



Meeting Thursday, March 24, 2016

Greater Los Angeles Veterans Affairs Medical Center
Wadsworth Bldg. (500)11301 Wilshire Blvd. LA
90073 Operator: 310-478-37116400 (6th floor)
SW corner San Diego Freeway (405) & Wilshire Blvd.
Exit Wilshire Blvd West from 405, right on to campus
west of freeway. Free parking in visitor lots
5:30PM free dinner 6:00 meeting (no RSVP needed)

1. General Announcements- open forum
2. **Hearing Their Voice: Advance Care Planning for the Homeless.**

Jeannie Meyer, CNS, Lori Koutouratsas
M.Div. Palliative Care, SM-UCLA Medical Center

3. **Memories of Ron Miller, MD.**

Consideration for endowing a meeting in his name.

4. Preparing for **implementation of EOLA (End of Life Assistance Option)** in June.

"What is your healthcare system doing to be ready"?

Ron Baker Miller, M.D. 1933-2016

Memorial service April 16th 11-2 pm
Library Room University Club UC Irvine
Dr. Miller, died peacefully at home 3/ 9, following a
short illness.

Graduated Princeton University and College of
Physicians and Surgeons, Columbia University.
postgraduate studies in nephrology
Boston Medical College faculty
started Renal Disease program at UC Irvine
authored more than 100 publications
sabbatical in Clinical Medical Ethics at Pritzker
School of Medicine Ethics 1989-90, U of Chicago
Started & directed Program in Medical Ethics until
2001 UC Irvine.

His family has suggested that donations be made to the
Jerome Tobis Endowed Lecture in Medical Ethics:
UCI Foundation, 555 Aldrich Hall, Irvine CA 92697-
5600. ph: (949)824-5618. www.give.uci.edu/contact
check to UCI Foundation, Attn: L.Haghi,
19722 MacArthur Blvd, Irvine 92697

Comments from his peers:

*Ron employed the First Amendment consistently. Bioethics Committees may be the last bastion of 'free speech' due to confidentiality: discussion by knowledgeable people, concerns about 'the other' instead of self-interest. He exercised each of those, raising new questions, advancing the process by stating new thoughts in different ways, not trading agreement when not truly present. He didn't mind being in the minority

as long as he made his point and others heard it. He was much more about determination to look, examine, weigh and balance. ~ Carol A. Peters, Esq
*He was such a major contributor to the meetings. I will miss him.~ Barbara Speyer
*All who knew him will agree that his devotion to the subject of medical ethics was intense and mighty admirable for a man at his stage of career. He accomplished much in his lifetime. ~ Paul Schneider

Gene Insertion Technology

Now Available/Affordable ...Ethical?

A mover and shaker in the world of Seed Saving, Bill McDorman, **Executive Director, Rocky Mountain Seed Alliance**, when asked his opinion on the most ethical concern of our time, quickly referenced the **Crispr-Cpf1** Technology that allows gene insertion to potentially alter animals and possibly humans as we know them. Cpf1 is the latest version of Crispr. More accurate, more dangerous.

This technology has been developed within the past decade. Watching the hen house are a few notable bodies and conferences. An Asilomar Conference on the Monterey Peninsula convened first 1975. A recent one was held at the NIH in Washington involving the UK, USA and China and another in Napa. Oddly there is more public buzz around GMOs in our foods than in our species. It would seem that medically oriented technical organizations may need to educate themselves about this technology and the issues it presents in order to prepare the populace for the hard decisions that will need to be confronted in the near future's brave new world.

Gene editing is now, says Hank Greely, a bioethicist at Stanford, "Something that someone with a BS and a couple thousand dollars' worth of equipment can do."

"In 1975 no one was asking whether a genetically modified vegetable should be welcome in the produce aisle. No one was able to test the genes of an unborn baby, or sequence them all. Today swarms of investors are racing to bring genetically engineered creations to market. ..In an odd reversal, it's the scientists who are showing more fear than the civilians," says science writer Amy Maxmen writing in

Wired.



Weigh in with the Editor: Ed-in-chief: Kendra Fleagle Gorlitsky, M.D. kfgorlitsky@gmail.com
Contributors: Richard Boudreau, MD, JD, Elvis Amaya, Ken Murray, MD

UCLA Journal Club - 2nd Wed of the mo. _____

Who is Responsible? In the City

Is the lead surveillance clean up in East Los Angeles neighborhoods assisting the necessary households soon enough? **Exide Battery**, a Georgia based business, recycling facility in Vernon is thought to have contaminated 1.7 miles around its plant in a low income area.

As many as 3,000 homes are on track to be cleaned up by the end of June 2017. State legislators, supervisor, and mayor seem relieved that Governor Brown has promoted increasing funds allocated for more lead testing and cleanup. Liza Tucker, of Consumer Watchdog, laments the difficulty recouping funds for the cleanup. "It would have been far easier if (Toxic Substance Control) had done its job in the first place by following state law that compels (participating companies) to collect the money up front for cleanups as a condition of operation."

Contrasting the delay in funding and attention to the East LA environmental hazard to the more robust efforts in the affluent area of Porter Ranch. Tucker remonstrates, "(Whether) less wealthy, not white... You basically deserve equal treatment when it comes to toxic contamination."

[Elizabeth Aquilera, 2/17/16 Molly Peterson/kpcc](#)

Who is Responsible? In the State

Porter Ranch gas leak of methane is claimed to have deposited greenhouse gas emissions in the air to be compared to over 572,000 automobiles in a year. As residents return to their home, questions remain regarding what the health impact might be on the most closely exposed [NBC Channel 4 3/2/2016](#).

In the Country: Where does the buck stop?

Tap water fans preferring the "safe and ecologically correct" free municipal variety to bottled versions, have had to rethink their trust in what was once thought of as a right--to safe and clean drinking water. When high levels of lead were permitted to contaminate the city water long enough to raise the lead levels in children, citizens want accountability.

The Flint fiasco has pointed fingers at many (and from both parties and races) the mayor, a state appointed City Manager, the governor, the EPA officials, the Michigan Water District Board, the water testers and engineers. some restrictions around the.

But as much as Americans are eager to designate villains, they also appreciate heroes. Two have come into the light:

---**the Pediatric Residency Director of Hurley Medical Center, Mona Hanna-Attisha, MD and MPH** noting the rise in lead levels among her patients had courage to withstand criticism when she spoke up, --**a Virginia Tech water specialist, Civil Engineer Professor Marc Edwards** familiar with the potential problem from investigating water in Washington, D.C. confirmed Flint's contamination. Summons by a worried citizen, his team incurred major expenses in the effort. His research team received support from the National Science Foundations' and commits to an ethnographic research tool espoused by Dr. Lambrinidou around "**transformational listening.**" Dr. Edwards could now become part of the solution as he was appointed by the governor of Michigan in January to be part of the "Flint Water Interagency Coordinating Committee," tasked with finding a long-term strategy to address the water crisis. [The Washington Post 1/27/2016 Colby Itkowitz](#)

In the World: No Separate Peace

Doctors without Borders were hit (over 80 attacks on medical facilities in Syria alone) per their official website. They continue to appeal to the world community to respect the integrity of medical care centers.

Cluster bombs, infamous during the Viet Nam War era for causing damage to civilians encountering them long after the original target was missed, were banned under the *Convention on Cluster Munitions*, signed by many countries, but not by the USA. The bombs, made in Massachusetts, have been found dropped in Yemen by a Saudi Arabian led coalition as reported by [Human Rights Watch 2/14/2016](#).

Saudi Arabia admitted using CBU-105 Sensor Fuzed Weapons in April 2015 in a CNN interview but "against vehicles." US policy permits export under certain restrictions.

In 2008, Secretary of Defense Robert Gates issued a directive that only cluster munitions that "do not result in more than 1 percent unexploded ordnance across the range of intended operational environment." The receiving country must agree that they "will be



used against clearly military targets and will not be used where civilians are known to be present or in area normally inhabited by civilians.”

Human Rights Watch reports, however, many incidents of civilian injuries some occurring well after the intended attack with significant numbers of the cluster bombs not detonating when expected. US Representative Jim McGovern said, “If we have evidence that countries are not complying with US law that ought to be enough to say we sell these weapon to them no more.” He urges the US to sign the ban agreement on Cluster Munitions.

From the Halls

Richard Boudreau, MD, JD, MBA, DDS, PHD, Faculty Loyola Marymount Univ. The Bioethics Institute Dept. of Theological Studies

'Publish or Perish,' More Ethical Concerns

'Publish or Perish' is an often heard phrase in academia. The need to have sufficient publications in order to achieve promotion and tenure, while still fulfilling teaching and service obligations, is a constant concern. Such pressures have, unfortunately, led to numerous instances of scientific misrepresentation involving invented studies, made-up data or modified results. A recent review of over 2000 biomedical and life science articles indexed by PubMed as “retracted” found 43% were attributable to fraud or suspected fraud. Moreover, a meta-analysis of the results of 21 surveys of researchers who were asked if they or their colleagues had fabricated or falsified research found that almost 2% admitted to having fabricated or modified data at least once. Such incidents in the scientific and clinical literature can have serious consequences in terms of proper patient care.

To maintain the quality of the papers published, journals rely on the peer review system. However, peer review is an imperfect process that depends on the editor to select reviewers with appropriate time, interest and especially ability. Some journals even ask the authors to recommend reviewers for their article (who) may also be colleagues or friends. When asked to review a manuscript for a journal, one needs to remember that *his or her ethical responsibility is not to the author but to the readership and, ultimately, to the public*, which may be benefited or harmed based on the accuracy of the report.

Whereas the concept of publish or perish in terms of academic advancement can obviously lead to negative consequences; when applied to other circumstances it can represent a positive challenge: the effect that good research and clinical publications can have on the nature of medical practice. It certainly will not perish as a result of a lack of such contributions to the literature, but its stature will definitely diminish and the quality of patient care will definitely remain static....a matter of concern not only to those in academic positions, but also to those in clinical practice

Who's Baby Is It?

The drama of surrogacy and the determination of who has parental rights continues and is variable from state to state, invariably requiring the input of attorneys. One solutions might lie in transplant technology, a subject tackled by

UNDERGRAD Corner Elvis Amaya, S M College

The first uterus transplant in the US failed, **Chicago Tribune 3/14/16**. The transplant, which used a uterus from a woman in her 30s who had died suddenly, was performed on Feb. 24, the first of 10 uterine transplants planned by the Cleveland clinic, in an experimental program meant to enable women without a native uterus to give birth. The study planned to include 10 women, is ongoing with a commitment to eventually provide an additional option for women and families. I am reminded of the self-portrait by Frida Kahlo “Broken Column,” 1944. In it Kahlo's nude torso is split, replicating the ravine-laced earth behind her and revealing a crumbling, ionic column in place of her spine. Her face looks forward, unflinchingly, though tears course down her cheeks. In spite of the brokenness of her internal body, her external sensuality is unmarred. She lost the ability to carry a child to full term in 1925 in a trolley collision where a handle bar tore through her uterus.

Most do not know Kahlo was pre-med before she that collision after which she took up painting. She states that painting saved her life allowing her to show how she felt. In doing so she did not have to grieve alone. Being alone in something like this brings to mind a single butterfly in a dessert contrasted to 600 million to 1 billion monarch butterflies that travel 2500 miles yearly to breed in Mexico. They are not alone, though many never reach their destination.





What is the point of life if we do not share it though we stumble? The Cleveland clinic says it will not stop the quest to help people start families. Kahlo said "At the end of the day, we can endure much more than we think we can."

Glossary

Transformational Listening:

In an Ethnography in Engineering Ethics Education: A Pedagogy of transformational Listening
121st ASEE annual Conference and Exposition Indianapolis, IN 6/15-18 2014 Paper # 10155 Lambrinidou, Yanna, et al
"contends that listening can facilitate transformational engagement between engineers and the public by

- challenging stereotypes on both sides,
- foregrounding the technical and ethical relevance of diverse knowledges,
- exposing relationships of structural inequality that privilege technical expertise, and
- replacing such relationships with partnerships of trust that generate meaningful and effective solutions"

This "aims to offer students an alternative to their education's 'culture of disengagement' that empowers, inspires, and motivates them to practice... through collaborative engagement with society... making possible new research, technologies, and solutions that are better able to minimize risk, prevent harm, and improve the condition of humankind. ...to cultivate such transformation not only on the individual level, but also within the very institutions that produce and reproduce our 'risk society.'"

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Tackling Zika Virus

Is it ethical to infect volunteers to speed vaccination development to see if a potential Zika vaccine can protect people i.e. give volunteers a candidate vaccine, and then later inject Zika virus into them, to produce answers faster? The concerns about giving a healthy person something that could lead to microcephaly in offspring, or develop Guillen Barre is troubling. Of concern is that the Ebola vaccine development was so slow that the epidemic seemed under control before its effectiveness could be tested. <http://www.npr.org/sections/health-shots/2016/02/25/468120804/why-scientists-hope-to-inject-some-people-with-zika-virus>

Lessons from Ebola [www/bioethics.gov](http://www.bioethics.gov)

As new cases of Ebola have been discovered in New Guinea we recall some of the ethical issues addressed during the height of that epidemic. A Presidential Commission for the Study of Bioethical Issues on Ethics and Ebola Public Health Planning and Response was published 2/2015 and diplomatically included both sides of the argument as to whether placebo controlled trials should be conducted in the midst of a deadly outbreak. The case was made for "adaptive strategies" that would at least shorten the period of placebo control in an effort to move subjects at deadly risk into a potential for benefit group, while not completely abandoning scientific methodology of exacting research more likely to be reproducible.

stats re End of Life Option Act

courtesy Ron Koons, M.D. rkoons@uci.edu

In Oregon's 18 years' experience:

0.5% of people who died obtained the medicine.

1/3rd of those die without using it.

(very high use in Oregon of palliative care, hospice and pain management education)

Most common reasons why Oregonian patient's say they ask for the prescription are:

*Losing autonomy. 91.6%

*Less able to engage in activities making life enjoyable. 89.7%

*Loss of dignity. 78.7%

*Losing control of bodily functions. 48.2%

*Burden on family, friends/caregivers. 41.1%

*Inadequate pain control or concern about it. 25.2%

*Financial implications of treatment. 3.1%