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Editor's Forum

Paul Byrne, MB, ChB, FRCPC

Interim Director, John Dossetor Health Ethics Centre, University of Alberta

In this final issue of *Health Ethics Today* for 2004, we feature presentation synopses from the Health Ethics Symposium, organized by the John Dossetor Health Ethics Centre (JDHEC). The symposium was aimed at health care practitioners and held on 18 June 2004 at the University of Alberta. The one-day symposium examined different issues of health ethics with a variety of topics (e.g., electronic health records, face transplants, etc.). Fifty five attendees participated actively in discussions at the end of each presentation and interacted over the breaks. This was the second JDHEC symposium and its success has encouraged the faculty to make it an annual event.

Teaching ethics to students, residents and faculty within health care disciplines is recognized as an ongoing challenge in many ways. Formal philosophy based didactic teaching has given way to more small group, clinical case based approaches involving dialogue between students and teachers. Controversy persists as to the best approach in teaching, what content is required, who should teach, what balance of ethical theory and clinical reality is best. There remains a paucity of research to demonstrate the superiority and effectiveness of any particular approach. Novel methods include the use of simulated patients using actors, mock ethics consultations with one-way mirror observation, and narrative based humanities approaches using literature, theatre and film.

A series of videotapes developed by Sharon Warren and JDHEC colleagues in research ethics education were presented at the symposium and demonstrate how effective film can be in highlighting ethical issues in clinical practice and research settings.

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The book review by Wendy Austin describes the recent publication, *Ethics for the Practice of Psychology in Canada*, a standard text for practicing psychologists. This book review should not be regarded as only relevant to psychologists. A recent description of an Ontario Court case in MD Canada (Brean, 2004) involving a family physician who has been accused of sexually abusing a patient stemming from psychotherapy highlights the danger for all practitioners in this area.

As this is the final 2004 edition of *Health Ethics Today* I will pass on Best Wishes for the Holidays and Good Health and Happiness for 2005 to our readers on behalf of the JDHEC staff. ■

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Electronic Health Records and the Protection of Privacy

Glenn G. Griener, PhD

Associate Professor, Department of Philosophy, University of Alberta

Associate Professor, John Dossetor Health Ethics Centre, University of Alberta

Two decades ago, Mark Siegler declared the traditional principle of medical confidentiality was "old, worn-out, and useless" (1982). The advent of Alberta's Electronic Health Record presents an opportunity to revisit this issue. Can professional confidentiality be revived and revitalized, or should it be replaced by the privacy paradigm?

Traditional notions of confidentiality focus on the disclosure of information. Within the privacy paradigm collection, use, and disclosure are equally important. Siegler (1982) noted that health professionals are often blind to any issue about disclosure to other members of the team caring for the patient. The patient's information may flow freely within this group. The privacy paradigm threatens to interrupt this flow. An individual chooses to divulge information to a particular person, for a particular purpose. Any disclosure to a third party, even if necessary to achieve that purpose, requires additional consent. Further, any use of the information for a different purpose requires additional consent.

The fundamental reason for creating electronic medical records is exactly the same as the reason for recording information in any other format: to improve the care provided to individuals. Electronic medical records can achieve this directly by ensuring that accurate and relevant information is available at the point of care when it is needed for clinical decisions. The care of the patient can also be improved by incorporation of decision tools into the system.

For instance, the system may automatically alert care providers to drug-drug interactions. A province-wide system, such as the Alberta Electronic Health Record extends these benefits over a wider area.

There are additional benefits to be achieved. This is why all of the major public inquiries into the Canadian health care system, from Mazankowski (2002) through Romanow (2002), have urged governments to invest health care dollars in information technology. Among the promised benefits are enhanced quality assurance, additional health research, and improved public health surveillance.

The promised benefits do not come without some risks. Hackers may invade the system and view sensitive health information, or, far worse, change it. Health records may be lost through computer failures. But dangers such as these are common to all sorts of electronic records. There is no reason to doubt our ability to manage them adequately using the state-of-the-art technology and practices developed for other arenas of the electronic environment.

A more serious concern is the misuse of information by those who have legitimate access to the system. Creation of electronic medical records does not create this problem. As soon as an individual reveals sensitive information to a health professional the potential for misuse exists. Electronic medical records exacerbate it simply because more people can access the information.

How should we protect ourselves against these dangers? The privacy paradigm tries to protect individuals by giving them control over the collection, use and disclosure of their information. It encumbers the system with stringent requirements to obtain their informed consent at each step. An alternative approach is to revitalize the tradition of professional confidentiality. First, professionals should more closely scrutinize the flow of information within the team, considering carefully who has a need to know. Second, each professional must constrain his/her access to, and use of, information which is available at the touch of a keyboard. ■

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Care for Patients in a Vegetative State: Reflections on Pope John Paul II's Recent Statement

Doris M. Kieser, MA

Lecturer, St. Joseph's College, University of Alberta

Brendan Leier, PhD

Postdoctoral Fellow, John Dossetor Health Ethics Centre, University of Alberta

On March 20, 2004, Pope John Paul II addressed the participants of a conference considering life sustaining treatments and the vegetative state. In his address, “Care for Patients in a ‘Permanent’ Vegetative State”, the Pope made an unprecedented distinction in official Roman Catholic teaching regarding the status of artificial nutrition and hydration (ANH). Claiming that “the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act”, cleared the way for the Pope to classify its use as “ordinary and proportionate” and therefore morally obligatory.

In so doing, the Pope seems to have done a number of things. First, he has affirmed his well-documented defense of human life, particularly of those most vulnerable among us. Second, he has articulated a position that goes against the developed pastoral wisdom that understands the application of ANH in patients in a Persistent Vegetative State (PVS) as a medical act and therefore subject to refusal when disproportionately burdensome. Third, he seems to have taken the practical decision regarding what is disproportionate treatment away from the immediate decision-makers. Given the above, the application of this Statement could create practical, ethical difficul-

ties within healthcare settings for Catholic patients and families.

It is important to note the weight of this Statement within Roman Catholic teaching. Catholics are expected to reflect on this Magisterial Statement delivered with the intention of clarifying dialogue on moral issues surrounding death and dying, and give due respect to the authority invested in the Pope's office. However, this Statement does not fall within the category of infallible teaching; nor does it mandate the assent of Catholics given to these teachings.

It is helpful to identify two distinct streams of argument which occur in the Papal address. The first we can identify as an epistemic or 'knowledge based' argument, the second an ontological or essentialist argument. The epistemic stream of argumentation appeals to the perceived lack of both diagnostic and prognostic capacities regarding PVS patients. Much mention is made of both the difficulty of correctly diagnosing PVS and the inability to prognosticate apart from statistical likelihoods regarding the potential of a patient's possible recovery from this state. We can paraphrase the epistemic argument as follows: "In the cases where there is even an unlikely chance of recovery from PVS, healthcare providers must make possible the conditions for such a recovery, especially if we remain uncertain about our clinical abilities to diagnose with certainty the profundity of the insult to the brain." The important aspect of this skeptical argument is that it is grounded in clinical evidence. The implied cautionary principle of always respecting life in the provision of ANH therefore hinges on the prospect of new or improved clinical techniques and their ability to prognosticate more accurately the outcomes of PVS patients. More importantly, the epistemic approach claims that this clinical evidence will provide an important contribution in determining the proportionality or disproportionality of the continuation of ANH in PVS.

The ontological or essentialist approach in the Papal address is reflected in the unilateral nature of the remarks concerning the discontinuation of ANH in PVS patients. By his remarkable exclusion of the traditional proportionate/disproportionate criteria used to evaluate the appropriateness of treatment, the Pontiff suggests that either ANH is essentially distinct from other forms of medical treatment and



therefore always indicated, or that PVS is essentially different from other illnesses in which one may ethically choose to discontinue medical intervention. We find both of these suggestions to be potentially problematic, especially the possibility of these pronouncements being applied via 'a slippery slope' to other clinical situations where the cessation of treatment is regularly an ethical option. As well, if ANH is to be considered always as ordinary care, then patients will no longer be able to control via advance directive or surrogate decision-making the removal of such life-prolonging interventions, even if they themselves or their surrogates consider the treatments disproportionately burdensome. ■

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Research Ethics Education Forum (REEF): A Video Series on Health Research Ethics

Sharon Warren, PhD

Professor, Faculty of Rehabilitation Medicine, University of Alberta

The John Dossetor Health Ethics Centre and the Rehabilitation Research Centre, University of Alberta, have collaborated to produce a series of five short videos aimed at teaching health research ethics:

#1: Turning a Blind Eye. An anthropologist is studying a Neonatal Intensive Care Unit. Through a chance meeting with some parents in the study, she learns that their now six-month old child has just been diagnosed with hypothyroidism. In reviewing files, she notices information (unrelated to the research) that the family had a history which should have triggered screening the baby. Without screening, and the resulting treatment, the baby has suffered brain damage. The anthropologist wonders whether to report the error.

#2: Michael's Journey. A graduate student has just acquired the subjects he needs to meet a grant deadline when the wife of one of the study participants arrives, asking to see and change some of her husband's responses. Later the student is approached by another subject, who tells him that out of respect for her parents' sense of family integrity, she wants her information withdrawn. The student considers not removing these subjects' data, because it will jeopardize his project being funded.

#3: The Almighty Dollar. A drug company recruits a physician to enroll patients in a trial of a drug for depression, offering to pay a substantial amount for each patient who completes the testing and monitoring phases. Since few of her patients fit the eligibility criteria, the physician gains access to colleagues' files to find other candidates. A student helping with chart reviews mentions that one patient the physician plans to enroll does not meet the study criteria and that another patient is unlikely to be able to give informed consent. The physician ignores the student. Later she refuses to remove a subject from the study who appears to be deteriorating on the investigational drug.



#4: A Line in the Sand. A university researcher acquires drug company funding to study reactive airways disease and the effectiveness of a new inhaler. The drug company-researcher agreement states that: the study data become the property of the company; nothing can be published without company approval; the terms of the agreement are strictly confidential. During the study, the researcher discovers that a small subgroup of subjects is developing fibrosis and fears it may be related to the inhaler. The drug company agrees to withdraw those subjects from the trial but questions his request to alert as yet unaffected participants or future enrollees. The company also refuses to allow the researcher to report the fibrosis development in a conference presentation.

#5: Closer to the Heart. An aboriginal student wants to present research at an upcoming conference. His supervisor suggests they contact the medical clinic on the student's reserve to see if some database information would be available to do an exploratory, secondary data analysis. The clinic nurse agrees to release the data (including names), provided the names do not appear in any report. The student later reveals his findings on HIV prevalence on the reserve to a friend who is a reporter, without telling him not to use the information. When the headline appears

in a local paper, the aboriginal chief wants to know how data was collected from the reserve without her knowledge.

The videos will be available for purchase in March 2005. ■

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Prenatal Ultrasound and “Unexpected News”

Paul Byrne, MB, ChB, FRCPC

Interim Director, John Dossetor Health Ethics Centre, University of Alberta

Jeanne Van der Zalm, PhD, RN

Project Leader – Patient Care Administration, Royal Alexandra Hospital

Assistant Adjunct Professor, John Dossetor Health Ethics Centre, University of Alberta

Perinatology has developed as a speciality within obstetrics largely due to the clinical application of ultrasound imaging technology to the foetus in utero. The past two decades have seen a dramatic increase in the use of prenatal ultrasound both as a screening procedure and as a diagnostic tool. Most pregnant women in the western world today have at least one screening prenatal ultrasound to “confirm dates and assure that the baby is okay”. Prenatal ultrasound is a very effective diagnostic tool for a variety of clinical conditions including foetal anomalies, multiple gestation, growth abnormalities, abnormal placentation and uterine anomalies. Neilsen (1998, 2004) described medical benefits from prenatal ultrasound for mother and foetus in terms of clinical management of complicated pregnancy. Yet very little research exists on women’s perspectives, understanding, psychological and emotional reactions to the experience of prenatal ultrasound.

We recently completed stage one of a qualitative study of pregnant women who received ‘unexpected news’ after prenatal ultrasound. Thirteen women were recruited who had received ‘unexpected news’ of either a diagnosis of multiple gestation or a foetal anomaly after prenatal ultrasound. Each woman had a semi-structured interview about her experience of the prenatal ultrasound, the ultrasound findings, the communication of the ‘unexpected news’ and the clinical course of the pregnancy. For this presentation we will focus on selected quotations describing the ultrasound experience itself and highlight the fact that the mothers immediately recognized when the ultrasound technologist had detected unexpected findings on the ultrasound screen, and discuss the ethical dilemma of the technologist caught in this ‘real time’ situation. This recognition by the mothers places the ultrasound technologist in a position of ethical conflict between a need for honest and open communication with the mother and limited authority to confirm ultrasound diagnosis.

Analysis of the interview transcripts revealed that women identified positive and negative aspects of the ultrasound experience relating to whether



they were made to feel included or excluded by the ultrasound personnel. Ultrasound technologists who made efforts to make the women comfortable and to involve them (and their companions) in conversation were praised highly. All women described in detail the physical layout of the room, the temperature, the ultrasound jelly (cold!), the lighting, the height of the examination table in detail. They related these things to their own physical comfort or discomfort and with efforts made by the ultrasound technologist to assist them. They described the ultrasound technologist’s behaviour as being very important in determining whether the ultrasound experience was good or bad.

Technologist behaviour which was exclusionary made the women feel objectified and was described as contributing to a bad ultrasound experience independently of the nature of the ‘unexpected news’ received. All mothers detected non-verbal and verbal clues that something unexpected was seen on the ultrasound screen and that the ultrasound technologist was not communicating this information. While mothers recognize that ultrasound technologists may not have the authority to tell them exactly what is on the ultrasound screen, they do not appreciate being left in the dark while awaiting confirmation by a physician. Mothers requested that they simply be told that something on screen needed confirmation rather than evasive answers in response to the question “is something wrong?”

The study findings indicate that women’s descriptions of the use of this very common prenatal technology are associated with both good and bad experiences at the hands of health care professionals. Women describe personnel behaviour, which makes them feel objectified and identify difficulties and delays with communication of ‘unexpected news’ on ultrasound. The communication difficulties relate to practice limitations placed on the technologists’ authority to discuss ultrasound findings before confirmation by a physician. ■

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Acknowledgements

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In Memoriam - Mary Lou Cranston

It was with sadness that I learned of the sudden death of Mary Lou after a recent illness. Mary Lou was a leading member of the ‘Bioethics Community’ in Alberta for many years and served tirelessly on many committees as the fledgling community developed. I first met her when she asked me to speak to her ethics class at St Joseph’s College about ethical decision-making in the Neonatal Intensive Care Unit. She told me it ‘would be good for these students to hear what the real world of difficult decisions is all about’ and I agreed. She was passionately committed to teaching ethics to students and health care professionals. After that first encounter (I passed the test with her class!) we became close colleagues and friends. She emphasized the importance of making ethics real for students which is why I liked her teaching style so much. She helped students with her exceptional theological and ethical expertise combined with being very down to earth and her sense of humour. Mary Lou also undertook clinical ethics consultations in various health care settings using her great understanding and humanity to assist families and health care professionals with their struggles around ethical decision making. Our society is short of selfless pioneers such as Mary Lou and her passing is a great loss. May She Rest in Peace.

Paul Byrne, MB, ChB, FRCPC

Interim Director,
John Dossetor Health Ethics Centre

Coming to a Head Near You: face transplants!

Barbara Russell, PhD, MBA

Assistant Clinical Professor, John Dossetor Health Ethics Centre, University of Alberta

Clinical Ethicist, University of Alberta and Stollery Children's Hospitals

In the past two years, a surgical team from Britain and the United States has publicized they are ready to do the world's first face transplant. Their announcements in the media may be attempts to initiate needed public and professional debate about such a radical intervention. The transplant involves removing the full face of one person, taking skin, muscle, arteries, veins, and even cartilage or bone and connecting it to the muscular and circulatory levels of another person's face. My talk examined whether such innovative surgery is or is not ethically defensible.

I confess my initial response to the idea was "yuck!" I wondered "when is enough, enough?" in terms of what people are willing to do to their bodies. My reaction was reinforced by Frank's (2004) article on various medical efforts to "fix" bodies to comply with whatever society extols. Or, he asks, are there aspects of me that "I am called upon to live with and live as?"

With further reflection, however, the idea of facial transplants has merit for two reasons: the state of

current therapeutic measures and the importance of the human face. First, prospective patients for this surgery are people whose faces have endured cancer, severe burns, or major traumatic injuries. Though significant advances have occurred in reconstructive techniques, the final result is often what I describe as a "failed face." In other words, the person's face is still disfigured, scarred, asymmetrical, sensation-less, expression-less, and mask-like. Is it fair to these individuals to ask them just to wait for society to become more tolerant and disfigurement become less stigmatized?

Second, our faces are important for a host of reasons. A face is part of a person's identity. As affirmed by how unnerving identical twins are, a face is presumed to be a unique identifier¹. It is also a medium through which we interact with others and communicate. A face contributes to experiential life: smiling lifts and frowning brings down one's spirits. A face can reveal one's heritage in terms of linkage to family members, ethnic or racial groups. And finally a face can carry markers of the life one has lived: you



eventually get the face you deserve². In summary, helping to achieve “capable faces” continues to be a worthwhile medical objective.

But is full transplantation the preferred approach? According to a position paper by the Royal College of Surgeons of England (2003), 30-50% of these transplants will be rejected within 3 to 5 years (p. 7). Anti-rejection of the transplanted face is a possibility, just as it is for any major organ transplant. In the case of facial transplantation, rejection could result in a disturbing death because of the face’s visibility or the start of years of more surgery. Given the persistently low rates of solid organ donations, even lower rates of facial donations are likely. In an informal survey by Butler (2002) of 120 British physicians and nurses, all supported the idea of facial transplantations but none predicted they would ever donate. Since only a few face transplants will likely occur annually, decades will be needed to develop the expertise to produce good outcomes, given the complexities of transplanting skin, muscle, nerves, veins, and arteries.

In conclusion, I contend that facial transplantation is an idea that should not be pursued at this point in time. It will take too long to produce acceptable results for too few using current techniques. Instead research should continue to be directed to techniques currently employed: improving skin grafts, improving anti-rejection medications, improving scar-reduction methods, and so on. ■

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Notes

1. Surgeons predict that the recipient of a facial transplant will not look identical to the donor because of the different bone structure of the recipient's face. (Royal College working paper).
2. A comment attributed to Abraham Lincoln.

Book Review

Ethics for the Practice of Psychology in Canada

Authors: Derek Truscott and Kenneth H. Cook

Publisher: The University of Alberta Press, 2004

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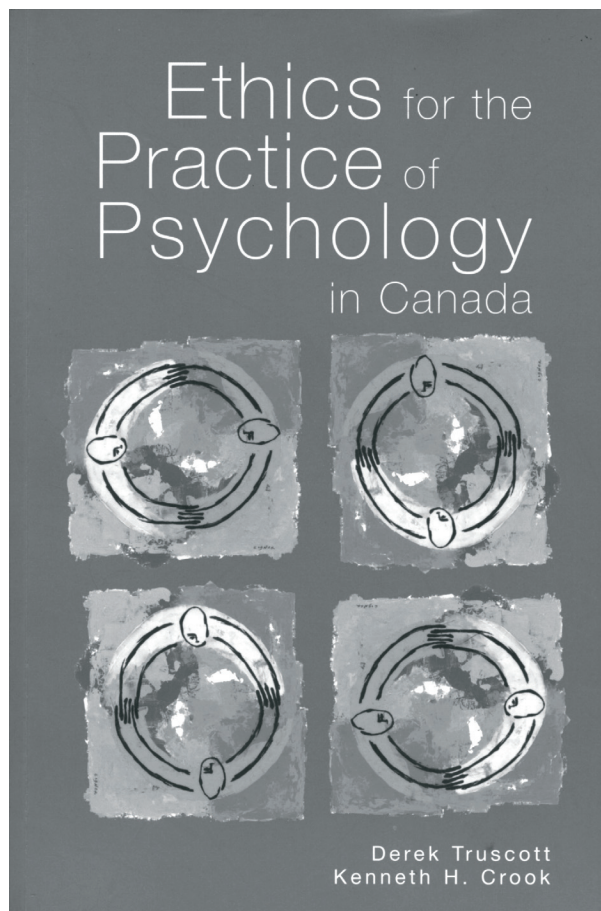
Legislation and codes of ethics serve as important guides to healthcare practice and research. They are, however, not enough. Laws and regulations can be disregarded and circumvented or their spirit ignored (Sass, 1983). Acting ethically must be about more than simply adhering to rules and practice guidelines. There needs to be cultivated, on the part of professionals, an attentiveness and responsiveness to the ethical demands of their discipline (Vetlesen, 1994). A new text, *Ethics for the Practice of Psychology in Canada*, successfully integrates this message into a comprehensive examination and interpretation of relevant guidelines, such as the *Canadian Code of Ethics for Psychologists*.

Derek Truscott, a professor in Educational Psychology at the University of Alberta and Kenneth Crook, a Vancouver lawyer with expertise in insurance law and medical malpractice, have coauthored the first ethics text for psychologists from a Canadian perspective. Although they emphasize the necessity of reason and the intellect in addressing ethical issues, they also argue that that psychologists should act ethically because it feels right. Professionals need to be aware of situations and circumstances that require ethical reasoning and to acquire the knowledge and skill that will enable them to respond fittingly. “Ultimately, it is the choice to act ethically that is the greatest lesson” (p. 132).

Written in a clear and straightforward manner, this text begins with an overview of ethical principles and systems and then addresses both professional and legal standards. Ethical decision-making is discussed, using the *Canadian Psychological Association's (CPA)* model. Key ethical issues on which the authors focus are free and informed consent, confidentiality, professional boundaries, maintaining and enhancing competence, providing services across cultures and social justice and responsibility. Each chapter addresses one of these issues and contains a realistic case vignette (incidents used include sexual abuse, parental refusal of services, boundary crossing) with related questions for consideration. There are recommended readings for those wanting to explore the issues further, and the appendices include the *Canadian Code of Ethics for Psychologists*, the *CPA Practice Guidelines for Providers of Psychological Services*, CPA's *Guidelines for Non-discriminatory Practice* and a contact list of regulators and associations.

The authors' style is concise and precise, yet not simplistic. They manage to capture the complexity of ideas, issues and situations while retaining brevity and clarity. The definitions they provide are good examples of this. Wisdom, for instance, "is intellect in the service of compassion (p.132)," while compassion "is the realization that others are as important as ourselves and not behaving purely out of self-interest" (p. 132).

Warning their readers to avoid being overly rigid in their attempts to maintain integrity, the authors exhort psychologists to be genuinely and persistently mindful of their ethical selves. Their approach embraces the understanding that the particularities of specific situations influence how questions of ethics must be resolved. In fact, Truscott and Crook, as does



the CPA itself, grant that there may be times when the individual psychologist will feel s/he must base an ethical decision on personal conscience. To be better prepared for such times, and for everyday practice, this Canadian guide offers psychologists coherent guidance, vicarious experience through the use of vignettes, and a language to speak about ethical issues.

In their preface, Truscott and Crook acknowledge the text's multiple potential audiences, including psychology students, psychologists in training, and professional psychologists. While readily evident as a useful teaching tool and

textbook, *Ethics for the Practice of Psychology in Canada* should not be underestimated as an asset for practitioners. In recent research at the John Dossetor Health Ethics Centre on the moral distress of mental health practitioners, we have learned that psychologists can feel very alone when internal and external barriers constrain their attempts to practice ethically. Having this book upon the shelf may provide relief for the lone psychologist. It brings a strong sense of the values expressed by the Canadian psychological community. It is a substantial resource. ■

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Wendy Austin, PhD, RN

Canada Research Chair: Relational Ethics in Health Care; Professor, Faculty of Nursing, and Professor, John Dossetor Health Ethics Centre, University of Alberta

Upcoming Events

Dossetor Centre Health Ethics Seminars:

Please check the John Dossetor Health Ethics Centre website at www.ualberta.ca/BIOETHICS/ for an updated seminar schedule in the New Year.

2005 Health Ethics Symposium:

Plans are in progress for the 2005 Health Ethics Symposium. Please watch for details to be posted on the John Dossetor Health Ethics Centre website at www.ualberta.ca/BIOETHICS/ as they become available.

Bioethics Week 2005:

Bioethics Week will take place from 7 – 13 March 2005

UAH/SCH Clinical Ethics Committee:

Grand Rounds

For the 2005 schedule, please check the John Dossetor Health Ethics Centre website at www.ualberta.ca/BIOETHICS/ in the New Year.

Health Ethics Through the Arts

Using literature, film, art work, poetry, photography and music as a novel way to learn about and debate ethics in ordinary situations. No registration needed for these informal sessions.

Second Wednesday of every month, 5:00 – 6:30 p.m.

Room 5C1.06, Walter Mackenzie Health Sciences Centre

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Third Wednesday of every month, 12:00 – 12:45 p.m.

Room 5C1.06, Walter Mackenzie Health Sciences Centre

Announcement

The Friends of the University Hospital and the University of Alberta/Stollery Children's Hospitals are pleased to announce that they are co-sponsoring the annual meeting of the Society for the Arts in Healthcare (SAH) from June 22 to 25, 2005 in Edmonton. This will be the first time that the conference is held outside the United States. The theme for the meeting is "No Borders: pARTners in HEALTHcare" and the presentations and workshops promise to be challenging, informative, and stimulating. In terms of health ethics, the arts are now acknowledged to be powerful ways to expand and refine a person's ethical insights and skills.

Founded in 1991, SAH is a non-profit society committed

to helping the arts become an integral part of healthcare. The Society assists with development and management of arts programs for patient/client groups, provides education and resources to both clinical as well as arts professionals, and promotes research into the positive contributions of the arts in healthcare. The annual meeting will interest not only those working in the arts, but also those providers who are responsible for everyday care of and interactions with patients, clients, and residents.

More information on SAH can be found at www.thesah.org. Up to date information about the 2005 meeting can be found at this website as it becomes available. ■

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University of Alberta
John Dossetor Health Ethics Centre
5-16 University Extension Centre
EDMONTON, AB T6G 2T4
Email: dossetor.centre@ualberta.ca

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Editor • Paul Byrne

Assistant Editor • Carol Nahorniak

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John Dossetor Health Ethics Centre
University of Alberta,
5-16 University Extension Centre
Edmonton, Alberta, Canada T6G 2T4
Telephone: (780) 492-6676 • Fax: (780) 492-0673
Web Site: www.ualberta.ca/BIOETHICS/
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Northern Alberta Office, 206 Aberhart Centre Two
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