

Provincial Health Ethics Network
Annual Report 2004-05 and Business Plan 2005-06

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

The year 2005 marks the tenth anniversary of the establishment of the Provincial Health as an organization mandated to facilitate ethical deliberation and decision-making in all aspects of the health system. In its relatively short history, it has built a reputation for developing innovative, cutting-edge programs, raising the profile and highlighting the importance of ethical reflection, and providing a resource for all those who work with and are beneficiaries of the health system.

The goals for the Network were first articulated in the *Rainbow Report* of 1989, 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, the fourth goal being to **"increase individual accountability, and public acceptance of responsibility for maintenance of their own health."** Under this goal is Strategy #3: **"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 co-ordinating and delivering resources for ethics education and consultation throughout the province. In January 1999, Canada Customs and Revenue recognized PHEN as a registered charity.

The Network's services are targeted to provide support to several key constituencies. These include health care providers and administrators, health policy decision-makers, the bioethics community, teachers and students in the Alberta school system and the general Alberta 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.

In the period 2004-05, the Network made significant progress in bolstering and expanding its offerings. Noteworthy achievements included: (1) Completion of a Board visioning and strategic directions exercise to provide greater clarity of direction, (2) Continued offering and strengthening of core education programs, (3) Expansion of services to new target sectors such as schools and teachers, (4) Strengthening of linkages and dialogue with a number of community and health organizations sharing similar goals, (5) Hosting of tenth anniversary celebration and networking event as well as a visioning exercise to identify opportunities over the coming decade, (6) Completion of a successful Ethics and Accreditation workshop designed to provide support to Alberta health organizations seeking to better meet Canadian accreditation standards in the area of ethics services, (7) Launching of an initiative to develop end-of-life decision-making materials for families and patients struggling with difficult care choices.

Challenges encountered during this period in achieving its objectives included the allocation of limited organizational resources to meet growing need and demand in the area of ethics, ensuring that the needs of a broad rather than narrow range of care providers - including physicians, nurses, allied health providers and others - are considered and addressed through PHEN services, raising the profile of the Network, engaging the Alberta public in a way that is meaningful and useful, and overcoming misinterpretations or misunderstandings about the nature of ethics inquiry and the goal of PHEN as a non-partisan body.

This report and proposal provides an overview of a number of these achievements and challenges encountered in 2004-05 as well as a summary of the Network's vision and strategic direction for the years ahead.

The Network looks forward to the continued support of Alberta Health and Wellness, the Province's Regional Health Authorities and Provincial Boards, PHEN's broad member base, and its various committed community and non-profit partners in promoting clear, informed and thoughtful dialogue and action on ethical issues that affect the health of Albertans.

II. Mission, Guiding Perspective, Vision and Core Businesses

Our Mission

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

Guiding Perspective

- **Philosophical Neutrality:** Playing a facilitative role, the Network sponsors and encourages discussion but it does not promote any particular point of view or adopt any positions on ethical issues. The PHEN board and staff recognize that they operate within a pluralistic society, and therefore must, as far as possible, approach health ethics issues from multiple viewpoints.

Our Vision

Alberta Health and Wellness recognizes that a broad range of factors influence achieving the vision "Healthy Albertans in a Healthy Alberta". PHEN's role in working with Alberta Health and Wellness and all Albertans in realizing this vision is to promote and facilitate ethical reflection within the decision-making process in health and health care.

This may involve helping an RHA consider the ethical implications of their resource allocation decisions. It also involves providing support and resources to people facing difficult choices. The Network is instrumental in linking people who work in a consultative capacity or on Ethics Committees, enabling them with resources to support their activities.

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 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 workers, 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 further consultation is required.
- Albertans are aware of legislative and policy issues affecting their health and health decisions (e.g. personal directives).
- RHAs are supported in meeting their obligations in providing resources for ethics education and ethical reflection within their organizations.

Core Businesses & Priorities

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

- **Education:** To ensure a continuum of education for the public, for health professionals and for other health care providers as well as agencies/institutions and their Boards. 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 including Regional Health Authorities, governments and the general public 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.
- **Co-ordination:** To provide a means of communication and co-ordination of ethics consultation, ethics education, and ethics services.

III. Governance: Board Activities

The Network has been fortunate over its history to be governed by a team of highly committed and visionary individuals. Board members represent three constituencies: 1) Representatives of the Health Boards of Alberta 2) Appointees of the previous PHEN Board and 3) Electees from the organization's general membership. A description of the members of the board and staff as of March 2005 is provided in Appendix I.

Sadly, PHEN and the bioethics community in Alberta lost a staunch supporter and friend in the passing of Mary Lou Cranston in July 2004. At the time, she was serving as the Vice-Chair of the PHEN Board. Randall Sargent, Medical Director, Bethany Care Centre, Calgary has since assumed her position on the Board.

As the longest-standing existing member of the PHEN Board, Joe MacGillivray, Health Administrator, continued to provide leadership as the Board Chair, working to build both the visibility and credibility of the organization within the health system. John Boksteyn, former Chair of the Palliser Health Authority, serves as the organization Treasurer.

The Board held a retreat in October 2004 in Calgary to re-evaluate its goals and identify key strategic directions as detailed in this document. It was agreed that taking the Network to next level of its growth required focused attention on appropriate allocation of resources between the various levels of programming from clinical to policy-making, concerted efforts to build stronger linkages with external like-minded organizations and stakeholders, expansion of the financial base through marketing of quality products and services, and identification and articulation of PHEN's value to the broader community.

IV. Operations & Accomplishments

Network activities are co-ordinated through a Northern Alberta office in Edmonton and a Southern Alberta office in Calgary. The core staff of the Network include Southern Alberta Co-coordinator/Executive Director Al-Noor Nenshi Nathoo, Office Administrator Deb Fisher and Programming Coordinator Amy Middleton. 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 contract staff are engaged on an on-going basis to assist and support the core team in the delivery of Network services. These include Special Projects Consultant Bashir Jiwani, Southern Alberta Executive Assistant Debra Zelisko, and IT Consultant/Webmaster Richard Chiu. Other ethics support personnel from across North America are engaged on a contract basis for special educational programs and projects as needed.

The primary programs and services of the Network are described below in relation to each segment of the organization's core businesses: Education, Connection and Coordination. Additional information is provided on projects in development. Supporting documents and materials relating to a number of these initiatives accompany this submission.

Education

- **Annual General Meeting and Conference, May 14, 2004**

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 14, 2004 Conference, held in Red Deer, addressed the theme *Nurturing Respect and Compassion; Building Skills for Ethics Consultation*. Registered participants numbered 140; registration was intentionally limited in order to provide maximum opportunity for small group and workshop learning and role-play. Conference evaluations collected from participants were positive; 83% of respondents rated the conference as good or excellent.

- **Article Database**

The PHEN Article Database is a popular resource comprised of over 1000 articles, indexed by health ethics topic, available to the any Alberta organization or individual. There is an ongoing process in place to upgrade and expand this database and the Network continues to regularly receive several requests a week for this information.

- **Bioethics Week 2005**

Bioethics Week was held during the period March 7-13, 2005 across Alberta. 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 bioethics committees and bioethics issues across the province. This year's theme was *Ethical, Health Communities*, with the explicit goal of encouraging individuals and organizations to put aside the way things are now and think about how they could be. What kind of community would they like to live in? What values do they think the community should uphold? What impediments or barriers are there to achieving health and well-being? How should we promote these values in our communities?

The event was held in conjunction with three partner bioethics organizations: the John Dosssetor Health Ethics Centre of the University of Alberta, the Office of Medical Bioethics of the University of Calgary and the Alberta Catholic Health Corporation Ethics Services.

Across the province, RHAs, health institutions/organizations and community-based health groups were invited to participate in Bioethics Week by hosting or sponsoring local events such as workshops, presentations, video screenings, etc., with the goal of raising awareness amongst their staff and communities of ethics issues in health. PHEN serves as the provincial co-ordinating and resource body for the initiative. This involved the publication and distribution of activity/resource guides and posters for organizations and committees who were interested in hosting an activity. The resource guides provided guidance on the planning and implementation of bioethics educational events.

In all, approximately 40 events took place throughout the province in celebration of Bioethics Week 2005. The educational events addressed a variety of topics including *Living at Risk: Ethical Issues for Healthcare Providers, Ethical Considerations in Surgical Decision Making, Palliative Sedation From an Ethical Perspective, Human Rights and*

HIV/AIDS: Accessing Medical Services and Understanding Patients' Cultural Values and Norms to Enhance Delivery of Care amongst others. A wide variety of formats were used, ranging from panel sessions and presentations to use of telehealth presentations.

- **Bioethics Week Anniversary Celebration and Consultation**

On March 9, 2005, during Bioethics Week, PHEN was pleased to coordinate, with the support of Alberta Health and Wellness, a celebration of the accomplishments of bioethics in Alberta on the occasion of the ten-year anniversary of the establishment of the Network as a Society. The celebratory event was attended by approximately 100 members of the bioethics and health communities, and featured Neil MacDonald of Alberta Health and Wellness as well as PHEN founders Janet Storch and John Dossetor as special guests and speakers.

In conjunction with the celebration, PHEN also hosted a special consultation and brainstorming meeting with several key individuals who played crucial roles in the establishment of the Network or have worked closely with the organization in the delivery of its programs and services over the course of its history. The session offered the opportunity to reflect on the accomplishments of the past decade and to brainstorm or 'blue-sky' possible programs that could be coordinated and delivered by PHEN in the years ahead. The meeting was extremely successful and provided a plethora of ideas and suggestions for PHEN to meet the growing needs of its stakeholders and solidify its position as bioethics resource organization of international importance. The proceedings of the meeting were recorded and are in the process of being transcribed and summarized.

- **Canadian Bioethics Society Annual Conference and Meeting**

The Canadian Bioethics Society (CBS) held its annual national meeting in October 2004 in Calgary. PHEN provided support to the conference through financial support and publicity. The conference received very positive feedback and provided an opportunity for many members of the Alberta bioethics community to network and share learning and best practices from across Canada.

- **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.

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. PHEN staff continue to serve on various health ethics committees within their geographical areas, providing on-going support and ethics consultation services where possible.

- **Clinical Ethics Committee Member Manual**

As clinical ethics committees based in health care centres across the province (and across North America) continue to develop and assume increasingly central roles within their institutions, they are being called upon to provide greater support to care providers and patients/families addressing complex moral issues. Many of the members participating on these committees have had limited exposure to the field of health ethics and difficulty accessing information regarding the function, roles, processes, challenges and opportunities of clinical ethics committees. In response to this need, PHEN has developed a draft Clinical Ethics Committee Member Manual. The binder is designed to be a comprehensive introduction to the nature 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. The Manual is expected to be published and available by May 2005.

- **Distance Education Course: Introduction to Bioethics, Alberta**

In February 2001, the Network launched a unique **Distance Education Course on 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 accessibility to formal education resources. Due to the overwhelmingly positive feedback received from the past course participants, the Network has offered the course again during the period January 10 to May 10, 2005, and expects to continue to do so on an annual basis.

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 nurses, physicians and health care administrators and many are members of their institutional or regional ethics committee.

Applications for this year's course offering exceeded the maximum of twenty-five participants that is the current registration limit. Participants are primarily Albertans with a number of individuals participating from outside of the province. News of this course has also reached the international bioethics community as indicated by the two applications that were received from individuals living overseas. The Network has already received inquiries expressing interest in next year's course offering. Participants in the course engage in distance learning through the use of video, readings, web-based discussion and teleconferences. Course instructors include some of world's most distinguished bioethicists, amongst them Robert Veatch, Jim Childress, Maggie Little and Edmund Pellegrino of the Kennedy Institute of Ethics at Georgetown University.

- **Distance Education Course: Introduction to Bioethics, RHAs**

The popular Introduction to Bioethics Distance Education Course, tailored for delivery in particular RHAs and focused to provide greater emphasis on skills of conducting ethics consultation, was offered in the 2004-05 year in conjunction with the Calgary Health

Region for selected members of its various clinical ethics committees. Twenty individuals participated in the intense course. Feedback indicates that the course is seen as an excellent introduction to clinical ethics issues and provides a grounding for members of ethics committees to better meet the needs of their committees and health care centres in the area of ethics. Discussions are underway to further modify and deliver the intense course within other Alberta RHAs in the coming years.

- **Education Fund**

In the 2004-05 period, PHEN supported the further training in health ethics of three individuals through its **Education Fund**. The Education Fund allows PHEN to continue to support bioethics human resource capacity building in Alberta. This initiative is an important component in meeting PHEN's mandate of building health ethics resources in the province, making health ethics resources more accessible to rural parts of the province, providing opportunities for linkage to bioethics personnel in various parts of the country and continent, and ensuring the continued expansion of a network of knowledgeable and informed individuals in the field. Individuals who receive support through the Education Fund are required to make a contribution to their local workplaces, committees or associations, upon the completion of their training, by sharing their experiences and knowledge gained.

- **Libraries**

The Network maintains libraries in both its Edmonton and Calgary offices. Books, videos, audiotapes and DVDs on a wide variety of bioethics topics are listed on the PHEN website and available on loan to any Albertan or PHEN member. The Network expanded the library collection with recent titles in health ethics literature, regularly updated the list of holdings on the PHEN website and fills weekly requests to borrow materials.

- **Modules**

One of the most popular and well-established services provided by the Network is PHEN's comprehensive set of multimedia teaching modules. These 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 in excess of 400 modules and presentations for a variety of Alberta groups from Regional Health Authority boards and staff, to continuing care centre personnel, health professional association members 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.

- **Periodicals - In Touch - Monthly Membership Bulletin**

In order to maintain consistent contact with the membership and provide an alternate vehicle for discussion of ideas, PHEN continued in 2004-05 to publish *In Touch*, a quarterly newsletter for distribution to members. The format of the newsletter was

revamped to reflect an updated look. Publication of this periodical provides the opportunity to keep members informed and up to date with regards to Network activities and other ethics-related announcements, and also the opportunity for members to hear the perspective of a fellow PHEN member showcased in the featured health ethics-related article.

- **Periodicals - Communiqué - Monthly Email Updates**

In order to supplement distribution of *In Touch*, PHEN launched the monthly email *PHEN Communiqué*, sent to PHEN members on a monthly basis, providing announcements and information on bioethics events.

- **Periodicals – Health Ethics Today – Bi-Annual Newsletter**

In conjunction with the John Dossetor Health Ethics Centre, University of Alberta, the Network publishes *Health Ethics Today*, designed to provide insightful ethics analysis of pressing issues in health care in an accessible format and writing style. Topics covered in 2004 issues included *Clinical Error and Scarce Organs*, *Electronic Health Records and Protection of Privacy*, *Care for Patients in Vegetative State: Reflections on John Paul II's Recent Statement*, and *Prenatal Ultrasound and Unexpected News* amongst others.

- **Print Resources**

The Network has several print resources that are made available to members of the general public. Revenue generated from sales of the materials are used to develop additional resources.

An Introduction to Health Ethics Committees was designed as 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. Over the year 2004-05, this publication has continued to be an exceptionally popular resource. The book is currently in its fourth print run.

Ethics and Health Resource Allocation: A Primer for Policy Makers was developed by PHEN as part of its Resource Allocation Ethics Project and was 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 with several hundred copies being sold. It is now in its second printing.

The *PHEN Personal Directives Kit* is another popular print resource often requested by Network members as well as the general public. The kit supplements the Office of Public Guardian print material on personal directives with information about writing a directive, a booklet entitled *Preserving Dignity*, sample personal directives and wallet cards.

- **Schools Program**

In 2004, PHEN launched a pilot project designed to provide tools to Alberta teachers at the Kindergarten to Grade 12 levels to assist them in incorporating bioethics discussions and activities into the classroom. An introductory booklet along with exhaustive targeted

information posted on the PHEN website offers an explanation of how bioethics relates to students and Albertans, suggestions for interesting classroom activities on bioethics, and a complete guide to the areas of the Alberta Learning Curriculum that have direct relevance to issues of bioethics. The resource booklet was mailed out to selected schools and school divisions in Alberta, encouraging them to consider possibilities for assisting their students in developing their critical thinking skills. Staff from PHEN hosted information booths at four teacher's conventions in the province, sharing information directly with teachers and administrators. Response to date has been very positive. PHEN intends to continue to develop these resources and conduct a review of evaluation of the success of the initiative.

- **Website**

PHEN's website, located at *www.phen.ab.ca*, continues to be the most heavily utilized of PHEN'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 outside the province and the country, further bolstering PHEN's position as an international leader in providing access to relevant bioethics resources for care providers and the general public. Recently updated or added sections include *Health Ethics in the News, Upcoming Bioethics Events, Featured Bioethics Video Clips, Library Materials, Bioethics Organizations in Alberta, Canada and the World, Bioethics Conferences, Resources for and Listings of Ethics Committees in Alberta, Bioethics for Schools and Teachers, and Advanced Education Resources in Bioethics in Alberta and Canada.*

The Network has now completed it's process of developing e-commerce capability for its website. This has allowed for more efficient ordering and timely delivery of PHEN resource materials, and is expected to increase total net revenue earned from sales.

Connection

- **Ethics Committee Listserv**

Based on requests from individuals across the province for more on-going opportunities to network and share information on bioethics services best practices, PHEN launched a pilot email listserv for members of clinical ethics committees in Alberta. Participants receive bi-weekly updates on relevant bioethics events in the news, and can initiate discussions with others relating to issues arising at their local institution. The list has been under-utilized and will be re-evaluated in the coming year and at the upcoming Regional Ethics Representative Forum to ensure that the needs of ethics committee members in this area are properly met either through continuing the listserv or through other means.

- **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, eligibility to receive financial support in bioethics training through PHEN's Education Fund, notification of upcoming PHEN initiatives and events, and

access to various PHEN services such as module delivery. Individual and institutional membership in the Network in the 2004 calendar year totalled in excess of 200.

- **Human Resource Directory**

The *Health Ethics Resource Directory for Alberta* is a directory of individuals and institutions across the province with an interest in, or that are available as resource people on, bioethics. The print version of this directory was originally compiled in 1995, as part of the feasibility study into the establishment of the Network, and then updated in 1998. While the print version is still available, the directory has been kept updated and expanded in a web version, available on the PHEN website. PHEN Members may choose to have their information listed on the directory, along with their primary areas of interest and/or expertise. The Directory serves as one means of connecting these individuals and organizations with each other and will remain an important service of the Network offices.

- **RHA and Provincial Board Representative Ethics Forum, May 13, 2004**

A key function of the Network is to provide a stronger linkage between the RHAs and health institutions in Alberta as they develop or strengthen their various mechanisms for the systematic and informed resolution of health ethics issues. To this end, PHEN hosted the seventh annual RHA and Provincial Boards Ethics Representative Forum on May 13, 2004 in Red Deer. This meeting provides an opportunity for RHA representatives 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. Alberta's RHAs and Provincial Boards were widely represented at the 2004 meeting. A summary of the proceedings is available on PHEN's website. Feedback on the value of the session was once again very positive, and the eighth annual forum is being planned for Tuesday, May 10, 2005, in conjunction with the Annual PHEN Conference.

Co-ordination

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

Following up on the appointment of a PHEN representative to its predecessor Advisory Committee, the Network was invited to appoint a representative to the Organ and Tissue Donation and Transplantation Implementation Committee. Mary Lou Cranston, Ethics Consultant and PHEN Vice-Chair, was appointed on behalf of the Network to provide an ethics perspective on the development, implementation, coordination and evaluation of organ and tissue donation and transplantation in Alberta. Due to her unfortunate passing in the summer of 2004, Gary Goldsand, PHEN Board Member and Clinical Ethicist for the Royal Alexandra Hospital in Edmonton, is now serving as representative to the Committee.

- **Accreditation and Ethics Session**

PHEN hosted a joint workshop with the Canadian Council on Health Services Accreditation (CCHSA) in September 2004 to provide guidance and support for health

organizations seeking to better understand how to meet accreditation requirements relating to ethics. The event was attended by 40 individuals from across the province and provided detailed information on the CCHSA's requirements in this area, as well as on how to build ethics structures and processes to meet the needs identified by the standards.

- **Health Ethics Resource Information**

PHEN operates 1-800 lines from both its Northern and Southern Alberta offices and to date has responded to hundreds of inquiries and requests 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 background information for those who seek, or could be assisted by, additional material.

- **Values-based Frameworks for Public Consultation on Priorities in Health and Health Care**

Over the 2004-05 period PHEN has continued work on Phase 1 of a research program designed to develop a framework for soliciting informed, reasoned and thoughtful public input on the values and directions that underlie health systems. Work to date has underscored the need for and dearth of existing resources in the area of public values-based consultation in health. This has involved conducting an extensive literature review in the topic area, collecting information on existing (limited) resources/frameworks in this area and exploring various options for further phases of the project. The compilation of a research report summarizing the findings of Phase 1 is currently underway and is expected to be completed by the end of Summer 2005.

Projects In the Development

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

- **Bioethics Week Resources for Health Organizations**

PHEN is in the process of putting to use its significant Bioethics Week materials by incorporating them into a Bioethics Week Information Kit. The Kit will provide a comprehensive set of tools for any organization to develop a sustained set of activities to promote bioethics within their institution, and in particular to organize a Bioethics Week. The Kit will be targeted and promoted to health institutions and organizations in the USA and Canada, with proceeds from sales of the Kit used to fund future Bioethics Week initiatives in Alberta.

- **Bioethics Education Resources for Ethics Committees**

The Network is currently developing a package of materials based on its Distance Education Course, that would enable health organizations across North America to offer,

with tools provided by PHEN, intensive courses in introductory bioethics for their staff and stakeholders. Proceeds from the sale of these packages are intended to be channelled into further developing and updating the distance education course available to Albertans.

- **Clearinghouse for Policies on Health Ethics Issues**

For many institutions and regions across the Province who are currently developing or revising their health policies, it is often helpful to have access to similar policies in place elsewhere. In keeping with the Network's goals of providing linkages and communication across the province regarding health ethics issues, PHEN is in the process of developing a comprehensive, accessible and up-to-date collection of the health policies developed by regions and institutions in Alberta on issues with significant ethics implications, e.g. DNR, Conflict of Interest, Personal Directives.

- **Distance Education Course: Part Two**

To meet the advanced learning needs of those individuals who are interested in pursuing educational opportunities in health ethics but who have either completed the Network's introductory course or already have some background in the field of health ethics, the Network is developing an advanced distance education opportunity in bioethics. The response from the classes who have already completed the current course offering indicates that many of these individuals would be interested in further distance education learning opportunities. PHEN is in the early stages of determining the appropriate delivery mechanisms and curriculum for this advanced offering.

- **End-of-Life Decision-Making Materials**

PHEN is in the early development stages of an initiative designed to facilitate the developing, printing and dissemination of printed brochures/materials that will assist patients and families facing complex and difficult care decisions. The intent is to have the materials available in hospitals, continuing care centres, hospices and other health centres where they might be most needed. A number of Alberta organizations have expressed an interest in participating in the project. If deemed feasible, the Network hopes to establish a team to develop these materials and produce drafts in the 2005-06 year, with publication and dissemination in 2006-07.

- **Ethics Committee Accreditation/Quality Improvement Program**

PHEN is in the early stages of exploring the need for, and feasibility of, a voluntary accreditation or quality improvement program for health ethics committees. The aim of the initiative is to ensure that minimal quality standards are met by committees operating in the province. 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 Service**

The Network is exploring the feasibility of and demand for a fee-for-service program for Alberta RHAs and health organizations that provides swift access to an ethics

consultant. The project will involve the examination of models used elsewhere and their respective challenges and successes.

- **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 financial support for further phases of the project, which will focus on developing useful, pragmatic tools such as decision-making frameworks and processes which can be implemented during a decision-making process at the administrative and policy levels in health organizations.

- **Supporting Development of Guidelines on Long-term Tube-Feeding**

Based on a growing interest and concern regarding the ethical issues raised by long-term tube-feeding, the Network plans to build on an existing Capital Health Region initiative to revise and reprint a guide for patients, families, and care providers on this subject. The intent is to make the guide available across the province once it has been piloted in the Capital Region.

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.

- **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.

- **Strengthening PHEN's financial base**

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 on-going programs will provide one means of strengthening PHEN's financial base. Continued partnership with

external organizations and granting organizations also provide opportunity for PHEN to capitalize on its past successes. Increasing the Network's activities in this area is both a challenge and opportunity to be addressed in the coming years.

- **Developing stronger linkages with key stakeholder organizations**

Given the increasing focus on health issues in society, PHEN needs to pursue a strategy of growth and development to meet these emerging needs. This will be increasingly accomplished by partnering with and soliciting support from organizations that share or support its vision and mandate. The support in recent years of several Alberta community foundations/agencies, as well as of other bioethics centres and academic groups speaks to the potential for creating more such partnerships in the future.

- **Meeting increasing demand for PHEN's services**

Increasing demands for PHEN's services place strain on its staff and 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 on-going 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 on-going challenge for PHEN as it seeks to bridge the gap between academic bioethics and those working and using the health system.

VI. Goals and Strategies

The goals and strategies of the organization emerging from recent strategic planning initiatives of the PHEN Board are summarized below.

Goals	Strategies
<p><i>To further develop a financial base for expanding PHEN's mission.</i></p>	<ul style="list-style-type: none"> • Allocate resources towards enlisting support from key stakeholders and the private sector to ensure ongoing support for PHEN's mission and objectives. This includes building on PHEN's status as a registered charity to establish greater credibility and solicit support from private partners. • Continue to study opportunities where PHEN may provide services that offer a financial return to the organization and further its mission. • Explore avenues of generating support from alternative levels of government as well as private granting foundations.
<p><i>To align available resources with key priorities.</i></p>	<ul style="list-style-type: none"> • Ensure that the needs of health care providers, administrators and policy makers are met as effectively and efficiently as possible. • Develop long-range plans for more extensive provision of services and resources to members of the Alberta public as enhanced resources allow. • Explore joint initiatives with Alberta universities and non-affiliated institutions to support the work of ethics education, connection and coordination in the province. • Ensure that priorities are set so that resources are allocated to those areas which can provide and produce the greatest value and impact.
<p><i>To further develop formal collaborative and cooperative linkages with organizations and individuals to further the understanding and realization of its Mission and Values</i></p>	<ul style="list-style-type: none"> • Provide support and linkages for Network members that will enable them to become more fully involved in PHEN's development. • Continue to work closely with external organizations in developing and undertaking projects of joint concern. • Continue to strengthen links with ethics committees across the province. • Build or establish relationships with identified key organizations and stakeholders • Continue to foster and maintain relationships with health care leaders throughout the province in order to ensure the continued relevance of PHEN services in a changing health system.

<p><i>PHEN will identify and articulate its value to the health systems and to Albertans</i></p>	<ul style="list-style-type: none"> • Continue to improve PHEN's profile and links to the general public through public forums, publications, the Internet, and media relations. • Adopt a more concerted and focused approach towards evaluations and measurements to more clearly identify the value that PHEN brings to the health system as well as avenues for improvement and growth
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VII. Financial Plan and Budget

The Network is pleased with its progress in working towards expanding its funding and support base by working in conjunction with community and private partners. The continued support of PHEN by the Regional Health Authorities and Provincial Boards in addition to increasing amounts raised through fees for services underscores the relevance of PHEN's activities to its constituents and the potential for increasing revenue through innovative means.

PHEN's proposed budget for the 2005-06 fiscal year is \$489,500. Of this, PHEN requests support from Alberta Health and Wellness in the amount of \$314,000. Additional funds are expected to be derived from continued RHA support, private funding and fee-for-service income.

While the Network continues to seek new and innovative methods of meeting its severe resource constraints in light of increasing demand and interest in its programs and services, the maintenance of a strong core of funding will assist in providing the necessary stability to explore new partnerships and revenue sources.

The Network looks forward to continuing to strengthen its relationship with Alberta Health and Wellness, the Regional Health Authorities and its various partner organizations in keeping Alberta at the leading edge of health ethics in Canada and the world.