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by Amy Haddad, PhD

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New Partnerships Near and Far Expand Horizons for CHPE

by Amy Haddad, PhD

Shortly after the inauguration of the Master of Science in Health Care Ethics (MSHCE) online degree program, the Center began discussions with the Office of Medical Education in the School of Medicine to explore the possibility of offering a dual degree to Creighton medical students. It is particularly appropriate for a Catholic, Jesuit institution such as Creighton University to offer medical students the opportunity to go well beyond the basic overview of ethics and law in the School of Medicine curriculum. Both parties were enthusiastic about the prospect and worked diligently to craft a program of study to meet the unique demands of both degrees. Nationally, there are several dual degree programs for medical students in the areas of public health (MPH) and business (MBA) but very few in ethics and even fewer in an online format. Creighton University's MD/MS in Health Care Ethics program is specifically designed so that medical students can graduate within five years with both an MD and MSHCE degree.



Amy M. Haddad, PhD, Director of the Center for Health Policy & Ethics

Since the maxim of CHPE is “Anchored in ethics, reflecting Jesuit values,” the MSHCE program clearly reflects the Jesuit value of concern for the poor and marginalized and seeks to form and educate agents of change by integrating critical self-reflection on attitudes, actions, and personal development into the program. We believe that the dual degree program will provide medical students invaluable insight to the ethical issues encountered by physicians and will be a wonderful complement to the science- and clinic-focused MD degree. Additionally, the medical students who choose to pursue a dual degree will benefit from interacting not only with Center faculty but also with other MSHCE students who are nurses, physicians, researchers, chaplains, and other professionals, all bringing different perspectives to the program. First-year medical students would be eligible to apply for admission and begin the program as early as July 2010.

Please visit <http://www.creighton-online.com/programs/online-masters-degree-in-healthcare-ethics.asp> for more information about the content of the M.S. in Health Care Ethics program.

Another “partnership” that the Center is developing is with colleagues at the new School of Medicine campus in Phoenix at St. Joseph’s Hospital and Medical Center. Several years prior to the joint announcement on June 30, 2009 regarding the academic affiliation that created the Creighton University School of Medicine at St. Joseph’s Hospital and Medical Center, CHPE faculty met with colleagues in clinical ethics in Phoenix and in Omaha. After the formal announcement, it seemed appropriate to create opportunities on both campuses to work together in the area of ethics, health policy, and education. St. Joseph’s Hospital has had an active institutional ethics committee and clinical ethics service since the early 1980s. CHPE has been involved in clinical ethics consultation since its inception in 1984. So, mutual interest in sharing expertise in clinical ethics and the opportunity to look more deeply at the rooted values of the two sponsors, i.e., the Sisters of Mercy and the Society of Jesus, seemed like good first steps. Discussions with the leadership at St. Joseph Hospital and Medical Center in the areas of Mission and Academic Affairs are on-going as we work to find the appropriate time to hold a conference to explore common areas of strength and support.

Physician Assisted Suicide and Euthanasia: Some Cautionary Reflections on Two New Developments in The Netherlands

by Jos VM Welie, PhD

In 2008, the state of Washington followed Oregon's lead and became the second state to legalize physician assistance in suicide (PAS). But many more states have tried to do so of late. According to the tally by the International Task Force on Euthanasia & Assisted Suicide (1), in the past 15 years there were 113 legislative proposals in 24 states, including three in Nebraska (1996, 1997, 1999). In fact, the history of American attempts at legalizing PAS and euthanasia dates back much further, all the way to the beginning of the 20th century. As early as 1906, bills were proposed in the legislatures of Iowa and Ohio, and in 1937 Nebraska's Unicameral discussed a bill that would have legalized both PAS and euthanasia (2). These early developments are particularly remarkable in view of the fact that the Nazi government in Germany, though secretly engaging in the practice of euthanasia, never dared to attempt formal legalization of the practice, fearing too much public opposition.

The fact that six attempts at legalizing PAS were launched in 2009, and none succeeded, suggests that it will not be easy for advocates of PAS and euthanasia to decriminalize these practices in more US states. However, the number of attempts undertaken of late suggests that we will see many more bills in the years to come. It may, therefore, be insightful to have a look at two recent developments in the country that has the most extensive experience with legalized PAS and euthanasia, that is, my home country of The Netherlands.

The history behind the 2001 legalization of PAS and euthanasia is complex and those interested in learning more about the details will find many dozens of volumes written on this history besides my own 2005 book (co-authored with Henk ten Have) on "Death and Medical Power. An Ethical Analysis of Dutch Euthanasia Practice" (3). As the title indicates, the main thesis of this book is that the practice of PAS and euthanasia, though typically defended in reference to the principle of respect for patient autonomy, is actually more indicative of the views of Dutch physicians about the end of life.

Whereas 20 years ago terminal sedation was rejected by some advocates of legalized euthanasia as a dishonest, even cowardly act, ever since the legalization of euthanasia in 2001 (which law took effect in 2003), there has been a renewed interest in palliative care, including terminal sedation. In fact, the Royal Dutch Medical Association, which had been one of the primary movers towards legalization of euthanasia, favors the term "palliative sedation" in order to make clear that the purpose of such sedation is fundamentally different from that of euthanasia. Whereas such sedation is aimed at rendering the patient unconscious for the remainder of her life (and in that sense is "terminal"), euthanasia is aimed at terminating the patient's life (4).

An odd detail is that the Royal Dutch Medical Association's guideline on palliative sedation, which was revised in 2009, restricts the practice of terminal sedation to patients who are expected to die within two weeks. If a patient is expected to live more than two weeks, it would be admissible to provide intermittent sedation, but not permanent sedation, until the patient passes away. No such time restriction applies to euthanasia. Hence, a patient who is suffering unbearably but likely to live for more than two weeks could request and receive euthanasia, but if she were to request palliative sedation, this option could not be granted. Remarkably, neither explanation nor justification of this paradox is provided in the aforementioned guideline. It does underscore, however, that the autonomy of the patient is not the primary factor in end-of-life decision making but rather the medical profession which exercises its autonomy through the arbitrary creation of medical classifications.

The second development could be seen as an attempt to escape from this medical power. "Uit Vrije Wil" (literally "Out of Free Will", i.e., Freely Willed) is a new initiative to break open the legal monopoly that physicians hold on assisting in suicide. This organization is striving to elicit public support for yet another revision of the Dutch criminal law such that individuals other than physicians are legally able to assist in another person's suicide. Interestingly, the organization justifies this expansion in reference to the class of people who would be enabled to commit suicide: Dutch citizens who are 70 years or older and who believe their life is complete and want to die but who are not ill in the medical sense of that term. And since they are not ill, physicians are neither authorized nor qualified to assist in their suicide – a different profession needs to be trained to assist these elderly with their suicide (5).

As expected, the Royal Dutch Medical Association has rejected this new initiative (which claims to have collected almost 80,000 approvals from Dutch citizens; note, however, that there are 17 million inhabitants in the country). The Association agrees with "Uit Vrije Wil" that it is not within the physician's domain of competence to assist in a person's suicide when the underlying motive is purely existential and not medical. But the Association fears that the meticulous process that currently surrounds the practice of PAS will be undermined when patients who are not granted their wish for assistance in suicide by their physicians can simply cross the street to get their wish granted by these new professionals (6).

I do not consider it likely that this new initiative will result in a change of the law. The 40-year history of Dutch jurisprudence on euthanasia has made it patently clear that only physicians will be granted this power. Whereas no Dutch physician has ever gone to jail for committing euthanasia (before it was legalized) or even involuntary termination of life (i.e., murder of a patient), nurses and lay people have. The parliamentary records surrounding the legalization of euthanasia underscore that this license was to be granted to physicians only. And when the Dutch Supreme Court in 2002 was faced with a physician assisting in the suicide of a former Dutch senator who was tired of living (but not suffering from a serious medical condition), it found against the physician, thereby ending the gradual expansion of euthanasia and PAS from the paradigmatic case of the patient with metastatic cancer to depressed patients and then to those tired of living.

However, the new initiative is very troublesome in a different way. It underscores, once more, the eugenic philosophy underlying the euthanasia practice. If freedom and self-determination were decisive, why the minimum age of 70 years? Apparently this group believes that the lives of people younger than 70 are never complete, but once you hit 70 it soon may be. Currently, the State of Oregon considers only the last 6 months of life to be of lesser value (for only patients who have 6 months or less to live can receive medical assistance in their suicide). But this 6 months limit is ultimately as arbitrary as the 70 year limit now proposed by "Uit Vrije Wil."

(1) On-line at <http://www.internationaltaskforce.org/usa.htm>

(2) Lavi SJ. The Modern Art of Dying: A History of Euthanasia in the United States. Princeton UP, 2005.

(3) Have, Henk AMJ & Welie, Jos V.M.: Death and Medical Power. An Ethical Analysis of the Dutch Euthanasia Practice. London: Open University Press, 2005.

(4) Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (Royal Dutch Medical Association): KNMG-richtlijn palliatieve sedatie [in Dutch: KNMG Guideline Palliative Sedation]. Utrecht: KNMG, 2009. On-line at <http://knmg.artsennet.nl/web/file?uuid=f3e026ba-23ec-47f1-a698-212153427fd7&owner=a8a9ce0e-f42b-47a5-960e-be08025b7b04&contentid=37350>

(5) On-line at <http://www.uitvrijewil.nu/index.php?id=1>

(6) On-line at <http://knmg.artsennet.nl/Nieuws/Nieuwsarchief/Nieuwsbericht-1/Niet-tornen-aan-zorgvuldige-euthanasiepraktijk.htm>

Broadening the Health Focus: CHPE Contributions to Public Health Programming
by Christy Rentmeester, PhD, and John Stone, MD, PhD

The evidence is solid. To improve health, many causes must be addressed “upstream” from clinicians’ encounters with patients at medical centers or clinics because they involve social and community-based determinants of health. The field of public health targets these issues. Thus, in collaboration with on-campus and community leaders in public health, CHPE has helped initiate two programs to integrate public health education and inquiry more strongly into the intellectual and teaching life at the university. These efforts should also motivate and inform research that aims to improve community health. The most promising such model is CBPR, community-based participatory research.

The two programs we have helped initiate and in which we participate are as follows:

(1) **The Public Health Journal Club** meets monthly for “brown bag” sessions at the Creighton University Health Sciences Library and is open to all students, staff, and faculty. Goals of these sessions are to:

- Enhance participants’ knowledge of cutting edge issues in public health, particularly those at the intersections of communities and academic health sciences centers;
- Facilitate participants’ learning about how healthcare professionals’ leadership and advocacy can improve practice aims and public health;
- Motivate innovation and development of skills healthcare professionals need for enhancing public health and eliminating disparities in health status and access to healthcare services; and
- Cultivate understanding of intersections of clinical ethics, organizational goals, and health policy.

Sessions are led by faculty. Readings are available to all participants on electronic reserve at the library.

(2) **The Graduate Medical Education Curriculum in Public Health** now in Phase 1 comprises interactive, case-based, one-hour sessions to medical residents on topics such as vaccine innovation, health literacy and communication, community collaborations, public health leadership, epidemiological versus clinical case review practices, inequalities in health status and access to healthcare, chronic disease management, evidence-based practice, relationships between environmental conditions (such as lead exposure) and health outcomes, climate change and its implications for population-based health, and green healthcare. This program in graduate medical education fits recent initiatives of the American Association of Medical Colleges.

The sessions seek to expand resident physicians’ knowledge about patient care and public health and to motivate the following learning outcomes:

- Enhance resident physicians’ appreciation of (a) how public health issues can significantly influence an individual patient’s health and (b) how public health policy and systems-wide healthcare financing influence their practices;
- Increase resident physicians’ understanding of ecological models of health that address background causality of illness and disease;
- Advance resident physicians’ knowledge of the kinds of public health leadership roles they can assume in their careers; and
- Offer content with objectives that motivate residents’ development of skills in the six Accreditation Council for Graduate Medical Education (ACGME) Competency Areas.

Residency Program Directors have helped us shape the program, as well as a number of contributing faculty. Residents’ learning is assessed at the end of each session and results are shared with Residency Program Directors, who use these data in their annual reports to the ACGME. Please contact the authors of this article if you would like more details.

Premiere Event Featuring Nursing and Ethics
by Winifred J. Ellenchild Pinch, PhD

A stellar event is in store for you. The Center for Health Policy and Ethics will be hosting the premiere showing of a newly created documentary, *Ethics and Nursing: The Foundation of the Profession*. The premiere is scheduled for May 12th at 7 PM and will be held in the Stanley and Dorothy Truhlsen Lecture Hall on the lower floor of the Durham Museum. The free premiere showing will be preceded by a reception at 5:30 PM in the Soda Fountain and Candy Shop area on the Main Level of the Museum.

The documentary video features segments from interviews with distinguished nurse ethicists who participated in a nursing and ethics project at the Center. These scholars were interviewed and videotaped as part of this project when they met at the Center for a two day working seminar in the spring of 2007. Using a predetermined set of questions, each person's career trajectory, attraction to ethics, view of the ethical challenges of the discipline, and perspectives for the future of ethics in nursing were explored and discussed. The resulting set of interviews is both a valuable historical record of these experts' insights into health care ethics as well as a salient commentary on the future of nursing as it relates to ethics. Selected segments utilized in the video are particularly provocative or prophetic. Ms. Tessa Young from the Creative Services Department of Creighton University, consulting with the project directors, Drs. Amy Haddad and Winifred Ellenchild Pinch, planned and developed the video. Relevant archival video footage, photographic stills, and music augment the nurse ethicists' commentary.



Some of the nurses who appear on the video.

Contributions utilized in the video include twenty-one of the participants. These remarks are framed within four themes in the video. Part One addresses the nurses' Journey to Ethics which varies from experiences on a psychiatric ward, to viewing the effects of poverty on health status, to witnessing a need to protect patients within the vagaries of the health care system. The second part focuses on Finding a Voice. Some nurses voiced differences in their perceptions of nurses as belonging to a rich, powerful profession and others who passionately disagreed. The importance of hierarchies in the health care system, team work, and the need for patients to be central in all situations were all noted. Healing a Broken System frames the third part. Here there was greater consensus in identifying the limitations and discrimination present in our current health care system. A look into the future, Creating an Ethical Generation, comprises Part Four. How to teach ethics challenged most educators as they considered the various options available to them in the academic setting. A special concern for women and children was also raised as well as the lack of investment in ethics scholars in nursing. The video concludes with a poetry reading from the book.

This video can provide a valuable teaching device especially when accompanied by the use of the anthology from this same project, *Nursing and Health Care: A Legacy and a Vision*, distributed by NurseBooks, the publishing program of the American Nurses Association.

In addition to the Center's financial support of the endeavor, a generous donation from the School of Nursing played a significant role in the successful completion of the production. Partial funding for the premiere showing was contributed by the Iota Tau Chapter of Sigma Theta Tau International, the honor society for nursing. We are grateful for their interest in the project as well as their financial support.

May 12th is the last day of Nurses' Week, so plan to come and conclude the week of celebrating the nursing profession by attending the premiere. Seating for the event is limited. Beginning April 1, register to attend by going to <http://chpe.creighton.edu>. For additional information call 402.280.2017.

Good Books by Bad People

by Jim Bothmer, Assistant Vice President for Health Sciences and Director of the Health Sciences Library;

Thomas H. Quinn, PhD, Professor of Anatomy and Surgery, Department of Biomedical Sciences;

Jos VM Welie, PhD, Professor of Medical and Dental Ethics, Center for Health Policy and Ethics

What to do with books that are of high scholarly quality but have been written by rather evil people? This librarian's conundrum was the topic of a Roundtable held at the Center for Health Policy and Ethics earlier this year. More specifically, Creighton's Health Sciences Library owns the first and several later editions of the renowned multi-volume anatomical atlas named the Pernkopf Atlas after its principal author, the Austrian anatomist Eduard Pernkopf. The production of the atlas was commenced shortly before World War II, and several of the volumes were completed during this period. It was reprinted several times since in different languages, including English, and is still in use. And yet this atlas has been characterized as "the archetype of highly reliable data 'tainted' by its association with Nazism" (Riggs 1998).



Tom Quinn and Jim Bothmer with the Pernkopf Atlas

Why the label "highly reliable?" The Austrian anatomist Eduard Pernkopf, who became Dean of the Vienna Medical School in 1938 and who appears to have been a very popular lecturer, set out to create a four volume set of atlases called *Topographische Anatomie des Menschen* (Topographical Anatomy of the Human Being) in the mid 1930s. The detailed text was illustrated with over 800 drawings, produced by some of the leading medical illustrators of his days, including Lepier, Batke, Schrott, and Endtresser. The text and particularly the drawings are of such high quality that the atlas continues to be one of the best resources for human anatomy for anatomists, surgeons, and students. The work has become an inspiration for many later artists who have referenced the information contained in it. The Pernkopf Atlas, it seems, has entered the intellectual fabric of the study of gross anatomy.

So in what way is this highly reliable atlas "tainted"? Pernkopf not only was an excellent anatomist, he was also a long-time Nazi Party member. When he became Dean shortly after the German invasion of Austria, Pernkopf immediately "purged" the faculty of Jews and other "undesirables". He charged the remaining faculty to follow practices of eugenics in order to preserve racial purity through their practice of medicine. Some of the artists incorporated Nazi SS or swastika designs into their signatures to show solidarity with the Nazi Party. And most importantly, evidence began to surface in the late 1980s, with follow up historical research in the 1990s, showing that many or most of the bodies of persons used for the dissections had died in the Nazi concentration camps, notably in Mauthausen. Subsequent editions of the Atlas, including the English language edition, have been "cleaned"; the Nazi symbols have been carefully removed from the drawings. But the developmental history of the Atlas cannot be "airbrushed" away. In that sense, this set of books remains as tainted as it was ever.

Now that this history has been uncovered and made public, how should we proceed? The current publisher, in cooperation with the University of Vienna, has issued a letter to the libraries holding copies of the atlas; the connection to the Nazis is acknowledged. What should owners, but particularly public libraries, do with these books? Some believe that the work should be suppressed or even destroyed. If we suppress them, then only the original edition or all subsequent editions as well? Others believe that its value as an aide to understanding human anatomy stands as a monument to those whose lives were lost. If we retain them, should access be open as well or restricted, and if so, restricted to whom?

The Health Sciences Library exists primarily to ensure and support the success of our users, both those seeking education and those engaged in research activities. At the same time, the Library aspires to be an institutional conscience and a moral compass through our support of intellectual freedom, copyright and fair use, and advocacy for our clients' right to privacy and their right to information. We maintain a sort of neutrality on campus, applying these values to everyone equally. But conflicts can occur when the principle of freedom of information, a principle valued by librarians, clashes with the ethical standards of scientific research, one of which involves the obligation to only obtain data with ethically sound methods and means.

The Health Sciences Library believes that the Pernkopf atlas serves a double role: (1) It teaches anatomy very well, and (2) it reminds us of the horror that any science can impose. Thus, the Library believes that the volumes should be retained, not only the "cleaned" versions but also the original edition. In doing so, the Library follows the advice of several others who have written on this important issue (see, for example, Atlas 2001) and adheres to the American Library Bill of Rights, which states in part "materials should not be excluded because of the origin, background, or views of those contributing to their creation. Libraries should provide materials and information presenting all points of

view on current and historical issues. Materials should not be proscribed or removed because of partisan or doctrinal disapproval. Libraries should challenge censorship in the fulfillment of their responsibility to provide information and enlightenment." (American Library Association "Library Bill of Rights" reaffirmed January 23, 1996)

In order to serve both of the aforementioned roles, the Health Sciences Library will retain all copies of the Pernkopf Atlas in the Reserve section of the library so that those needing them for educational and scholarly purposes have access to them. But a note is posted on the electronic record for this title indicating that certain material in this atlas may violate the ethical standards of the medical community. The aforementioned letter from the publisher of the original Atlas, explaining the origins of the volumes, has been pasted in the first volume of the original edition.

This strategy does not resolve the ethical conundrum, and probably no strategy will ever satisfactorily dissolve the problem. After all, even burning the books will not undo the evils that led to their creation. The problem of history is that it cannot be undone. And as the discussions during the January 27 Roundtable at the Center made clear, many other practical questions remain, for example: Can we wait for users of the Pernkopf Atlas to discover on their own exactly how these books are tainted, or should the instructors of anatomy in the various health sciences schools volunteer such information? If so, only when they use images from this Atlas in their lectures, or should every course in anatomy make mention of it; after all, modern anatomy is indebted in many ways to the work of Pernkopf and his colleagues. Indeed, there is probably no discipline in the health sciences that has an ethically clean slate. Should all health sciences lecturers make their students aware of our troublesome roots, lest we forget?

Atlas, Michel. "Ethics and access to teaching materials in the medical library: the case of the Pernkopf atlas". *Bulletin of the Medical Library Association* 2001 January; 89(1): 51-58.

Riggs, G. "What should we do about Eduard Pernkopf's Atlas?" *Academic Medicine* 1998, 73(4): 380-386.

Personnel News by Marybeth E. Goddard, MOL

Creighton University Associate Professor and Center for Health Policy and Ethics' Faculty Affiliate, Dr. Robert Garis, Dies

It is with a heavy heart that the Center acknowledges the passing of one of its own. CHPE Faculty Affiliate Dr. Robert Garis died of cancer November 13, 2009. He was 59. Dr. Garis's primary appointment was that of Associate Professor of Pharmacy Sciences in Creighton University's School of Pharmacy and Health Professions. He spent much of the last decade exposing costly and often questionable practices among pharmacy benefit management companies (PBMs). In fact, Dr. Garis and his Creighton colleagues were the first to question and perform research on drug pricing policies, excessive mark-ups, inefficiencies and other dubious practices within the PBM industry, which serves as an intermediary between many employer-sponsored prescription drug benefit programs, pharmaceutical manufacturers and retail pharmacies.

In 2005, the Creighton School of Pharmacy and Health Professions awarded Dr. Garis its Distinguished Service Award.

Dr. Amy Haddad, Director of the Center for Health Policy and Ethics, states, "From the day Bob became a Faculty Affiliate of CHPE, he offered freely of his talents and time to any project or event where he was needed. He was truly a gentleman and a scholar."



Robert Garis

Dr. Gail Jensen, CHPE Faculty Associate, Receives Prestigious University Award

Dr. Gail Jensen, CHPE Faculty Associate, Dean of the Graduate School and Associate Vice President for Academic Affairs, received the 2010 Mary Lucretia and Sarah Emily Creighton Award during Creighton University's annual Committee on the Status of Women Founders Week luncheon, Thursday, February 11, 2010.

The All University Committee on the Status of Women presents the Mary Lucretia and Sarah Emily Creighton Award every year during Founder's Week to individuals associated with Creighton University who create an environment that supports women's achievements; serve as role models for accomplishments for women; and encourage women faculty, administrators, staff or students in the development and use of their talents.



**Gail Jensen with CSW Chair
Michele Starzyk**

For Dr. Jensen, this award recognizes her efforts to go above and beyond to create an environment supportive of achievement for women. Known as a role model who is very visible in her advocacy, one example of her efforts is the creation of the Office of Online Learning, bringing together the talents and skills of many throughout the University to improve distance learning. She has worked to develop new faculty, supported faculty and research initiatives, and served as a team leader for the Higher Learning Commission, assuring that voices were heard from all disciplines and business units.

CHPE Welcomes New Staff Member

CHPE is happy to welcome Dee Sledge as its newest staff member. Dee began her tenure in mid-January as the Center's Administrative Assistant II. Dee holds a Master of Arts in Computer Resources and Information Management from Webster University and received her Bachelor of Science in Business Administration from Regis University. Prior to coming to the Center, Dee held positions at Con Agra Foods in Omaha and Lockheed Martin in Colorado Springs. In her spare time, Dee enjoys reading, walking, and crafts.

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