



Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

ANNUAL REPORT



2003 - 2004

Canadian Hospice Palliative Care Association
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Mission Statement

The Canadian Hospice Palliative Care Association (CHPCA) is the national association which provides leadership in hospice palliative care in Canada.

CHPCA offers leadership in the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened.

CHPCA will strive to achieve its mission through:

- collaboration and representation;
- increased awareness, knowledge and skills related to hospice palliative care of the public, health care providers and volunteers;
- development of national norms of practice for hospice palliative care in Canada;
- support of research on hospice palliative care;
- advocacy for improved hospice palliative care policy, resource allocation and supports for caregivers.

Definition of Hospice Palliative Care

Hospice palliative care aims to relieve suffering and improve the quality of living and dying.

Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement.

Hospice palliative care aims to:

- treat all active issues
- prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

The Honorary Patron of the Canadian Hospice Palliative Care Association:
His Excellency John Ralston Saul, C.C.

2003 - 2004 Board of Directors

Executive Committee

Gael Page – *President*
Dr. Jose Pereira – *Vice-President*
Eugene Dufour – *Past President*
Pat Van Den Elzen – *Secretary/Treasurer*
Keith Conrad
Dr. Larry Librach

Provincial Board Members

Wendy Wainwright
BC Hospice Palliative Care Association

Andrea Taylor
Palliative Care Association of Alberta

Stella Swertz
*Saskatchewan Hospice Palliative
Care Association*

Ngaire Abernethy
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Keith Conrad
Hospice Association of Ontario

Dr. Larry Librach
Ontario Palliative Care Association

Dr Louis Roy
Réseau de soins palliatifs du Québec (AQSP)

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*New Brunswick Hospice Palliative
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Judy Simpson
Nova Scotia Hospice/Palliative Care Association

Mary Hughes
*Hospice Palliative Care Association of
Prince Edward Island*

Rev. Fred Stacey
Newfoundland and Labrador Palliative Care Association

Member-At-Large

vacant

President's Report

It is with pleasure that I update you on the work of the CHPCA Board of Directors since our last annual general meeting held in June, 2003 in Quebec City. This has been the first year of my tenure as President, and 'Change! Grow! Inspire!' has become my mantra!

These are exciting times in the field of hospice palliative care in Canada. While momentum in the field is growing it is critical that we focus on escalating the momentum even further. This past year witnessed the development of the Canadian Hospice Palliative Care Association (CHPCA) 2004 Advocacy Strategy as we sought to influence health care policy at the national level. Meetings were held with various federal government departments to further their awareness of hospice palliative care issues. As champions for hospice palliative care we all carry a tremendous responsibility to ensure that one day every Canadian has access to quality hospice palliative care services. We all have a crucial role to play! Inspire!

The CHPCA Workplan for the past year reflected the focal points of the CHPCA's Strategic Plan developed in Victoria, BC in 2001 by members of the national and provincial boards of directors. The six main thrusts of the Strategic Plan – Advocacy, Health & Public Policy; Communication & Awareness; Fundraising & Development; Governance; and Administration remained the headers for the 2003-2004 Workplan. The synopsis of the Workplan is reflected on pages 4 - 10 of this report.

I would like to mention a number of areas where your association was active during the 2003-2004 fiscal year:

- Groundwork was laid regarding the work of the newly formed CHPCA International Cooperation Committee – a tremendous new venture we have embarked upon!
- CHPCA assisted with the preparations for the writing of the first nursing certification exams for hospice palliative care which took place in April 2004 – very exciting in the evolution of hospice palliative care!
- CHPCA Committees and Interest Groups such as the Volunteer Issues Committee and the Canadian Network of Palliative Care for Children (CNPCC) [formerly the CHPCA Pediatric Interest Group] focused their efforts on the development of companion norms of practice documents. These companion norms will further strengthen the volunteer and pediatric hospice palliative care components as they build on A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (CHPCA, 2002). Tremendously exciting!
- In January of 2004 the CHPCA entered into a partnership with the Association of Canadian Medical Colleges (ACMC) to partner on a project entitled "Educating Future Physicians in Palliative and End of Life Care (EFPPEC).

More information on these items can be found in this report on page 8 under the section on "Projects".

The CHPCA continues to be an active partner supporting and encouraging the work of Health Canada's Secretariat on Palliative and End-of-Life Care. The Secretariat's five Working Groups (Best Practices & Quality Care, Education for Formal Caregivers, Public Information & Awareness, Research and Surveillance) have solicited members from a variety of different disciplines and have created individual workplans which when completed will bring positive change to hospice palliative care policy and service delivery in Canada. It is our hope that the

work of each Working Group will continue to evolve as planned. The hospice palliative care community in Canada owes a great deal of thanks to Senator Sharon Carstairs for her commitment and leadership as Minister with Special Responsibility for Palliative Care which led to the creation of the Secretariat on Palliative and End-of-Life Care within Health Canada. Although the Senator is no longer the Minister with Special Responsibility for Palliative Care, we know she remains a strong ally and influencer on our behalf.

The administrative structure of the CHPCA continues to evolve as our association grows. As any organization matures, change is required. Managing the changes within our association has resulted in a process to examine the governance model used by the CHPCA. At the Board's request, 2004-2005 will see the Board taking time to analyze various Board governance models to ensure that the association is using the best model to govern the association and the day-to-day operations of the administration.

In 2003, Terms of Reference were updated or established for all eleven (11) Committees of the Board, as well as all ten (10) CHPCA Interest Groups. Effective communication between the CHPCA Committees and the Board of Directors is key – to that end members of the Board of Directors have volunteered to act as the official liaison to each of the CHPCA Committees and to be the 'voice' for that committee at meetings of the Board of Directors.

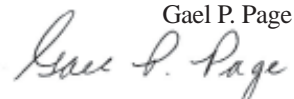
A variety of policies and procedural guidelines to assist the work of the Board of Directors were created in 2003-2004. One such policy was drafted by the CHPCA Bylaws Committee to guide the office staff when dealing with requests for official endorsement on behalf of the CHPCA. It is a measure of our visibility and credibility that the CHPCA is asked to provide this type of support.

In 2003-2004 we said 'farewell' to a number of CHPCA Board Members whose term as a member of the CHPCA Board of Directors was completed. Each contributed tremendously to the operation of the Board and the work of the association. Service pins were presented in June 2003 to: Ms. Marjorie Vessey (PEI), Ms. Dennie Hycha (Alberta) and Dr Bernard Lapointe (Past-President); and in April 2004 to: Judy Simpson (Nova Scotia) and Dr Louis Roy (Quebec). With the retiring of Board members comes the joy of welcoming new members to the Board. Replacing those who retired were: Ms. Mary Hughes (PEI), Ms. Andrea Taylor (Alberta), Ms. Ann McKim (Nova Scotia) and Dr. Justine Farley (Quebec).

In closing I would like to take a moment to sincerely thank the CHPCA Staff for their tremendous dedication and work on our behalf. In many ways they are the glue that holds all of our work together; their skills are invaluable! Thank you to Sharon Baxter (Executive Director) for her leadership; and to Greg Adams, Micheline Ash, Christina Panait, Gillian Baxter, Sallyann Isaac, Sandie Lessard and Ineke Van Zeeland for making the administration all come together. To the Board of Directors – my personal thanks for your insight, energy and sense of humor – all key activities which enhance our work together.

Change! Grow! Inspire!

Gael P. Page



President

Annual Report 2003 - 2004

The Canadian Hospice Palliative Care Association (CHPCA) is pleased to provide you with this summary of the association's activities during the 2003-2004 fiscal year. The CHPCA is a very active association so we have selected the main highlights for this annual report. Should you wish more detail on anything in this report please contact the national office at 1-800-668-2785 or by e-mail at info@chpca.net.

CHPCA works in a number of key areas that include: Advocacy, Health and Public Policy; Communication & Awareness; Fundraising & Development; Governance; Administration and Projects. Please find brief summaries of each of these areas in the following pages.

I Advocacy, Health and Public Policy

Liaison and Leadership to the Canadian Strategy on Palliative and End of Life Care

Over the past year the CHPCA has participated in the ongoing development of the Canadian Strategy on Palliative and End-of-Life Care (CSPELC). Health Canada's Secretariat on Palliative and End-of-Life Care has taken the lead on the development of the CSPELC with the CHPCA continuing to work with the Secretariat by providing leadership and expertise as the Strategy is developed. Currently a CHPCA staff person co-chairs the Canadian Strategy Coordinating Committee and CHPCA representatives are involved on a number of the Strategy's five (5) Working Groups. (Best Practices & Quality Care, Education for Formal Caregivers, Public Information & Awareness, Research, and Surveillance). CHPCA is committed to continued participation in this process.

To meet the growing need for access to hospice palliative care services in Canada, the CHPCA developed and implemented the 2004 Advocacy Strategy to ensure that the Canadian Strategy is well funded and sustainable. This strategy includes work at both the bureaucratic and political levels. CHPCA continues to involve parliamentarians in advocacy and policy issues with regard to hospice palliative care. CHPCA also continues to have a high profile with regard to review and renewal of the Canadian health care system in Canada and will continue to disseminate key information on the Canadian health care system to

its members.

You can find a copy of the 2004 Advocacy Strategy on the CHPCA website located at http://www.chpca.net/public_policy_advocacy.htm.

Quality End-of-Life Care Coalition (QELCC)

The CHPCA is pleased to continue to act as the Secretariat for the Quality End-of-Life Care Coalition (QELCC). As the Coalition Secretariat, the CHPCA coordinates the work of the Coalition including development and coordination of the QELCC Workplan, leadership with regard to advocacy, and report writing. The 29 national member organizations held a face-to-face meeting in January 2004 to develop and discuss the Coalition's 2004-2005 Workplan. This meeting was also an opportunity to reflect back on the

work accomplished in the past year with regard to the Coalition's five (5) main areas of work which are: Advocacy, Research, Family and Caregiver Support, Public Information and Awareness and Professional Education.

The CHPCA continues to represent the Coalition when appropriate to the general public, to government and to other national health care organizations. More details concerning the Quality End-of-Life Care Coalition and their 2004-2005 Workplan can be found on the Coalition web pages located on the CHPCA website: http://www.chpca.net/quality_end-of-life_care_coalition.htm.



Development of Policy Champions and Policy Alerts

The CHPCA continues to develop a list of key policy champions across Canada who are sent periodic information on current issues in hospice palliative care. This list of champions is an effort to contact key individuals who are interested in advocacy and public policy who might not be contacted through provincial hospice palliative care associations or via monthly updates from the CHPCA office. Occasionally these champions are asked to respond to requests for action or may just be kept up-to-date on current issues. The policy champions list is used to relay policy information on key policy issues in a timely manner and was used a number of times in 2003 & early 2004 most notably regarding the new Human Resources and Skills Development Canada Compassionate Care Benefit and the Canadian Strategy on Palliative and End-of-Life Care. Alerts are traditionally sent to provincial hospice

palliative care associations, provincial presidents, provincial staff, provincial and national Boards of Directors and individual champions. This list has been continually updated and will continue to expand in the coming year to ensure representation from across the country. Should you wish to be included in the policy champions e-mail list please contact the association by e-mail at info@chpca.net.

National Norms of Practice Follow-Up

Since its publishing date in 2002, copies of *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* (“the Model”) have been disseminated across Canada at provincial hospice palliative care conferences and through provincial hospice palliative care associations. We would like to thank those who have made this dissemination possible.

The CHPCA continues to work with designated Norms Champions and has supported Norms trainers in hosting presentations in various locations across the country. The CHPCA will continue to monitor where and when these presentations occur.

The CHPCA continues to work with the Norms Committee co-chairs to ensure further dissemination of the Model as well as the development and publication of journal articles where appropriate.

The CHPCA also undertook a small project in the last fiscal year to solicit official endorsement of the Model by key national health professional organizations. This project was supported by a financial contribution by Health Canada.

National Policy Development Framework

In 2003-2004 the CHPCA contacted its stakeholders and asked them to complete a national survey to identify key policy areas for the association to focus on. The survey was sent to provincial hospice palliative care associations, policy champions, members and key partners. The results of this survey were disseminated broadly to members and key partners in the CHPCA Monthly Updates.

II Communications / Awareness

AVISO

AVISO is the association’s newsletter. This bilingual (English & French) newsletter was published three times last year by the CHPCA and was distributed to each current member of the association. Release dates were mid-February, mid-June, and mid-October. Submissions to the newsletter were solicited from the hospice



palliative care community across Canada as well as internationally. The purpose of the newsletter is to inform the association’s membership about news and information concerning the hospice palliative care community in Canada.

Monthly Office Updates

The Monthly Office Updates are prepared at the end of each month and sent electronically to CHPCA members and those with an interest in hospice palliative care issues. The updates focus on informing recipients about recent activities at the national office. By taking advantage of the Internet, the Monthly Update allows the CHPCA to disseminate current information to a large number of people in a short period of time. Currently the Monthly Update is distributed to more than 1,700 e-mail addresses.

National Hospice Palliative Care Week Initiatives



The dates for the 2004 National Hospice Palliative Care Week were May 4 – 10, 2004. CHPCA was able to secure funding for this campaign from The GlaxoSmithKline Foundation which enabled CHPCA to hire

a project coordinator and to form an advisory committee to assist with the development of the 2004 campaign. With the resources available the CHPCA coordinated the following items for the campaign including: a National Theme (“*Caregivers: The many gifts that all caregivers bring*”); National Poster with Logo; a Public Service Announcement for Television (PSA); National Media Press Releases; and a Local Resources Kit which was posted on the CHPCA websites in a downloadable format.

The Local Resource Kit contained: an introductory letter; template local press release; two versions of a PowerPoint presentation about hospice palliative care; a copy of the *Living Lessons*® “*A Guide for Caregivers*”; and media fact sheets.

Customized information kits were also sent to all federal Members of Parliament and Senators.

***Living Lessons*® Campaign**

The *Living Lessons*® public awareness campaign continues to provide hospice palliative care information to all Canadians. Access to the campaign materials is by toll-free telephone service, fax, surface mail, e-mail and a bilingual website. (<http://www.living-lessons.org/>)



Through this campaign the CHPCA responds to information requests and provides assistance for inquiries regarding:

- Resources for patients, caregivers, volunteers, family members, doctors, nurses and the general public
- Available hospice palliative care programs and services
- Resources on how to care for loved ones facing the end of life
- Resources and information for bereaved caregivers, volunteers, family members and friends
- Information, reading material, statistical data, and practical assistance

The campaign continues to track monthly detailed activity and charts reports of transaction requests.

This campaign was developed in 1998 and continues to be funded and supported by The GlaxoSmithKline Foundation.



National On-Line Directory of Hospice Palliative Care Programs and Services

The On-Line Directory of Hospice Palliative Care Programs and Services has enabled broad access to information on the availability of hospice palliative care programs and services in every province and territory in Canada. In 2002, individual programs and services were invited to register with the Directory by going on-line and filling in a registration form. Since that time more than 380 programs and services have registered with the Directory. The information collected is providing the CHPCA and Health Canada with statistics for future projects. Initial funding for the development of this on-line directory was provided by Health Canada's Canadian Breast Cancer Initiative, and Health Canada's Palliative and End-of-Life Care Secretariat.

Since the directory went on-line Health Canada has provided some additional support to continue to increase the number of programs and services registered with the directory.

CHPCA Websites – Development and Maintenance

CHPCA maintains an English website – <http://www.chpca.net/> and a French website – <http://www.acsp.net/>. The use of the Internet continues to be a key component of the Communications/Awareness Strategy of the CHPCA. As technology improves and advances, we will continue to use the Internet to communicate our issues to the general public. The CHPCA continues to maintain and update the

information contained on these sites on a regular basis.

CHPCA Interest Group Web Pages

The CHPCA maintains web pages on its websites for the use of all ten (10) CHPCA Interest Groups including: Aboriginal Issues Group; Canadian Network of Palliative Care for Children; Northern Issues Group; Nurses Group; Pharmacists Group; Physiotherapists Group; Rural Issues Group; Social Workers/Counsellors Group; Spiritual Advisors Group and Volunteer Issues Group.

The basic information contained on each of these pages is the contact information of the chair(s) of each Group and the Terms of Reference for each Group. For those Groups that make a request, the CHPCA has agreed to post information and resources specific to the interests of the Group.

III Fundraising and Development

Development of Fundraising Synopsis for 2003-2004

This activity created a fundraising synopsis of program and project ideas that were planned and carried out in 2003-2004. The brief descriptions within the fundraising synopsis detailed and profiled opportunities for the private sector and government funders.

Endorsement of Three-Year Fundraising Plan

The CHPCA developed a three-year fundraising plan during the 2003-2004 fiscal year. This plan was presented to the CHPCA Board of Directors for approval. The Fundraising Committee has been utilizing this document to guide future work.

IV Governance

Board of Directors

The Canadian Hospice Palliative Care Association is led by an active, committed Board of Directors which meets face-to-face twice per year. Between Board meetings the Executive Committee meets regularly via teleconference. In June 2003 the Board of Directors hosted the Association's Annual General Meeting in Quebec City. The Board of Directors is also responsible for the preparation of the Annual Report and the Audited Statements for the CHPCA.

Board Committees

The CHPCA has 10 Board Committees (By-Laws Committee; Communication Committee; Executive

Committee; Fundraising Committee; HIV/AIDS Committee; International Cooperation Committee; Membership Committee; Nomination Committee; Norms of Practice Committee and Volunteer Issues Committees) which assist the Board of Directors in the effective operations of the association. Terms of Reference for each Committee were revised and approved by the Board of Directors at their November 2003 meeting. A copy of each Committee's Terms of Reference are located on the CHPCA websites.

CHPCA Interest Groups

CHPCA continues to support the work of the CHPCA Interest Groups. (See page 11 for listing of Groups.) Within reason CHPCA has provided administrative support and logistics for all ten (10) CHPCA Interest Groups. Terms of Reference were developed/revised for each Interest Group and approved by the Board at the November 2003 meeting. Each Interest Group keeps CHPCA abreast of the work of the Interest Group and how the Interest Group can interact with the CHPCA.

Provincial Hospice Palliative Care Association Liaison and Support

This activity supports CHPCA's role in relation to the provincial hospice palliative care associations. CHPCA continues to liaise with the provincial hospice palliative care associations in a number of ways: Firstly, each provincial hospice palliative care association appoints a representative to sit as a member of the CHPCA Board of Directors. It is the responsibility of each provincial Board Member to act as an effective liaison between the CHPCA and their provincial hospice palliative care association. Second, the CHPCA coordinates and monitors an e-mail list which contains the addresses of each provincial president as well as the CHPCA president. This e-mail list allows the provincial presidents to communicate easily with the other provincial and national presidents when appropriate. It is our hope that this service will assist provincial hospice palliative care associations with inter-provincial dialogue.

A member of the CHPCA Board of Directors is presently working with the CHPCA's Executive Director to develop a draft of a Memorandum of Understanding between the provincial hospice palliative care associations and the CHPCA. The draft Memorandum of Understanding will be reviewed by the CHPCA Board of Directors in 2004 – 2005 and will then be distributed to the provincial boards of directors for consultation and endorsement.

To foster excellent communication the CHPCA is

constantly looking for opportunities to connect the CHPCA with the provincial hospice palliative care associations both jointly and severally.

By-Laws and Procedural Policy Development

This activity continues to support the By-Laws Committee of the CHPCA Board of Directors. The By-Laws Committee has prepared draft procedural policies in specific areas such as meeting guidelines, conference guidelines and other policies as they arise. These procedural policies work in conjunction with but do not affect the association's By-Laws. The procedural policies drafted in 2003 were presented to the CHPCA Board of Directors for endorsement and where necessary were also presented to the Annual General Meeting for endorsement.

CHPCA Award of Excellence

The 2003 CHPCA Award of Excellence was presented during the association's Annual General Meeting held in Quebec City, Quebec in June 2003, to a most deserving candidate: Mme. Andrée Gauvin, a unique individual with a passion and energy to ensure quality end-of-life care for all citizens.



Mme. Andrée Gauvin

Mme. Gauvin exemplifies the spirit of this award. A pioneer in the field, she has worked tirelessly in the field of hospice palliative care for more than 20 years. She has championed quality end-of-life care eagerly at the local, national, and international level.

Mme. Gauvin's achievements are many and among them include:

- In 1979 she co-founded the first palliative care unit in the French-speaking world at Montreal's Hôpital Notre-Dame
- Assisted with the establishment of numerous palliative care teams throughout Quebec, New Brunswick, and Europe
- Co-founder of Palli-Ami, an organization that provides significant financial support to the palliative care unit at Hôpital Notre-Dame
- Recipient of the Order of Canada, 1997
- A member of the Knight of the National Order of the Legion of France
- Member of the organizing committee of the first Francophone international conference on palliative care held in Montreal in 1985
- Served on the scientific committees for both provincial and national hospice palliative care conferences ensuring that these conferences meet the training needs of volunteers

- Publishing books, abstracts, and journal articles for specialized journals

Mme. Gauvin's accomplishments are best described by her nominators who state: "Since the foundation of the palliative care unit at Hôpital Notre-Dame, and throughout its evolution, she has dedicated herself unfailingly to the heart and *raison d'être* of the unit: the patients, their needs, and their families' needs."

The Communication Committee continues to lead the selection process for the recipient of this award.

CHPCA Leadership Award

The first recipient of the Canadian Hospice Palliative Care Leadership Award is Senator Sharon Carstairs. Senator Carstairs was presented with the award in her home province of Manitoba on Friday, May 2nd, 2003, at the 8th Annual Hospice & Palliative Care



Minister Sharon Carstairs (right) and Doug Nanton, Public Affairs, GlaxoSmithKline

Manitoba Celebrate Life Fundraising Breakfast. Dr. Paul Henteleff introduced this new award and this year's recipient, and CHPCA Board Member Merle MacAulay presented Senator Carstairs with the award on behalf of the CHPCA.

Hospice palliative care is an issue that has been of interest to Senator Carstairs for many years. In the Fall of 1999, Senator Carstairs chaired a Subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology, which reviewed the federal government's response to a 1995 Senate report entitled *Of Life and Death*. The final report from this Subcommittee was released in June 2000 in a document entitled, *Quality End-of-Life Care: The Right of Every Canadian*. This report made 14 key recommendations to the federal government and since its release, has had an impact on the government's response to end-of-life care issues in Canada.

On March 14, 2001, Prime Minister Jean Chrétien appointed Senator Carstairs as Minister with Special Responsibility for Palliative Care. In this new role, Minister Carstairs worked alongside the Health Minister to support the federal government's interest in the development of hospice palliative care by working with provinces, territories and non-governmental organizations, to ensure that hospice palliative care

services are meeting the needs of Canadian patients, families and caregivers. The term of the Senator's appointment as Minister with Special Responsibility for Palliative Care was completed in December 2003 and was a positive step forward in the federal government's commitment to quality end-of-life care in Canada. Senator Carstairs has truly been a leader and champion for hospice palliative care in Canada.

Administration

Office and Financial Administration continues on a day-to-day basis and is managed out of the CHPCA office in Ottawa.

V Projects

Hike for Hospice Palliative Care

May 4th, 2003 marked the first ever, national Hike for Hospice Palliative Care. Taking a cue from the BC Hospice Palliative Care Association who has "Hiked" for years, the



Canadian Hospice Palliative Care Association (CHPCA) launched a country-wide awareness and fund raising event for hospice palliative care.

With founding financial support from the GlaxoSmithKline Foundation, the CHPCA was able to coordinate the Hike for Hospice Palliative Care from a national perspective and produce the tools necessary for local groups to host an event in their community. Host sites were required to register with the CHPCA. Materials were then shipped out to each registered site and a website was created that listed all the Hike sites so that Canadians could locate the site nearest their community. Turtle Beach Clothing and Promotions was the official supplier of the 2003 Hike for Hospice t-shirts that were made available for Hike sites to distribute to their Hikers and volunteers. Forty-five hundred posters, 22,500 post cards and 22,000 brochures were distributed across the country. A Public Service Announcement highlighting both the 2003 National Hospice Palliative Care Week and the Hike for Hospice was created and aired on many radio and television stations nation-wide.

Hike for Hospice events took place in nine of our ten provinces and British Columbia boasted the most sites with a total of 28 host communities. The event was organized by individuals and committees in a total of 79 Canadian towns and cities. Each Hike for Hospice Palliative Care had its own flavour depending on the

needs and objectives of its community. While some regarded it as a prime opportunity to raise much needed funds for their local hospice palliative care unit or committee, others used it to raise awareness of the need to provide hospice palliative care for members of their community.

With most of the participants having experienced hospice palliative care in some way or another, some chose to Hike in memory of a loved one while others chose to Hike in honour of a palliative care volunteer who has made a difference in the lives of others. Either way, Hikers everywhere understood that Canadians must have the best quality care available to them at the end-of-life.

When all was said and done, thousands of Hikers donned their running shoes and hiking boots to support hospice palliative care in their community. Many thanks need to be expressed to the hundreds of volunteers who helped make the event happen in their community. Finally, we are especially pleased that this first annual event raised in excess of \$300,000 nationally with every penny remaining in the local community. An evaluation was completed in June 2003 and can be found posted on the CHPCA websites.



Congrès national de soins palliatifs
National Conference of Hospice Palliative Care

Bi-Annual National Conference

On June 15th, 2003 close to 1,500 participants descended on Quebec City for the 2003 National Conference of Hospice Palliative Care. This year's theme "So Many Ways to Care, So Much Dedication to Share" encapsulated the diversity of those who work in the field of hospice palliative care. Co-hosted by the CHPCA and the Réseau de soins palliatifs du Québec (AQSP), the three-day conference proved to be an excellent event. Participants came from across Canada as well as from various other countries.

The program was divided into four plenary sessions, over 70 workshops, poster presentations, pre-conference CHPCA Interest Group meetings, an exhibit hall, and an art exhibit.

We were fortunate to have a number of distinguished plenary speakers at this year's conference: Dr. Derek Doyle, spoke on the conference theme of "So Many Ways to Care, So Much Dedication to Share", Ms. Barbara Sourkes, spoke about "Armfuls of Time: What children can teach us about end-of-life care", Ms. Chantale Hivon shared her personal experience as a

family caregiver, and Drs Claude Lamontagne and Louis Roy spoke on the theme of "Turning Dedication into Commitment and Action". Each plenary session was challenging and informative.

The workshops presented at this year's conference were of excellent quality and reflected the diversity of hospice palliative care. Presentations were made on every aspect of the care provided to patients and their families at the end of life.

An exciting feature of this year's conference was the inclusion of an art exhibit entitled "Hues of Humanity/ Tissus d'humanité". 15 well-know Quebec artists were asked to "share the art of caring", and the result was 30 works which were displayed in the exhibit hall. This landmark, cultural event, was organized in partnership with Quebec City's Galerie Linda Verge and a magnificent calendar was produced featuring a selection of the works. Proceeds from the sale of the calendar will support the CHPCA and the Réseau de soins palliatifs du Québec.

All in all, this year's national conference provided a forum to challenge and enrich each participant. Sincere thanks must be extended to Dr. Louis Roy, Chair of the Conference Steering Committee, and all those who worked so tirelessly to produce this year's conference.

VOICE in Health Policy: The Role of Informal Caregivers in Palliative and End-of-Life Care in Canada: A Discussion of the Legal, Ethical and Moral Challenges

This project began in the late fall of 2003 and will be completed in 2004. The CHPCA, in collaboration with Health Canada, will provide for the first time in Canada – a critical assessment of the *legal, ethical and moral challenges* faced by informal caregivers (family, friends and loved-ones) at the end of life – particularly as they relate to new health care reforms and initiatives, such as Human Resources and Skills Development Canada's Compassionate Leave Benefit.

Informal Caregiver Inventory

In the spring of 2003 the Canadian Hospice Palliative Care Association (CHPCA) began a project funded by the Voluntary Sector Initiative of Health Canada. The project consisted of conducting a survey to identify existing informal caregiver information and resources in an effort to build a national inventory. An advisory committee was created to assist with the preparation of the survey and to oversee the project.

The project's goals were to:

1. Survey hospice palliative care associations in the provinces and territories, local

- programs and services and Quality End-of-life Care Coalition members to create an inventory of resources and information to recruit and train informal caregivers.
2. Evaluate and disseminate resources and information that will equip and support informal caregivers providing end-of-life care.
 3. Make recommendations regarding new resources and information to be developed.

The survey has identified numerous resources such as pamphlets; handouts; books; videos & CD-Roms; programs and services; networking opportunities; web-based information; referral information and other types of resources and information that is currently being used in communities across Canada. The Informal Caregiver Inventory was completed in 2004 and the complete Inventory can be found on the CHPCA websites.

International Issues

In 2003 the CHPCA constituted an International Cooperation Committee to look for avenues to share Canada’s end-of-life care resources and expertise. The CHPCA’s International Cooperation Committee met in October 2003 and has developed an ambitious Workplan that is available upon request.

Educating Future Physicians in Palliative and End-of-Life Care

In 2003 the Association of Canadian Medical Colleges (ACMC) and the Canadian Hospice Palliative Care Association embarked on a four-year project in palliative and end-of-life care in medical education. The

project strives to bring palliative care education to all undergraduate medical students and clinical postgraduate trainees at Canada’s sixteen medical schools so that they will graduate with competencies in these areas by the year 2008.

The project is managed by a team including a physician leader with experience in medical education in palliative care; a project manager, an administrative assistant, and representation from the Association of Canadian Medical Colleges and the Canadian Hospice Palliative Care Association.

National Pediatric Norms of Practice for Hospice Palliative Care

The main goal of this Workplan item was to prepare a draft National Pediatric Norms of Practice document based on foundational work already completed by Pediatric Hospice Palliative Care Committee of British Columbia (Vancouver) and Sick Kids Hospital (Toronto). The draft document that was produced is based on the document *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*. This project was supported by Health Canada.

Acknowledgements

The work of CHPCA is supported by a number of private and public funders. We would like to take this opportunity to thank each of our funders and supporters for helping to make the work of the Canadian Hospice Palliative Care Association possible. A complete list of our private and public funders can be found on page 12 of this report.

Prepared by Sharon Baxter, Executive Director



CHPCA Committees

To support the work of the CHPCA Board of Directors the Board is supported by the following Committees:

By-Laws Committee Chair: Dr. Jose Pereira	International Cooperation Committee Chair: Bernard Lapointe
Communication Committee Chair: Eugene Dufour	Membership Committee Chair: Larry Librach
Executive Committee Chair: Gael Page	Nomination Committee Chair: Eugene Dufour
Finance Committee Chair: Pat Van Den Elzen	Norms of Practice Committee Co-chairs: Frank Ferris & Heather Balfour
Fundraising Committee Co-chairs: Wendy Wainwright & Karen Chow	Volunteer Issues Committee Chair: Keith Conrad
HIV/AIDS Committee Co-chairs: Lois Brummet & Deborah Randall-Wood	

Terms of Reference for each Committee were revised in 2003 and approved by the Board of Directors in November 2003. Information on each committee can be found on the CHPCA website at:

<http://www.chpca.net/committees.htm>

CHPCA Special Interest Groups

To support the continued development of hospice palliative care in Canada, and in recognition of the interdisciplinary nature of hospice palliative care, the CHPCA maintains the following Interest Groups:

Aboriginal Issues Group Chair: Rosella Kinoshameg	Physiotherapists Group Chair: Janice Hagel
Canadian Network of Palliative Care for Children (formerly the Pediatric Interest Group) Co-chairs: Filomena Nalewajek & Laura Beaune	Rural Issues Group Chair: Anne Pollett
Northern Issues Group Contact: Barbara Frain-Gower	Social Workers/Counsellors Group Chair: Wendy Wainwright
Nurses Group Chair: Darlene Grantham	Spiritual Advisors Group Chair: Rev. Dan Cooper
Pharmacists Group Chair: Eve Sample	Volunteer Issues Group Chair: Jerry Rothsetin

Terms of Reference for each Interest Group were revised in 2003 and approved by the Board of directors in November 2003. Information on each Interest Group can be found on the CHPCA website at:

http://www.chpca.net/interest_groups.htm

As part of its commitment, the CHPCA supports the Interest Groups in the following ways:

- Each Interest Group is given the opportunity to meet annually in conjunction with the CHPCA Annual General Meeting. The meeting is coordinated through the CHPCA office. The agenda and operation of the meeting is coordinated by the Chair of the Interest Group in consultation with the CHPCA.
- Each Interest Group is provided with space on the CHPCA websites.
- In the spring of 2003, the CHPCA created and hosts List Serves for each Interest Group. The purpose of the List Serves is to provide each Interest Group with an efficient means of communication and sharing of information with others who share their interest. Those interested in being a part of an Interest Group List Serve should send an e-mail to the CHPCA at info@chpca.net.

2003 - 2004 Donors

Government Sponsorship

Health Canada / Santé Canada

Private Sector Sponsorship

PLATINUM SPONSOR (> \$10,000)

The GlaxoSmithKline Foundation
Coalition of National Voluntary Organizations
Solvay Pharma Inc.

GOLD SPONSOR (\$5,000 TO \$10,000)

Canadian International Development Agency

SILVER SPONSOR (< \$5,000)

The Military and Hospitaller Order of Saint Lazarus of Jerusalem, Grand Priory of Canada
Continuing Education Department – GlaxoSmithKline Inc.
Employees Community Fund – Boeing Toronto Ltd.
River Valley Funeral Services Ltd.
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Ngaire Abernethy
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Deanna Hutchings
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United Way – Greater Toronto
United Way – Ottawa
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John & Diane Van Zeeland
Frankie Wong
Rita Young

AUDITORS' REPORT

To the Board of Directors of
Canadian Hospice Palliative Care Association

We have audited the statement of financial position of Canadian Hospice Palliative Care Association as at March 31, 2004 and the statements of operations and net assets and CHPCA Conference Fund for the year then ended. These financial statements are the responsibility of the Association's management. Our responsibility is to express an opinion on these financial statements based on our audit.

Except as explained in the following paragraph, we conducted our audit in accordance with Canadian generally accepted auditing standards. Those standards require that we plan and perform an audit to obtain reasonable assurance whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation.

In common with many charitable organizations, the Association derives revenue from donations and membership fees, the completeness of which is not susceptible to satisfactory audit verification. Accordingly, our verification of these revenues was limited to the amounts recorded in the accounts of the Association and we were not able to determine whether any adjustments might be necessary to such revenues, excess of revenues over expenses, assets and cumulative excess of revenues over expenses.

In our opinion, except for the effect of adjustments, if any, which we might have determined to be necessary had we been able to satisfy ourselves concerning the completeness of the revenue referred to in the preceding paragraph, these financial statements present fairly, in all material respects, the financial position of the Association as at March 31, 2004 and the results of its operations for the year then ended in accordance with Canadian generally accepted accounting principles.

BOURIS, WILSON LLP
Chartered Accountants

Ottawa, Ontario.
May 19, 2004.

CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION
STATEMENT OF OPERATIONS AND NET ASSETS
FOR THE YEAR ENDED MARCH 31, 2004

	2004	2003
Revenues		
Advertising revenue	\$ 458	\$ 6,681
Donations	160,777	368,607
Grants	276,200	167,956
Interest and dividends	8,226	8,670
Membership fees	52,339	45,794
Resource material	10,873	15,957
	508,873	613,665
Expenses		
Advertising and promotion	6,625	1,301
Bank charges	1,594	1,174
Depreciation	4,867	3,028
Dues and subscriptions	1,808	1,404
Human resources	273,393	344,965
Insurance	5,009	3,128
Meeting costs	6,270	17,201
Office rent	18,526	17,546
Office supplies	12,680	7,306
Postage	16,289	21,777
Printing	34,006	53,914
Professional fees	2,589	3,539
Teleconferences	5,522	4,983
Telephone and facsimile	8,607	9,515
Training and professional development	-	301
Translations	30,307	33,132
Travel	79,676	88,879
Voluntary recognition and honoraria	-	462
	507,768	613,555
Excess of revenues over expenses from operations	1,105	110
Conference loss	(20,000)	-
	(18,895)	110
Excess of revenues over expenses (expenses over revenues) for the year	(18,895)	110
Transfer to conference fund	(10,000)	-
Net Assets - beginning of year	189,277	189,167
- end of the year	\$ 160,382	\$ 189,277

BOURIS, WILSON LLP
Chartered Accountants

CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION
STATEMENT OF FINANCIAL POSITION
MARCH 31, 2003

	<u>2004</u>	<u>2003</u>
Assets		
Current		
Cash	\$ 164,938	\$ 177,070
Prime - 2.25% (2003 - Prime - 2.35%) Guaranteed Investment Certificate	101,455	95,045
Accounts receivable	118,460	39,365
Accrued interest receivable	4,170	2,662
GST recoverable	7,894	12,895
Prepaid expenses	4,292	10,613
	<u>401,209</u>	<u>337,650</u>
 2.75% (2003 - 2.00%) term deposit, due May 2005	 100,000	 100,000
Capital assets	<u>6,972</u>	<u>3,556</u>
	<u>\$ 508,181</u>	<u>\$ 441,206</u>
 Liabilities and Net Assets		
Current		
Accounts payable and accrued liabilities	\$ 75,440	\$ 14,077
Unearned revenue	<u>247,359</u>	<u>237,852</u>
	<u>322,799</u>	<u>251,929</u>
 Net Assets		
Net assets invested in capital assets	6,972	3,556
Unrestricted net assets	<u>153,410</u>	<u>185,721</u>
	160,382	189,277
CHPCA Conference Fund	<u>25,000</u>	<u>-</u>
	<u>185,382</u>	<u>189,277</u>
	<u>\$ 508,181</u>	<u>\$ 441,206</u>

BOURIS, WILSON LLP
Chartered Accountants

