



**Canadian Hospice Palliative Care Association**

**Association canadienne de soins palliatifs**

# **ANNUAL REPORT**



**2004 - 2005**

Canadian Hospice Palliative Care Association  
Annex B, Saint-Vincent Hospital  
60 Cambridge Street North  
Ottawa ON K1R 7A5  
CANADA

Telephone: (613) 241-3663  
Toll Free: 1-800-668-2785 or 1-877-203-4636  
Fax: 613-241-3986  
E-mail: [info@chpca.net](mailto:info@chpca.net)  
Web Site: <http://www.chpca.net/>

Charitable Registration Number:  
13760 4195 RR 0001

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



# Canadian Hospice Palliative Care Association

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## Association canadienne de soins palliatifs

### 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.

**Hospice palliative care** is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.

**Hospice palliative care** may complement and enhance disease-modifying therapy or it may become the total focus of care.

**Hospice palliative care** is most effectively delivered by an interdisciplinary team of healthcare providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice. These providers are typically trained by schools or organizations that are governed by educational standards. Once licensed, providers are accountable to standards of professional conduct that are set by licensing bodies and/or professional associations.

## 2004 - 2005 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*

Ngairé Abernethy  
*Hospice & Palliative Care Manitoba*

Keith Conrad  
*Hospice Association of Ontario*

Dr. Larry Librach  
*Ontario Palliative Care Association*

Justine Farley  
*Réseau de soins palliatifs du Québec (AQSP)*

Dr. Sydney Grant  
*New Brunswick Hospice Palliative  
Care Association*

Ann McKim  
*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

Solange Levesque (*Montreal*)

## President's Report

It is with pleasure that I present the 2004-2005 annual report of the Canadian Hospice Palliative Care Association (CHPCA). This has been the final year of my tenure as President, and 'Change! Grow! Inspire!' has become my mantra.

These are exciting times in hospice palliative care, as our momentum builds; but it is also a critical time as we focus on escalating the momentum. The past year witnessed the development of the CHPCA Advocacy Strategy as we sought to influence change in the 'right places'. Meetings were held with various federal government departments to further their awareness of hospice palliative care in Canada. As advocates for hospice palliative care we carry a tremendous responsibility to see that Canadians receive the quality of hospice palliative care they deserve; we all have a crucial role in this advocacy. Inspire!

The CHPCA Workplan for 2004-2005 reflected the focal points of the association's Strategic Plan developed in Victoria, BC in 2001. The six main thrusts – Advocacy, Health & Public Policy; Communication & Awareness; Fundraising & Development, Governance, and Administration remained the headers for the Workplan. Groundwork was laid with respect to the work of the newly formed CHPCA International Issues Committee – a tremendous new venture we have embarked on. The first hospice palliative care nursing certification exam was written in the spring of 2004 – how exciting in the evolution of hospice palliative care! Congratulations – to those who prepared the nursing standards, core competencies, the exam, and to those who wrote. The work of the Committees and Interest Groups focusing on the development of Volunteer and the Pediatric norms and standards to accompany the CHPCA Model will add strength to the original work. Tremendously exciting! The recently initiated project entitled "Educating Future Physicians in Palliative and End-of-Life Care" (EFPPEC) is a huge step forward. Please read through this Annual Report for more detailed information about the various workplan items completed this past year.

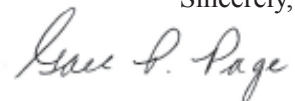
The CHPCA continues to be an active partner with Health Canada's Secretariat on Palliative and End-of-Life Care. The five Working Groups (Best Practices and Quality Care, Education for Formal Caregivers, Public Information and Awareness, Research, and Surveillance) have undertaken exciting work over the past year. It continues to be our hope that this work continues to evolve as planned. On behalf of the CHPCA I extend sincere thanks to Senator Sharon Carstairs for her advocacy, vision and leadership that have shaped the formation and work of the Secretariat. Although hospice palliative care is no longer an official responsibility for her, we know she remains a strong ally and influencer on our behalf.

The structure of CHPCA continues to evolve as our association develops. Managing the 'growth' has necessitated an examination of the current structure and governance model. As an organization matures, change is required. Terms of reference were updated/established for all eleven (11) CHPCA Committees, and a generic set of terms-of-reference were developed for the twelve (12) Interest Groups. Communication between the committees and the Board is key; to that end individual Board members were assigned official responsibility to be the liaison to each of the committees, and to be 'the voice' for that committee at the Board table. The Bylaws Committee brought forth an Endorsement Policy to guide Staff in dealing with requests for endorsement of conferences, books and materials. It is a measure of our visibility that we are asked to provide support in a variety of ways. A variety of policies and procedural guidelines to assist the Board in its work have also been completed. At the Board's request the new fiscal year will see a focus on the association's governance structure. With the support of Sharon Baxter, our excellent Executive Director, it will be time to transition to a true governance model, which will allow Staff to do their work, and keep the Board focused on its responsibilities.

In 2004-2005 we said 'farewell' to two Board members, who contributed tremendously to the work of the association. At our April 2004 meeting, pins and certificates of thanks were presented to Judy Simpson, who represented Nova Scotia for the past 3 years, and Dr. Louis Roy who represented Quebec for 6 years. 'Change' presents itself in this regard, as our membership fluctuates. In September 2004 we welcomed Ann McKim from Nova Scotia and Dr. Justine Farley from Quebec.

I would like to take a moment to sincerely thank the staff at the national office for their tremendous dedication and work on our behalf. They may be small in number, but are the glue that holds all of our work together; their skills invaluable! Thank you to Sharon Baxter for her leadership; Greg Adams for his administrative skills, Micheline Ash for coordinating *Living Lessons*<sup>®</sup>, Ryan McCarthy, and Tammie Winsor for their project management support, Gillian Fernie for her administrative support, and Sandie Lessard for her financial management. To the Executive and Board members – my personal thanks for your insights, energy and sense of humor – all key activities to enhance our work together.

Sincerely,



Gael P. Page  
President  
2003-2005

## Annual Report 2004 - 2005

The Canadian Hospice Palliative Care Association (CHPCA) is pleased to provide you with this summary of the association's activities during the 2004-2005 fiscal year. The following are some selected highlights. 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](mailto:info@chpca.net).

CHPCA focuses on a number of key areas including: 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 work of the federal government's 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 and implementation of the CSPELC with the CHPCA continuing to work with the Secretariat providing leadership and expertise. Currently a CHPCA staff person co-chairs the Canadian Strategy Coordinating Committee and CHPCA members are involved with the work of many of the Strategy's Working Groups. (Best Practices & Quality Care, Education for Formal Caregivers, Public Information & Awareness, Research, and Surveillance). CHPCA is committed to continued participation towards the development of a long-term, sustainable Canadian Strategy on Palliative and End-of-Life Care.

To meet the growing need for well-funded and sustainable access to hospice palliative care services in Canada, the CHPCA developed and implemented its 2005 Advocacy Strategy. This strategy included suggestions for action at both the bureaucratic and political levels. You can find a copy of the 2005 Advocacy Strategy on the CHPCA website located at the following address: [http://www.chpca.net/public\\_policy\\_advocacy.htm](http://www.chpca.net/public_policy_advocacy.htm).

CHPCA continues to involve parliamentarians in advocacy and policy issues related to hospice palliative care. Information packages were delivered to Parliamentarians twice during the fiscal year. Copies are available upon request.

CHPCA also maintains its high profile with regard to the review and renewal of the Canadian health care

system, and will continue to disseminate key information to its members when appropriate. Throughout the last fiscal year, Sharon Baxter, Executive Director of the CHPCA, accepted opportunities to raise awareness of hospice palliative care issues and spoke at numerous events and conferences (keynote speaker, plenary speaker and workshop presentations).

In the spring of 2005 the CHPCA was asked to prepare a submission for the Update Report "*Still Not there. Quality End-of-Life Care: A Progress Report*" released by Senator Sharon Carstairs on June 2<sup>nd</sup>, 2005. This update report reviewed the progress in the field of hospice palliative care since the 2001 Senate Report "*Quality End-of-Life Care: the Right of Every Canadian*". You can find a copy of the report as well as other resources by following the link on the CHPCA's home page at [www.chpca.net](http://www.chpca.net).

#### **Quality End-of-Life Care Coalition of Canada (QELCCC)**



CHPCA acts as the Secretariat for the Quality End-of-Life Care Coalition of Canada (QELCCC), a coalition of 31 national organizations with an interest in end-of-life care. As the Secretariat, the CHPCA coordinates the work of the Coalition including work planning, leadership with advocacy, and report writing.

Members of the QELCCC met face-to-face in January 2005 to plan the coming year's workplan. This meeting was also an opportunity to reflect back on the work accomplished in 2004. The QELCCC has identified five key areas for their work: Advocacy, Research Utilization, Family and Informal Caregiver Support, Public Information and Awareness and Professional Education.

In September 2004 the QELCCC released a status report on end-of-life care in Canada entitled "*Dying for Care*". This report highlighted provincial inequities with regard to access to hospice palliative care services and provided recommendations to policy makers to address these inequities. A national press conference announcing the release of the report was held in Ottawa on September 9<sup>th</sup>, 2004. A record number of media outlets covered the press conference, which resulted in news articles in more than 50 media outlets across Canada. CHPCA staff as well as national and local spokespersons were also interviewed by various news outlets for their reaction to the release of the report.

The QELCCC completed an evaluation project in the



winter of 2005 that examined the operating structure of the QELCCC to identify the successes and challenges of the Coalition. The results of the evaluation led to the development of recommendations that the QELCCC's Executive have begun to address. As part of the evaluation project, a PowerPoint presentation has been developed to share the lessons learned with the wider community. The presentation has been delivered at various events.

CHPCA continues to represent the QELCCC when appropriate in the public, with governments and with other national health care organizations. More details on the Quality End-of-Life Care Coalition can be found on their web pages located on the CHPCA website at: [http://www.chpca.net/quality\\_end-of-life\\_care\\_coalition\\_of\\_canada.htm](http://www.chpca.net/quality_end-of-life_care_coalition_of_canada.htm).

### ***Development of Policy Champions and Policy Alerts***

The CHPCA continues to develop a list of key policy champions across Canada. These champions are periodically sent information e-mails containing news about current issues in hospice palliative care. Occasionally the champions are asked to respond to requests for action or may just be kept up-to-date on current issues. The policy champions list was used to relay information on key policy issues including the CHPCA's Advocacy Strategy, the Compassionate Care Benefit, the Canadian Strategy on Palliative and End-of-Life Care and the update report released by Senator Sharon Carstairs in June of this year.

Alerts are traditionally sent to provincial hospice palliative care associations, provincial presidents, provincial staff, provincial and national Boards of Directors and individual policy 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](mailto:info@chpca.net).

### ***National Norms of Practice Follow-Up***

In the last year CHPCA has moved forward concerning the dissemination and uptake of *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice*. Some highlights include:

- The Norms Committee co-chairs continue to meet via teleconference with the CHPCA to ensure the ongoing dissemination of the Model, as well as the development and publication of journal articles where appropriate.
- Norms workshops were presented at various conferences and meetings.
- The Pallium Project designed its service

delivery initiatives using the Model as a guide.

- A Norms Toolkit entitled "*Applying A Model to Guide Hospice Palliative Care: An Essential Companion Toolkit for Planners, Policy Makers, Caregivers, Educators, Managers, Administrators and Researchers*" was developed. This Toolkit was designed to assist groups with the implementation of the Model within their program or service by providing concrete examples of how the Model has been used by actual programs and services.
- Draft Pediatric Norms of Practice, based on the Model, were developed in both English and French. These Draft Pediatric Norms can be downloaded for review from the CHPCA website ([www.chpca.net](http://www.chpca.net)) or the Canadian Network of Palliative Care for Children's website at [www.cnpcc.ca](http://www.cnpcc.ca).

### ***National Policy Development Framework***

Each year the CHPCA develops an Advocacy Strategy as it pertains to current health policy related to hospice palliative care. The 2005 Advocacy Strategy was circulated widely via e-mail and is also available on the CHPCA website. The workplan detailed in the Advocacy Strategy was for the most part completed. The provincial hospice palliative care associations have continued to meet with their provincial/territorial governments when possible. At a national level the CHPCA continues to develop key messages and frameworks for a well-funded national strategy on palliative and end of life care. The CHPCA has also taken advantage of opportunities to meet with federal Members of Parliament and Senators when possible. With the expectation of an election in early 2006 the CHPCA is beginning to prepare its federal election strategy that will be widely distributed throughout our communications networks.

## **II Communications / Awareness**



AVISO is the association's membership newsletter. Published in February, June and October in print and electronic formats, the newsletter provides information to the CHPCA membership regarding the state of hospice palliative care in Canada. Members can choose to receive the newsletter via e-mail or by regular mail. Regular features in the newsletter include: President's Report, Executive Director's Report, Provincial Association Updates, suggested Resources, updates on CHPCA Projects and updates from the CHPCA Interest Groups and Committee work. AVISO regularly features

articles submitted from the hospice palliative care community on a variety of topics.

### ***National Hospice Palliative Care Week***

National Hospice Palliative Care Week 2005 took place from May 2<sup>nd</sup> to May 8<sup>th</sup>. This year's theme, 'The Many Faces of Caregiving' was all-inclusive as it reflected the many different forms of caregiving at the end of life.



This year's event was the biggest ever as the CHPCA expanded its distribution list to include the membership of several of the Quality-End-of-Life-Care Coalition of Canada members for a total of 1,139 information packages disseminated across the country. Information about the Week was also included in a regular mailing to the Members of Parliament and the Senate.

In addition to the dissemination of resources, on May 2<sup>nd</sup>, The Honourable Dan Hays, Speaker of the Senate, hosted a breakfast on Parliament Hill in celebration of the Week. The event was attended by Members of Parliament, the Senate, as well as representatives from the hospice palliative care community in Ottawa. Speakers at the breakfast included The Honourable Dan Hays, Speaker of the Senate, The Honourable Ujjal Dosanjh, Minister of Health, and Sharon Baxter, Executive Director of the CHPCA.

Another exciting event which occurred during the Week was a press conference held on Parliament Hill on May 5<sup>th</sup> hosted by The Honourable Tony Ianno, Minister of State (Families and Caregivers). The purpose of the press conference was to launch 'A Caregiver's Guide' – A Handbook About End of Life Care'. This new resource is a revised national edition of a handbook that was originally developed and published in Alberta in 2000 by the Palliative Care Association of Alberta and The Military and Hospitaller Order of St. Lazarus of Jerusalem. Initial copies of the national guide were distributed to hospice palliative care programs and services that were registered with the CHPCA's On-line Directory as of December 1<sup>st</sup>, 2004. The handbook is available to family and informal caregivers free of charge. The national version of the Handbook was a joint project of the CHPCA and the The Military and Hospitaller Order of St. Lazarus of Jerusalem.

National Hospice Palliative Care Week provides hospice palliative care programs and services across Canada with a chance to showcase their services and encourages people to discuss end-of-life care issues. We thank all of those organizations that hosted events

during the week.

We also wish to thank this year's sponsors: Health Canada and The GlaxoSmithKline Foundation.

### ***Communication Strategy***

The CHPCA Board of Directors has approved a Communication Strategy for the association that will guide our work for the next year. This strategy elaborates on the association's key messages, the environment we work in, and key activities and opportunities for policy change. The Communication Strategy will be reviewed and revised annually in conjunction with the development of the association's annual Workplan.

### ***Government Relations Strategy***

The CHPCA has moved forward this past year with respect to its Government Relations Strategy. The CHPCA is actively engaged with the following federal departments or agencies: Health Canada, Human Resources and Skills Development Canada, Social Development Canada, Canadian International Development Agency and the Prime Minister's Office (PMO). The CHPCA liaises with other federal government agencies as needed. Through its relationship with the QELCCC, the CHPCA has been in correspondence with provincial and territorial governments regarding provincial health policy and to date has received positive responses from all levels of government.

### ***Media Relations Strategy***

The CHPCA is pleased to report that it garnered an increase in contact from national and regional media this past year. The QELCCC's launch of the "Dying for Care" Report (Sept. 2004) raised further awareness among the media that hospice palliative care continues to be "an important" issue. As reported earlier in this report, the media coverage of the release of the QELCCC's "Dying for Care" report was very positive. To ensure effective media coverage of hospice palliative care issues in Canada, the CHPCA maintains an up-to-date media list of national and regional media outlets.

### ***Monthly National Office E-mail Updates***

The CHPCA prepares monthly e-mails that are 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. In 2004-2005 the monthly updates were used to provide information about: the *Dying for Care* report; the 2005 Advocacy Strategy; the Hike for Hospice Palliative Care and National Hospice Palliative



Care Week; project updates; and the 2005 National Hospice Palliative Care Conference. The distribution of the Monthly Update allows the CHPCA to disseminate information in a timely manner. Currently the Monthly Update is sent to 2,000 individuals. Persons wishing to receive copies of the CHPCA monthly updates can be added to the distribution list by sending a request to [info@chpca.net](mailto:info@chpca.net).



### ***Living Lessons® Information Service***

The *Living Lessons®* Information Service continues to provide end-of-life information and support to Canadians across the country and around the world.

Since its inception in 1997, the service has engaged in a number of activities to raise the awareness of patients, caregivers (professional, family and informal), policy-makers, decision-makers, and the general public regarding hospice palliative care resources, programs and services in their community. Some of the elements of the campaign have included the following resources: a media training kit for health care workers, a Caregivers Bill of Rights, information pamphlets including the *You are Not Alone* brochure, a bilingual website ([www.living-lessons.org](http://www.living-lessons.org)); a Physicians Training Guide, an advocacy campaign directed at Canadians, elected officials and the media; and the very popular *A Guide for Caregivers*.

In 2004-2005 the *Living Lessons®* Information Service responded to 4,396 requests and provided assistance with enquiries regarding:

- General resources for patients, caregivers, volunteers, family members, doctors, nurses, social workers, spiritual counsellors, physiotherapists, those working in pediatrics, rural health workers, pharmacists, alternative medicine, aboriginal issues, volunteer groups and the general public.
- Availability of hospice palliative care programs and services in Canada and other countries.
- Specific resources and information on how to care for loved ones facing the end of life.
- Resources and information for bereaved caregivers, volunteers, family members and friends.

In 2004, 95% of the requests were received from within Canada with 5% being international requests for information.

More than 25,000 copies of the *Living Lessons® - A Guide for Caregivers* as well as other *Living Lessons®* materials were published and distributed in 2004

The CHPCA recognizes The GlaxoSmithKline Foundation for the ongoing partnership with the CHPCA and the financial support of the *Living Lessons®* Information Service. In September 2004 the CHPCA presented the association's Leadership Award to The GlaxoSmithKline Foundation and the staff at GlaxoSmithKline for their leadership, vision, dedication and contribution to hospice palliative care in Canada.

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

Since going on-line in 2002, the CHPCA's Canadian Directory of Hospice and Palliative Care Programs and Services has enabled broad access to information concerning the availability of hospice palliative care programs and services in every province and territory in Canada. The Directory currently contains the contact information of over 450 hospice palliative care programs and services and continues to be a self-registering service where programs and services can update their information when necessary.

In 2005 the CHPCA began using the On-Line Directory as its distribution list to disseminate complimentary resources such as National Hospice Palliative Care Week materials and complimentary copies of the *A Caregivers Guide: A Handbook About End of Life Care*.

### ***CHPCA Websites – Development and Maintenance***

The CHPCA maintains two websites, one in English and a parallel site in French. The use of the Internet continues to be a substantial component of the association's Communications Strategy allowing the CHPCA to operate at a national and international level. The CHPCA continues to maintain and update the information on the websites on a regular basis.

### ***CHPCA Interest Group List Serves***

The CHPCA continues to offer e-mail List Serves to each of the CHPCA Interest Groups. Established in the summer of 2003, the List Serves have become a useful tool for those working in hospice palliative care as they facilitate communication with others who share their particular interests. Questions and comments posed to the list serves range from inquiries about discipline-specific educational programs and courses, to requests for ideas and suggestions regarding patient care. No matter the content, the discussions are lively and informative. Individuals wishing to join a list serve (see list of Interest Groups on page 13) can send a request to Gillian Fernie at [info@chpca.net](mailto:info@chpca.net).

### III Fundraising and Development

In 2004-2005 the CHPCA was active in the fundraising and development area to limited success. CHPCA developed and distributed a fundraising synopsis that included brief descriptions and profiled sponsorship opportunities for the private and government sectors. The CHPCA re-constituted its Fundraising Committee last fiscal year and is actively looking for other key participants.

The CHPCA has developed a Three-Year Fundraising Plan that has been endorsed by the Board of Directors. Copies of the Fundraising Plan are available from the national office.

### IV Governance

#### *Board of Directors*

The Canadian Hospice Palliative Care Association is led by an active, dedicated Board of Directors who meet face-to-face twice each year. When the Board is not in session, the Executive Committee is charged with conducting the business of the association and meets regularly via teleconference. In September 2004 the Board of Directors hosted the association's Annual General Meeting in Montreal, Quebec. 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. The Committees assist the Board of Directors in the effective operation 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 can be found on the CHPCA websites.

#### *Annual General Meeting (AGM)*

The Board of Directors hosts the CHPCA Annual General Meeting each year. The 2004 Annual General Meeting was held on Monday Sept. 20<sup>th</sup>, 2004 at the Palais des congrès in Montreal, Quebec. Regular

agenda items include: the Executive Director's Annual Report; presentation of the Audited Financial Statements; the election of Members-at-Large to the Board of Directors; presentation of the CHPCA Award of Excellence; presentation of the CHPCA Leadership Award, and presentation of the CHPCA Board of Directors for the coming year. Other association business is included on the agenda when necessary. The 2005 Annual General Meeting is scheduled for Sunday, September 25<sup>th</sup>, 2005 at the Shaw Conference Centre, Edmonton, Alberta.

#### *By-Laws and Procedural Policy Development*

This activity continues to support the By-Laws Committee of the CHPCA Board of Directors. In 2004 the By-Laws Committee prepared draft procedural policies for the Board's consideration. These procedural policies work in conjunction with, but do not affect, the association's By-Laws. When necessary, procedural policies are presented to the Annual General Meeting for endorsement.

#### *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: First, 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 that 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.

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.

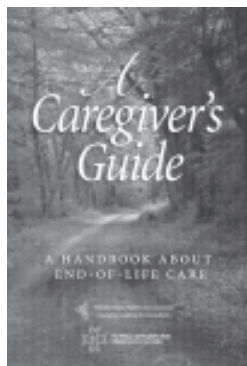
## ***CHPCA Strategic Planning***

In 2001 the CHPCA developed a Strategic Plan in consultation with each of the provincial hospice palliative care associations. In 2004 the CHPCA Board began the process to update and evaluate the current Strategic Plan. The process is well under way and will be completed in the 2005-2006 fiscal year.

## ***Membership Issues***

The CHPCA reconstituted the Membership Committee this past year by soliciting representation from across the country. The Committee has met a number of times via teleconference and has been spending its time examining the current membership situation regarding benefits of membership, the membership fee structure, and what actions the CHPCA can take to provide further assistance to the membership. This committee has also overseen a comprehensive membership survey that was distributed early in the 2005-2006 fiscal year.

## **V Projects & Initiatives**



### ***A Caregiver's Guide – A HANDBOOK ABOUT END-OF-LIFE-CARE***

In January 2005 the CHPCA co-published “*A Caregiver's Guide – A handbook about end of life care*”, a joint project with The Military and Hospitaller Order of St. Lazarus of Jerusalem.

“*A Caregiver's Guide*” presents family and informal caregivers

with the information they need to care for their loved ones at the end of life. The medical and supportive information in the book is presented in clear, easily understood language, helping family and informal caregivers understand the journey upon which their loved ones have embarked. This new national guide gives family and informal caregivers the tools they need to become effective, informed members of the hospice palliative care team and to provide essential physical, spiritual and emotional support to their loved one.

“*A Caregiver's Guide*” is an example of a regional initiative that grew to have national application. Seven years ago the need was identified in Alberta for a publication to complement the information given to family caregivers by home care and hospice palliative care nurses. Working with the Palliative Care Association of Alberta and the Edmonton regional program, a team of experienced hospice palliative care professionals including nurses, doctors, homecare workers, social workers and spiritual advisors

developed the framework and content which was then peer reviewed. The provincial version of “*A Caregiver's Guide*” was published in Alberta in 2000 with the financial support of the The Military and Hospitaller Order of St. Lazarus of Jerusalem.

With the success of the rollout of “*A Caregiver's Guide*” in Alberta, it was decided to make this resource available to all Canadians. A national advisory committee was struck to review the provincial guide and make necessary adjustments for a national release in both official languages.

Limited complimentary copies of the handbook were distributed in January 2005 to hospice palliative care programs registered with the CHPCA's On-Line Directory of Services. Copies of “*A Caregiver's Guide*” are available from the CHPCA national office in Ottawa.

This national project was made possible through financial support from The Military and Hospitaller Order of St. Lazarus of Jerusalem, and additional funding from Great-West Life, London Life and Canada Life.

## ***CHPCA Award of Excellence***

In 2004 the Canadian Hospice Palliative Care Association Award of Excellence was presented to a most deserving candidate; Mr. Jerry Rothstein, a unique individual with a passion and energy to ensure quality end-of-life care for all Canadians.



***Mr. Jerry Rothstein***

A visionary regarding the role volunteers play as part of the interdisciplinary hospice palliative care team, Mr. Rothstein is driven by a deep commitment to the ideals, principles and values of the hospice palliative care movement. As the former Coordinator of Volunteer Services and Quality Care at Victoria Hospice Society, Mr. Rothstein played a key role in the development of the volunteer component at a local level. As a member of the CHPCA Volunteer Issues Committee and a member of the Best Practices and Quality Care Working Group, Secretariat of Palliative and End-of-Life Care, Mr. Rothstein has taken his commitment to a national level working on the development of national norms of practice for hospice palliative care volunteers. Mr. Rothstein is writer and contributor to a number of professional and academic publications and has been invited to speak at numerous conferences and workshops. He is described by his peers as passionate, driven and dedicated.



### ***CHPCA Interest Groups***

CHPCA continues to support the work of the CHPCA Interest Groups. (See page 13 for the Interest Group List) Each Interest Group operates autonomously and is governed by terms of reference approved by the CHPCA Board of Directors. Interest Groups are provided with meeting space each year in conjunction with the CHPCA Annual General Meeting. The last face-to-face meeting of the CHPCA Interest Groups was in September 2004 in Montreal. The 2005 meetings will be held at the Shaw Conference Centre in Edmonton Alberta on September 25<sup>th</sup>, 2005. The Interest Group meetings are a time for each group to meet and discuss current and emerging issues within their interest. Issues of national relevance are communicated to the CHPCA Board of Directors for discussion and possible action. The CHPCA also maintains web pages for each of its Interest Groups. The basic information contained on the Interest Group web pages is the name and contact information of the chair of the Interest Group. When requested, the CHPCA will post additional information and resources on the web pages on behalf of the Interest Groups. The CHPCA provided administrative support and logistics for each of the CHPCA Interest Groups in 2004-2005.

### ***CHPCA Leadership Award***

The Canadian Hospice Palliative Care Association Leadership Award was presented to The GlaxoSmithKline Foundation in September 2004, in recognition of the Foundation's outstanding contribution to the field of hospice palliative care in Canada. The award was accepted by Ms. Karen Chow, Manager, Community Partnerships & Philanthropy, on behalf of The GlaxoSmithKline Foundation at the 2004 Annual General Meeting in Montreal, Quebec.

The Canadian Hospice Palliative Care Association Leadership Award is given to an individual or group,



*From Left to Right: Dr. Larry Librach (CHPCA Board of Directors), Mr. Paul Lucas (President, The GlaxoSmithKline Foundation), Ms. Sharon Baxter (Executive Director, CHPCA)*

in recognition of their exceptional leadership, dedication and vision in advancing hospice palliative care for all Canadians. The Foundation has helped to achieve significant progress in hospice palliative care by initiating and supporting groundbreaking programs and bringing much needed attention to this issue.

### ***Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC)***



Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC) is an initiative that strives to bring education in palliative and end-of-life care to all undergraduate medical students and clinical postgraduate trainees at Canada's seventeen medical schools so they will graduate with competencies in these areas by the year 2008. EFPPEC was established as part of national efforts to address the crucial need for appropriate education and training for all health professionals who are involved in providing palliative and end-of-life care. EFPPEC is a joint project of the Association of Faculties of Medicine of Canada and the Canadian Hospice Palliative Care Association with funding from Health Canada.

#### Key Achievements

In 2004/2005, EFPPEC:

- was launched and, within three months, established a Management Committee with broad local, national, and multidisciplinary representation, comprised of leaders from existing Canadian networks in palliative and end-of-life care;
- obtained the support of the Deans of Medicine at all seventeen faculties of medicine to utilize a model of local inter-professional teams at each of the Faculties of Medicine;
- gained the support of key people in the Royal College of Physicians and Surgeons, the College of Family Physicians, the Canadian Association of Schools of Nursing, and the Association of Faculties of Pharmacy of Canada;
- facilitated the designation of local leaders at all of the faculties of medicine and the establishment of local teams at fourteen of the seventeen faculties;
- reached consensus on a set of six core competencies and learning outcomes for undergraduate training in palliative and end-of-life care through its on-line Core Competencies Survey, an iterative process in collaboration with the local teams;
- designed and implemented the Curriculum Inventory Tool for local teams to identify current curriculum content and gaps in physician education in palliative and end-of-life care;

- planned and organized the EFPPEC Symposium 2005, April 28 – 30, 2005 for educators, care providers, policy makers and opinion leaders to share ideas and information about curriculum development and educational research for physician education in palliative and end-of-life care;
- established the Learning Resources Working Group to collaborate with local teams in identifying good learning resources to address the learning objectives of the six core competencies; and began planning for an on-line resource base with an annotated bibliography and a forum for sharing curriculum and teaching programs.

### ***Hike for Hospice Palliative Care***

2005 marked the third year for the CHPCA's Hike for Hospice Palliative Care. The slogan for the 2005 Hike was 'Come Hike With Us!' The 2005 Hike took place on Sunday, May 1<sup>st</sup>.



Approximately 5,000 people across the country hiked raising over \$525,000! 90 hospice palliative care organizations took part which was a 13% increase over 2004. Of the 90 organizations that hosted a Hike, 24 were first-time Hike sites.

Thanks to the generous support of the founding sponsor, The GlaxoSmithKline Foundation, 100% of all proceeds remain with the host sites.

The purpose of the Hike is not only to raise much needed funds for hospice palliative care in Canada, but also to raise awareness of the many challenges faced by hospice palliative care and to promote the work of all volunteers and professionals in the field.

The funds raised may provide expert medical care to help with pain and symptom management, information about financial and legal services, planning with loved ones for a team approach to care, telephone counselling in crisis situations, respite care to give family and informal caregivers a break and ongoing bereavement support after the death of a loved one.

The role of the CHPCA was to organize the Hike at the national level by creating many of the tools local sites require to host their event. Some of those tools included a planning document, posters, brochures, media releases, and newspaper ads. In total the CHPCA distributed 6,731 bilingual posters and 34,752 bilingual brochures. CHPCA does not get involved in the logistical details of running the Hike at the local level; however, the planning document does provide sites with great detail on areas they may want to consider as they plan their Event. CHPCA also made arrangements for all

sites to order T-shirts from Colortex Screen Printing. This arrangement secured a volume rate to make the purchase of T-shirts affordable by each site.

Feedback from the 2005 questionnaire stated that this year's Hike was the most successful ever. The 2006 Hike will take place on Sunday, May 7, 2006.

### ***International Issues***

CHPCA struck an International Cooperation Committee that first met in the fall of 2003. This committee has met face-to-face twice to plan and coordinate the international work that CHPCA might engage in. The international committee has set three main goals for its work: Awareness / Knowledge Transfer; Twinning; and Advocacy.

In the 2004-2005 fiscal year CHPCA has been involved in a number of international initiatives including:

- Hosted an international satellite in Montreal in September 2004 on HIV/AIDS and palliative care in Africa.
- Worked with the South African hospice palliative care community and the Canadian International Development Agency on a proposal for funding.
- Proposed a hospice palliative care plenary session to be held during the next World AIDS Conference scheduled for Toronto in August 2006.
- Attended the 2<sup>nd</sup> Global Summit of National Hospice and Palliative Care Associations in Korea. A Declaration was signed and distributed to all participating countries. The Declaration has been endorsed by the CHPCA Board of Directors and a copy of the declaration can be found on the following web site: [http://www.chpca.net/about\\_us/monthly\\_updates/March2005Korea\\_Declaration\\_final\\_draft\\_march\\_2005\\_EN.pdf](http://www.chpca.net/about_us/monthly_updates/March2005Korea_Declaration_final_draft_march_2005_EN.pdf).

### ***Pediatric Hospice Palliative Care: Guiding Principles and Norms of Practice***

The CHPCA published *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice* in March of 2002. Based largely on an 'adult' model of care, it was realized by pediatric hospice palliative care programs and services in Canada that to provide quality end-of-life care to children living with a life-threatening illness and their families, it would be necessary to develop a modified version of the national norms of practice to be used in pediatric hospice palliative care. Working in partnership with the Canadian Network of Palliative Care for Children (formerly the Pediatric Interest Group) the CHPCA



undertook a project to draft national pediatric norms of practice based on the CHPCA Model. The process to create draft national pediatric norms of practice was facilitated by foundational work already completed by the Hospital for Sick Children in Toronto, Ontario, and the Pediatric Hospice Palliative Care Committee of British Columbia. The draft document “Pediatric Hospice Palliative Care: Guiding Principles and Norms of Practice” was published in both official languages by the CHPCA in July 2004. The next step in the process towards national consensus is a project to conduct a national consensus building process to refine the draft pediatric norms document. It is hoped that this consensus project will be funded in the 2005-2006 fiscal year.

***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 was completed in 2004 and resulted in the creation of a discussion document that provides a critical assessment of the legal, ethical and moral challenges that family and informal caregivers face in Canada. A draft policy document was also produced that provides five policy options to explore in addressing these critical issues which will be further developed for future policy work in this area. These areas will be explored particularly as they relate to new health care reforms and initiatives, such as the Compassionate Leave Benefit. To assist with the ongoing work, the CHPCA struck a Family and Informal Caregivers advisory committee to advise the staff regarding issues related to this critical area.

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: Wendy Wainwright	Membership Committee Chair: Larry Librach
Executive Committee Chair: Gael Page	Nomination Committee Chair: Gael Page
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 Chair: Deborah Randall-Wood	

Terms of Reference for each Committee can be found on the CHPCA website at:

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

## CHPCA Interest Groups

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

Aboriginal Issues Group Chair: Rosella Kinoshameg	Pharmacists Group Chair: Eve Sample
Canadian Network of Palliative Care for Children (formerly the Pediatric Interest Group) Co-chairs: Filomena Nalewajek & Mike Harlos	Physiotherapists Group Chair: Janice Hagel
Complementary/Integrative Therapies Group Chair: Dr. Doreen Oneschuk	Rural Issues Group Chair: Anne Pollett
Long-term Care/Continuing Care Group Chair: Janice Chobanuk	Social Workers/Counsellors Group Chair: Wendy Wainwright
Northern Issues Group Contact: Cathy Routledge	Spiritual Advisors Group Chair: Rev. Dan Cooper
Nurses Group Chair: Darlene Grantham	Volunteer Issues Group Chair: Jerry Rothsetin

Terms of Reference for each Interest Group can be found on the CHPCA website at:

[http://www.chpca.net/interest\\_groups.htm](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](mailto:info@chpca.net).

## 2004 - 2005 Donors

### *Government Sponsorship*

Health Canada  
Human Resources and Skills Development Canada

### *Private Sector Sponsorship*

#### PLATINUM SPONSOR (> \$10,000)

The GlaxoSmithKline Foundation  
The Diana, Princess of Wales Memorial Fund  
The Pallium Project  
Solvay Pharma Inc.  
US Department of Health and Human Services, Health Resource and Services Administration

#### SILVER SPONSOR (< \$5,000)

Canada's Research-Based Pharmaceuticals  
Purdue Pharma

### *Public Donations*

Ngaire Abernethy  
Jean Bacon  
Maria Boulanger  
Nancy & Fred Chipman  
Keith Conrad  
Entertainment Publications Employees  
Justine Farley  
Rosella Kinoshameg  
Robert Koop  
Michael Levesque  
Mark Schell  
Nancy & Steve Silcox  
Judy Simpson  
United Way of Greater Toronto  
United Way of Lower Mainland  
United Way of Oakville  
United Way of Ottawa  
United Way of Peel Region  
Ineke Van Zeeland & Greg Adams  
John & Diane Van Zeeland  
Wendy Wainwright

## 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, 2005 and the statements of operations and net assets and CHPC 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, 2005 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.  
April 27, 2005.

CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION  
STATEMENT OF OPERATIONS AND NET ASSETS  
FOR THE YEAR ENDED MARCH 31, 2005

	<u>2005</u>	<u>2004</u>
<b>Revenues</b>		
Advertising revenue	\$ 500	\$ 458
Donations	177,307	160,777
Grants	371,794	276,200
Interest	7,667	8,226
Membership fees	52,793	52,339
Resource material	15,667	10,873
Miscellaneous revenue	<u>12,656</u>	<u>-</u>
	<u>638,384</u>	<u>508,873</u>
<b>Expenses</b>		
Advertising and promotion	3,902	6,625
Bank charges	1,655	1,594
Conference donations	10,000	-
Depreciation	5,102	4,867
Dues and subscriptions	1,420	1,808
Foreign exchange loss	374	-
Human resources	354,332	273,393
Insurance	5,339	5,009
Meeting costs	11,296	6,270
Office rent	23,807	18,526
Office supplies	13,602	12,680
Postage	21,818	16,289
Printing	43,914	34,006
Professional fees	5,006	2,589
Teleconferences	5,074	5,522
Telephone and facsimile	8,641	8,607
Training and professional development	3,382	-
Translations	48,088	30,307
Travel	78,144	79,676
Voluntary recognition and honoraria	<u>767</u>	<u>-</u>
	<u>645,663</u>	<u>507,768</u>
Excess of revenues over expenses (expenses over revenues) from operations (note 9)	(7,279)	1,105
Conference loss	<u>-</u>	<u>(20,000)</u>
Excess of expenses over revenues for the year	(7,279)	(18,895)
Transfer to conference fund	-	(10,000)
Net Assets - beginning of year	<u>160,382</u>	<u>189,277</u>
- end of the year	<u>\$ 153,103</u>	<u>\$ 160,382</u>

BOURIS, WILSON LLP  
Chartered Accountants



CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION  
STATEMENT OF FINANCIAL POSITION  
MARCH 31, 2005

	<u>2005</u>	<u>2004</u>
Assets		
Current		
Cash	\$ 60,966	\$ 164,938
4.50% (2004 - 2.75%) Guaranteed Investment Certificate	100,000	101,455
Accounts receivable	126,844	118,460
Accrued interest receivable	3,958	4,170
GST recoverable	10,572	7,894
Prepaid expenses	1,938	4,292
	<u>304,278</u>	<u>401,209</u>
2.75% term deposit, due May 2005	-	100,000
Capital assets	<u>5,155</u>	<u>6,972</u>
	<u>\$ 309,433</u>	<u>\$ 508,181</u>
Liabilities and Net Assets		
Current		
Accounts payable and accrued liabilities	\$ 28,983	\$ 75,440
Unearned revenue	<u>127,347</u>	<u>247,359</u>
	<u>156,330</u>	<u>322,799</u>
Net Assets		
Net assets invested in capital assets	5,155	6,972
Unrestricted net assets	<u>147,948</u>	<u>153,410</u>
	153,103	160,382
CHPCA Conference Fund	<u>-</u>	<u>25,000</u>
	<u>153,103</u>	<u>185,382</u>
	<u>\$ 309,433</u>	<u>\$ 508,181</u>

BOURIS, WILSON LLP  
Chartered Accountants

CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION  
NOTES TO THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED MARCH 31, 2005

9. In September 2004, the CHPCA Board of Directors received notice from SCO Health Services, (the Landlord) that the lease for the CHPCA office was being terminated with cause, as the SCO Health Service required the office space for their own operations. The CHPCA was forced to seek new office space for the association. Expenses related to the office move, which were not accounted for in the 2004-2005 Budget, totalled \$7,279.00. Recognizing that this expense was beyond the control of the Board of Directors and the national office staff, the Board of Directors passed a motion at the April 2005 Board Meeting to transfer up to \$7,300.00 from the accumulated surplus to offset the expenses related to the move from 43 Bruyère Street, Ottawa to 43 Empress Avenue, Ottawa.