



The JCB Voice

In This Issue

- 1 [Feature: Interview with Randi Zlotnik Shaul](#)
- 3 [Director's Corner: Tempus Fugit](#)
- 6 [Announcements](#)
- 10 [Review: The 4th Annual Sue MacRae Lecture on Ethics and Patient-Centred Care](#)
- 13 [Article: Why Use of Advance Directives with the Dementia Population Is Problematic](#)
- 16 [Article: The Ethics of Integration](#)
- 18 [Article: Ghost Writing and Scientific Misconduct: What does this reflect?](#)
- 20 [Calls for Submission](#)
- 22 [Seminars, Events & Conferences](#)
- 25 [Recent Publications](#)
- 26 [Submission & Contact Information](#)

Feature: Interview with Randi Zlotnik Shaul

Tell us a bit about the Bioethics service at SickKids. Have there been any significant changes or innovations you have been part of that you would like the community to know about?



Randi Zlotnik Shaul
Bioethicist, The Hospital
for Sick Children

The Department of Bioethics at The Hospital for Sick Children (SickKids) was initiated in January 1991 as an academically grounded and clinically focused bioethics service. The Hospital for Sick Children is affiliated with the University of Toronto Joint Centre for Bioethics.

The roles of the department bioethicists include consultation, education of bioethics students and health care professionals (both those in practice and in training), research, policy preparation and dissemination, participation in the life and culture of the organization in a variety of ways, and involvement in the bioethics community more broadly. Our consultation service is available to all decision-makers, including patients, families, and health care practitioners, who want assistance with ethical decision-making.

While I have been and continue to be part of many exciting changes at SickKids, one innovation that has been particularly significant was the development of the hospital's Clinical Innovation policy. Through the policy, we established an innovation pathway and accountability framework for introducing procedures that are new to the hospital, though not new to the world. What began with a bioethics consultation, developed into a body of research on innovation, was translated into an evolving hospital policy and in October 2010 was recognized as a leading practice by Accreditation Canada.

SickKids®

cont'd...

Feature: Interview with Randi Zlotnik Shaul (cont'd)

How did you get involved in applied ethics?

As with most bioethicists, mine was an exciting journey that looking back seems naturally to have led me to Bioethics. I have always been interested in theories of justice. I went to Law School thinking it would be the operationalizing of political theories I studied during my undergraduate degree. First year law school focused more on what the law is than what it should be. To make up for the normative analysis I was missing, I spent the summer working at what was then the McGill Centre for Medicine Ethics and Law. One summer working with among others, Margaret Somerville and Benjamin Freedman and I was hooked on interdisciplinary analysis.

Passionate about working for the public good, I articulated and practiced law at the Ontario Ministry of Health. While there, I felt especially challenged by issues of scarcity and was inspired to do graduate work under the supervision of Bernard Dickens, exploring the legal and ethical implications of making resource allocation decisions based on economic analysis. I had expected that by pursuing a Masters of Law degree on this topic I could return to the Ministry of Health with "all the answers". Upon completion of this degree, rather than all the answers, what I had was a more sophisticated appreciation of the complexity of the issues. I decided to address these through a Ph.D.

It was during a conversation with Peter Singer (then Director of the JCB) and Bill Harvey (then Director of the JCB Collaborative Program) about my 5 year plan for life after my Ph.D., that they suggested that I may find my knowledge base, personality and interests well suited for applied ethics in a hospital setting. I was fortunate enough to do a Post Doc with Christine Harrison and Mary Rowell in the Bioethics Department at SickKids. I am thrilled to be able to say that I have

[T]he achievement I am honestly most proud of, is facilitating significant and genuine moments of "aha!" in paediatric bioethics for patients, families, colleagues and students.

been working at SickKids as a Bioethicist and collaborating with JCB colleagues ever since.

What is the biggest challenge you have faced?

As a Bioethicist, my role includes clinical consultation, education, policy development and research. There is so much opportunity to pursue meaningful fascinating work in each of these domains. My biggest challenge is accepting the fact that limited time makes it impossible to be a part of every wonderful opportunity that comes my way.

What achievement are you most proud of?

I am unsure how to answer this question. There are several formal accomplishments that I am proud of including (1) my role as PI working with a fabulous research team on a CIHR funded study on Dual Accountability of Physician-Researchers, (2) publications that bring bioethics issues from "the trenches" to the literature and (3) recently receiving the Peacemaker Tapestry Award for Cultural Competency. However the achievement I am honestly most proud of, is facilitating significant and genuine moments of "aha!" in paediatric bioethics for patients, families, colleagues and students. I have happily seen this achievement snowball and gain momentum as others are inspired to bring a paediatric bioethics lens to their work or context.

Director's Corner: *Tempus Fugit*

It is hard to believe that five years have passed and I am completing my term as the Director of the Joint Centre for Bioethics. I must say it has been a whirlwind. I have learned more in the five years as Director that I ever dreamed possible.

It has been an amazing time as Director. For those interested in complexity studies, being the Director of the JCB is certainly an in-depth experience with a complex organization. The scale, scope, and variety of work that members of the various networks and partnerships engaged with the JCB are nothing short of breathtaking.

There are many clichés one can utter on one's final editorial and it is hard to avoid them. One does need to express gratitude to all the people that have made my work such a joy. Quite simply, the willingness of the members of the network to engage in advancing bioethics as a scholarly endeavour, as a mode of teaching for health professionals, and as a form of healthcare practice, is remarkable. The high level of academic citizenship displayed by members of our network, as well as the true collaboration in an interdisciplinary and interprofessional environment, is exemplary. Given the intense interest in both interdisciplinarity in the academic world and interprofessionalism in the health care world, people would do well to look at the JCB as an outstanding model for both. So my hat is off to all members of the JCB and the sup-

porting partnering institutions for their forbearance of me as Director and for contributing so much to my learning.

I must, however, give particular thanks to members of the core JCB Secretariat. Their work behind the scenes coordinating all of the activities of the networks and connecting with partners—academic and in the health care sector—is nothing less than stellar. I know that many Members of the JCB have come to appreciate the core function of the secretariat at the JCB. But from my perspective the people are irreplaceable gems.

Barb Secker, in her coordinating role in education, CORE Network, and the Academic Fellowship is a tireless worker. She shows such tremendous concern and empathy, for students and for bioethicists working in the hospital. She embodies what it means to be a bioethicist.

Jennifer Gibson is an emerging bioethics research superstar. Her strategic sense and her passion for organizational ethics are remarkable. I am certain that her pioneering work on the 'Excellence in Bioethics' project will be regarded as the gold standard in the field. This report was absolutely crucial in our external review as well as in aiding and assisting in our partnership renewal efforts.

cont'd...

Given the intense interest in both interdisciplinarity in the academic world and interprofessionalism in the health care world, people would do well to look at the JCB as an outstanding model for both.

Director's Corner: *Tempus Fugit* (cont'd)

Brenda Knowles is an outstanding academic administrator whose understanding of human resources and policies has helped us bring clarity to all roles in the JCB environment. She has been an invaluable advisor and wise presence and her sense of humour has been a salve to me. Having her skilled administrative and business acumen has been absolutely essential for us to be able to move forward and continue our development as an organization.

Carmen Alfred has been a fantastic academic secretary supporting the work of the academic programmes, particularly the MHSc. She is the lifeline to the students.

Connie Carrozza has assured that our books have been kept in order and her cheerful presence is well known to all.

Beth Woods is the first person everyone meets when entering the JCB, a role she conducts with aplomb. I thank her for keeping the seminar series functioning well.

Special thanks go to Rhonda Martin for having the unenviable task of managing my unruly schedule and providing endless support for me in my role. I simply could not have functioned without her. She and Brenda have managed to keep me on track these five years and I simply have no idea how I am going to survive without them.

There is a thematic unity to the set of articles in this month's Voice. By sheer co-incidence they involve the issues that I will take up in a research capacity in my life post directorship. I was fortunate, in March 2011, to be renewed for another five years as the Canada Research Chair in Primary Care Research. An integral component of my research platform is advancing our

understanding of how to provide care for seniors with multiple concurrent chronic diseases. To me this is one of the great practical challenges in primary care, but rests on a normative foundation.

This issue is taken up by Martin McKneally in his account of the 4th Annual Sue MacRae Lecture on Patient Centred Care. The speaker, Karima Velji is a long time JCB supporter and now Vice-President, Clinical and Residential Programs and Chief Nursing Executive at Baycrest Centre for Geriatric Care. Her well attended and provocative talk entitled "Will you be there when I am Old? Ethical Considerations Related to Aging" outlined the ethical challenges facing the health system by caring for a growing population of older adults. Her conclusion that we are not yet prepared is one that I completely agree with and one I hope to address in my future research.

Continuing with the theme of aging, Marcia Sokolowski, bioethicist at Baycrest, demonstrates some of the challenges with the use of advanced directives in persons with dementia. Her article "Why Use of Advance Directives with the Dementia Population is Problematic" is a thought provoking, well reasoned and timely contribution. Finally, Leah Justason and I argue that more attention should be spent making explicit and defending the values underpinning arguments for a better integrated system of health care. This is particularly important for seniors and others with heavy treatment burdens.

However, this issue also celebrates the opposite end of the life cycle. We are delighted to feature Randi Zlotnik-Shaul and the bioethics program at SickKids. As well, we note with considerable pride that Christine Harrison was awarded the 2011 Lifetime Achievement Award by the Canadian Bioethics Society.

cont'd...

Director's Corner: *Tempus Fugit* (cont'd)

Finally, Professor Solomon Benatar provides an overview of a recent workshop convened by Professor Trudo Lemmens concerning the disturbing practice of ghostwriting in the medical literature. This well attended workshop raised significant ethical concerns about the integrity of reported findings in pharmaceutical trials that strike to the heart of the academic enterprise. He writes:

Adverse effects on professionalism and scientific integrity threaten the community spirit and public responsibilities of academia that are so essential for the sustainability of the academic endeavour and healthcare as socially valued institutions. The question is whether we have the courage and the vision to act both locally (specifically) and globally (generally) to begin to reverse these adverse trends.

The contents of this issue reinforce what I have learned over the past five years: The JCB is one of

the outstanding centres for bioethics in the world, and there is no shortage of challenging ethical issues that require concerted attention.

I have every confidence that this shall continue to be true with the new director, Dr. Larry Librach. Larry is an internationally recognized expert in the field of palliative care. He is one of the pioneers in the field in Canada and has made substantial contributions to education, advocacy and scholarship. He also has longstanding ties to the JCB, having served on the Centre for Bioethics Executive in the 1990's. His profile is included in the announcement next page. I am particularly pleased to welcome Larry to the directorship as he brings immense experience and wisdom, and expertise in end of life issues which are so central to bioethics practice, and most of all, as he continues the streak of having a family physician leading the JCB! I encourage you all to make time to meet with Larry, tell him about your engagement in bioethics and welcome him to the community.



Ross Upshur

Director, Joint Centre for Bioethics;
Director, Primary Care Research Unit;
Canada Research Chair in Primary Care Research;
Professor, Department of Family and Community Medicine,
and Dalla Lana School of Public Health, University of Toronto

Announcements

Dear Colleagues,

I am delighted to announce the appointment of **Professor Larry Librach as Director of the Joint Centre for Bioethics** for a 5-year term effective July 1, 2011.

Professor Librach has held leadership positions in both family medicine and palliative care since 1982, playing a central role in the development of palliative care—locally, provincially, nationally, and internationally. He now serves as the Director of The Temmy Latner Centre for Palliative Care at Mount Sinai Hospital.

Professor Librach is the W. Gifford-Jones Professor in Pain Control and Palliative Care at the University of Toronto, where he also holds the position of full professor in the Department of Family and Community Medicine and is the Director of its Division of Palliative Care. Professor Librach is an associate in the Joint Centre for Bioethics and the Centre for Studies in Pain at the University of Toronto, and the Buehler Centre for Aging at Northwestern University in Chicago. He is an academic educator with the Centre for Professional Development. Professor Librach was the physician leader of the national Educating Future Physicians for Palliative and End of Life Care Project (EFPPEC), which introduced curriculum in palliative and end of life care to Canada's 17 medical schools. He is a member of the Board and Past-President of the Canadian Hospice Palliative Care Association and an education consultant to the Education in Palliative & End of Life Care (EPEC) project in the USA.

Professor Librach has published extensively and has delivered over 500 lectures and workshops. He is the author of the Pain Manual (over 150,000 copies distributed) and co-editor of the textbook, Palliative Care: Core Skills and Clinical Competencies (now in its second edition). He has been a member of a number of national task forces on euthanasia and assisted suicide and advance care planning.

Professor Librach is the recipient of a number of awards from a number of organizations including the Canadian Hospice Palliative Care Association, the Ontario Palliative Care Association, the Ontario Medical Association, the College of Physicians and Surgeons of Ontario, and the University of Toronto.

I extend my sincere thanks and gratitude to Professor Ross Upshur for his leadership during his term as Director of the Joint Centre for Bioethics.

Please join me in congratulating Professor Librach on his appointment.

Sincerely,

Catharine Whiteside, MD, PhD, FRCP
Dean, Faculty of Medicine
Vice-Provost, Relations with Health Care Institutions



Professor Larry Librach

Announcements

Solomon Benatar has been awarded the **Mayor's Medal of the City of Cape Town** in April 28, 2011. The Mayor's Medals were awarded to six organizations and 15 outstanding civilians for their individual contributions to community development, cultural affairs, sport and conservation. Dr. Benatar was honoured for his contribution to the city and its residents in Social Affairs and Services area.



He is Professor Emeritus of Medicine, the founding director of the University of Cape Town Bioethics Centre and the director of the Fogarty International Centre programme for capacity building in international research ethics in Southern Africa.

Barry Goldlist (Department of Medicine, JCB Member) is the 2011 recipient of the **Ronald Cape Distinguished Service Award**. This Award, presented at the Canadian Geriatrics Society Annual Meeting, recognizes the contributions of an individual who has done much for the health care of older adults in Canada. (Source: MedEMail, May 12, 2011)

Congratulations to **Blair Henry** (Ethicist, Ethics Centre, Sunnybrook Health Sciences Centre) on his academic appointment to **Lecturer (Status-Only) with the Department of Family and Community Medicine** at the University of Toronto!



Christine Harrison was honoured for her contributions to health-care ethics in Canada by receiving the **Canadian Bioethics Society's 2011 Lifetime Achievement Award**.



Christine Harrison has been actively involved in the Canadian Bioethics Society since its inception, and served as President from 2000-2002. She received her BA and Master's degrees (Philosophy) from the University of Guelph, and her PhD in Philosophy (specializing in biomedical ethics) from McMaster University. Christine worked as a bioethicist, then Director of Bioethics, at The Hospital for Sick Children (Toronto) from 1993-2011. During this time she has provided leadership in Paediatric Bioethics in her work with organizations such as the Canadian Paediatric Society, through her invited lectures, and her publications. She is an Associate Professor in the Department of Paediatrics at the University of Toronto, and a member of the University of Toronto Joint Centre for Bioethics where she has made significant contributions, playing a key role in the development and implementation of curriculum in the discipline of bioethics.

Heather J. Ross (Department of Medicine, JCB Member) has received a **grant-in-aid from the Heart & Stroke Foundation** of Ontario for her project "Do Palliative Care Instruments Predict Heart Failure Severity When Compared to Standardized Heart Failure Instruments?" (\$25,942) (Source: MedEMail, May 12, 2011)

Announcements

Kim Ibarra won a **HPME MSc Student Oral Presentation Award**.

Her presentation titled "Exploring Ethicists' Perspectives of Healthcare Ethics Program Effectiveness" was given at HPME's Research Day 2011 and won "Best Oral Presentation for Group 3: Care Delivery". Kim will also be presenting preliminary results at the Canadian Bioethics Society Conference on June 3rd, 2011.



Barbara Secker (Director, Education and Practice, Joint Centre for Bioethics; and Assistant Professor, Department of Occupational Science and Occupational Therapy) has been reappointed by the School of Graduate Studies to the position of **Director of the Collaborative Program in Bioethics** for a five-year term (July 1, 2010–June 30, 2015).



Congratulations to **Shawn Winsor** who has accepted admission to the full-time **Ph.D. program (Health Policy) at the Centre for Health Economics and Policy Analysis at McMaster University**.



Shawn has been awarded both a Graduate Scholarship and a Research Scholarship. He will be supervised by Professor Mita Giacomini.

We are happy that Shawn will remain an active member of the JCB, including Course Co-Director of MSC3008Y (Practicum) in the MHSc in Bioethics Program at the University of Toronto. He will also be co-teaching PHL384S (Ethics, Genetics, and Reproduction) with Dr. Kyle Anstey in the Winter semester 2012.

The Faculty of Medicine Decanal Promotions Committee recommends the following candidates for promotion to the rank of Associate Professor effective July 1, 2011.

Listed below are JCB members. To see the complete list, go to: May 25, 2011 *MedEMail*, <http://www.facmed.utoronto.ca/Assets/FacMed+Digital+Assets/about/medemail/MedEmail+V19n17.PDF>.

- **James Lavery** (Dalla Lana School of Public Health)
- **Monica Branigan** (Department of Family and Community Medicine)
- **Scott Berry** (Department of Medicine)
- **Denyse Richardson** (Department of Medicine)

Ethics and Health Unit Newsletter

Go to the link below to view **World Health Organization's Ethics and Health Unit Newsletter**.
http://www.who.int/ethics/publications/ETX_Newsletter_May2011.pdf

Announcements

Congratulations to the Winners of 2011 CBS Conference Student Abstract Award!

Jacky and Nausheen are among the winners of 2011 Canadian Bioethics Society Conference Student Abstract Award. There were 61 submissions to the competition from which six winners were selected.

Jacky Parker's abstract is titled "Ethicist to the ER stat! Championing ethical care amidst chaos and crowding". Jacky also presented recently at ICCEC in Amsterdam on a related topic.



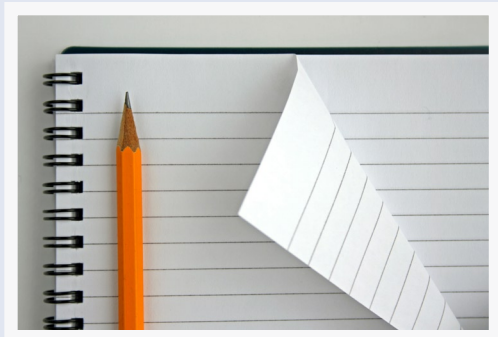
Jacky is an ER Physician at the Ottawa Hospital and just completed the second year of the MHS in Bioethics Program at the JCB.

Nausheen Saeed's abstract is titled "Human Milk: scarce resource and commercialization".



Nausheen is a Fogarty International Fellow in the MHS in Bioethics Program.

JCB Seminar Series



JCB Seminars will resume **September 14,** 2011 with a new time.

4:10 to 5:30 p.m.

Join us on Wednesdays at

The Joint Centre for Bioethics

155 College St., 7th Floor, Suite 754.

Review: The 4th Annual Sue MacRae Lecture on Ethics and Patient-Centred Care

“Will you be there when I am Old?” Ethical Considerations Related to Aging” was the title of the 4th annual Sue MacRae Lecture on May 25, 2011. Karima Velji, RN, PhD, Vice-President, Clinical and Residential Programs and Chief Nursing Executive at Baycrest Centre for Geriatric Care gave a spirited and highly informative lecture about the high demand for care of the aged, which intensifies on January 1, 2012. That day marks the start of the wave of retirements of the baby boomers in Canada, a large demographic group that will swell from 15% of the population at present to 30% by the year 2030. Currently, there are 1.5 million seniors in Ontario, 40% of Canada’s senior population. This number will double over the next two decades.

Karima answered her title question by stating clearly that: “We are not there now,” much less will we be there for the aging population in the future. Many Canadian seniors are housed in long-term care facilities, a remarkably large number when compared to Western Europe. “Seniors tell us that they would greatly prefer to be at home.” Nevertheless, we added 20,000 long-term care beds in the early 1990s and those beds are now filled, many of them by those who could age at home with adequate support systems. The frail elderly, those over 80 years of age are the largest per-

centage of users of long-term care. At the present rate, we will need 700,000 more long-term care beds for the elderly in Canada over the next decades, if we do nothing to change the alarming trends. The cost will be many billions of dollars. There are currently 500,000 persons with dementia in Canada, a number that will soon double. Karima spoke movingly about the loss of personhood when memory and ability to recognize loved ones disappear.

Such patients become marginalized as they undergo this tragic metamorphosis. The current experience of caring for the elderly does not emphasize the values of autonomy and dignity that older people cherish.

The average age of patients in long-term care facilities is currently 80 years. They have care needs that approach those of patients in acute and complex care institutions. They stay on average about 3 years in Ontario long-term care facilities. This is in sharp contrast with the 3 months average in some European facilities. Ontario has the highest complexity score of long-term patients in Canada, including mental health issues such as depression. Most of these facilities have minimal staffing patterns that emphasize the lowest skill providers and absence of mental health services. In Ontario, one in six long-term care patients is placed on antipsychotic drugs to enable behaviour management and sleep. Ninety percent of care is given by PSWs (Personal Support Workers) who have 6 months or less of training, usually in non-standardized pro-



Karima Velji
VP, Clinical and Residential Programs & Chief Nursing Executive, Baycrest

The current experience of caring for the elderly does not emphasize the values of autonomy and dignity that older people cherish.

cont'd...

Review: The 4th Annual Sue MacRae Lecture on Ethics and Patient-Centred Care (cont'd)

grams that are not customized to care of the elderly. There are 20,000 people on the waiting list for long-term care in Ontario. The average wait time is three months if they are in a hospital and six months if at home. Ninety eight percent of long-term care beds are full.

Alternate Level of Care beds account for 18%-20% of the beds in acute care facilities in Ontario. Despite efforts to reduce this number, it is constantly increasing. Their occupants, who are often the older adult population, are disparagingly referred to as "bed-blockers."

In 2009/10, in long-term care facilities, 18% of residents had bladder problems, 14% had undergone a recent fall, 11% were restrained, though restraint is technically illegal, and 32% were on antipsychotic drugs. "We wouldn't accept the standard of care they receive in pediatrics or in adult acute care. The

outcomes that are tracked in long-term care are risk related outcomes such as falls, pressure ulcers and restraint use. While these outcomes are important to monitor in order to keep residents safe, Baycrest has begun to focus on autonomy indicators. For example, the organization will emphasize mobility as one of the outcome areas of focus because enabling movement and participation in clients has a beneficial effect on many fronts, including resident well-being." A singular focus on falls for example can lead to inadvertent outcomes of restraining clients in order to prevent them from falling.

The World Health Organization lists several myths about aging. Among them we can find: 1. aging means decline; 2. aging is a medical condition; 3. people should expect deterioration with age (the vast majority don't); 4. elderly people are dependent; 5. experience doesn't contribute to benefit society (Baycrest has 1500 staff, 3000 volunteers—mostly elderly); 6. hospital beds and nurses are the solution. Older patients take away resources from the young and the larger society (The per capita cost of elder care is dropping in Sweden, and even though there are progressively more older Swedes, the country is still able to spend on schools and roads because of a better system). Karima emphasized that we need an integrated life-span strategy, supported by research and evaluation of data on home care, physical and mental fitness programs and incentive based systems

cont'd...



(From left) Karima Velji, Sue MacRae and Ross Upshur

Review: The 4th Annual Sue MacRae Lecture on Ethics and Patient-Centred Care (cont'd)

to keep us healthy and at home. She mentioned the green house concept in long-term facilities in which groups of 10-15 people are housed in homelike settings, emphasizing autonomy, compared to the large hospital type long-term care facilities.

Kyle Anstey asked about what a life span strategy should look like. Karima answered that aging begins at birth and we should be enabling successful aging throughout life. This means fitness (93% of Ontario youths don't meet standards of participation in physical fitness programs). It also includes mental fitness planning and pension planning. This should begin early in life. Shawn Tracy described Ross Upshur's clinic for older patients. It sounds expensive to many because of the time spent analyzing the complex care of these patients. A one and a half hour consultation has a very different impact on the budget of an outpatient facility, compared to the usual 15-minute turnover. However, the saving will come downstream with less fragmentation of care. Ross asked: "What are the outcomes we want?" Karima answered this question with Baycrest CEO William E. Reichman. They reflected that the desired outcome is health, not illness; vibrant flourishing, typified by an active life with one's children and grandchildren. Like rehabilitation, goal-setting should be the first focus in caregiving. Dr. Reichman added "I personally want to know how long I can be healthy, in other words to compress the period of illness and dependency so that most of life is spent at a very high level of function and satisfaction. Autonomy should be preserved, even when we are dependant. Dependant people who cannot feed or clothe themselves still want to set the menu and choose their clothing." He reinforced Ross's point that the downstream savings are not accounted for under the current healthcare financing.

Barbara Secker asked about the work at Baycrest on narrative ethics. Karima said that Marcia Sokolowski's narrative ethics program has been a great contributor to the vibrant life of residents at Baycrest. She also described the Council of Residents and Families that give "a voice of their own." The staff and management work with these councils and get their help and input in figuring out clinical and institutional challenges. The lived experience of residents and families which guides the organization is a vibrant force in the day-to-day life at Baycrest.

Sue MacRae thanked Karima for a thoughtful and caring presentation and asked if it is appropriate for us to think differently about consent in this population in order to help preserve their autonomy. Karima described the complexity of capacity assessment. "It is not dichotomous, that is, you are not perpetually capable or incapable based on singular assessments of capacity. One is not either capable or incapable. Capacity is situational; it fluctuates with time and circumstance. At Baycrest we will be working to cultivate a new definition of what it means to be capable."

The lecture closed with a very enthusiastic audience applauding and joining Karima for a spirited reception. All had been reminded clearly that each of us needs to develop an integrated life plan that builds on the values of autonomy and personhood.

Martin F. McKneally

Professor Emeritus of Surgery
Department of Surgery
University of Toronto



Article: Why Use of Advance Directives with the Dementia Population Is Problematic

Advance directives came into existence based upon good intentions. Generally, the idea is to project medical treatment wishes into a future time of potential incompetence when treatment decisions might need to be made.

However, my experience as an ethicist, working in a long-term care facility that provides medical treatment to patients with Alzheimer's Dementia, portrays a range of significant concerns, mainly irresolvable that arise out of the use of advance directives, at least in terms of how they are currently being used. Some arise out of faulty premises upon which the notion of the advance directive was initially built.

The dominant conception about Alzheimer's Dementia is that it is a disease of horrific tragedy, and necessarily leads to "loss of personhood." You become less and less of who you were, apparently in ways that matter a great deal. The continuous belief in this portrayal of Alzheimer's plays a very significant role in the devaluing of persons with dementia, and has all kinds of negative consequences, both obvious and subtle, when it comes to how we care for and respect persons with dementia. The negative stereotype of Alzheimer's is often at the root of why people write directives that state their desires to forego treatment if and when dementia strikes. It can be especially problematic to have such a directive if the demented person is generally happy.

It is problematic that the legal concept of autonomy employs a very narrow definition and explicit criteria that have to do with autonomous decision-making, and specifically with informed consent (itself a specialized legal notion in this context). Rather than considering directly what is important to being an autonomous person, this standard concerns itself with legal criteria for making an autonomous decision. For an

independent person without dementia, this approach may have made sense. For persons with dementia who cannot necessarily meet the legal standard, it fails to accord with their preferences or states of mind, and undermines their participation in processes where medical treatment decision-making may have very significant results for them. The chances of them being able to meet the required threshold, raised in proportion to perceived risks, are, predictably very slim, and even potentially slimmer as the kinds of decisions that matter the most are presented. When deemed incapable of making a current autonomous decision, the default standard becomes the advance directive. This problem arises in part because of the mistaken assumption that a legal standard appropriate at most to a particular range of circumstances can successfully be applied to complex and nuanced clinical situations that persons are embedded within. It fails to take into consideration the context from within which these standards are to be applied. It privileges a very narrow account of autonomy, one I described as 'hyper-cognitivist', which does not cohere with what it means to be an autonomous person in a fuller sense and what it means to respectfully care for human beings who have dementia. The relational aspect of autonomy is not reflected in the principle of autonomy as it is represented in medical contexts.

An additional and related problem is to assume that most people with dementia (beyond the very early stage) could not be autonomous. This has to do with the conflation between an important but limited notion of autonomous decision-making (being able to make an informed decision) and being autonomous, and as well the conflation between autonomy and competence. If a person with dementia could be autonomous in some degree, then an advance directive would play a much more circumscribed role than the

cont'd...

Article: Why Use of Advance Directives with the Dementia Population Is Problematic (cont'd)

one it is typically taken to play. This issue, that the person with dementia is assumed to be non-autonomous, does not fit with what I experience in clinical situations. Persons are larger than their abilities to make informed decisions. Nor is there consistency amongst practitioners in terms of how their determinations are arrived at.

One faulty premise underlying the conception of an advance directive is that one can actually project his or her own treatment wishes into the future; another is that doing so would remedy the initial problem of the patient with dementia not being able to express autonomous treatment wishes. This concept of applying previous wishes to a future demented person's circumstances is known as "precedent autonomy." The idea of the directive was founded on the assumption of legal and moral equivalence between everyday (contemporaneous) autonomy and precedent autonomy. Largely due to unknown future circumstances and associated lack of information, coupled with predictive moral imagination fallibility, in the vast majority of cases the authors of directives are neither able, nor *could* be able (largely due to reasons extrinsic to themselves) to understand the pertinent information they would need, nor to appreciate the consequences of their refusal or acceptance of treatment. Due to

these epistemic problems, as well as to the problem of irreversibility of decisions, I suggest that precedent autonomy is not morally (nor should legally be considered) equivalent to contemporaneous autonomy. In fact, the notion of precedent autonomy being foundational to the concept of the advance directive is at best, quite weak and only in very selected cases could it deserve much moral weight.

It is also problematic to assume that having a Substitute Decision-Maker (SDM) to interpret the directive and provide the requisite informed consent generally adds merit. In practice it is not unusual for an SDM to apply a best interest standard when contemplating whether or not to give consent to directives, either as the sole standard, or in conjunction with an autonomy standard. When SDMs apply a best interest standard he or she might be privileging particular kinds of interests over others, and not necessarily the patient's interests over others. SDMs do not always follow even relatively clearly expressed treatment wishes, for a variety of reasons. We also know that physicians and/or other team members do not necessarily always intend to follow what the patient or the SDM expects. There is potentially tremendous subjectivity, variation and inconsistency occurring with regard to the conceptual-

cont'd...

[P]erhaps the advance directive's greatest virtue of all is the role it is playing in motivating healthcare professionals to embrace the intention of honouring the demented person's wishes, interests and values, but to do so through engagement in advance care planning with their patients as an ongoing process and in a proactive way.

Article: Why Use of Advance Directives with the Dementia Population Is Problematic (cont'd)

ization of the advance directive, how its contents gets interpreted, its intended and actual use, and, how and if it gets applied.

I also think it would be a mistake to assume that the author of the directive behaves in a more predictable fashion. It would not be exceptional for him or her to neither expect nor even want the directive to be perceived as definitive. Some do wish for it to be literally complied with. Others want their interests at the time of incompetence to prevail, some interests taking precedence over others, while others expect a combination of directive wishes and current best interests to be determining. Rarely, however, are these expectations or wishes known to the SDM. Even if they were, they would not necessarily prove to be the current expectations or wishes of the patient with dementia. By chance, however, a previous wish that a currently demented patient continues to hold might be consented to by the respective SDM. After all, there are only two possible outcomes, consent, and refusal.

While advance directives often create more problems than they are worth, a directive completed by someone in close temporal proximity to an event or illness (that will render their immediate interests, values and wishes unknowable), is likely to have some merit, provided the state was explicitly described and the wishes well articulated. In such a situation, an advance directive would likely be a better option than not having any idea about what to do. A person in a comatose state would be in such a situation, and the relevance of the advance directive increases to the extent that the person in question is not known by anyone in the position of needing to make a medical decision. Interestingly enough, I imagine an advance directive might prove to be its most useful when

someone is a complete stranger to us, one who cannot communicate through any means, wishes, interests or values. A stranger in a coma is the most likely type of person to potentially accrue some benefit from a directive.

But persons with dementia are not moral strangers to us, unless we choose to treat them as such.

Finally, I wish to return to my initial statement, that the intentions behind the creation of the advance directive were honourable. There is something rightly important about giving voice to a demented person's wishes with regard to consent or refusal of medical treatments being currently offered. Aside from chance, I estimate that rarely would that end up happening through the usual way we have been utilizing advance directives with the dementia population. Nonetheless perhaps the advance directive's greatest virtue of all is the role it is playing in motivating healthcare professionals to embrace the intention of honouring the demented person's wishes, interests and values, but to do so through engagement in *advance care planning* with their patients as an *ongoing process* and in a *proactive* way.

Marcia Sokolowski, PhD
Co-Director of Ethics, Baycrest
Centre for Geriatric Care



Article: The Ethics of Integration

With the Federal-Provincial/Territorial Health Accord set to expire, on March 31, 2014, a hot topic in Canadian politics and health policy has centered on the fiscal sustainability of our universal health care system. Canada is currently one of the highest per capita spenders on universal health care services as compared to other industrialized nations.¹ It has been noted by the Parliamentary Budget Officer in the 2010 Fiscal Sustainability Report that the current Canadian expenditures on health services are unsustainable. In the last five years, health care spending has increased by 6.8 percent annually, outpacing both the growth in national GDP and government revenues.² The unsustainable expenditures of the current health care system has become a prominent topic of national debate, as it has highlighted the fact that our health care system does not adequately or appropriately meet the needs of Canadians in the 21st century.³ Yet in presenting the main failure of the health care system as primarily an issue of financial instability, the present functioning of the Canadian health care system as a whole is overlooked. Particular aspects of the system are determined as detrimental to system function, such as Emergency Room (ER) wait times and Alternative Level of Care bed allocations (ALC) but questioning the root causes of these phenomena needs to be more intensively investigated. The focus of health care sustainability needs to be centered on the fragmentation and lack of integration across different health care sectors, preventing an optimal level of efficient and effective patient care. Specially, an issue of growing concern is the Canadian health care systems failure to address the need for integration of chronic disease management across a continuum of care.

Canadian population demographics are undergoing a transformation. As census data indicates, Canadians are presently living longer as medical advancements

have altered life threatening acute illnesses into more manageable chronic diseases that our current health care system is not designed to handle.⁴ According to the Commission on the Future of Health Care in Canada, the proportion of Canadians 60 years and older will jump from 17 percent today to just over 28 percent by 2031.⁵ In many ways the Canadian population served by the publicly funded health care system has and will change, posing multiple challenges to the way in which patients move through the health care system throughout their lifespan. In particular, many recent reports have indicated that there are critical problems with respect to how individuals navigate transitions through the health care system, with a lack of integration of health services across a *continuum of care*, defined as

*"the array of services, regardless of the age of the recipient, ranging from primary care (including health promotion and illness prevention), through institutionally based secondary and tertiary care for acute medical situations, to community- and-home-based services that promote health maintenance and rehabilitation for people with chronic problems, and finally to palliation at the end of life"*⁶

Currently we do not have a comprehensive continuum of care, as each health sector seems to function independently with a lack of overall communication between sectors to follow individual patient outcomes. Long ER and ALC wait times are symptoms of a larger problem of a failure to properly integrate chronic disease management into the Canadian health care system.

The basis of our health care system was formed on the belief that Canadian citizens value a system based on shared risk, which supports citizens based

cont'd...

Article: The Ethics of Integration (cont'd)

on need rather than ability to pay for medical services.⁷ The concept of universal Medicare was founded on five valued principles of universality, accessibility, comprehensiveness, portability and public administration developed in the 1960's and adopted in 1984 under the Canada Health Act (CHA).⁸ The CHA set the only national standard in health care across the country, defining provincial standards in terms of what service requirements must be met in order to receive federal funding. The Act was designed to cover hospital and medical services and did not anticipate the current need for community-based management of chronic diseases. Therefore, there is no national standard for a wide variety of services included under the umbrella of the continuum of care.⁹ As a result, a system that was designed to focus on acute care services is not meeting the needs or values of Canadians today, as it is neither efficient nor effective at managing the growing number of patients living in their communities with multiple chronic conditions.

The 2002 Romanow Commission Report determined that Canadians still value the principles of Medicare developed 40 years ago, however, the present structure of our health care system is not necessarily aligned to maximize these principles, nor can these principles necessarily all be maximized simultaneously.¹⁰ There is no doubt that economics play an integral role in the functioning of the health care system. More critical analysis is needed to question the underlying assumptions of the economic models applied in health care. We need to foster deeper reflection and public engagement concerning how we align financial incentives with values in health care. We believe one of the missing elements in the discourse thus far has been a focus on ethics and values issues. As medical technology evolves there is much that we can do and will do for patients

but there is a lack of sustained discussion on what we should do.

The discipline of bioethics offers something unique to this issue as it occupies a domain of scholarship and practice in health care that focuses on the normative; that is the considerations and weighing of arguments for and against what we ought to do. In a forthcoming White Paper entitled "The Ethics of Integration Project", a Working Group made up of a host of practitioners and bioethicists connected to the University of Toronto's Joint Centre for Bioethics hopes to address these issues. The paper will look at a series of scenarios to illustrate problems associated with a lack of system integration. It is the hope of the Working Group that the scenarios based on the working experience of front line health care providers and bioethicists will display some of the value issues inherent within navigating our current health care system.

cont'd on page 19

Leah Justason
Research Assistant



Ross Upshur
Director
Joint Centre for Bioethics



Article: Ghost Writing and Scientific Misconduct: What does this reflect?

Trudo Lemmens and his colleagues Hamid-Reza Raziee and Simon Stern are to be congratulated on organizing an excellent seminar on *'The ethics of ghost authorship in biomedical research'*. A diversity of speakers discussed topics that included empirical data on the extent of the problem, personal experiences from a range of perspectives, thoughts on how and why this problem is becoming increasingly pervasive, and potential remedial actions. Education of researchers, promulgation of institutional policies on scientific and professional integrity, and the design and implementation of legal sanctions and new regulations were all discussed in some detail.

Two major points of contention featured repeatedly throughout the day. The first was double standards regarding the approach to students and faculty—with students being treated harshly if they are found guilty of plagiarism, while faculty are treated very leniently when they display such professional misbehavior. No adequate explanation was provided for this discrepancy, despite persistent questions from social scientists who expressed dismay both with the way their medical colleagues behave and with the general lack of accountability within institutions. Pressure to publish and the increasing dependence on pharmaceutical companies for research support, play a significant explanatory role. The second contentious issue was the extent to which the pharmaceutical industry, in collusion with medical journals (even some of the most prominent), 'manage' ghost writing and related practices to promote their drugs, often with co-option of otherwise good scholars, and sadly at the potential cost of people's lives through high profile dissemination of distorted data.

Ghost authorship was generally addressed in the seminar as though it were an isolated problem that could

be understood within the context of the competitive academic environment in which academic recognition is based on increasingly narrow (easily measurable) criteria (publications) and on the role of pharmaceutical companies in both funding medical research and in setting priorities in the research agenda.

However, some saw the issue as one of many signs of a profound and pervasive malaise within a progressively dysfunctional 'global system' that has brought much of great benefit to the world, but is now becoming increasingly divisive. The still evolving global economic crisis is an example of how distortions of dominant ways of thinking have allowed abuses that undermine the lives of many. It can be noted that there is an analogy between the lack of accountability mentioned above and the way in which most of those associated with massive financial misconduct have also not been brought to book. On the contrary, they have profited greatly.

The writings of J. K. Galbraith many decades ago ('The Affluent Society' and 'The New Industrial State') were perspicacious in identifying four myths that underpin modern economics (extreme individualism, unlimited desires, short-term self-interest and a form of 'rationality' that emphasizes calculable and measurable issues). In his view these would have devastating long-term consequences. Those scholars who ignored him (and others with similar insights) have now been shamed. The last book Galbraith wrote 'The Economics of Innocent Fraud' eloquently described how much of the way in which the modern economic system operates is characterised by fraud, perpetrated not necessarily by bad people but rather under the influence of corporations that seem to have the defining characteristics of psychopaths (see 'The Corporation' by Joel Bakan).

cont'd...

Article: Ghost Writing and Scientific Misconduct: What does this reflect? (cont'd)

In the same way as health care systems all over the world are becoming even more 'distorted, dysfunctional and unsustainable than ever' (as I mentioned in the March JCB Newsletter, <http://www.jointcentre-forbioethics.ca/enewsletter/docs/2011mar.pdf>), under the influence of the dominant economic myths, so it seems these shortcomings are also becoming more apparent within the vast medical research enterprise as a 'system'. 'Systems' failure is widespread and lies at the core of the challenge to our global future. Medical error, climate change and environmental degradation are other examples of systems failures. Adverse effects on professionalism and scientific integrity threaten the community spirit and public responsibilities of academia that are so essential for the sustainability of the academic endeavour and healthcare as socially valued institutions. The question is whether we have the courage and the vision to act both lo-

cally (specifically) and globally (generally) to begin to reverse these adverse trends.

"The Ethics of Ghost Authorship in Biomedical Research: Concerns and Remedies" Workshop was held on May 4th, 2011 at the Faculty of Law, University of Toronto.

Solomon R. Benatar

MBCbB, DSc (Med), FRCP
Professor Emeritus of
Medicine, University of Cape
Town; Professor, Dalla Lana
School of Public Health and
Joint Centre for Bioethics,
University of Toronto



Article: The Ethics of Integration (cont'd from page 17)

- 1 **Canadian Medical Association.** (2010). "Health Care Transition in Canada: Change that Works. Care that Lasts". Ottawa. http://www.cma.ca/multimedia/CMA/Content/Images/Inside_cma/Advocacy/HCT/HCT-2010report_en.pdf (accessed 18 April 2011): pg 3-4.
- 2 **Ibid.**
- 3 **Ibid pg iv.**
- 4 **Morgan, M., Zamora, N., Hindmarsh, M.** (2007). "An inconvenient truth: a sustainable healthcare system requires chronic disease prevention and management transformation", *Healthcare Papers*, 7(4): pg 7.
- 5 **Kenny, N.** (2004). "What's fair? Ethical decision-making in an aging society". Canadian Policy Research Networks Research Report. http://www.cprn.org/documents/29378_en.pdf (accessed 26 March 2011): pg 5.
- 6 **Canadian Medical Association.** (2010). "Health Care Transition in Canada: Change that Works. Care that Lasts". Ottawa. http://www.cma.ca/multimedia/CMA/Content/Images/Inside_cma/Advocacy/HCT/HCT-2010report_en.pdf (accessed 18 April 2011): pg 14.
- 7 **Kenny, N.** (2004). "What's fair? Ethical decision-making in an aging society". Canadian Policy Research Networks Research Report. http://www.cprn.org/documents/29378_en.pdf (accessed 26 March 2011): pg 5.
- 8 **Department of Justice Canada.** (1985). Canada Health Act, Ottawa. <http://laws-lois.justice.gc.ca/PDF/C-6.pdf> (accessed 12 May 2011).
- 9 **Canadian Medical Association.** (2010). "Health Care Transition in Canada: Change that Works. Care that Lasts". Ottawa. http://www.cma.ca/multimedia/CMA/Content/Images/Inside_cma/Advocacy/HCT/HCT-2010report_en.pdf (accessed 18 April 2011): pg 27.
- 10 **Kenny, N.** (2004). "What's fair? Ethical decision-making in an aging society". Canadian Policy Research Networks Research Report. http://www.cprn.org/documents/29378_en.pdf (accessed 26 March 2011): pg 5.

Calls for Submission

• *Call for Abstracts* •

11th Conference of the International Association of Bioethics: THINKING AHEAD, Bioethics and the Future, and the Future of Bioethics June 26-29, 2012; Rotterdam, The Netherlands

THINKING AHEAD: the conference will focus on issues that will be highly relevant for the future, looking at societal and global problems, new technologies and ethical approaches to such themes. This also implies thinking about the future of Bioethics itself.

We kindly invite contributions on the following themes:

Bioethics for the future

- Ageing and longevity
- Responsibility for future generations
- Enhancement
- Telemedicine
- Animal ethics
- Global justice
- Environmental ethics
- Robotics and ethics
- Synthetic biology
- The end of life in the future
- Public health ethics
- Clinical ethics
- Biobanks
- Nursing ethics
- New emerging diseases
- Neuro-ethics
- Food ethics
- ICT and ethics
- Ethics and research
- Multicultural identity and ethics
- Reproductive technologies in the future

Bioethics of the future

- Teaching of bioethics
- The role of ethicists in health care
- New methods and approaches in a multidisciplinary context
- Principles for the future
- Ethics and policymaking

Submission Deadline: November 30, 2011

<http://bioethicsrotterdam.com/submit-an-abstract-3>

• *Call for Abstracts* •

12th Asian Bioethics Conference Sept 28-Oct 1, 2011; Taipei, Taiwan

By attending this Conference with unique program features on Bioethics and Cultural Engagement: Asia and Beyond, you'll be able to examine, from the perspectives of Asian multi-culture and value tradition, the convergence, confrontation, cross-supplementation and development of bioethics in various culture regions; especially the issues encountered during socio-economic development and/or medicine practices in Asia.

Conference Scope:

1. Aging and long-term care
2. Animal and human relationships
3. Artificial and designer life
4. Assisted reproductive technology
5. Climate change and Environmental ethics
6. Concept of health and disease
7. Enhancement
8. Ethics and Education
9. Health care system and management
10. Intellectual property right
11. Law, Policy and Ethics
12. Medical tourism and commercialization

Calls for Submission

13. microRNA and genetic screening
14. Neuroethics
15. Nanoethics
16. Organ transplantation
17. Privacy and Information
18. Research Integrity
19. Science, Technology and Society
20. Vulnerable populations

Submission deadline: July 23, 2011

For abstract submission instruction, go to:

<http://blc.web.nthu.edu.tw/ezfiles/184/1184/img/807/ABC12AbstractSubmissionForm.doc>

<http://www.blc.nthu.edu.tw/abc12>

• **Call for Abstracts** •

26th European Conference On Philosophy Of Medicine And Health Care

"Worst case bioethics"

15 – 18 August, 2012; Nazareth, Israel

This conference will be organised by the European Society for Philosophy of Medicine and Healthcare (ESPMH) and the Max Stern Yezreel Valley College, Nazareth, Israel. Abstracts addressing the following topics will be favoured, although work on other topics can also be submitted:

- Ethical issues in providing healthcare during war, pandemics and disasters
- Risk assessment in public health
- Dealing with fatal conditions
- Bioethics and international justice
- Bioethics and intergenerational justice

The programme of the conference includes plenary sessions as well as parallel sessions. Anyone wishing to present a paper at the conference should submit an abstract (500 words maximum) **before March 1, 2012**. The Conference Programme Committee will select abstracts for oral presentation.

Please send abstracts by e-mail to: Professor Bert Gordijn, Secretary of the ESPMH, Institute of Ethics, Dublin City University, Dublin 9, Ireland
E-mail: bert.gordijn@dcu.ie

<http://www.springer.com/journal/11019>

• **Call for Applications** •

**Age+ Prize 2011-12
CIHR-Institute of Aging**

The CIHR-Institute of Aging Age+ Prize recognizes excellence in research on aging carried out by emerging Canadian scholars. Up to 15 awards are offered annually to meritorious authors of published, scientific articles on aging. The Age+ Prize is aimed at graduate students, postdoctoral fellows and residents from all disciplines, working in the field of aging. Articles may cover any of the Institute's priority research topics (<http://www.cihr-irsc.gc.ca/e/26935.html>).

Applications Deadline: October 1st, 2011

For details, go to: <http://www.cihr.gc.ca/e/26987.html>

Seminars, Events & Conferences

June 15-16, 2011

Art Exhibition "The 7, 024th Patient"

This is an open and free event. The details can be found at: <http://www.ryerson.ca/nursing/pdf/The7024thPatient.ExhibitionEvite.FINALMarch23.pdf>

It is a unique dissemination method based on research that explored patients' experiences of open-heart surgery and recovery. This exhibition embodies their lived experiences in an intimate landscape of poetry and photographic images. The research and creative team is composed of individuals from Ryerson University and Toronto General Hospital including Dr. Jennifer Lapum, Dr. Terrence Yau, Dr. Kathryn Church, Dr. Alison Matthews David and Perin Ruttonsha.

Location of exhibition: DeGasperis Conservatory at Toronto General Hospital, 585 University Avenue, 4th floor, west elevators.

Date of exhibition: It is opened on Wednesday June 15, 2011 from 8:00am to 9:00pm with a reception, lecture and reading at 3:30pm. It is also opened Thursday June 16 from 8:00am to 7:00pm. Come and see it anytime and stay as long as you like.

This research dissemination project was supported by CIHR. All are welcome to attend. Please forward to those who you think might be interested.

For more information, please contact:
Dr. Jennifer Lapum Associate Professor, PhD, RN
jlapum@ryerson.ca Daphne Cockwell School of Nursing
Faculty of Community Services Ryerson University
Toronto, Ontario 416-979-5000, ext. 6316

June 16, 2011

Bioethics Grand Rounds "Social Media in Action: An Offline 'Chat' of the Ethical and Legal Issues with the Creators and Users"

Professional Panel Presentation

12:00 Noon to 1:00 p.m.

Room 1250, Burton Wing, The Hospital for Sick Children

July 5-6, 2011

Clinical Ethics Summer Institute 2011

"Ethics: More than window dressing..."

Trillium Health Centre, Mississauga ON

During the 2-day Institute, you can expect to:

- Engage with expert faculty and colleagues in an interactive learning environment
- Improve ethical decision-making knowledge and skills
- Acquire concrete strategies and practical tools for developing ethics programs
- Discover "Made in Canada" clinical ethics innovations and international perspectives
- Become better prepared to meet and exceed ethics accreditation standards

Guest Faculty Include:

- [Dr. George Webster](#)
- [Dr. Michele Chaban](#)
- [Dr. Jennifer Gibson](#)

For more details and registration, go to:
<http://clinicaethics.ca/>

Seminars, Events & Conferences

July 14-16, 2011

The Center for Bioethics & Human Dignity 18th Annual Summer Conference "The Scandal of Bioethics: Reclaiming Christian Influence in Technology, Science, & Medicine"

Trinity International University, Deerfield, IL

Who Should Attend?

Physicians, physician assistants, nurses, lawyers, scientists, philosophers, theologians, public policymakers, educators, media professionals, chaplains, clergy, students and anyone interested in the opportunities and challenges of bioethics.

Featuring:

Plenary Speakers

Themed Workshops

Paper and Poster Presentations

Meet the Author Booksigning

Screening of Eggsplotation, featuring a Q & A session with Executive Producer Jennifer Lahl, RN, MA

Networking

For details, go to:

<http://cbhd.org/events/the-scandal-of-bioethics>

To register, go to:

<http://www.regonline.com/builder/site/Default.aspx?EventID=934266>

July 22-23, 2011

Seventh Annual Pediatric Bioethics Conference

"Who's Responsible for the Children? Exploring the Boundaries of Clinical Ethics and Public Policy"

Bell Harbor Int'l Conference Center, Seattle

Discussion Topics

- ◇ Under what circumstances should individual providers or healthcare institutions extend medical care to children whose families cannot pay?
- ◇ Do providers' responsibilities extend beyond the walls of the clinic? How do we balance obligations to provide better healthcare with obligations to improve other factors that influence health, such as diet, exercise, housing and education?
- ◇ Do providers have an obligation to tell families about healthcare options that are not "available" or will not be provided because of financial constraints?
- ◇ Should care to children be prioritized based on social, physical or mental health status?
- ◇ How will healthcare reform affect the goal of providing for the basic healthcare needs of all children?

For details and registration, go to:

<http://seattlechildrens.org/research/initiatives/bioethics/events/pediatric-bioethics-conference/>

October 4-5, 2011

The 2011 Research Data Centre Conference

"Canada Coming of Age: The Policy Impact of an Aging Population"

Sutton Place Hotel, Edmonton

The 2011 RDC conference on "Coming of Age: The Policy Impact of an Aging Population" will engage researchers, policymakers and practitioners from across Canada in a critical examination of the many social and economic issues arising from population aging.

The goal of the 2011 RDC Conference is to bring together researchers, policymakers and practitio-

Seminars, Events & Conferences

ners from diverse disciplinary backgrounds who are engaged in issues related to an aging population in Canada to:

- Share research findings relevant to policy and practice on aging;
- Build an agenda for future research that will inform decisions and practice on issues of aging;
- Identify data requirements for future research on aging in Canada;
- Stimulate discussion among researchers, policy makers and practitioners on the significant issues arising from an aging Canadian society; and
- Develop a network of contacts who are producing and utilizing research evidence in addressing significant issues in aging.

Early Bird Registration Deadline: July 31, 2011

<http://rdc-cdr.ca/conference/>

October 11-15, 2011

The 12th International Congress of Human Genetics and the 61st Annual Meeting of The American Society of Human Genetics

Montreal, Quebec

Colleagues from around the world are invited to attend the Congress. Registration is required for admittance to all scientific sessions, exhibits, posters, and other meeting events.

Early Registration Deadline: August 30, 2011

<http://www.ichg2011.org/>

October 2011-May 2012

Intensive Courses in Bioethics

Erasmus Mundus Master of Bioethics
Leuven University, Leuven, Belgium

The intensive courses are part of the Erasmus Mundus Master of Bioethics programme organised by a consortium of three European universities, namely the Katholieke Universiteit Leuven (Belgium), Radboud Universiteit Nijmegen (The Netherlands) and the Università degli Studi di Padova (Italy). Because of this combination, participants of the intensive courses will join Master students from all over the world.

Leuven

- Publishing in Bioethics: 3 - 6 October 2011
- Ethics of Reproductive Technologies: 16 - 18 November 2011
- Nursing Ethics: 7 - 9 December 2011

Nijmegen

- End-of-life decisions: February 2012
- Human Genetics and Medical Technology: March 2012

Padova

- Clinical Bioethics: 16 - 20 April 2012
- Research Ethics: 14 - 18 May 2012

For details, go to:

http://med.kuleuven.be/Faculteit_Geneeskunde/english/borders/erasmus-mundus-bioethics/intensive-courses

Comments on articles in this Newsletter? Email your response to newseditor.jcb@utoronto.ca. We may publish your comments in the next issue.

Recent Publications

Bruni R, Wright L. Sharing organs with foreign nationals. *Progress in Transplantation*. 2011; 21 (1): 78-82.

Cronin A, Ross K, Wright L. Directed and conditional donation: Reflections on principles and practice. In: Wimar W, Bos MA, Busschbach JJ, eds. *Organ Transplantation: Ethical, Legal and Psychosocial Aspects – Expanding the European Platform*. Pabst Science Publishers, Lengerich, Germany. 2011.

Daar AS. Chronic Non-communicable Diseases as a Threat for All: Recent Global Initiatives. *Sultan Qaboos University Medical Journal*. 2010; 10(3): 306-9.

Gershon A, Croxford R, To T, Stanbrook MB, Upshur R, Sanchez-Romeu P, Stukel T. Comparison of Inhaled Long-Acting β -Agonist and Anticholinergic Effectiveness in Older Patients With Chronic Obstructive Pulmonary Disease: A Cohort Study. *Annals of Internal Medicine*. 2011; 154(9): 583-592.

Gibson BE, Stasiulis E, Gutfreund S, McDonald M, Dade L. Assessment of Children's Capacity to Consent for Research: A Descriptive Qualitative Study of Researchers' Practices, *Journal of Medical Ethics*. JME Online First, June 2, 2011.

Henry B, Lin YJ, Callum J. 'Tweaking' potential research participants to meet clinical trial eligibility criteria: ethical concerns and scientific implications. *Clinical Investigations*. Feb 2011; 1(2): 181-185.

Henry B, Librach L, Cellarius V, et al. "To Sleep Until Death" Letter to the editors based on Jeffery Berger's article "Rethinking Guidelines for the use of palliative sedation" *Hasting Centre Report*. Jan-Feb 2011; 41(1): 4-5.

Masum H, Batavia H, Bhogal N, Le K, Singer PA.

Franchising rabies vaccine delivery: The case of Indian immunologicals. *PLoS Neglected Tropical Diseases*. 2011; 5(4): e946.

Mogyoros A, Smith M, Silva DS, Purdy S. Reflections on the current status of bioethics education. *Journal of Healthcare, Science, and the Humanities*. 2011; 1(1): 143-149.

Reichman T, Fox A, Adcock L, Wright L, Abbey S, Levy G, Grant D. Anonymous Living Liver Donation: Donor Profiles and Outcomes. *American Journal of Transplantation*: 2010; 10: 2099-2104.

Russell B. 'My Place': ethical differences between shelter, housing, and home. *CrossCurrents Winter* 2010/11; 14(2): 5.

Russell B, de Vlaming D. Priority Setting Up Close. *Journal of Clinical Ethics*. 2011; 22(1): 61-70.

Silva DS, Goering PN, Jacobson N, Streiner DL. Off the Beaten Path: Conducting Ethical Pragmatic Trials with Marginalized Populations. *IRB: Ethics and Human Research*. 2011; 33(3): 6-11.

Singer PA, Ansett S, Sagoe-Moses I. What could infant and young child nutrition learn from sweatshops? *BioMedCentral Public Health*. 2011; 11: 276.

Wright, L, Silva DS. Organ Donation and Transplantation: The Canadian experience. In: Farrell AM, Price D, Quigley M, eds. *Organ Shortage: Ethics Law and Pragmatism*. Cambridge University Press, Cambridge, England. 2011.

Wright, L. Living donors: The current Canadian situation. In: Caillé Y, Doucin M, eds. *Don et transplantation d'organes au Canada, aux États Unis et en France*. L'Harmattan. Paris. 2011: 215-221.

The JCB Voice



Submission & Contact Information



The purpose of this newsletter is to facilitate communication among people interested in bioethics throughout the Joint Centre for Bioethics, participating institutions and elsewhere. The newsletter is published and distributed by email at the beginning of each month. If you would like to receive the newsletter, please contact:

Editor: Na Young Lee
Email: newseditor.jcb@utoronto.ca
Fax: (416) 978-1911



Submissions to the newsletter must be made by the 20th of the preceding month.

Previous issues of the newsletter are posted on our website at:
<http://www.jointcentreforbioethics.ca/newsletter/newsletter.shtml>

The University of Toronto Joint Centre for Bioethics

The Joint Centre for Bioethics (JCB) is a partnership among the University of Toronto; Baycrest Centre for Geriatric Care; Centre for Addiction and Mental Health; Centre for Clinical Ethics, a joint venture of Providence Centre, St. Joseph's Health Centre, and St. Michael's Hospital; Holland Bloorview Kids Rehabilitation Hospital; The Hospital for Sick Children; Humber River Regional Hospital; Mount Sinai Hospital; North York General Hospital; Sunnybrook Health Sciences Centre; Toronto Community Care Access Centre; Toronto Rehabilitation Institute; Trillium Health Centre; and University Health Network.

Joint Centre for Bioethics
University of Toronto
155 College Street, Suite 754
Toronto, Ontario M5T 1P8
Canada

Phone: (416) 978-2709
Fax: (416) 978-1911
Email: newseditor.jcb@utoronto.ca
Web: <http://www.jointcentreforbioethics.ca/>