

The deVeber Institute for Bioethics and Social Research

Spring 2011

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

DeVeber Appears before Parliamentary Committee for Palliative and Compassionate Care



Jean Echlin, RN., M.S.N., is a pioneer in hospice palliative care, past director of nursing at Windsor Regional Hospital, and 2004 recipient of the Dorothy Ley Award of Excellence for Palliative Care. She presently teaches a seminar on Palliative Care at the University of Windsor and is a member of the Advisory Council of The deVeber Institute.

In April 2010, a new Federal Parliamentary group was formed. Thanks to the vision of some members of Parliament who voted against the Euthanasia Bill C-384, a non-partisan, multi-party group called the Parliamentary Committee on Palliative and Compassionate Care (PCPCC) began deliberations.

On Oct. 19, 2010, Jean Echlin and Dr. L.L. (Barrie) deVeber, presented to the Parliamentary Committee's hearing, in the West Block of the federal Parliament Buildings. The deVeber Institute's submission "Proposal for Integrated Palliative Care" points out the need for earlier patient referrals to palliative care specialists and for the expanded education of all health care providers in palliative medical practices.

"Personally, I am in awe of the enormity of the work this parliamentary committee has undertaken." Ms. Echlin was asked to co-author the summary report by the Parliamentary Committee on Palliative and Compassionate Care (PCPCC).

The committee focused on four interrelated but distinct challenges:

- promotion of palliative care for all Canadians facing endof-life issues such as pain and symptom management;
- mental health crisis and suicide prevention;
- elder abuse, including lack of compassionate care;
- and issues encountered by persons with disabilities.

"Many programs involved with hospice palliative care and pain management exist in Canada," commented Jean Echlin to the Windsor Star (Nov 13th, 2010) but are not evenly available across Canada.

"The utilization and effectiveness of these programs make it abundantly clear that there is no need for Canadians to spend much of their lives immobilized by chronic pain or to die in pain, loneliness, anxiety and bereft of dignity. We must keep pushing for appropriate, knowledgeable and compassionate care regardless of a person's diagnosis, (physical or mental illness), age, gender, culture or religious persuasion" Echlin concluded.

Speaking to the committee, Jean Echlin said, "All of the work that I have seen supports the position of the deVeber Institute, for the need of earlier integration. Their recommendations are profound. Medical professional colleges need to train proper palliative care. At the centre of this report, is the need to make good palliative care available to all Canadians."

"We were listened to with great interest" commented Ms Echlin. "A heartfelt thanks to the special donors who supported this important effort. What an honour and amazing life-experience to present The Institute's paper to the Parliamentary Committee on Palliative and Compassionate Care".

We would like to thank Aaron Mix-Ross for his extensive work on this submission during his summer internships with the de Veber Institute.



From the deVeber Submission to the Parliamentary Committee for Integrated Palliative Care

- "Palliative care as currently practised in Canada has not yet achieved all the benchmarks set by the World Health Organization... research indicates that palliative care introduced earlier into a patient treatment plan, even while curative treatments are ongoing, can be highly beneficial to patient recovery and/or long lasting remission from illness."
- "It cannot be overstated that palliative care is more than the provision of analgesics... psycho-social support as well as pain and symptom management must be provided throughout the treatment stages."
- "These advancements can only be achieved through increased funding to Canadian palliative care programs."

(This 6-page submission is available online at www.deveber.org or call 416-256-0555)

Push for Palliative Care, Prevent Euthanasia

deVeber Hosts Public Lecture on Palliative Care

This past September the deVeber Institute invited three experts to speak at a public lecture and dinner held at Huron House in London, Ontario. **Dr. Barrie deVeber**, co-president of the deVeber Institute, was a pioneer in paediatric palliative care, particularly for children suffering from cancer. "My experience of 30 years running the cancer unit at Children's [Hospital], was starting with a cure rate of 5% in the 1960s, and 85% when I left. I took a great interest in families.

I only had two requests for euthanasia in all those years in oncology. One was a 14 year old girl with 4th stage cancer and only a 10% chance of a cure. After chemo she was so sick her parents asked me to put her to sleep, I said no. The next day she asked me, "Did my parents ask you to put me to sleep? Don't listen to them! I want to live." She lived, she's now married with three kids."

Jean Echlin is a renowned palliative care nurse. "Palliative care addresses the concept of total pain: physical, mental, emotional, spiritual, and social pain." Ms Echlin emphasizes, "But we need it for all Canadians, not just cancer patients. The cornerstone in palliative care excellence is control of physical pain. Control physical pain and then we can work on other pain."

"Lack of appropriate pain management is medical and I would add, nursing malpractice. We have no right not to manage pain."

Alex Schadenberg, executive director of the Euthanasia Prevention Coalition, spoke of his experience with educating Members of Parliament on euthanasia and assisted suicide. Mr. Schadenberg emphasized the importance of building relationships and a group focused on the real issues.

Schadenberg's work was central to the defeat of Bill C-384 to legalize euthanasia in Canada, by a vote of 228 to 59 in April 2010.

"I'm so grateful to the deVeber Institute for hosting this lecture on palliative care", commented one attendee. "This has helped me to become much more informed on this critical debate and better equipped to discuss the issue in general."

And we are especially grateful for the vision and skill of this event's organizer Nathan Welch. Congratulations!

Available now! Audio CD recording of this event is available for \$15.00 Copies can be ordered by calling 416-256-0555.

"Every mother... should be cherished in every possible way"

This past November the deVeber Institute was privileged to have the founder and director of MaterCare International, Dr. Robert Walley of Newfoundland, as guest speaker at its Annual General Meeting held at the University of Toronto.



Dr. Robert Walley greets a patient in Kenya.

MaterCare International headed by Dr Robert Walley, is an organization of medical professionals "dedicated to promoting the dignity of mothers and their babies."

In Kenya, MaterCare has trained traditional birth attendants; in Haiti they brought in obstetrical and paediatric care within days of the January 2010 earthquake. MaterCare is a volunteer Catholic team of doctors and nurses, who volunteer their time and expertise to help mothers living in extreme poverty in developing countries to deliver their babies safely and to reduce maternal and infant mortality rates.

As an obstetrician, Dr Walley spoke on the dignity of mothers and on the dignity of the obstetrician. He recounted the time during which abortion was becoming legalized as a period of much confusion for medical professionals. For many obstetricians, they felt they were being forced to choose between their conscience and their profession, leading to the degradation of the profession.

"As obstetricians" said Walley, "we have the most privileged of all specialties when we're there to help the co-creators of human life when things go wrong." However, when the very professionals who have been trained to help bring life into the world have become the destroyers of life, they destroy the dignity of that profession as well. A renewed understanding of the dignity of obstetricians needs to take place, according to Walley.

"As a new mother", commented one AGM attendee, "I was particularly touched by Dr Walley's moving words; all mothers deserve to be treated with dignity."

Also speaking at the AGM was summer intern Genevieve Bonomi and deVeber's Director of Research Ian Gentles.

Ms Bonomi presented a report on a nation-wide study she conducted while an intern with the Institute to find out what support services are available to pregnant and parenting students on post-secondary campuses. Of the 86 institutions surveyed the majority had very limited resources or support services for students on their campus. "The resources seemed unavailable so to women it would seem like their choice was already made for them" reported Bonomi.

Commenting on the fact that more women than ever are attending post-secondary schools Ms Bonomi said, "You need to start registering the changes in the institutions and make it more family friendly and more women friendly."

lan Gentles, professor at York University and Tyndale College gave a report examining the effects of legalized abortion on maternal mortality rates internationally. Although international



Genevieve Bonomi

agencies such as the United Nations continue to purport that abortion on demand is absolutely necessary for improving maternal health, Gentles' research has revealed that the opposite is in fact the case.

Comparing countries that have ceased abortion to those that have lax abortion laws, Gentles uncovered some startling findings. "The countries that have banned abortion in the last 20 years have experienced much greater improvements in maternal and infant health than countries which allow abortion on demand."

Chile, El Salvador and Poland are three such countries that have seen maternal and infant mortality rates drop significantly.

For more information on MaterCare please visit www.matercare.org
For a DVD of Dr Walley's complete lecture please contact the
deVeber Institute.

To read the complete reports by Ms Bonomi and Prof Gentles, please visit the deVeber Institute website www.deveber.org

There's no shortage of work: Summer Interns come on board for research and development

This past summer 2010, the deVeber Institute was successful in securing funding from the Canadian government's Canada Summer Jobs program.

We had young women and men, enrolled in universities across Ontario, assist us in conducting and disseminating research developed with our team. Topics included: women's testimonies after abortion; resources available to pregnant and parenting students across Canada; elder abuse; genetic testing and maternal mortality.

One journalism student assisted filmmaker, Keith Neely in the development of the script for an upcoming documentary film.

Additionally, translations of our materials into French were completed and will be made available both online and in upcoming prints of our brochures and pamphlets.



Dr. Barrie deVeber and Patricia Dolente Matijczyk

deVeber events such as our Summer Fundraiser on Sept 10th, 2010 held at the lovely home of Mr. Luigi Dolente, father of deVeber Board member Patricia Dolente Matijczyk, was the first of its kind. Catered by deVeber interns, this candle-lit evening featured a local live jazz quartet, appetizers and wine.

Special thanks to you our supporters – you enable us to continue our work, to host these events, to direct interns and provide research that matters, promotes good health care, and touches lives. Thank you!

DeVeber welcomes Co-op student

Kimberly Cooney, a grade 11 student at Father John Redmond C.S.S is interested in writing and has plans to become an author.



Kimberly Cooney

Kimberly started at de Veber Institute on February 15th 2011 and comments "It has been really fun. I have edited reports, written a blog and written reviews for the newsletter. I have had the opportunity to learn and write about issues that matter."

"The de Veber Institute is a great resource to me and my school. I have learned about medical and scientific challenges and how medical procedures affect lives around us. I am privileged

to read and learn of research and personal accounts from people who are willing to share their story so others can be helped. "

Pub Talk and Buffet



Palliative Care: Where are we Going? The Canadian Experience

2 renowned Physicians and Professors:

- Dr. José Pereira (University of Ottawa, Bruyère Continuing Care)
- Dr. Gary Rodin (Princess Margaret Hospital, Psychiatry Research)

Thursday April 28th, 2011
Fox and Fiddle Pub
280 Bloor Street West, Toronto
Doors open 5:00pm, complimentary buffet 5:30pm, lecture begins at 6:00pm. See flyer for details.

CIHR Funded. Call to RSVP 416-256-0555 or email bioethics@deveber.org before April 20th, 2011 **Seating is limited! RSVP today!**

The deVeber Institute for Bioethics and Social Research Founded in 1982

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