San Diego*

Upcoming Exploring Ethics Forums

**January 6, 2010
*Deep Brain Stimulation***

**February 3
*To be announced***

**March 3
*Are Vaccines Safe?***

For updates, visit our
Website
<http://www.ethicscenter.net/>

Ethics Center In the News

Reasonable Arguments: Thoughtfulness Trumps Dogma at The Center for Ethics in Science & Technology

San Diego Union-Tribune, June 28, 2009

“The center hosts monthly forums on topics current and controversial. ... These forums regularly draw 100 or more people, nearly all willing to thoughtfully grapple with difficult questions. Maybe that's a reflection of the center's careful and evenhanded approach. Maybe it's an indication of San Diego's fabled laid-back nature. Or maybe this is a sign that the center is only now approaching maturity – and notoriety.”

<http://www3.signonsandiego.com/news/2009/jun/28/1c28ethicsm222154/>

Science Meets Conscience

San Diego Magazine, May 2009

“Rather than impose a subjective idea of ‘proper’ ethics on a given issue, the Center for Ethics fosters debate about matters of importance—including stem-cell research and performance-enhancing drugs in sports—to determine ‘what the questions are—what people should be thinking about,’ says Dr. Michael Kalichman.”

<http://www.sandiegomagazine.com/media/San-Diego-Magazine/May-2009/Front-Pages/index.php?cparticle=3&siarticle=2#artanc>

Ethics in the Age of the Robot

KPBS-FM's “These Days,” March 3, 2009

“As part of our monthly series on ethics in science and technology, we'll discuss the role of robots in our lives. They hold out the promise to relieve us from danger and drudgery, but what are the risks? ...

<http://www.kpbs.org/news/2009/mar/02/ethics-in-the-age-of-the-robot/>

Ethics and Science on the San Diego Horizon: Column by Michael Kalichman

Voice of San Diego, March 2009

“Although biomedical research and development are among San Diego's greatest strengths, such work requires that we begin by testing new products that may turn out to be neither safe nor effective. Scientists know that they have a special ethical obligation to think through the risks posed by such research.”

<http://www.voiceofsandiego.org/articles/2009/03/05/opinion/kalichman030409.txt>

Fifth-Anniversary Exploring Ethics Forum: The Public's Role in Science Ethics

For its Fifth-anniversary public celebration, the Center devoted the October 7 “Exploring Ethics” forum to an exploration of its core mission: fostering public debate of ethical issues in science & technology.

The forum on “What is the Public’s Role in Addressing Science Ethics?” featured a keynote address by Laurie Zoloth, a distinguished Northwestern University bioethicist who is director of the Feinberg School of Medicine’s Center for Bioethics, Science and Society. She is also past chair of the Howard Hughes Medical Institute’s Bioethics Advisory Board.

In her presentation, “What Makes Research Fair? Just Science in an Unjust World,” Zoloth said the central ethical challenge in research policy decisions is “why we need to think and plan for justice in basic science.”

Citing principles established by such thinkers as Immanuel Kant and John Rawls, Zoloth reviewed trends in science policy, with a focus on health care access decisions, and she concluded with a challenge to the audience: “Your participation in ethics discourse is not just about prohibition and enthusiasm. It is responsible for answering the final question: what must I do in response to the suffering of the other?”

In the Q&A discussion that followed, Zoloth and the audience addressed a range of specific issues in research ethics, including:

- Basic research allows scientists latitude in pursuing ideas, and this unfettered approach can generate transformational knowledge. But research funding tends to be driven by disease-centric “road map” decisions, and such decisions can result from a narrow public focus on a disease area, e.g., onco-fertility issues.
- How do we involve people who have strong opinions but won’t engage in public debate and societal decision-making?
- Research “fairness” is complicated by the geo-political distribution of scientific attention and resources. Do we focus on “do-able” science on public health outbreaks, like malaria, that beset the poor in developing countries? Or do we focus on diseases that are as yet untreatable, including “cosmetic” conditions (hair loss)?
- The research marketplace has gone wild. Discoveries should be made publicly available, especially when they derive from research that is publicly funded. Most U.S. research is publicly funded and driven by societal choices. That model produces remarkable triumphs, like research on AIDS: from unknown disease to identification of HIV to possibility of vaccine.
- In classroom discussions of the science of cloning, both middle-school and GED students express strong opinions about the rightness or wrongness of cloning. But those students wouldn’t attend an Ethics Center forum on cloning.
- As a society, we act on different values than the values we express. We are committed to justice, but there are vested interests in preserving the status quo. Can we explore the neuroscience of what’s happening on a molecular level in the brains of violent young men? Or does that constitute an invasion of privacy? And do we even have the courage to ask such questions?
- Translational science is needed to treat human disease. At some point, not-for-profit research produces for-profit therapies. The market model of competition does provide an incentive for good science. But who pays for what, and who profits from what? Who pays for clinical trials? Who gets the royalties from patents?



“The most important asset is scientific attention. I want to live in a world where scientists are given as much as possible.” Lau-



Zoloth summed up the forum’s exchange by posing two questions: “To what do we aspire? How do we shape our goals?” She congratulated the Center on hitting the 5-year mark, and she issued a challenge: “I want to push you because you’re a great center – and you’re Californians! – to think about the next thing, and help us find the next step to take.”

Exploring the Ethics of Electronic Identity Theft

Is the convenience of online shopping worth the risk of credit card fraud?

If someone posing as you bills your health insurer for her detox stay, will your records list you as a former drug user? And why can't the latest technologies outpace such high-tech swindling?

The November 4, 2009 "Exploring Ethics" forum, "Technology and Identity Theft" asked audience participants to grapple with these and other privacy dilemmas. Two panelists led the discussion by presenting two aspects of the ID theft problem.

Sharla Leigh Evert from the Financial Crimes Division of the San Diego County District Attorney's Office delved into financial ID theft, now ranked as the fastest growing fraud in America.

Pam Dixon from the World Privacy Forum discussed the new phenomenon of medical ID theft and how it can wreak havoc with a victim's insurance eligibility, rates, and claims.

Evert began by noting that she herself has been a victim of identity theft: "The thieves used my credit card number to buy online pornography." Electronic fraud is proliferating, she noted, because perpetrators are sophisticated and law enforcement is too understaffed to pursue what are labor-intensive investigations.

"The medical profession is struggling with this outbreak. Banks are used to dealing with identity theft, but health care providers are not set up for dealing with this." Pam Dixon

a range of tips that included filling out checks in green ink (harder to wash out chemically) and calling 1-888-5-OPT-OUT to request removal from credit card solicitations.

Dixon reported that criminals who steal data for procuring medical services or goods are typically health care workers who sell the information. "Think medical files, not shopping sprees," she said. "The medical profession is struggling with this outbreak," she added: "Banks are used to dealing with identity theft, but health care providers are not set up for dealing with this."

Because patient records are difficult to alter, "if your medical identity is used inappropriately, there is little recourse for you to get it cleaned up," Dixon said. As with credit card fraud, the burden of prevention and detection falls on consumers. Dixon urged the audience to keep full copies of medical files, request frequent updates, and monitor all correspondence regarding claims for medical benefits.

The audience discussion touched upon the need for more vigorous technological enforcement and harsher penalties for ID thieves. Many expressed concern about the impact on young victims, including newborn infants and college students whose Social Security Numbers are part of their campus records.

Overall, there was a general sense of resignation in the face of rampant electronic data access; as one participant put it, "Aren't we living under an illusion that we've got privacy? Isn't all information already out there?"



Panelists at the November "Exploring Ethics" forum on "Technology and Identity Theft" were Sharla Leigh Evert (left) from the SD County District Attorney's Office and Pam Dixon (center) from the World Privacy Forum. SDSU's Stuart Henry (right), Ethics Center Co-Director, served as moderator.

Greater agency coordination can help shut down theft rings, and "regional task forces are making real inroads," Evert said. But deterrence remains the best method for fighting ID theft, and that duty rests largely on consumers. Evert offered

“Sound and Fury”: When Medical Advances Present Tough Cultural Choices

A special Exploring Ethics event scheduled on a Saturday drew a capacity audience into a passionate discussion. The core question was a recurring focus for the Ethics Center: When grappling with the challenges of a technological advance, how do we replace the uncompromising perspective of an either-or dichotomy with dialogue and a continuum of ideas?

The November 7, 2009 “Sound and Fury” forum centered on a long-standing controversy within the deaf community about whether deaf children should be fitted with cochlear implants. Director Josh Aronson screened two of his films, the original “Sound and Fury,” a 2001 Academy Award nominee for Best Documentary Feature, and the new “Sound and Fury: Six Years Later.”

Both films followed conflicts within the extended Artinian family about how cochlear technology might affect deaf identity and family unity. Two deaf cousins, 6-year-old Heather and 18-month-old Peter, are candidates for surgery. Will surgery-induced hearing estrange them from their deaf parents and grandparents? Will opting out of surgery close future doors to educational opportunity and a full social life?

The two documentaries were heart-wrenching and uplifting. The discussions that followed ranked among the most stimulating exchanges in the Center’s 5-year history. The audience included members of San Diego’s deaf community, college students, and health care professionals. Their perspectives covered a broad spectrum of viewpoints, but throughout the afternoon, a few unifying themes emerged.

Decisions about surgery on deaf children are excruciating in part because of time pressures – the younger the patient, the better the outcome – and only the parents can decide. “Parents have both the right and the obligation to make choices for their children,” said Aronson. “If the parent waits until the child is old enough to make a decision about whether to have a cochlear implant, then the parent has made the decision.”

As with many other dilemmas, choices can sometimes be made easier, but in other cases even tougher, as advances in technology change the equation. State-of-the-art cochlear implants in the original “Sound and Fury” operated on one channel. Six years later, implants operated on 24 channels, and the vast improvement in sound quality prompted one deaf couple to reconsider their earlier decision.

The debate over implants quickly led the audience to a discussion of the need for better language instruction for all children. Educators warned that deaf children can suffer as much from inadequate literacy schooling as they do from an inability to hear. And deaf advocates emphasized that children with implants who learn oral language can and should become fluent in sign language. As one advocate said, “It is absolutely an American problem to think that people can only learn one language at a time.”

Perhaps the most salient point arose when audience members likened the cochlear implant controversy to debates over the impact of bilingual education and the biological nature of homosexuality. What happens when generations in the same household speak different languages? Can the straight parent of a gay youngster impose a change in sexual orientation?

The “Sound and Fury” forum was organized by Dr. Dena Plemmons, a cultural anthropologist and Ethics Center Fellow who teaches research ethics at both SDSU and UCSD.



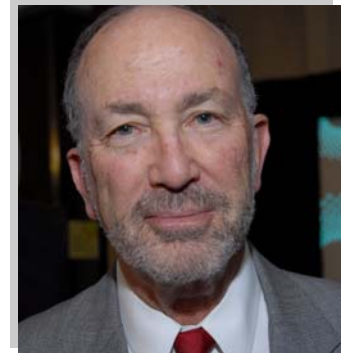
“Sound & Fury” Director Josh Aronson: “What this film is about is not deaf people, it’s about identity and culture.”

Q&A: Jeffrey Kirsch, Ph.D., Executive Director, Reuben H. Fleet Science Center

Dr. Jeffrey Kirsch began his career in science with a doctorate in aerospace engineering from the University of Southern California. Ten years later, he entered the field of science education when he took the helm of the KPBS-TV Science Center and created award-winning programs about science and society. Since becoming Executive Director in 1983, Dr. Kirsch has led the Fleet Center to new heights in membership (quadrupling to 12,000 families), physical space (doubling to 95,000 square feet), K-12 impact (reaching 100,000

students each year), and national prominence in the production of IMAX films.

When Dr. Kirsch joined the Ethics Center Board of Advisors, he helped launch a partnership between the two Centers to extend opportunities for public dialogue about science and ethics. That alliance has produced the popular “Exploring Ethics” forums, held on the 1st Wednesday of each month and recently including a special Saturday program (Page 5).



“The Ethics Center has demonstrated that, when innovations in science and technology have ramifications for society at large – and they generally do – society needs to be aware of those ramifications and discuss them.” Jeffrey Kirsch

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

I was invited to join the Board at a time when the Center was looking to expand its programming beyond the university campuses, and that exactly matched what the Fleet Center wanted to do. When people can talk about serious science in a friendly community environment, their understanding becomes enriched, and we have seen that happen with “Exploring Ethics.”

How has the collaboration between the two Centers evolved?

This partnership has exceeded my expectations. It can be difficult for people to engage in ethical debates for all sorts of reasons. Our forums help audiences leave their pre-conceived notions at the door and open their minds to the possibility that other viewpoints need to be heard. Both centers exist to open people’s minds. Our shared mission doesn’t put us on one side or another of any given issue. It puts us on the side of creating a pipeline for dialogue.

How can the Ethics Center do a better job of expanding that dialogue?

We have to be more responsive to the needs of the community, and we have to let many more people know that the Ethics Center is a place where they will always learn something new. That’s what we offer, and that’s what we must improve upon. We have taken on the challenge of influencing how science and technology are understood by society at large. That’s important, and we have to make sure we continue to succeed at it.

What has been the Center’s most significant achievement in its first 5 years?

We’ve grown in impact, and we are now ready to take on a more ambitious agenda. We’ve shown that a collaboration among major universities to launch a community-oriented center for public dialogue is both practicable and fruitful. The Ethics Center has demonstrated that, when innovations in science and technology have ramifications for society at large – and they generally do – society needs to be aware of those ramifications and discuss them.

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

We should be better known to the community for the benefits we offer. We need to improve our methodologies. At the Fleet Center, we can make the forum room a better place for dialogue. The Ethics Center’s relationship with KPBS is a beautiful coming-together, and we can build on that. We should look at social media as a means of expanding our impact. It’s very inexpensive, and it’s an amazingly fast way of spreading the word about our programs. And we have to get on a better financial footing so we can bring in people from outside the community to give us state and national perspectives. San Diego is a world-class science and innovation city, and the issues we’re dealing with resonate around the state and around the country.