



The mission of the CFAR is to provide a multidisciplinary environment that promotes basic, clinical, behavioral and translational research in the prevention, detection and treatment of HIV infection.

NEWS BRIEF:

-The **TRIANGLE DANCE FESTIVAL for AIDS** will take place on Friday, March 25th at 7:00 pm in Memorial Hall (114 East Cameron Avenue, Chapel Hill, NC, 27514). Tickets are FREE to all students and community members. Call 919-843-3333 (10am-6pm) or pick up at Memorial Hall box office. Tickets will also be available in the pit from March 21-25 from 11AM - 2PM. All proceeds benefit these direct-service HIV/AIDS organizations: Development in Gardening (DIG) and United Clayton Area Network for Youth (UCAN).

-The **AIDS WALK & RIDE** is happening on Saturday, May 21 from 6AM - 6PM at the Halifax Mall behind the NC General Assembly in downtown Raleigh. This is a full day celebration, where participants can travel on walking or cycling routes. Free HIV/STD testing will be available, along with music, food and fun. Visit www.aidswalkandride.org for more information.

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Center for AIDS Research

University of North Carolina at Chapel Hill

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The Center for Bioethics: Connections and Collaborations

Where do innovative HIV/AIDS researchers turn when they realize that a patient in one of their prevention trials becomes HIV positive? In this newsletter, Stuart Rennie, PhD, a well known ethicist explores the emerging field of bioethics and considers how it plays a pivotal role in the research efforts of our CFAR faculty. Rennie explains, "You can see CFAR's activities as a matrix of ethical challenges. They [CFAR scientists] are doing the best cutting-edge research. For someone in research ethics, it's almost like a dream to be in the same neighborhood as people like that. You get a lot of new problems which are very real-world because they arise from people's actual research, not some theoretical ethical issue you come up with sitting in a room". Rennie has traveled around the world exploring ethical issues related to HIV/AIDS.

When asked how the ethical challenges in HIV/AIDS research have changed since 2004 when he first joined an HIV-focused research project at the UNC School of

Public Health, he says, "One shift is the difficult balance between treatment and prevention. When I started, treatment access was the big focus. "Access to all" was the cry. In Thailand at the International AIDS Conference that year, that was the main focus - lowering drug costs, problems with rolling out ARV treatment, particularly in the developing world". Rennie explains that as people realized we couldn't "treat ourselves out of this epidemic", the focus started to shift back again towards prevention. Thus, "the field of HIV prevention ethics gained more prominence. You heard a lot about microbicides, PrEP (pre-exposure prophylaxis), circumcision...and each one has its own ethical challenges".

The connections Rennie makes between the world of bioethics and HIV/AIDS research highlights the interdisciplinary possibilities for the new UNC Center for Bioethics. Eric Juengst, PhD, is Director of the Center. He explains that the idea for a center of bioethics began in 2006 with Larry Churchill, the former chair of the Department of Social Medicine. It really got off the ground when Etta Pisano, the new vice-dean of the School of Medicine at the time, took a personal interest in the project. When Pisano brought Juengst down to interview for the position, he "found a robust cohort of faculty and a lot of student interest in bioethics. There were a ton of courses being taught and they had organized themselves spontaneously into a faculty interest group - Bioethics at UNC. They said "we really need a clubhouse" - an institutional home at UNC that could facilitate collaborative research and teaching. That made the creation of the center very easy". Juengst mentions that he plans to collaborate with the Hospital Ethics Committee, "an active group that does ethics consultations in all the hospitals and does educational series". Arlene Davis, an attorney with a nursing background, and co-chair of the Hospital Ethics Committee, is one of the core faculty members for the new center. Juengst is pleased that "the TraCS institute already has an Ethics Core...Gail Henderson, Arlene Davis and Rebecca



Rennie works to educate members of the Burundian National research ethics committee at the Centre National de Référence en matière de VIH/SIDA (CNR) - or National HIV/AIDS Reference Center - in Bujumbura, Burundi (January 2010).

Spotlight on Dr. Eric Juengst, Ph.D.

Eric Juengst, PhD, Director of the UNC Center for Bioethics comes from Case Western Reserve University, where he held appointments as Professor of Bioethics and Director of the Center for Genetic Research Ethics and Law. This move was not an easy feat: he had just received funding for an ROI research grant at Case Western, and he had to coordinate his move while his research team remained there. Now, Juengst has a full plate between collaborating with the team there and his new appointments in Social Medicine and Genetics at UNC.

Juengst's new research project is one of many bioethics investigations that he has launched since 1985. Juengst explains that, in college in the 1970's, "the recombinant DNA debate was swirling around in the

news and scientific circles. Here was a group of scientists who called for a moratorium on their own work because of concerns about unpredictable risks and had a system set up for vetting that work by the government". Juengst wondered, "Where can I go to study these interesting issues on the interactions of science and society?" and he landed in a bioethics PhD program at Georgetown.

Years later, he is the Principal Investigator on a project that examines "the way in which personalized genomic medicine is being interpreted". Juengst explains that genetic medicine is "often touted as a new paradigm for healthcare. There's a lot of hype around it and a lot of stakeholders gather under that banner - commercial companies, hospitals, medical educators, journal editors, scientists. But unsurprisingly, they all have a slightly

Center for Bioethics, Cont.

Walker have already begun to mount educational programs on issues in clinical research, aimed at investigators and research staff". Juengst likes that, "we don't have to spend a lot of time inventing those structures and programs – we can focus on providing interesting content for them. One of our strengths I think will be interest in global issues in biomedical research and implementation of public health strategies". Dr. Rennie will spearhead many of the global projects at the new center. Juengst hopes to expand the definition of the field, stating, "Bioethics is really booming on the international scene - it's really interesting to see how this has caught on, not just in Europe and the first world, but in the developing world... We think that we have as much to learn from the way this field is interpreted through other eyes as we have to teach".

Rennie's definition of bioethics is "the study of the ethical issues that arise from research, practice, and policy in medicine and public health". Ethical problems involve conflicts of values, Rennie states, because there is a plurality of things that humans care about, such as protection of research

participants on one hand, and the pursuit of useful knowledge on the other. Rennie says of these conflicts, "these are non-scientific concerns rising out of science, and that's where bioethics starts". He argues that bioethics "should be helping to discover the right way to do things, a path that does the least damage to the values we care about." As an example, he explains the predicament that researchers face when subjects become HIV positive during a prevention trial. "If you've got HIV infection as an end-point to a study, you need to have people who end up HIV positive in order to get a grip on the effectiveness of the intervention you're using. So the question becomes: what should you do as a researcher when research participants become HIV positive in a research study?" Rennie explains that there has been a general consensus in the research community that HIV treatment should be provided to these individuals, but where should this come from? Rennie asks, "Should it be the researchers, the funders, the local government? Some people who are on the philosophical side of ethics claim there is no rational basis or obligation to treat. But there's a political basis for it, because if you don't (treat these people), the community is not going to be happy". He explains that many

ethical issues in HIV research stem from "the complication that you need to provide lifelong treatment"; the lack of a cure leads to treatment issues and ethical concerns, and the lack of a vaccine creates ethical issues related to prevention.

There are many emergent issues in the field of HIV/AIDS research that Rennie describes as "ripe with ethical challenges and concerns" such as "PreP studies, genomics investigations, and clinical safety studies". The Center for Bioethics and the CFAR are already starting to collaborate because the NIH Office of AIDS research is forming an Ethics and HIV Genomics Working Group. Rennie explains that there has been a good deal of interest at NIH "in the ethical issues related to research and HIV at the genomic level. We are trying to identify different priority areas in ethics in this particular field". These opportunities will continue to arise as the field of HIV/AIDS research changes and as CFAR scientists continue to create and conduct innovative research projects. The potential for fruitful collaborations between the CFAR and the Center for Bioethics can be expected to expand.

Juengst, Cont.

different idea of what they are talking about". As the fields of genomics and bioethics expand, Juengst seeks to map these different ideas of how to define genetic medicine and then tease out "the implications for clinical medicine".

Juengst has taught medical ethics and the philosophy of science on the faculties of the medical schools of the University of California, San Francisco and Penn State University. Globally, he has collaborated with the University of Salamanca in Spain, Linkoping University in Sweden, Di Tella University in Argentina, and the University of Newcastle in the UK. He plans to use these connections to expand the knowledge base about ethics at UNC. Juengst is hopeful that the new Center for Bioethics will serve as a good resource for scientists and students who are interested in exploring the field. He encourages faculty and graduate students to "get involved with our research projects if their interests coincide with ours". Most of the current bioethics courses offered at UNC are in the medical school, but for undergraduates, "we have met with people who are interested in starting an undergraduate bioethics society or interest group". The new website (<http://bioethics.unc.edu/>) will be the main bulletin board for the program, listing all bioethics-related events and courses.

Juengst looks forward to collaborating with the CFAR and has "put in a proposal to a private foundation to support dedicated developmental awards for people interested in doing bioethics research related to HIV research and clinical care". With the two centers co-sponsoring these projects, the CFAR and the Center for Bioethics would have a real chance to further develop their research efforts.



Ethical Issues and HIV: An Editorial

Over a quarter century of the HIV/AIDS epidemic has demonstrated that some of the most vexing dilemmas faced in research, prevention and care have been ethical in nature. Indeed, issues surrounding HIV/AIDS have caused a redefinition of public health ethics and led scientists and clinicians to fundamentally re-evaluate their relationships to communities.

Investigators have had to consider how the research designs especially in clinical trials may raise ethical and community concerns. Scientists and participants have asked difficult questions about the risks entailed in research and what should remain behind as a benefit when a study is concluded. Experiences with HIV/AIDS have helped to redefine the conduct and meaning of informed consent, both in research and in clinical care. The epidemic has raised questions about what it takes to be fully informed, who has the capacity to decide about participation and access, and how to monitor the content of consent-related interactions. HIV/AIDS research has heightened awareness of what comprises a vulnerable population and how to deal with perceptions of risk and benefits in the context of vulnerability.

HIV/AIDS has stretched scientists and clinicians to define a reasonable standard of care and to ask how that level of care may best be delivered across nations, cultures and populations. The epidemic has caused professionals to consider how to deliver news and information to affected persons and communities and how to share the results of research in an equitable and effective manner.

These and many other ethical and social concerns have motivated the UNC CFAR to devote considerable effort and resources to the study of ethics related to HIV/AIDS. This issue of the newsletter serves to introduce you to UNC-Chapel Hill's approach and provides a window into the excitement of having UNC ethicists working alongside basic, social and clinical researchers.

Dr. Ronald P. Strauss is UNC-CH's Executive Associate Provost, Chief International Officer, and a faculty member in the Schools of Dentistry and Medicine.