

## Provincial Health Ethics Network

Funding for the Provincial Health Ethics Network is provided primarily by Alberta Health and Wellness and Alberta's Regional Health Authorities and Provincial Boards. To become a member or for more information, visit [www.phen.ab.ca](http://www.phen.ab.ca).

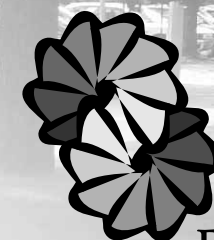
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Provincial  
Health Ethics  
Network

1995 - 2005



## Message from the Chair

The year 2005 marks an exciting time in the history of the Provincial Health Ethics Network. Established as a Society in 1995, the organization's ten year anniversary reminds us that surviving and flourishing in today's rapidly morphing world of health and health care is no small feat. Nor is beating a trail into territory as uncharted and complex as promoting and supporting reflection on ethical issues.



When I agreed to join the Steering Committee to establish the Network many years ago, I was fueled, like so many of us, by a desire to promote compassion and fairness in the health system, within the inescapable constraints of economics and human frailty. Being part of an organization that systematically attempts to do this at the clinical, administrative and policy levels has reaffirmed my belief that carving out space to pay attention to moral issues *can* have an impact, and that ethics discussions, despite being oft caricatured as flighty and ineffectual, are *essential* to bringing rigour, clarity, and practical wisdom to bear on some of most the profound issues of our time.

The growth and development of the Network, unique in North America in terms of its mandate and size, is an achievement of which all Albertans can be proud. This report provides a summary of the organization's key achievements as well as a glimpse of the opportunities that lie ahead. While the impact of PHEN and other ethics organizations cannot be easily measured, this cannot be a deterrent to assessing our performance and identifying an achievable vision for the future. I invite you to join me in reflecting on where we should set our sights in the coming decade, and what it would take to get there. I look forward to hearing from you.

Regards,

Joe MacGillivray, Chair



## Provincial Health Ethics Network (PHEN)

### **Mission**

PHEN's mission is to facilitate examination, discussion and decision-making with respect to ethical issues in health and health care.

### **Guiding Perspective**

PHEN does not advocate for or take positions on substantive ethical issues; its role is to facilitate thoughtful, informed and reasoned ethical decision-making from a variety of perspectives.

### **Goals**

- **Connection:** To connect individuals and organizations with an interest in health ethics with each other and with health ethics resources.
- **Coordination:** To promote coordination of ethics consultation, education and awareness-raising activities
- **Education:** To provide support for ethical reflection and decision-making

PHEN's vision is to make a contribution to the common good by supporting those involved in health and health care in Alberta. Achieving this vision means that:

- Albertans have access to informed consultation when they face dilemmas with an ethical dimension in health.
- Albertans have an understanding of the ethical dimensions of health policy alternatives.
- Albertans from all walks of life become involved in a province-wide network to support their interest in examining ethical issues faced by and within the health system.
- Alberta decision-makers are able to turn to PHEN as a resource in facilitating a social consensus around health and health care policy.
- Alberta's health workers, who serve as advocates and are the first contacts with people seeking services, are valuable sources of health ethics information and are linked to resources available in the province if further consultation is required.
- Albertans are aware of legislative and policy issues affecting their health and health decisions
- Alberta's Regional Health Authorities (RHAs) and Provincial Boards are supported in meeting their obligations in providing resources for ethics education and ethical reflection within their organizations.



## A Vision for the Future



## Operations

PHEN is funded by Alberta Health and Wellness, the Health Boards of Alberta, fee-for-service income and philanthropic contributions.

The Network maintains a Northern and a Southern Alberta office, located in Edmonton and Calgary. These offices act as hubs in the network, linking individuals and organizations from across the Province with each other and providing access to ethics resources.

PHEN is a registered charity and society with a membership ranging from 200-400 individuals and institutions spanning all regions of the Province as well as Canada and the U.S.

As the only organization of its kind and scope, PHEN is an 'experiment in process'. Its offices aim to keep abreast of the ethics resource needs of users and stakeholders of the health system in Alberta and to continually adapt and respond to these as they arise.

## Governance

Accountable to the Ministry of Health and Wellness, the Health Boards of Alberta, PHEN members and the Alberta public, PHEN is governed by a Board of twelve individuals. As stipulated in its bylaws, four of these are elected by the general PHEN membership, four are appointed by the Health Boards of Alberta, and the remaining four are appointed by the previous Board. The Board of PHEN oversees and sets direction for the organization, consistent with the Network's by-laws.

### 1989

- *Premier's Commission on Future Health Care for Albertans (the Rainbow Report)* identifies public concern regarding ethics in health care and the need for an ethics resource centre

### 1991

- *Partners in Health*, the official government response to the *Rainbow Report*, supports the recommendation of an ethics resource centre

### 1992

- Alberta Health invites key stakeholders to develop a preliminary proposal regarding the establishment of a health ethics network

### 1993

- Provincial needs assessment conducted regarding ethics resources in health care
- Proposal submitted to Alberta Health for the creation of a Provincial Health Ethics Network

### 1994

- Alberta Health business plan announces strategy to “establish an ethics network to facilitate the examination of moral and ethical issues and to facilitate individual decision-making related to health, health care and quality of life”

### 1995

- First Alberta health ethics human resource directory published

### 1995

- PHEN established as a society under the Alberta Societies Act

### 1996

- Operations launched; offices opened in Calgary and Edmonton

## History





## Historical Summary of Programs and Services

In October 2004, the Board of the Provincial Health Ethics Network engaged in a process of strategic planning, identifying areas of opportunity and challenge for the organization in the context of the modern health system. The Board reaffirmed the existing mission and goals for the Network and identified several key strategic directions for the period 2005-07:

- 1) PHEN will identify and articulate its value to the health systems and to Albertans
- 2) PHEN will further develop, disseminate and market its resources in Alberta and beyond.
- 3) PHEN will strengthen formal collaborative and cooperative linkages with organizations and individuals to further the understanding and realization of its mission.
- 4) PHEN will continue to foster and maintain relationships with health care representatives throughout the Province in order to ensure the continued relevance of its services in a changing health system.

## Strategic Directions



### **EDUCATION**

#### **Annual Spring Conference**

Networking opportunity for those interested and working on ethics issues in health

#### **Article Database**

Over 1000 articles available on a variety of health ethics topics

#### **Bioethics Journals Summary**

Regular distribution of listings of recent articles appearing in bioethics journals

#### **Bioethics Week**

Annually highlights the importance of and raises awareness of health ethics issues

#### **Bioethics Week Resources For Teachers**

Resources for K-12 teachers to introduce bioethics topics in the classroom

#### **Canadian Bioethics Society Conferences**

Financial/planning support for national conferences in Calgary and Edmonton

#### **Distance Education Course in Bioethics for Alberta**

Provides intensive, high-quality bioethics education to care providers and administrators

#### **Distance Education Course in Bioethics for RHAs**

Bioethics education tailored for individual RHAs, focus on clinical consultation skills

#### **Education Fund**

Financial support for individuals and organizations undertaking educational initiatives

#### **E-Commerce Project**

On-line purchasing of bioethics resources and registration for education events

**End-of-Life Care Conference**

Special event with Grant MacEwan College on ethical issues in end-of-life care

**Ethics and Accreditation Workshop**

Guidance for RHAs and health organizations to meet new standards regarding ethics

**Ethics Committee Membership & Support in Consultation**

Support for consultation services at several hospitals & continuing care centres

**Ethics, Health Care and Resources at the End of Life Conference**

Organization of post-conference to national bioethics conference in Edmonton

**Ethics and Health Resource Allocation: A Primer for Policy-Makers**

Booklet providing intensive introduction to resource allocation ethics for policy-makers

**Handbook of Health Ethics**

Booklet for front-line providers; publication by Capital Health and Dossetor Centre

**Health Ethics Today**

Periodical published with and coordinated by the Dossetor Centre, University of Alberta

**Introduction to Health Ethics Committees**

Booklet providing guidance on developing and sustaining clinical ethics committees

**Library**

Hundreds of bioethics books and videos available on loan to health organizations

**Personal Directives Resources**

Materials on personal directives and ethical issues related to end-of-life questions

**Personal Directives Conference**

Joint project with AMA to provide information to physicians on personal directives

**Premier's Council on Future of Health Care**

Presentation and report on ethical considerations in health system planning

**Resource Allocation Ethics Conference**

Exploration of ethical issues arising in allocation of limited health resources

**Support for Development of Regional Ethics Resources/Committees**

Consultation for regions wishing to develop their ethics services capacity

**Video Reviews**

Extensive reviews of several hundred health ethics videos available at Alberta libraries

**Workshops and Modules**

Several hundred standard and specially-tailored workshops and presentations delivered



Historical Summary  
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Historical Summary  
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**CONNECTION**

**Alberta Organ and Tissue Donation and Transplantation Implementation Committee**

Support on considering ethical implications of provincial policy initiative

**Ethics Committee Listserv**

Discussion list for members of ethics committees in Alberta

**Health Ethics Human Resource Directory**

PHEN member and bioethics human resource listing in booklet/web format

**In Touch**

Membership bulletin featuring articles by bioethics community on pressing topics

**Membership**

Membership of 200-400 individuals and institutions annually

**PHEN Communiqué**

Monthly email bulletin to PHEN members on bioethics programs and events

**PHEN Tenth Anniversary Reception and Consultation**

Networking reception and consultation events to review accomplishments and opportunities

**Regional Ethics Representative Forum**

Annual meeting of RHA and clinical ethics committee representatives

**Web Site Resources**

Extensive resources on a wide range of bioethics topics

**COORDINATION**

**Ad Hoc National Ethics Consultation Team**

Facilitation of ad hoc national ethics consult committee to provide secondary ethics review

**Canadian Council on Health Services Accreditation AIM Standards**

Facilitation of regional sessions to review new draft standards regarding ethics

**Community Research Ethics Board of Alberta**

Historical support for establishing and administering committee

**End-of-Life Decision-Making Pamphlets**

Development of user-friendly brochures on ethical and legal end-of-life issues

**Ethics Committee Member Manual**

Information repository on function, consultation, purpose and resources of ethics committees

**Ethics Committee Resources**

Compilation and organization of on-line resources available for clinical ethics committees

**Ethics Policies Database**

On-going effort to collect and exchange regional and institutional policies

**Health Information Act**

Consultation on ethical implications of draft legislation

**Joint Statement on Resolving Ethical Conflicts**

Facilitation of sessions to review draft document on resolving patient-provider conflicts

**Long-Term Care Policy Advisory Report**

Facilitation of submission providing feedback on selected components of Broda Report

**Public & Care Provider Inquiries**

Response to inquiries for information & referral through 1-800 lines

**Values-Based Frameworks for Public Consultation on Priorities in Health/Health Care**

Framework to solicit informed and thoughtful public input on values and priorities in health

**PROJECTS PRESENTLY IN THE DEVELOPMENT STAGES**

**Article Database Updating and Revision**

Upgrading of existing article database to provide access to recent bioethics literature

**Bioethics Week Essay Competition**

For students in Grades 11-12 to raise awareness of importance of bioethics inquiry

**Bioethics Week Resources**

Development of Bioethics Week Resource Kit adaptable by jurisdictions outside of Alberta

**Clinical Consultation Guide**

Development of a handy guide to conducting ethics consultations

**Discussion Papers**

Briefs providing ethics analysis of significant health policy issues

**Education Resources for Ethics Committees**

Development of package of resources for self-education of ethics committees

**Ethics Committee Quality Improvement/Review**

Provincial program to support health organizations in maintaining ethics service quality

**Guidelines on Long-Term Tube Feeding**

Publication and wide dissemination of existing regional guidelines

**Pandemic Planning: Ethical Considerations**

Facilitation of team to develop decision-making model/process for addressing ethical issues in a pandemic



Historical Summary  
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Historical Summary  
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**PHEN Organizational History**

Document reflecting on the experiment of PHEN in Alberta to share learning

**Resource Allocation Ethics Toolkit**

Development of practical, hands-on tools for those facing difficult resource allocation decisions

**Resource Allocation Project**

Phase II and III follow-up to Resource Allocation Ethics Conference

**Telehealth/Teleconference Bioethics Education**

One-hour, stand-alone educational sessions for care providers delivered via distance

**SELECT PROJECTS PRESENTLY BEING CONSIDERED FOR FEASIBILITY/NEED**

**Ethics Consultation Broker Service**

Link RHAs and health organizations with fee-for-service ethics consultation services

**Bioethics Retreat**

Two to three-day retreat for providers or administrators in health care

**Bioethics Week in Canada**

Development of a proposal to facilitate establishing a Canadian Bioethics Week

**Collaborative Conferences**

Joint annual conferences with community health organizations

**Distance Education Course in Introductory Bioethics, Part II**

Advanced version of the existing PHEN Distance Education Course

**Ethics and Disability Forum**

Initiation of meaningful dialogue between disability and bioethics communities

**Justice in the Workplace**

Exploration, with union and management, of how health organizations live their values

**Media Resources**

Provide media with information and support on reporting bioethics issues

**Medical Errors & Ethics Project**

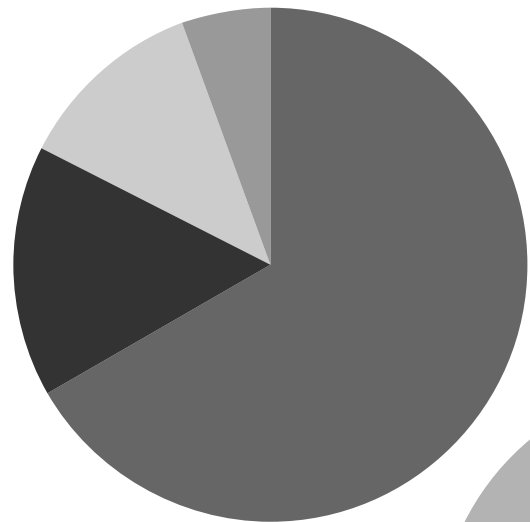
Facilitation to develop document outlining ethical considerations in disclosure of errors

**National Health Ethics Network**

Facilitation of the establishment of inter-provincial network to share resources

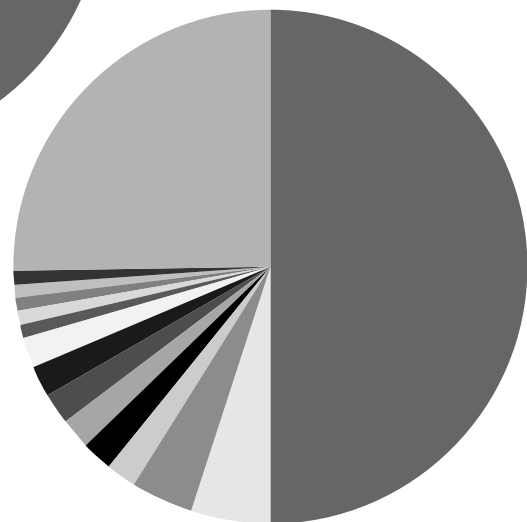
**Resuscitation and Care of Extremely Premature Infants**

Provincial/national facilitation to establish/review guidelines on newborn resuscitation



**Revenue (\$478,124)**

- Provincial Grant - 67%
- Workshops and fees for services - 16%
- Regional Health Authority funding - 12%
- Other - 5%



**Expenses (\$484,635)**

- Human Resources - 50%
- Office - 4%
- Organization development and outreach/publicity - 3%
- Communication - 2%
- Depreciation - 2%
- Travel and meetings - 2%
- Publications - 2%
- Board of Directors - 2%
- Goods and Services Tax - 2%
- Postage and courier - 1%
- Modules and consults - 1%
- Resource materials - 1%
- Insurance - 1%
- Other - 1%
- Special projects - 26%

**Financial  
Summary  
2004-05**



**Personnel 2004-05**

**Board Members**

- Joe MacGillivray, Chair
- Randall Sargent, Vice-Chair
- John Boksteyn, Treasurer
- Pat Evans
- Gary Goldsand
- Jean Graham
- Gordon McPherson
- Maureen O'Brien
- Margaret Plain
- Gregor Wolbring

**Staff**

- Al-Noor Nenshi Nathoo, Executive Director
- Amy Middleton, Programming Coordinator
- Deb Fisher, Office Administrator

**Part-time Contract Personnel**

- Richard Chiu, IT Consultant and Webmaster
- Bashir Jiwani, Special Projects Consultant
- Debra Zelisko, Assistant, Southern Alberta