



## A New Service for a New Era: Perinatal Palliative Care

Each year, approximately 2-3 % of children born in Canada have a serious congenital abnormality. These abnormalities include a wide range of conditions, and many children who are born with an abnormality live fulfilled adult lives. However, some children with severe abnormalities, approximately 0.19 % of live births, only live a short life and may never leave the hospital or celebrate their first birthday.<sup>1</sup>

A new service, perinatal palliative care, is emerging as an essential lifeline for those children with life-threatening anomalies and for their families. Perinatal palliative care provides comfort and relief from pain and symptoms for newborn babies who are dying, and emotional support and healing for their families.



**“Few programs provide support from the moment of diagnosis; the majority become involved only after the parents decide to continue the pregnancy.”**

### Prenatal Testing and Abortion

Prenatal testing has drastically increased the number of diagnoses of congenital anomalies in children before birth. Parents of babies in utero with anomalies are asked to make decisions for aborting or carrying to term. These decisions are often made with very little information about their child's illness or disability, about the effects of abortion, or about the services available to support the baby once born.

As a result of increased prenatal testing, the vast majority of children with genetic anomalies, whether moderate or severe, are aborted before birth. While for many the termination of pregnancy is an attempt to eliminate the suffering, research finds that 40% of women who abort for fetal abnormality suffer long-term emotional distress. A leading authority writes that “Women 2-7 years after were expected to show a significantly lower degree of traumatic experience & grief than women 14 days after termination... Contrary to hypothesis, however, the results showed no significant intergroup differences.”<sup>2</sup>

Women who chose abortion continued to grieve years later.

### A hopeful alternative

For many parents whose child has received a prenatal diagnosis of a life-threatening congenital abnormality, the outlook may seem bleak. Parents are usually urged to make the decision to terminate quickly.<sup>3</sup> An alternative to abortion for children with severe genetic abnormalities is perinatal palliative care. Now available at 45 American and 7 Canadian sites, perinatal palliative care programs offer counseling and support to the terminally ill child and her or his family. These programs typically include a support team of obstetricians, neonatologists, nurses, chaplains and social workers. Together they provide a hopeful option that values and supports the life of both the parent and the child by providing counseling and information during the pregnancy, birth, and after the child is born, however brief that time may be. *continued on page 2*

1. “Congenital Abnormalities in Canada: A Perinatal Health Report (2002) Public Health Agency of Canada ([www.phac-aspc.gov.ca/publicat/cac-acc02/index.html](http://www.phac-aspc.gov.ca/publicat/cac-acc02/index.html))
2. Kersting, A. et al. (2005) “Trauma and grief 2-7 years after termination of pregnancy because of fetal abnormalities”. *Journal Psychosoc Obstet & Gynae.* V26:V26, #1 9-14.
3. Ring-Cassidy E, Gentles I. (2003) *Women's Health after Abortion; The Medical and Psychological Evidence.* 2nd Ed. The deVeber Institute for Bioethics and Social Research.



## Summer Students Make an Impact

Students delve into deVeber research to learn about the effects of abortion and the resources available for single mothers, and to develop new resources. Look for the results of their work on our new website.

### New pamphlets

Have you ever wished you had the deVeber research in a concise format that you could hand out at schools, doctor's offices, or to your friends? Flora Lafferthon is helping to make that a reality. Passionate about making scientific information more understandable to the general public, Flora Lafferthon joined the Institute as a summer student to help write pamphlets on topics covered *Women's Health After Abortion; The Medical and Psychological Evidence*. As a recent graduate of the University of Ottawa and current law student, she brings her interest in this topic to others through her writing.

### Updated research

Benjamin Turner has been giving his time to the deVeber Institute research team while studying medicine at the University of Western Ontario. Working with Dr. Barrie deVeber, Turner has begun by updating and revising the Institute's research on informed consent as it applies to abortion. Delving into current health law, Turner is helping to develop a more accurate picture of the ethical considerations raised in *Women's Health After Abortion; The Medical and Psychological Evidence*.

### Universities surveyed

What resources are available to Canadian university students who are pregnant or parenting? Devin Cassidy is surveying campuses from coast to coast this summer to answer that question. As an undergraduate student at St. Mary's University College in Calgary, Cassidy is compiling data about post-secondary educational institutions. He is investigating the housing, child care, counselling, and financial assistance that are offered to pregnant and parenting students. This is a follow-up to the Institute's book *Going It Alone; Unplanned Single Motherhood in Canada*.

### New Look Online

[www.deveber.org](http://www.deveber.org)

We are pleased to present our updated website. Check out [www.deveber.org](http://www.deveber.org) to see our new look online. On the website, you can:

- Browse current research projects
- Reference research on Abortion and Women's Health
- Learn about upcoming events
- Peruse deVeber publications
- Find out how you can contribute
- Donate online

## Perinatal Care continued from page 1

### Supporting parents during decision-making

The choice between abortion and giving birth to a disabled child after genetic diagnosis often depends on the type of counseling offered to parents. In one study, 80% of parents who received 'non-directive' counseling chose to abort, while 80% of parents who were provided with the option of perinatal palliative care chose to carry their child to term.<sup>4</sup> **Parents who are offered support in continuing pregnancy and caring for their disabled child overwhelmingly choose to carry to term.**

In Canadian teaching hospitals, all counseling is described as 'non-directive.' However, this term may be misleading because many families feel pressure to abort based on the presentation of information that is negatively cast about their child's limited future. Elizabeth Ring-Cassidy notes that "'Non-directive' is supposed to mean 'just the facts', but these facts can be daunting. And no delivery of information is neutral."

Elizabeth Ring-Cassidy of the deVeber Institute has begun to study this topic, and the Institute hopes to continue to gather data on prenatal and perinatal palliative care. Currently few programs provide support from the moment of diagnosis; the majority become involved only after the parents decide to continue the pregnancy. With the help of donors and supporters like you, we will provide medical, social service, and community support groups with better information to support parents during the prenatal decision-making period. This includes information about perinatal palliative care, a service offered to the most severely disabled infants. Given the support that they need, families will be able to make a more informed decision when presented with difficult news after genetic testing.

4. Calhoun, BC, Napolito, P et al. (2003) "Perinatal hospice: comprehensive care for the family of the fetus with a lethal condition." *JReprodMed*. V48: 343-348.

# A Divisive Order

## What has Dr. Morgentaler done for Canada?

The Order of Canada committee announced the appointment of Dr. Henry Morgentaler to the Order of Canada. This announcement evoked public protests and diverse comments in the media about the nature of the award and about Dr. Morgentaler's contributions to Canada.

The award was granted for Dr. Morgentaler's "commitment to increased health care options for women, his determined efforts to influence Canadian public policy and his leadership in humanist and civil liberties organizations."<sup>5</sup>

### deVeber Institute leaders weigh in:

"The Order of Canada is supposed to recognize the best effort of Canadians, and I don't believe that Morgentaler's work represents the best that we have to offer as Canadians and to Canadian women.

### "Clinics, in fact, have no idea as to the condition of women after the abortion."

The claim is made that this is a reward for improving the health of Canadian women. In fact, those who, like Morgentaler, run abortion clinics are not in a position to make a claim as to the health of women after they leave the clinic. Any health or psychological repercussions are dealt with by emergency departments or psychiatric departments, or other counsellors or doctors, but women do not return with their problems to the clinics. Clinics, in fact, have no idea as to the condition of women after the abortion."

*Martha Crean, Co-President*

"Abortion remains a deeply controversial topic in Canada, and yet the Order of Canada has been awarded to one of the most prominent participants in that debate. Since there is no indication that any of the country's notable pro-life advocates is likely to be similarly honoured, it seems clear that the nation's cultural leaders have unilaterally declared victory for the viewpoint they favour. This not only damages the prestige of the Order of Canada, it also raises grave questions about the impartiality of those institutions – such as the Supreme Court – whose leaders sit on the Order's Advisory Council.

More deeply it undermines the process of democratic debate. To repress rather than to resolve deep societal differences undermines the legitimacy of the state. Altogether a disastrous and discreditable decision."

*Keith Cassidy, Board Member*

You can help the deVeber Institute to continue actively researching the effects of abortion on women's health. Through our research, we continually learn more about how Dr. Morgentaler changed health care for women, and what healing can be offered to women and families that have been affected by abortion.

5. Governor General Announces New Appointments to the Order of Canada. Press Release. July 1, 2008. << <http://www.gg.ca/media/doc.asp?lang=e&DocID=5447>

Currettes are widely used in Suction Aspiration and Curettage, an extremely common abortion procedure in Canada and one often used in Morgentaler clinics.



The deVeber Institute for Bioethics and Social Research presents:

## A Medical Detective Story: What You Felt Before You Were Born

A neurologist reveals surprising facts about prenatal development that have only recently come to light

Wed. Oct. 1st, 2008

7:00 p.m.

Free Public Lecture

81 St. Mary's Street. Charbonnel Lounge,  
St. Michael's College, University of Toronto

Dr. Paul Ranalli MD, F.R.C.P.C., is a neurologist at the Humber River Regional Hospital, Toronto Western Hospital, and the Toronto General Hospital. Dr. Ranalli serves on the Advisory Board for the deVeber Institute, and is an active researcher. He writes frequently about life issues in the media.

For more information, call 416-256-0555 or email [bioethics@deveber.org](mailto:bioethics@deveber.org)

## Distinguished Donors

All of our donors are extremely important to us, and the Institute would not be possible without every donation. The following are some donors who have recently distinguished themselves in their commitment to the Institute.

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Fr. Alphonse de Valk	The Jackman Foundation

Please keep us in mind when making your charitable giving plans.

## Why I support the Institute:

"When we call on the deVeber Institute, we know we can trust the people there, and the information they send out."

**Jeannie Hedley,  
Walkerton, Ontario**



We are grateful to Philip Sung Design Associates Inc for taking on the deVeber Institute as their non-profit beneficiary. It is thanks to them that we are able to continue improving our graphic design, including the layout and look of this newsletter.

## d-News in Your Inbox

New to your inbox this fall is the newsletter d-News. d-News will be emailed four times each year, and contains original news distinct from the paper newsletter Perspectives.

Subscribe to d-News to receive:

- Links to the latest news in bioethics
- Top research stories from the Institute
- Stories from Institute members
- Information about events and ways that you can be involved

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