

2008 | 2009

Annual Report

Provincial Health Ethics Network

Submitted December 2009

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I. Executive Summary and History of Provincial Health Ethics Network (PHEN)

During the last fiscal year (April 1, 2008 – March 31, 2009), the Provincial Health Ethics Network (PHEN) gained greater visibility both locally and nationally, developed successful partnerships with Alberta health organizations sharing similar goals, contributed to the advancement of public policy, and developed new and innovative health ethics resources. Despite these successes, the organization ended the period with great instability; after 13 years of support, Alberta Health and Wellness is no longer providing funding to the organization, effective April 1, 2009, citing financial constraints and a greater focus on governance over operations. While this loss provides significant challenges for PHEN, it is our hope that it will provide the opportunity to develop new relationships and funding arrangements that will ultimately strengthen the sustainability and viability of the organization.

The goals for PHEN were first articulated in the 1989 *Rainbow Report*, which outlined the need for a provincial body or network to assist Albertans with a wide range of ethical issues related to health and health care. The objective was supported by recommendations in *Partners in Health*, the 1991 official response to the Report, and echoed in 1994 with the tabling of Alberta Health's Three-Year Business Plan. The Plan contained four goals to improve the health of Albertans, including to "increase individual accountability, and public acceptance of responsibility for maintenance of their own health." Under this goal, Strategy 3 was 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." As a result, PHEN was formally established as a Society in December 1995 and became fully operational in February 1996. A new Board was appointed at a founding Annual General Meeting on May 24, 1996. PHEN was established as a non-profit society dedicated to coordinating and delivering resources for ethics education and consultation throughout the province. In January 1999, Canada Customs and Revenue recognized PHEN as a registered charity.

PHEN's services are targeted to provide support to several key constituencies, including health care providers and administrators, health policy makers, the health ethics community, and the general public. Services are provided and coordinated through offices located in Calgary and Edmonton, acting as hubs connecting individuals and organizations from across the province. The result is a true network of affiliates and structures dedicated to promoting and providing support for acknowledging and addressing ethical considerations in health decision-making.

Noteworthy achievements during the 2008- 2009 period included:

1. Two provincial conferences on moral distress among health professionals in May 2008 (Calgary) and September 2008 (Edmonton), hosted jointly with the College and Association of Registered Nurses of Alberta
2. Report summarising participant discussions at aforementioned conferences on moral distress, aimed at highlighting the experiences of moral distress faced by health care professionals and proposing strategies to address these challenges
3. Survey of Alberta's clinical ethics committees/ teams/ interest groups with the aim of identifying strengths and challenges in the way that clinical and organizational ethics services are delivered
4. Continued coordination of provincial collaborative to complete *Comfort, Hopes and Wishes* booklet, providing Albertans with straight-forward, accessible information on making difficult health care choices
5. Contribution to public policy through membership on the Personal Directives and Dependent Adults Acts Legislative Review Steering Committee and Capacity Assessment Sub-Committee
6. Continued development of an improved, world-class website of health ethics resources

The major challenge facing PHEN at this time is securing long-term, sustainable funding so the organization can continue to provide innovative and much needed education and resources in health ethics to those working in, governing and accessing the health system – a service that continues to grow in need and demand, especially given the recent restructuring of health services in Alberta. As we plan for the future of the organization, we look forward to continuing existing partnerships and developing new relationships with Alberta Health and Wellness, Alberta Health Services, Alberta’s health professionals and their regulatory bodies, community organizations, our broad membership base and other partners committed to the promotion of clear, informed and thoughtful dialogue and action on ethical issues that affect the health of Albertans.

This report provides an overview of a number of PHEN’s achievements and challenges encountered in 2008 - 2009 as well as a summary of the organization’s vision and direction for the years ahead.

II. Mission, Guiding Perspective, Vision and Goals

Our Mission

To facilitate reflection, discussion and decision-making with respect to ethical issues in health and health care.

Guiding Perspective of Philosophical Neutrality

PHEN does not advocate for or take positions on particular ethical issues. Our role is to provide resources on addressing ethical issues related to health from multiple viewpoints and to encourage and facilitate thoughtful, informed and reasoned ethical discussion and decision-making from all perspectives.

Our Vision

Since its inception in 1994, PHEN has worked with Alberta Health and Wellness to realize the Ministry's vision, *Healthy Albertans in a Healthy Alberta*, by promoting and facilitating ethical reflection and decision-making by providing resources to administrators, policy makers, health care providers, patients and families making difficult choices.

PHEN's vision is an Alberta health system that is sensitive to the myriad ethical issues faced in the planning and delivery of health care, and addresses these issues using thoughtful, informed, systematic decision-making explicitly based on the considered values of Albertans. Achieving this vision means supporting those working in, governing and accessing health care in Alberta so that:

- Albertans have access to informed consultation services when they face ethical dilemmas related to health
- Albertans have an understanding of the ethical dimensions of health policy alternatives
- Albertans work together to develop a health culture, which is comfortable and acceptable to all
- 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's leaders rely on PHEN as a resource in facilitating a social consensus around health and health care policy
- Alberta's health care providers, who serve as advocates and are the first contacts with people seeking services, are good sources of health ethics information and are linked to resources available in the province if required
- Albertans are aware of legislative and policy issues affecting their health and health decisions
- Health organizations are supported in meeting their obligations to provide resources for ethics education and ethical reflection

Goals & Priorities

With offices in Northern and Southern Alberta, PHEN strives to realize its mission and vision in the following ways:

Education: To ensure a continuum of education for the public, health professionals and administrators, and other agencies/ institutions. This will include the development of the skills of interested members of the public and health care providers to enable them to engage in ethical reflection and decision-making.

Connection: To provide health care professionals, policy-makers, governments and the general public with easy access and connection to each other and to ethics resources in order to discuss, reflect and deliberate about ethical issues in health and health care.

Coordination: To provide a means of communication and coordination of ethics consultation, ethics education, and ethics services.

III. Governance: Board Activities

An interdisciplinary team of visionary and highly competent individuals governs the Network. As of March 2009, Board members represented three constituencies:

1. Representatives of the Health Boards of Alberta
2. Appointees of the previous PHEN Board
3. Electees from the organization's general membership

A description of the members of the Board as of March 2009 is provided in Appendix I.

From March – May 2008, the Board Executive consisted of the following dedicated individuals:

- Chair: Margaret Plain, Capital Health Region Board member
- Vice- Chair: Bob Barraclough, then Executive Director of the Premier's Council on the Status of Persons with Disabilities
- Treasurer: Gordon McPherson, then Calgary Health Region Board member

From May 2008 - March 2009, the following Board members assumed Executive positions:

- Chair: Joan Cody, Administrator at Extendicare Athabasca
- Vice- Chair: Eric Wasylenko, then Medical Advisor with the Calgary Health Region's Clinical Ethics Service
- Treasurer: Albert de Villiers, then Medical Officer of Health for Peace Country Health

The organization's bylaws state that the Health Boards of Alberta appoint four board members to represent the health regions. Given the amalgamation of the province's health regions into Alberta Health Services (AHS), the PHEN Board acknowledges that this bylaw must be amended. PHEN is currently in discussions with AHS to determine how this restructuring of health services will impact the appointment of regional representatives to the PHEN Board.

The organization continued the execution of its 5-year strategic plan developed in October 2004, reaffirming the Network's existing direction and its focus on four key strategies:

1. Appropriately allocate resources between the various levels of programming from clinical to policy-making
2. Increase efforts to build stronger linkages with external like-minded organizations and stakeholders
3. Expand the organization's financial base through marketing of quality products and services
4. Identify and articulate PHEN's value to the broader community

Given the notice in February, 2009 of the loss of operational funding from Alberta Health and Wellness, effective April 1, 2009, the Board has been focusing its efforts on exploring alternate funding partnerships in order to secure a sustainable financial future for the organization.

IV. Operations

Network activities are coordinated through a Northern Alberta office in Edmonton and a Southern Alberta office in Calgary. Network staff is comprised of Executive Director Al-Noor Nenshi Nathoo, Programming Director Amy Middleton, Executive Officer Lori-Ann Dunphy and Victoria Seavilleklein who began as Ethicist and Policy Director in September 2008. Carmen Webber filled a maternity leave contract as Programming Coordinator from July 2008 to March 2009. A description of the members of the staff as of March 2009 is provided in Appendix II.

This core team acts as a hub for organizing activities and projects and for linking individuals and organizations with health ethics resources. Additional part-time and contract personnel are engaged on an ongoing basis to assist and support the core team in the delivery of Network services. These include Director of Development Joe MacGillivray, Webmaster Jason Coyne, and IT Consultant Zaheer Kursheed. Other support personnel from across North America are engaged on a contract and volunteer basis for special programs and projects as needed.

The primary programs and services of the Network offered in 2008 - 2009 are described below in relation to each of the organization's goals: Education, Connection and Coordination. Additional information is provided on projects in development.

Education

Alberta Collaborative Initiative on Decision Making at the End of Life

PHEN continues to coordinate the development and dissemination to Albertans of printed and online brochures/materials regarding health care decision-making at the end of life. The intent is to have the materials available in hospitals, continuing care centres, hospices and other health centres where they might be most needed as well as in community settings to promote advance care planning. The project has two main goals: 1) to provide Albertans - particularly those making difficult health care and treatment decisions - with accessible, accurate information on some of the ethical, psychosocial and legal issues that arise when making such decisions; 2) to provide materials that are at once a source of information and an access point to related resources.

A number of Alberta organizations and departments are involved in the project, including the University of Alberta John Dossetor Centre and Health Law Institute; Office of the Public Guardian; Alberta Association of Registered Nurses; Alberta Cancer Board; Calgary Health Region Ethics Service and Palliative & Hospice Care Services; Medicine Hat Regional Hospital; Red Deer College Faculty of Nursing; David Thompson Health Region Quality Improvement Department; University of Alberta and Stollery Hospitals; the Southern Alberta Huntington Disease Resource Centre; Hospice Calgary; Royal Alexandra Hospital; Southern and Northern Alberta Human Organ Procurement and Exchange Programs; Alberta Children's Hospital; Capital Health's Northern Alberta Renal Program; and University of British Columbia's W. Maurice Centre for Applied Ethics.

In 2008- 2009, the Network worked to complete a draft publication that will be distributed among health professionals, patients and members of the public for feedback. It is expected that the final version will be published and disseminated in Fall 2009.

Annual General Meeting and Conferences - May 22 and September 19, 2008

A primary networking opportunity for those involved and interested in the field of health ethics in Alberta continues to

be PHEN's Annual Spring conference and General Meeting of the Network. The May 22, 2008 Calgary Conference, *Between a Rock and a Hard Place: When Health Care Providers Experience Moral Distress*, was held in collaboration with the College and Association of Registered Nurses of Alberta. It was coordinated to offer those working in health care an opportunity to: 1) Identify situations that cause moral distress in the healthcare workplace; 2) Reflect on their own experiences; 3) Discuss practical strategies for dealing with moral distress at the individual and organizational level; 4) Explore how such situations can be turned into constructive opportunities to improve professional and therapeutic. Registration to this event was sold out, thus, due to extraordinary demand, a second conference was held in Edmonton on September 19, 2008. Overall, 675 health professionals attended the two events, demonstrating an extraordinary need for dialogue and resources around the issue of moral distress in the workplace.

Book Review Club

In an effort to provide PHEN members and other interested individuals with summaries and reviews of health ethics books recently added to the PHEN library, PHEN coordinates a Book Review Club. The Club also exposes ethics contacts in Alberta to new and useful literature in the field. When available, book reviews – written by PHEN members – are posted on the PHEN website.

Clinical Ethics Committees

PHEN has traditionally played a strong role in providing various avenues of support for ethics committees, at both institutional and regional levels, across the province. The nature of this support ranges from taking an advisory role in the formation and development of a new committee, to fulfilling workshop requests in order to further strengthen the efficiency and effectiveness of more established committees.

Clinical ethics committees play an important role in the delivery of health care by providing a neutral forum for thinking about and exploring various ethics issues that arise, which clinicians may not otherwise have the opportunity to systematically explore during the course of their practice. The role of ethics committees is not to make decisions or pass judgment on the actions of care providers, but rather to act in a supportive and advisory capacity through the ethics resolution process. The Executive Director and Ethicist both serve and support various health ethics committees in the province, providing on-going support and ethics consultation services where possible.

Communiqué - Monthly Email Update

PHEN distributes an email *Communiqué*, sent to PHEN members on a monthly basis, providing announcements on new health ethics activities and resources and information on upcoming health ethics events. Resources and programmes developed by PHEN as well as those from external organizations are included. PHEN Members are encouraged to share this email with others for whom it would be of interest.

Distance Education Course: Introduction to Bioethics - Alberta

In 2001, the Network launched a unique distance education course in introductory bioethics, in response to a need communicated by its membership for programs that would support the health ethics education of those in rural areas and those with limited access to formal education resources. Due to the overwhelmingly positive feedback received from the past course participants, the Network has been offering the course annually, educating approximately 225 individuals in its 9 offerings. The course was at capacity again this year, with 26 individuals participating from January - May 2009.

The course has been designed to create a bridge between academic bioethics and those working on the front lines of health care. The curriculum provides participants with the groundwork of formal bioethics theory before moving into

specific bioethics issues such as end-of-life care and resource allocation. The goal is that participants will take from the course a set of comprehensive tools and analytical skills that will assist them in addressing ethical dilemmas they face in their daily practice. Participants in the course come from a range of professional backgrounds including nursing, medicine, allied health and health care administration, and many are members of their institutional or regional ethics committee.

Participants are primarily Albertans with a number of individuals participating from outside of the province. Those enrolled in the course engage in distance learning through the use of DVD presentations, readings, web-based and teleconference discussions. Course instructors include some of world's most distinguished bioethicists, including Robert Veatch, Jim Childress, and Edmund Pellegrino of the Kennedy Institute of Ethics at Georgetown University.

Distance Education Course: Introduction to Bioethics - Health Regions and Ethics Committees

The popular *Introduction to Bioethics* distance education course is tailored for delivery in particular health regions and focused to provide greater emphasis on skills of conducting ethics consultation. It was offered in the Calgary Health Region twice during the 2008 – 2009 fiscal year. A course that began in January 2008 was completed in April 2008, while a second course was offered from January – April 2009. The courses are provided on a fee-for-service basis, above and beyond the base level of services offered by PHEN to health regions.

Feedback indicates that these courses are an excellent introduction to clinical ethics issues and provide a base of knowledge for members of ethics committees to better meet the needs of their committees and health organizations in the area of ethics.

Distance Education Course II

Based on the success of its *Introduction to Bioethics* distance education course, PHEN is in the process of developing an advanced distance education course in health ethics. Post-production was completed for two DVDs during the 2008- 2009 period: *Global Health Ethics: Duty, Justice and Responsibility* with James Dwyer, Associate Professor of Bioethics and Humanities, State University of New York and *Spirituality in Health Care: Dialogue, Decisions and Duties* with Daniel Sulmasy, Franciscan Friar and Associate Director, University of Chicago's MacLean Center for Clinical Medical Ethics. Until further DVDs are produced and the course is launched, the DVDs will be made available for purchase by individuals for self-study; by organizations and ethics committees to serve as a curriculum to provide training to staff in introductory bioethics; or by libraries seeking public performance rights. Proceeds from these sales will be used to continue to update and upgrade PHEN's educational resources to the benefit of those within Alberta.

Ethics in Health Care DVDs

This 12-DVD set provides an intense introduction to important issues in the field from some of its most renowned experts. This tool is recommended for clinicians, health administrators, members of ethics committees and anyone interested in furthering their understanding of compelling moral questions in health care. It can be used for individuals for self-study; by organizations and ethics committees to serve as a curriculum to provide training to staff in introductory bioethics; or by libraries seeking public performance rights. Proceeds from the sale of these materials will be used to continue to update and upgrade PHEN's educational resources to the benefit of those within Alberta.

Ethics and Pandemic Planning

In previous fiscal years, PHEN worked with Alberta Health and Wellness, Public Health Division (Disease Control and Prevention Branch and the Provincial Health Office) to coordinate the Alberta Pandemic Preparedness Ethics Working Group as recommended by the Alberta Clinical Subcommittee on Influenza Planning. The Committee provided support

and advice to Alberta Health & Wellness, health regions and the Cancer Board in addressing ethical issues likely to arise in the event of a pandemic. Specifically, it developed a framework for decision-making related to issues that may arise during a pandemic, including allocation of scarce resources and provided advice on the development of an information package for the public related to the above. Given the restructuring of health services in Alberta, this work was put on hold until such time when it can be updated and adapted for use by the newly formed Alberta Health Services.

PHEN continues to maintain its website containing an extensive collection of resources on ethical issues in pandemic planning. Developed as a resource for the aforementioned committee and in response to a growing interest in ethical considerations surrounding pandemic planning, the site includes existing ethics guidelines, current scholarly articles, tools and presentations and related news articles. This webpage is referred to and linked to from the World Health Organization's website *Addressing Ethical Issues in Pandemic Influenza Planning*.

Featured Article

PHEN continues to select recent and relevant articles from the health ethics literature to send to its members on a regular basis, with an accompanying executive summary. Article topics from the 2008 - 2009 period included ethical issues related to the *Global Migration of Health Care Professionals* and *Teaching Ethical Behaviour*. The feedback received from PHEN members indicates that this is a valuable service the Network provides to its members who are highly invested in health ethics issues, but often too busy to read current literature in the field.

Health Ethics Today – Bi-Annual Newsletter

In conjunction with the University of Alberta's John Dossetor Health Ethics Centre, PHEN publishes the periodical *Health Ethics Today*, designed to provide insightful ethics analysis of pressing issues in health care in an accessible format and writing style.

Health Ethics Week 2009

Health Ethics Week was held across Alberta during the period March 2- 8, 2009. This event was designed to: 1) highlight the importance of examining values underpinning the health system; 2) facilitate the health ethics education of various stakeholders in the system, from members of the community to institution staff; and 3) provide greater visibility for clinical ethics committees and health ethics issues across the province. This year's theme *Nurturing Respect and Caring in Times of Transition* asks us to consider how health organizations can best turn transition in the health system into a force for positive change, revisiting and reaffirming our organizational values, and promoting respect and caring in the workplace between health care providers, patients, staff and the public. The event was held in conjunction with the University of Alberta's John Dossetor Health Ethics Centre and the University of Calgary's Office of Medical Bioethics.

Across the province, health regions, health institutions/ organizations, ethics committees, community-based health groups, health professionals and members of the public were invited to participate in Health Ethics Week by hosting or attending local events such as workshops, presentations and video screenings, with the goal of raising awareness of ethics issues in health. PHEN served as the provincial coordinating and resource body for the initiative, distributing publicity and support materials, publicizing planned events, and assisting organizations and committees who were interested in hosting an activity. PHEN also facilitated, on a fee-for-service basis, the availability of Julie Devaney to perform her play *My Leaky Body*, exploring clinical interactions in the Canadian health care system from her perspective as a patient. Devaney's performances were extremely well received and appreciated.

Libraries

The Network maintains libraries in both its Edmonton and Calgary offices. Books, videos and DVDs on a wide variety of health ethics topics are listed for viewing on the PHEN website and available on loan to any Albertan or PHEN member. As a resource to library users, the Network recently updated its library webpage to include summaries of the videos available for lending. It continually expands the library collection with recent titles in health ethics literature, regularly updates the list of holdings on the PHEN website and fills weekly requests to borrow materials.

Print Resources

The Network has several print resources that are made available for purchase. These publications are used by health organizations in all regions of the country and throughout the USA and countries worldwide. Revenue generated from sales of the materials is used to develop additional resources.

Clinical Ethics Committee Member Manual - A comprehensive introduction to the structure and activities of ethics committees in general and, through modification and tailoring by local committees, a convenient introduction and resource to protocols, procedures and guidelines for each particular ethics committee. Over 500 copies have been sold and distributed within Alberta. There has also been a strong interest from outside the province for the material, as it is the known only resource of its kind.

An Introduction to Health Ethics Committees - A resource for those interested in becoming more informed members or chairs of health ethics committees. Subjects covered include an introduction to health ethics, the function of ethics committees, procedures and policies, decision-making frameworks, and regional ethics committees, amongst others. The book is currently in its sixth print run.

Ethics and Health Resource Allocation: A Primer for Policy Makers - Developed by PHEN as part of its Resource Allocation Ethics Project and developed for use at the *Tough Choices: The Ethics of Allocating Health Resources* conference held in 2003. Since then, there has been considerable demand for this resource. Several hundred copies have been sold, including as part of the curriculum for Hamilton Health Sciences' Ontario Health Care Leadership course, and it is now in its third printing.

Schools Program

PHEN is maintaining its *Bioethics in the Classroom* initiative designed to provide tools to Alberta teachers at the Kindergarten to Grade 12 levels to assist them in incorporating health ethics discussions and activities into the classroom. Updates were made to an introductory booklet along with exhaustive targeted information posted on the PHEN website that offers an explanation of how health ethics relates to students and Albertans, suggestions for fun and innovative classroom activities on health ethics, and a complete guide to the areas of the Alberta Learning Curriculum that have direct relevance to issues of health ethics.

Video Sharing Circle

In 2006, PHEN launched the Video Sharing Circle with the aim of stimulating and facilitating thought and discussion about health ethics issues in health care among clinical ethics committees in Alberta. Participating committees are provided with a video and suggested discussion sessions on a monthly basis and given an opportunity to share feedback and ideas about the videos with other members of the Circle. Given the significant interest in this initiative, in 2007 - 2008, PHEN offered a Level I for those ethics committees who had not previously been part of the Sharing Circle, as well as a Level II for those Committees who were part of Level I in the previous year. This programme was put on hiatus for the 2008 – 2009 period.

Website

PHEN's website, located at *www.phen.ab.ca*, continues to be the most heavily utilized of the organization's resources. Although it is targeted at Albertans, anecdotal evidence indicates that the website has also become an important source of health ethics resources for individuals from across Canada and worldwide, further bolstering PHEN's position as an international leader in providing access to relevant health ethics resources for care providers and the general public. In 2007 - 2008, PHEN secured \$30,000 funding from the Wild Rose Foundation to develop an expanded, revised website that will be a world-class resource on health ethics for the province. This will be launched in the 2009-10 period.

Workshop Modules

PHEN's comprehensive set of multimedia teaching modules can be tailored to the particular size and learning needs of each interested group and provide a unique opportunity for individuals to explore, discuss and analyze ethical issues. The teaching modules are specifically designed with the intention of providing a range of health professionals with practical information and tools that will assist them in the explicitly ethics related components of their daily decision making and practices. To date, the Network has delivered or facilitated hundreds of modules and presentations for a variety of Alberta groups from health region boards and staff, to continuing care centre personnel, health professional associations/ colleges and members of the general public. Information regarding the content of the sixteen available modules and the process of booking a workshop is disseminated to the membership and the general public in brochure format as well as via the organization's website. In the 2008 – 2009 period, PHEN continued to provide workshops and presentations to health departments and organizations around the province.

Connection

Clinical Ethics Committee Directory

The Alberta Clinical Ethics Committee directory is posted on the PHEN website and updated regularly. It contains the contact information for over 50 clinical ethics committees throughout Alberta. The directory serves as one way to connect the committees with each other and to connect the health care professionals, patients and patient families with the ethics committee in their institution or region.

Membership

Membership in PHEN, a registered society under the Societies Act, provides numerous benefits including a means of connection with others interested and involved in health ethics in the province, notification of upcoming PHEN initiatives and events, and access to various PHEN services such as module delivery and other educational materials. Individual and institutional membership in the Network in the 2008 - 2009 fiscal year totalled approximately 350. In 2007, PHEN eliminated membership fees, in order to make membership more accessible to a greater number of interested individuals.

Partnerships with Other Networks

PHEN continues to stay in contact with and facilitate discussion and collaboration among groups from outside Alberta interested in establishing of similar networks in other provinces or at the National level. The move to establish similar networks elsewhere stands as an affirmation of the success of PHEN in Alberta. In January 2008, Nova Scotia established the Nova Scotia Health Ethics Network (NSHEN). PHEN continues to foster positive relationships with the organization in order to share learning and make efficient use of resources.

PHEN Council

Through the delivery of PHEN's workshops, annual conferences and *Introduction to Bioethics* courses, the network has contributed to the development of ethics capacity throughout the province. In an effort to utilize the energy and expertise of these members of the ethics community and advance the aim and benefits of a vibrant network of individuals interested in the development of ethics, the organization formed the PHEN Council in April 2006. This body provides advice, support and feedback to PHEN management regarding the implementation and development of programs to fulfil the strategic direction established by the PHEN Board. There are currently 7 volunteer members from Edmonton, Red Deer and Fort McMurray and an Associate/External Member from outside the province, representing both the general public and those serving on ethics committees and actively working in the area of health ethics. The Council meets on a quarterly basis.

PHEN Membership Directory

The PHEN Membership directory is available on the PHEN website. PHEN Members may choose to have their names and primary areas of interest and/or expertise in ethics listed. The Directory serves as one means of connecting these individuals with each other and others interested in health ethics.

Regional Ethics Representatives Forum

One function of the Network is to provide a stronger link between the various health regions and organizations in Alberta as they develop or strengthen their mechanisms for the systematic and informed resolution and awareness of health ethics issues. To this end, PHEN hosts an annual Regional Ethics Representative Forum, providing an opportunity for regional and ethics committee representatives to discuss the status of their recent activities and existing procedures in this area. A further benefit is the opportunity to work towards consistency across the Province and to limit duplication of efforts in instances where sharing of resources would be appropriate.

Given the uncertainty surrounding the possible reorganization of ethics services in the province's restructured health system, this meeting was not held in the 2008 – 2009 period. Instead, PHEN kept in touch with regional and ethics committee contacts throughout the year and, through the Survey of Alberta Clinical Ethics Committees (discussed below), systematically sought input regarding the way that clinical and organizational ethics services are delivered in the province.

Coordination

Survey of Alberta Clinical Ethics Committees/ Teams

In January and February 2009, PHEN surveyed Alberta's clinical ethics committees/ teams/ interest groups with the aim of identifying strengths and challenges in the way that clinical and organizational ethics services are delivered in the province. The responses were compiled and used to develop several options for the structure of clinical ethics services in Alberta. This information was outlined in a report that was distributed to Alberta ethics committees and interested individuals, and submitted to Alberta Health Services for their consideration as they review the ethics structures and processes in the province.

Health Ethics Resource Information Lines

PHEN operates 1-800 phone lines from both its Northern and Southern Alberta offices and responds to hundreds of inquiries and requests each year for ethics-related information. While the Network is not designed to provide direct consultation services regarding ethical dilemmas, it continues to provide referrals to the most appropriate resources

(e.g. professional colleges/ associations, ethics committees or specific individuals) as well as sharing written or other background information for those who seek, or could be assisted by, additional material.

Policy Development and Coordination

PHEN continues to provide input into the development or review of new or existing public policy. Recently, Network representatives provided input as part of the existing review of Alberta's Personal Directives and Dependent Adults Acts. In addition, PHEN is a member of the Alberta Research Ethics Community Consensus Initiative (ARECCI), Phase III, coordinated by the Alberta Heritage Foundation for Medical Research. The purpose of this undertaking is to guide, oversee, and champion activities to develop and enhance processes of ethics screening and review of research as well as quality and evaluation investigations involving people or their health information in Alberta.

Projects in Development

In order to expand the services of the Network, be responsive to the needs of its members, and continue providing new and innovative resources to those utilizing its services, PHEN has several projects that are currently in various stages of development and implementation, as described below.

Continuing Ethics Education Program & Certificate in Health Ethics

This initiative would provide an overarching framework for health professionals earning continuing education credits in ethics. PHEN recognizes that expertise or experience in ethics may come in a variety of forms, thus is proposing this programme as a means for existing health professionals seeking further training in ethics to be recognized for their achievements. This would be the first program of its kind in Canada, situating Alberta on the leading edge of continuing ethics education & advancement

Ethics Committee Quality Improvement/ Review Program

PHEN is in the early stages of exploring the need for, and feasibility of, a voluntary quality improvement program for clinical health ethics committees. The aim of the initiative is to ensure that minimal quality standards are met by committees operating in the province by supporting them to engage in self-assessment, quality improvement review and establishment of performance measures to gauge success and address weaknesses in the delivery of ethics services. The project aims to provide support for committees in surpassing national accreditation guidelines and in implementing on-going processes to improve the quality of their services.

Ethics Consultation Broker and Secondary Review Services

PHEN is considering the feasibility of coordinating these consultation services for Alberta health organizations and facilities. In cases where local ethics services are limited (such as rural settings), PHEN would be a link to an ethics consultant who would provide consultation services by telephone, Telehealth or in person, depending on location. Further, when required, PHEN would act as an independent body to coordinate a specially formed full ethics consultation team, with expertise from across the country, to provide secondary review of particularly difficult ethics consults in Alberta.

Partnership for Potential Projects

PHEN is seeking external partnerships and support for a number of initiatives under consideration, including conferences related to: *Bioethics for the People*, *Ethics Consultation Boot Camp*, *Teaching Bioethics*, and *Ethics & Disability*; further development of the *Health Ethics for Schools* project; *Intern and Ethics Fellowship* positions; a *Bioethics Wiki*; *Scripts for Bioethics-Related Plays and Skits*; *Part II of the Introduction to Bioethics Distance Education*

Course and a Rocky Mountain Summer Ethics Institute. Further information about these initiatives will become available as their planning proceeds to the proposal stage.

PHEN Evaluation Strategy

PHEN has developed a proposal for an evaluation strategy that will review the progress of the organization to date, specifically from the point of view of its stakeholders and intended beneficiaries. A full-scale evaluation of the organization is seen as essential to ensuring that the organization stays relevant, focused, and responsive to the needs of its constituents. PHEN is currently in discussions with the Health Quality Council of Alberta to determine if the HQCA will be able to carry out the proposed evaluation as part of its mandate.

Resource Allocation Ethics Project

Following up on the success of its Health Resource Allocation Ethics Conference in 2003, PHEN is in the process of developing plans and seeking support for further phases of the project. The initiative will focus on developing useful, pragmatic tools such as decision-making frameworks and processes that can be implemented during a decision-making process at the administrative and policy levels in health organizations.

Teleconference Ethics Series

The Network has developed a proposal to deliver short health ethics educational sessions by teleconference, providing an opportunity to engage with high-quality bioethicists, for those who would not otherwise have access to such resources. Under this proposal, participation in a series of teleconferences on an identified topic would constitute completion of a module on that subject and would provide credit toward the Certificate in Health Ethics (discussed above), if desired.

V. Challenges and Opportunities

The high demand and interest in ethics issues, broadly as well as in the health field, has generated both opportunities and challenges for PHEN. The most salient of these are outlined below.

Strengthening PHEN's Financial Base

Given the loss of the organization's main source of funding at the end of the 2008 – 2009 period, PHEN faces the challenge of securing an alternate sustainable funding base. While a significant and obvious hurdle for the organization, this provides the opportunity to continue to nurture established relationships and develop new partnerships with external organizations and granting bodies. Materials developed and services available through PHEN represent a substantial investment and asset for the Network. Leveraging those assets for use outside of Alberta and directing the resulting proceeds to the Network's ongoing programs will provide one means of strengthening PHEN's financial base.

Developing Stronger Linkages with Key Stakeholder Organizations

Given the increasing focus on health ethics issues in society, PHEN needs to pursue a strategy of growth and development to meet these emerging needs. This can be accomplished by partnering with and soliciting support from organizations that share or support its vision and mandate. The past support of and collaboration with several Alberta community foundations/ agencies, health professional associations/ colleges, bioethics centres and academic groups and institutions speaks to the potential for creating more such partnerships in the future.

Continuing to Build PHEN's Identity and Profile in the Province

As its services and structure become more widely known and accessed, PHEN can increasingly solidify its presence both within and outside of Alberta's health system as a valuable resource serving all Albertans. This will require time, credibility, and focused public relations and communications efforts. While an increasing number of health care providers are aware of PHEN's activities and mandate, much work remains to be done in this area. The Network must balance a desire to create greater awareness with a realistic sense of its capacity, given the resources available, to respond to the demands that such awareness generates.

Providing Support for Health Policy Decision-Making

PHEN has historically provided extensive services to, and garnered strong support from, those delivering care at the front lines. The years ahead provide an opportunity for an increasingly greater focus on the ethical implications of decision-making around health policy at the organization, regional, provincial and federal levels. In order to have maximum impact given the limited size and resources of the organization, and considering the long-term, 'trickle-down' effects of policies on those providing and administering health care and health systems, a greater attention to policy issues appears both prudent and pressing.

Meeting Increasing Demand for PHEN's Services

Despite the financial difficulties of the organization, demands for PHEN's services continue to increase, placing strain on its staff and limited resources. PHEN needs to continue to seek ways to meet demands through innovative approaches and judiciously allocate resources to those areas most closely aligned with its mission.

Providing an Institutional Role Model for Collaboration in Health Ethics

The position, structure and function of the Network, unique in Canada and North America, is being touted as model for the creation of similar bodies in other provinces and jurisdictions. The Provincial Health Ethics Network should continue to share and disseminate lessons learned from its challenges and successes, and support the expansion of both formal and informal health ethics networks from which health care providers, administrators and all Albertans can ultimately benefit.

Providing Resources in the Area of Public Consultation

Recent emphasis on the need for accountability and responsiveness of health system policy-makers to those whom the health system is meant to serve has underscored a need for greater focus and emphasis on the process of decision-making in health organizations. Designing fair, effective and ethical means of soliciting public input is a significant challenge for any health system. The unique position and nature of PHEN may provide opportunities to play a greater role in the on-going process of public consultation.

Expanding the Scope of Activities

While the relatively modest size of the organization places limits on the constituencies which it can effectively serve, the Network needs to explore new and innovative methods of reaching out beyond the confines of the health system to community groups and individual Albertans in order to raise awareness of bioethics issues and involve a broader cross-section of Albertans in ongoing dialogue around values and health.

Making Ethics Accessible

Ethics is often seen as a subject of academic discourse, of little relevance to our everyday lives. Demonstrating that, in fact, almost every decision we make somehow involves (implicitly) values and ethics, and that discussions around ethics and health are anything but irrelevant, will be an important and ongoing challenge for PHEN as it seeks to bridge the gap between academic bioethics and those working and using the health system.

VI. Strategic Direction

PHEN is in discussions with Alberta Health Services and other organizations regarding a potential renewed mandate and funding structure for 2009- 2010 and beyond. When the nature and source of the organization's operational funding is determined, PHEN's strategic direction will be revised. Until such time, the key strategic directions for the period 2004 - 2009 identified by the PHEN Board in October 2004 continues to serve as the blueprint for the organization's activities. The four key strategic directions are summarized below:

1. PHEN will identify and articulate its value to the health systems and to Albertans.
2. PHEN will more actively market its products and services in Alberta and beyond.
3. PHEN will further develop formal collaborative and cooperative linkages with organizations and individuals to further the understanding and realization of its Mission and Values.
4. PHEN will continue to foster and maintain relationships with health care leaders throughout the province in order to ensure the continued relevance of its services in a changing health system.

VII. Statement of Operations and Financial Plan

Statement of Operations	2009	2008
Revenue		
Alberta Health and Wellness	350,000	350,000
Health Regions	120,000	60,039
Fees for Services	43,295	57,812
Sale of Materials	23,624	47,615
Programming Contributions	19,874	44,704
Interest	4,395	4,527
Other	1,300	267
HRDC Summer Student Grant	---	3,043
Membership Dues	---	2,265
TOTAL REVENUE	562,488	570,272
General Expenses		
Human Resources	303,794	269,952
Rent	40,903	39,637
Communications	25,665	23,189
Office Expenses	16,049	23,334
Travel and Meetings	12,041	16,155
Board of Directors	7,807	6,544
Depreciation on Capital Assets	6,978	10,296
Postage and Courier	6,706	7,879
Professional Fees	6,519	6,175
Other	3,898	1,013
Insurance	3,385	3,351
Workshops and Consultations	2,133	922
Resource Materials	1,837	7,283
Organizational Development and Publicity	1,069	4,474
Publications	189	3,711
Loss on Disposal of capital Assets	---	616
	489,973	424,531
Special Project Expenses		
Introduction to Bioethics Courses	40,314	55,033
Conferences	33,689	36,890
Pandemic Planning Working Group	16,320	17,938
Health Ethics Week	13,744	17,019
Special Publications	7,897	4,546
Alberta Collaborative on End of Life Issues	3,844	27,473
Ethics Committee Member Manual	558	1,725
Special Projects – Other	---	2,365
Video Sharing Circle	---	1,133
PHEN Programming Council	---	56
	116,366	164,178
TOTAL EXPENDITURES	555,339	588,709
Excess (Deficiency) of Revenue Over Expenses	7,149	(18,437)

The Network continues to seek solutions to meet its severe and unexpected financial constraints for fiscal year 2009 – 2010 and beyond. It is our belief that a diversified funding base will provide financial stability for the organization - securing a strong core of funding will assist in providing the necessary stability to explore additional partnerships and revenue sources. PHEN is currently in discussions with Alberta Health Services and other organizations regarding a potential renewed mandate and funding structure for the organization. Determining the details of this arrangement, will allow the Network to develop a budget and financial plan for 2009 – 2010 and beyond.

The Network extends its gratitude for the tremendous support provided by Alberta Health and Wellness, Alberta's Health Regions and Cancer Board and PHEN's external partners over the years. Such support is a testament to the commitment these organizations have shown to ethical reflection and decision-making. It is our hope that PHEN can continue to nurture relationships and develop new and innovative partnerships with Alberta Health and Wellness, Alberta Health Services and other organizations and bodies with a view to providing Albertans with the tools to make thoughtful, informed and reasoned decisions during these times of transition and uncertainty in the health system.

Appendix I: PHEN Board of Directors – March 31, 2009

Appointed by the Regional Health Authorities

Thaine Olsen was appointed to the PHEN Board in December 2007. Until recently, he served as a member of the Chinook Health Board since 1998. As part of his board responsibility, he chaired the Ethics Committee for Chinook Health, and has been involved extensively with consultations and conferences with patients, family and staff. Thaine's three decades of teaching and administrating in schools throughout the province have given him many opportunities to deal with ethical issues and conflicts. Thaine previously served on the PHEN Board from 2001-2004, and is happy to have the opportunity to be involved once again.

Carol Secondiak was appointed to the PHEN Board in December 2007. She is the former Chair of the Palliser Health Region Board, and is a co-founder and Director of Nursing at ECS Safety Services Ltd., an independent occupational health practice with six offices throughout Alberta. Carol's extensive background in health care includes working as a Registered Nurse and Independent Nurse Practitioner (from large settings as the Foothills Hospital, to a small Arctic Nursing Outpost). She was appointed to the Premier's Task Force on Crystal Meth, which culminated in October 2006 with the release of the final report, "Fighting Back", containing 73 recommendations. Over the years, Carol has been extensively involved in numerous community organizations and has participated in a number of regional and provincial associations.

Elected by the PHEN Membership

Joan Cody, Chair, was elected to the PHEN Board by the membership in May 2006. She is a Registered Nurse with 30 years experience in acute care, medicine, home care and palliative care in both Ontario and Alberta. An administrator with Extendicare (Canada) Inc, Joan has managed the Athabasca Continuing Care Centre for the past 11 years. She is a member of the Aspen Regional Quality Council and the Aspen Regional Ethics Committee. Joan has her certificate in Palliative Care and completed PHEN's Introduction to Bioethics course. Her interests in ethics lie particularly with resource allocation, accountability for service delivery and end of life issues.

Claude Roberto was elected by the membership to the PHEN Board of Directors in May 2008. She is Vice-President of the Chronic Pain Association of Canada and an Advisory Board Member of the University of Alberta Multidisciplinary Pain Clinic in Edmonton. Claude is the author of the book *At Peace with Pain* and in 2004 she received a Queen Elizabeth II Golden Jubilee Award for inspiring others, improving their life conditions and volunteering for communities at the local and national levels.

Eleanor Stewart was elected by the membership to the PHEN Board of Directors in May 2008.

Eric Wasylenko, Vice-Chair, was elected by the membership to the PHEN Board of Directors in May 2005, and re-elected in May 2008. He is a Palliative Care physician in the Calgary Health Region (CHR), Medical Advisor for the CHR's Clinical Ethics Service, Medical Consultant for the CHR's End-of-Life Care Initiative, and leads a non-profit society that is building a free-standing rural hospice. Eric is (slowly) completing an undergraduate degree in Philosophy at the University of Calgary.

Appointed by the Previous PHEN Board

Albert de Villiers, Treasurer, was appointed to the PHEN Board for the term beginning May 2007. Albert, a Public Health specialist, is the Medical Officer of Health for Peace Country Health, and as such works extensively with Public Health and Environmental Health to ensure public safety when it comes to communicable disease control and environmental health risks.

He is leading the regional effort around Pandemic Influenza planning and is an active member of the Alberta Pandemic Preparedness Ethics Working Group. Albert currently chairs Peace Country Health's Regional Ethics Committee and, provincially, has served on the Community Research Ethics Board of Alberta (CREBA) since 2004.

Ed Hall was appointed to the PHEN Board for the term beginning May 2007. He has been a community representative on the Palliser Health Region Ethics Committee for the past twelve years, and currently serves on its Ethics Consultation Sub-Committee. After obtaining his Master of Social Work degree, Ed embarked on a rewarding, 23-year career as a therapist, social worker and regional manager with Alberta Mental Health Services. In 2001, he “retired” and established a successful private practice providing individual, marital and EAP counseling services until 2006. He also taught social work at Medicine Hat College from 2005-2007. Ed decided to fully retire (almost!), but still conducts home assessments for an adoption agency. He and Brenda, his wife of thirty years, live in Medicine Hat.

Debbie Leitch was appointed to the PHEN Board for the term beginning May 2008. Debbie is the Director of Maternal Child Services for the David Thompson Health Region (DTHR). She played a role in the establishment of the DTHR Ethics Committee, which she has co-chaired for the last 7 years. She has a Bachelor of Nursing from University of New Brunswick and a Masters of Nursing from University of Alberta. Debbie is committed to the creation of an environment in health care that is considerate of the needs of patients, families and health care providers.

Margaret Plain was appointed to the PHEN Board for the term beginning May 2004 and was re-appointed in 2007. She has been a Capital Health Board member since 1994 and served for 15 years as an Alderman for the City of St. Albert. Prior to the creation of health regions, Margaret was a member of the Sturgeon Hospital and the Capital Care Group Boards.

Appendix II: PHEN Staff – March 31, 2009

Lori-Ann Dunphy, Executive Officer, joined the PHEN team in the summer of 2007 providing administration and project support in the Calgary office. She has 19 years of executive administration, marketing and event planning experience in various Federal Government departments, private companies and associations in the Ottawa and Calgary areas. Lori-Ann is also involved in an international Bible education work, volunteering her time for this initiative. In her spare time, she enjoys hiking, biking and geocaching (when outdoors), and can often be observed attempting to replicate the latest recipe seen on the Food Network (when indoors).

Amy Middleton, Programming Director, has undergraduate degrees in Philosophy (Wilfrid Laurier University) and Health Studies (York University). She is currently pursuing an MSc in Health Promotion at the University of Alberta. Prior to beginning with PHEN in 2004, Amy worked in sport and recreation and with the YWCA of Edmonton.

Al-Noor Nenshi Nathoo, Executive Director, has a background in the field of ethics and social justice. He holds a B.Sc. in Biology/Human Genetics and the History and Philosophy of Science (McGill University) and an M.A. in Philosophy (University of Calgary) with a specialty in Ethics concentrating on issues of poverty and justice. His background in health care includes work in the areas of cancer research, home care and primary health care management. Al-Noor has worked as a consultant with various Ottawa and Calgary agencies on human rights and international development.

Victoria Seavilleklein, Ethicist & Policy Director, joined the PHEN team in 2008 to provide additional ethics and policy support to the province. She holds a Ph.D. in Philosophy, specializing in Bioethics, from Dalhousie University, an M.A. in Philosophy (Ethics) from the University of Calgary, and a B.A. in Philosophy from the University of Victoria. She has experience working with ethics in acute care, rehab, mental health, and home care settings as a result of completing a Fellowship in Clinical and Organizational Ethics at the Joint Centre for Bioethics, University of Toronto, and a two-year Associated Medical Services Bioethics Internship in Halifax, Nova Scotia. Her work in health ethics and policy is also informed by a four-year CIHR Strategic Training Program in Ethics of Health Research and Policy. Victoria's areas of research include prenatal and newborn screening, artificial reproductive technologies, health policy, and social justice.

Carmen Webber, Programming Coordinator, joined the PHEN staff in June 2008 to fill a maternity leave position. She has an MSc in Health Promotion Studies from the University of Alberta and has worked in research at the University of Alberta and Caritas hospitals, as well as with a local evaluation consultant. Carmen has an undergraduate degree in linguistics and has several years of experience working in health and human services settings doing both research and front-line work as a behaviour therapist. She has a particular interest in rural health inequity.