

New and Notable

- **deVeber Institute Advisor Barbara Farlow** was featured in the March 2009 Canadian Medical Association Journal article: Prenatal DNA Test Raises Both Hopes and Worries.
- A new review on **Prenatal Diagnosis** from the deVeber Institute is now downloadable from deveber.org. This review has also been sent to physicians across Canada.
- **Video trailers** for our two most recent DVDs can now be viewed at deveber.org/category/tags/video
- The **Palliative Care section of deveber.org** has expanded, and also includes commentary on the recent proposal of the Quebec College of Physicians to introduce euthanasia.
- A special thanks to **Tisha Kruk**, who completed her high school co-op term with deVeber this spring, for her help in the office and her work to create a youth section for deveber.org.

Distinguished Donors

Every single one of our donors plays a part in helping us to do our work. A special thanks to some donors who have recently distinguished themselves:

Marian McDougall	Jackman Foundation
Walkerton Right to Life	F.K. Morrow Foundation
ShareLife	Vancouver Right to Life
Timothy Egan	David Mikulis
Paul Ranalli	Don K. Dunbar Smyth
June Smith	Ian Gentles



Why I support the Institute

"I'm glad that our foundation is able to support [your work], and we must do everything we can to encourage life in all its forms."

Rev. Edward Jackman, The Jackman Foundation, on the occasion of the 2008 deVeber Institute Annual Public Lecture



The deVeber Institute thanks Elaine Zettel for all work with the Institute and wishes her well in her Midwifery program.

The deVeber Institute is sorry to say good-bye to **Elaine Zettel** as Executive Director. Elaine served as Executive Director for two years, and is starting a four year program to train as a midwife. Happily, Elaine will continue to be involved with the Institute. The Board and Advisory Council extend a warm welcome to the new Executive Director, **Kathy Matusiak**, and Associate **Elaine Drake**.



We welcome Kathy Matusiak (left), new Executive Director, and Elaine Drake (right), Associate.



The deVeber Institute for Bioethics and Social Research

305 Jane Street
Toronto, Ontario M6S 3Z3
Tel: 416-256-0555
Fax: 416-256-0611
Email: bioethics@deveber.org
Web: www.deveber.org

Co-Presidents

L.L. Barrie deVeber, MD, FRCP(C)
Martha Crean, BA, TESL

Vice President

Ian Gentles, PhD, FRHS
Research Director

Board of Directors

Keith Cassidy, PhD
Patricia Dolente Matijczyk, BA, MEd
Deborah Zeni, MD, CCFP

Advisory Council

Bridget Campion, PhD
Michael De Robertis, PhD

D. Jean Echlin, RN, MScN
Patricia Armstrong Egan, LLB, BCL
Barbara Farlow, BEngSci, MBA
Tom Lynch, BA, MDiv, STL, STD(Cand)
David Mikulis, MD
Heather S. Morris, FRCOG, FRCS(C), LLD (HON)
Robert Nadeau, LLB
David Novak, MHL, PhD
Nancy Olivieri, MD, FRCP(C)
Paul Ranalli, MD, FRCP(C)
Lorraine Williams, MSW
Paul Zeni, MD



Perspectives

The deVeber Institute for Bioethics and Social Research

Fall 2009

Research and Scholarship for an Informed Social Response to Human Life Questions

Door Closed on Pregnant and Parenting Students

Report reveals challenge of having both a child and university education

Western University student and summer researcher with the deVeber Institute, Genevieve Bonomi was surprised with the results she uncovered this past summer.

As an intern, Ms Bonomi undertook research on what services are available for pregnant and parenting students on 86 university campuses across Canada. The underlying motivation for the research was to assess how easy or difficult it was for pregnant students to stay in school, which in turn might affect the decision to abort. With few exceptions, most universities did not make it very easy to have a child and attain an education at the same time.

The study assumed that certain practical services and facilities contribute to a student's ability to parent. These include: day-care facilities, child co-ops, babysitter referral services, presence of baby change tables, pregnancy counselling, clothing and food banks, stroller access to buildings and flexible class times.

The results showed that Canadian universities lack the resources needed to properly address the changing needs of their students. Currently, numbers indicate that there are more women than men in university, and these women are at critical age when fertility is high and the possibility of pregnancy is increased.

"Students should not have to choose between attaining a university education and having a child. Canadian universities need to send the message that one's education is not over with pregnancy, and that women can indeed succeed in university with a child," says Ms Bonomi.

While results indicate a lack of resources on many campuses, a few shining examples demonstrated what is possible when university administrations and students work together to provide support to parenting students. The University of Toronto ranked far above the other universities in providing support. In addition to the above services and facilities, U of T goes further and provides private areas for breastfeeding, and allows for academic leave.

Another university that came up above the rest was Athabasca University, whose model could be equally appealing to a parenting student, as it offers a wide variety of distance education courses at both the undergraduate and graduate levels.

"Universities need to send the message that one's education is not over with pregnancy"

Genevieve Bonomi, Research Intern with The deVeber Institute this past summer



See the ten minute YouTube interview with Ms Bonomi at www.deveber.org/video/parentingstudents

Helping Those Living on the Edge of the Land of the Living

Palliative care allows dying patients to “live the best that they can while they are dying”,¹ according to Dr. Paul Zeni, a physician and palliative care specialist in Georgetown, Ontario. He notes that another often un-stated goal of palliative care is to allow patients to “feel whole, even if they do not feel well.”²

A thoughtful and compassionate approach to the end of life brings special challenges for the doctors and other care workers involved in providing palliative care. The physician endeavours to place as much emphasis on care as they do on cure. Palliative care must be interested in the patient’s well being physically, but also emotionally, psychologically, and spiritually.

“One’s final days are immensely valuable”

Ironically, patients requesting euthanasia illustrate the necessity of a multi-dimensional approach to end of life. A study done by the U.K. Royal College of Psychiatrists cited depression as a major contributor to terminally-ill patients’ requests for euthanasia. When a patient’s depression is treated effectively, 98-99 percent will change their opinion on their desire to die.³

Dr. Zeni notes that the treating of the patient’s physical and medical needs is often the least of the patient’s needs. Patients are suffering from tremendous loss, grief, and isolation. In the weeks leading to the patient’s end of life, the patient is experiencing a sense of “living on the edge of the land of the living, and that can be a very lonely place to be.”⁴

Palliative care requires that all parties concerned with a dying patient give a large portion of their time generously. If the patient is surrounded by loved ones, and cared for, the patient does not feel as burdensome and is given a more enjoyable passing.

One’s final days are immensely valuable, and should be respected as such. Viewing this generosity of time as an investment in the individual characterizes a value for life which all families can enjoy.

1. Note: Spoken by Dr. Paul Zeni during a palliative care description presentation in *Compassionate End of Life Care for Adults with Developmental Disabilities*, DVD. The deVeber Institute for Bioethics and Social Research, and L’Arche Toronto. (Toronto, 2009).

2. Ibid.

3. The United Kingdom’s Royal College of Psychiatrists. The document, entitled *Statement from the Royal College of Psychiatrists on Physician-Assisted Suicide (2006)*, can be viewed in full at: <http://www.rcpsych.ac.uk/pressparliament/collegeresponses/physicianassistedsuicide.aspx>

4. Morgan, *Compassionate End of Life Care for Adults with Developmental Disabilities*, DVD produced by The deVeber Institute for Bioethics and Social Research.

Aaron Mix-Ross comments on the experience of his research:

My study of palliative care has affected me on a personal level... With the few terminal patients I have encountered, I have struggled to learn what I should talk about, or what I should do... (But now, with a friend who is dying) I have become more comfortable and able to communicate with my friend than I thought I ever could be.

To see the entire article written by summer intern Aaron Mix-Ross, go to www.deveber.org/palliativecare/briefoverview. We are grateful to individual donors and Canada’s Summer Jobs program, which supported student research over the summer.

Depression is a major contributor to patients’ request for euthanasia. When a patient’s depression is treated effectively, 98-99% will change their opinion on their desire to die.



Robust Summer

Student Interns Move Important Research Ahead

We are grateful that continuing support from you, our donors, and a grant from the Canada Summer Jobs Program, enabled a flourishing summer research program here at deVeber. The importance of such research is illustrated by both articles in this newsletter, which resulted from summer research. Watch for ongoing developments in these and other areas thanks to the efforts of all our summer interns.



Summer Interns in above photo (left to right): Genevieve Bonomi, Duc Mai, Aaron Mix-Ross, Daniel Gibson, Marian DeCouto

Summer Intern work included:

- Identifying peer review biases, which affect how and if research is reported. This can affect what abortion data is reported.* (Daniel Gibson)
- Reviewing individual abortion studies in detail, as significant findings might be downplayed. For example, in one study the reported summary minimized the ovarian cancer risk following abortion. However the actual data from this same study showed a 30% risk of ovarian cancer due to abortion.^{5*} (Petra Gombos)
- Uncovering international data on the side effects of abortion. This can be particularly challenging as reporting is often not required in different countries. (Duc Mai)
- Examination of assumptions which influence opinion on bioethical issues. For example, though it is widely assumed that elective abortion is a medical necessity in the case of a severely disabled fetus, our research has shown this is not the case. (Raphael Ma) (For previous research on this subject, see Perspectives Spring 2009,

“Prenatal Tests – Hope or Distress? More Information and Care Needed for Parents and Children After Genetic Diagnosis” or www.deveber.org under Research & Publications, Newsletters

- Pregnant and parenting students are challenged to find adequate resources at university to make it possible to have both a child and an education, which may contribute to the decision to abort in this context. See story on front page. (Genevieve Bonomi)
- The importance of narratives in medical research and feminist research, especially as it pertains to Multi Fetal Pregnancy Reduction (MFPR). (Emma Coates and Marian DeCouto)
- A white paper on palliative care, and a summary of deVeber Palliative Care Community Talks (www.deveber.org/palliativecare/briefoverview (Aaron-Mix Ross)

* (For a much more in-depth discussion of this phenomenon in research, attend our Annual Lecture, Conflicts of Interest in Research; Examining Pressures in Research to Produce Specific Results. Advertisement this page.)

5. Gierach GL, Modugno F, and Ness R. Relations of Gestational Length and Timing and Type of Incomplete Pregnancy to Ovarian Cancer Risk. *American Journal of Epidemiology*, 2005; 458, Table 4.

The deVeber Institute for Bioethics and Social Research presents

Conflicts of Interest in Research Examining Pressures in Research to Produce Specific Results

**Wed. Nov. 11, 2009
(Remembrance Day)**

7:00 p.m.

**Charbonnel Lounge, University of Toronto,
St. Michael's College**

**Seating is limited. Contact us to reserve
your seat today. For more information,
call 416-256-0555 or email bioethics@deveber.org**

Dr. Nancy Olivieri is admired for her public struggle to protect her drug trial patients against a large pharmaceutical company, despite losing the support of her university.

She is considered a defender of research integrity, academic freedom, and informed consent. Elizabeth Ring-Cassidy is a senior researcher at deVeber, and will join her in exploring how pressure and even coercion can affect how research is conducted, reported and published.

Dr. Nancy F. Olivieri, MD FRCP(C)

Professor, Pediatrics, Medicine and Public Health Sciences, Senior Scientist, University Health Network, University of Toronto, Canada.

Elizabeth Ring Cassidy, MA

Psychologist and deVeber Institute researcher on abortion's risk to women.