



CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION

ASSOCIATION CANADIENNE DE SOINS PALLIATIFS

2011 - 2012 ANNUAL REPORT



"THAT ALL CANADIANS HAVE ACCESS TO QUALITY END-OF-LIFE CARE"

WWW.CHPCA.NET



VISION STATEMENT

“That all Canadians have access to quality end-of-life care.”

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.

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Charitable Registration Number: 13760 4195 RR 001

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PRESIDENT'S REPORT

Dear CHPCA Colleagues and Friends,

I am pleased that you are taking the time to read through the CHPCA Annual Report, celebrating with us the highlights of another successful year and thinking through the challenges that lay ahead. All of us have a vested interest in making sure that awareness about end-of-life care continues to grow with emphasis on planning for current and future needs. There are important debates occurring across the country on end-of-life care—now is the time to be heard.

The CHPCA team encompasses a broad range of people—the Champions Council, Volunteer Committee and Task Group members, corporate and individual supporters, members, staff and the Board of Directors. This past year we have seen the results of focused efforts by all members of the 'team.' Our Champion's Council members have advocated for end-of-life care before the Parliamentary Committee on Palliative and Compassionate Care (report published November 2011) and in many additional forums. Members and community volunteers worked through the year to design the new Learning Institute (held in June 2012). The Volunteer Training manual is done and anxiously awaited! My fellow Board members have dedicated hours to governance, new initiatives and building both national and provincial capacity.

In particular, the staff of CHPCA have shown their tremendous commitment to moving the strategic directions forward (see website for the Strategic Plan). Whether focusing on projects, new website development, institute planning or knowledge translation, this small group of staff working behind the scenes generate a mighty impact. Through it all, Sharon Baxter (Executive Director) seems to be everywhere at once keeping staff, and the rest of us, on track!

It's been a great year, thank you for sharing it with us and we hope to continue connecting with you in 2013!

Sarah Walker, MSW, RSW
CHPCA Board President





ANNUAL REPORT 2011-2012

The Canadian Hospice Palliative Care Association (CHPCA) is pleased to provide you with highlights of the CHPCA's activities throughout the 2011 – 2012 fiscal year.

The CHPCA Strategic Plan developed in 2010 guides the work of the association. The Strategic Plan can be found at www.chpca.net. Our Strategic Plan has six new strategies. These are:

- Strategy #1: Integrate hospice palliative and end-of-life care principles and practices into all health settings
- Strategy #2: Educate health care providers in all health settings
- Strategy #3: Promote evidence-informed policy
- Strategy #4: Build strong partnerships to improve hospice, palliative and end-of-life care
- Strategy #5: Raise awareness about hospice palliative end-of-life care
- Strategy #6: Build the capacity of the Canadian Hospice Palliative Care Association

The CHPCA focused most of its work in the six main areas above but continued to work on the following key areas in 2011 - 2012:

- Advocacy, Public Policy and Education
- Communication and Awareness
- Sustainability and Governance

The following are short captions of some of the work of the CHPCA. For more detailed information please contact our office at info@chpca.net or visit our re-vamped website at www.chpca.net.

Best wishes,

Sharon Baxter
Executive Director





ADVOCACY, PUBLIC POLICY AND EDUCATION

INFLUENCING NATIONAL POLICY DECISION MAKERS

The CHPCA continues to interact with the federal government aiming to improve hospice palliative care programs and services in Canada. In 2011-2012, the CHPCA engaged Health Canada, the Public Health Agency of Canada, Heritage Canada, Human Resources and Skills Development Canada, and other departments that play a pivotal role in end-of-life care.

The federal government has eight national strategies that are funded and supported to various levels. We believe that all health strategies should include palliation as a key pillar. The Canadian Partnership Against Cancer (CPAC) has included hospice palliative care in their new strategic plan and is an active member of the advisory committee of the Way Forward Integration Initiative.

The CHPCA is currently attempting to work with each of these strategies in some way. The eight strategies include:

- Canadian Partnership Against Cancer (CPAC)
- Heart Health
- Chronic Disease Management
- Seniors
- HIV/AIDS
- Diabetes
- Aboriginal Health
- Mental Health

POLITICAL STRATEGY

The CHPCA submitted a brief to the House of Commons, Standing Committee on Finance for the pre-budget consultation in August 2011. We were subsequently invited to present to the committee in October 2011 in Montreal, Quebec. In our presentation, we commended the government on their 3 million dollar investment in the Way Forward Integration Initiative and encouraged the federal government to continue to take steps towards improving hospice palliative care access and consistency across Canada. Please see more on The Way Forward Integration Initiative later in this report. CHPCA also highlighted the recommendations coming out of the Blueprint for Action: 2010-2020 (Quality End of Life Care Coalition on Canada).

In October 2011, the CHPCA was invited to speak before the Senate Committee on Social Affairs, Science and Technology on hospice palliative care and home care for the review of the 2004 health accord. The resulting Committee report *Time for Transformative Change: A review of the 2004 health accord*, was released in March 2012, and included several recommendations on improvements to hospice palliative care in Canada.

The non-partisan Parliamentary Committee on Palliative and Compassionate Care released their report *Not to Be Forgotten: Care of Vulnerable Canadians*, in November 2011. The CHPCA and its partner groups received quite a bit of media pick up, and the report was well received by all. The





CHPCA and the QELCCC will continue to work with this Committee in 2012-2013 to ensure the recommendations put forth in this report are seriously considered by the federal government.

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KNOWLEDGE TRANSLATION

The CHPCA was involved in several Canadian Institutes of Health Research (CIHR) funded knowledge translation projects throughout 2011-2012. Projects included: “Knowledge Translation of the Compassionate Care Benefit” with Allison Williams and McMaster University; and “Quality Palliative Care in Long Term Care” with Mary Lou Kelley and Lakehead University.

In 2011-2012, we also applied for CIHR funding to take on a knowledge translation project titled, “Caring about Caregivers: a collaborative approach to advancing knowledge and practice for family caregivers.” CHPCA is continuing to work with Robin Cohen and Kelli Stajduhar on this work. Funding was approved in February 2012 for one year and will be described in more detail in our 2012-2013 Annual Report.

The CHPCA contributes their time and efforts to these projects as they align well with the CHPCA’s belief that providers in all settings – including physicians, nurses, social workers, nursing aides, personal support workers and pharmacists -- must have the knowledge and skills to provide quality hospice palliative and end-of-life care, as well as the emotional and spiritual support to provide this care. The CHPCA hopes to continue contributing their time and efforts to many future knowledge translation initiatives as they relate to hospice palliative end-of-life care.

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QUALITY END-OF-LIFE CARE COALITION OF CANADA (QELCCC)

The CHPCA has served as the Secretariat for the Quality End-of-Life Care Coalition of Canada (QELCCC) since its inception in 2000, organizing the work of the Coalition including work-planning, coordination, and report writing. As the Secretariat, the CHPCA continues to host teleconferences for the six QELCCC Committees (Executive; Advocacy; Research Utilization; Communications & Public Awareness; Family and Caregiver Support; and Education). Since its inception in 2010, the QELCCC has used the Blueprint for Action: 2010 – 2020 report to guide its advocacy and policy efforts. In 2011-2012, these efforts resulted in the federal government funding of The Way Forward Integration Initiative. The QELCCC will continue to use the Blueprint to advocate for change so that all Canadians have access to high quality end-of-life care.

The QELCCC met in January 2012 to develop the 2012 workplan (available for viewing at www.qelccc.ca). The QELCCC’s major goal in 2012 is to continue to disseminate and use the Blueprint as an advocacy tool. The Blueprint guides the development of the QELCCC’s annual workplan, and serves as a touchstone for end-of-life care researchers, policy makers and providers. The QELCCC also extended their annual meeting by one day to discuss the workplan and stakeholders for the Way Forward Integration Initiative. This initiative will be managed by the CHPCA under the guidance of the QELCCC.

More information about the QELCCC, including its semi-annual and annual reports can be found at: www.qelccc.ca.





THE WAY FORWARD: MOVING TOWARDS COMMUNITY-INTEGRATED HOSPICE PALLIATIVE CARE IN CANADA

In the 2011 Federal budget, the Government of Canada announced a commitment of one-time funding of \$3 million to help support the development of new community-integrated palliative care models. The three year integration initiative, The Way Forward: Moving Towards Community-Integrated Hospice Palliative Care in Canada, led by the QELCCC and managed by the CHPCA, will engage all settings, sectors, professionals and governments in a dialogue regarding the implementation of community-integrated palliative and end-of-life care. Over the course of this Initiative, we will encourage engagement and dialogue based upon sound evidence and promising practices. This will result in a Framework with targets and strategies that all stakeholders will have a hand in shaping that reflect their needs and challenges, and therefore give them ability to implement these strategies at all levels.

A meeting of the QELCCC members was held in January 2012, just prior to the start of the project funding in February 2012, to engage members in the project from the onset. Coalition members are represented on an Integration Initiative Advisory Committee by the chairs of the five QELCCC Committees. The Advisory Committee met in March 2012 to develop a high-level year two workplan and a detailed engagement plan of key stakeholders. The Initiative team will begin work on a mapping document in May 2012. This document will map the partners/areas of interest and engagement and serve as the basis of the communication strategy. The federal Minister of Health will make an official announcement about The Way Forward integration initiative in the next fiscal year. Staffing for the project will be in place in early 2012/2013.




ADVANCE CARE PLANNING IN CANADA: A NATIONAL FRAMEWORK AND IMPLEMENTATION

Advance Care Planning in Canada: A National Framework and Implementation

This multi-year project is intended to raise awareness about the importance of advance care planning and to equip all Canadians – individuals, families, communities and health professionals - with the tools they need to effectively engage in the process.

The Speak Up: Start the Conversation about end-of-life care campaign, part of the advance care planning project, was officially launched on April 12, 2011 along with a new website www.advancecareplanning.ca. This campaign is about promoting conversations about wishes for end-of-life care and determining a substitute decision maker. Many new resources were developed: an advance care planning workbook, advance care planning video, wallet cards, bookmarks and other tools that can be used by health care professionals and families.





It's about conversations
It's about decisions
It's how we care for each other



The sponsors for this second phase of the project are: Canadian Partnership Against Cancer and The GlaxoSmithKline Foundation.

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ASSOCIATION TASK GROUPS

CANADIAN NETWORK OF PALLIATIVE CARE FOR CHILDREN (CNPCC)

The Executive Committee of the CNPCC is an active committee comprising of professionals from across Canada with an interest in pediatric issues. The purpose of the committee is to:

- Develop, coordinate and maintain a Canadian network for pediatric hospice palliative care.
- Collaborate on national and international activities and initiatives in the field of pediatric hospice palliative care and to seek opportunities for partnerships.
- Assume a role of leadership in pediatric hospice palliative care and to advocate for the needs of children with life-threatening illness and their families.

The committee spent the year focusing on education initiatives, promoting research, and monitoring and responding to pediatric palliative care issues across the country. The CNPCC also maintains a website, which is designed and managed by a volunteer and is found at: www.cnpcc.ca and is linked to the CHPCA's website at: www.chpca.net/about-us/our-team/task-groups.aspx.

A sub-committee of the CNPCC called The Canadian Network of Pediatric Hospices (CNPH) also meets regularly to discuss issues relating to pediatric hospices. The goals of the CNPH are to:

- Develop guidelines for establishing a pediatric hospice.
- Develop information about CNPH and pediatric hospices on the CNPCC website.
- Develop standards of practice for pediatric palliative care.
- Educate other health care professionals about pediatric hospice care.
- Conduct annual public awareness activities about pediatric hospice care.
- Advocate for pediatric hospices.
- Ensure consistency in description of pediatric hospice care.



INTERNATIONAL COOPERATION TASK GROUP AND INTERNATIONAL ISSUES

The International Cooperation Task Group continues to provide advice and guidance on issues pertaining to international cooperation. This committee hasn't been very active in 2011-2012 due to time constraints and lack of funding but continues to promote advocacy, twinning and education. We are optimistic that this work will continue and grow. Please visit the website at www.chpca.net for more details.

The CHPCA is also an active member of the Worldwide Palliative Care Alliance (WPCA) and the International Children's Palliative Care Network (ICPCN). Please refer to the last section of this report for more details on the WPCA and ICPCN.

VOLUNTEER ISSUES COMMITTEE

The Volunteer Issues Committee works towards championing the volunteer component of hospice palliative care in Canada. The committee functions to advise the CHPCA on issues related to volunteers and to encourage research into all aspects of the volunteer component. The committee also works to articulate the critical value of education for volunteers.

In 2010 funding was secured for the creation of a National Volunteer Manual. Throughout 2011 the committee worked towards completing the manual and is preparing for a public launch to occur in 2012-2013.

The CHPCA would also sincerely like to thank and recognize Rx&D: Canada's Research-based Pharmaceutical Companies and The Grand Priory in Canada of the Order of St Lazarus for their contributions to this important project.

COMMUNICATIONS/AWARENESS

COMMUNICATION STRATEGY

The CHPCA continues to closely follow the Communication Strategy outlined in 2009. The strategy is a three year plan which elaborates on the association's key messages, the environment we work in, and key communication activities. Additionally, the CHPCA has been using social media such as "Twitter" and "facebook," to continue connecting with a wider audience. Please see below for a more detailed description of our social media activities. Issues that continue to come up in the media include: access to hospice palliative care and the inconsistency of availability of hospice palliative care programs and services at the provincial and territorial level; issues around euthanasia and assisted suicide; and support for caregivers, including the Compassionate Care Benefit (CCB), for which the CHPCA continues to assist with Knowledge Translation projects to increase awareness. The CHPCA will continue to review its focus and activities in response to relevant socio-economic and political changes. In 2012-2013, the CHPCA will need to review and update the communications strategy.





MEDIA AND PUBLIC RELATIONS

There has been a sustained interest in hospice palliative care in the media throughout 2011-2012. There has been a sustained interest in hospice palliative care in the media throughout 2011-2012. The Globe and Mail did a feature on hospice palliative care and what it means for our aging population. Moreover, CTV News did a three part series on the Compassionate Care Benefit, interviewing Sharon Baxter, CHPCA's Executive Director, and Paul Lucas, member of the CHPCA's Champion's Council. The Hike for Hospice Palliative Care, National Hospice Palliative Care Week and the Canadian Hospice Palliative Care Conference, also garnered media interest, with these events being picked up in many local papers.

The CHPCA is actively engaged with the following federal departments or agencies: Health Canada, Human Resources and Skills Development Canada, and the Prime Minister's Office (PMO). Both independently, and through its relationship with the QELCCC, the CHPCA has been in correspondence with the federal government around national access to hospice palliative care. The CHPCA also continues to provide advice and support to the provincial associations as they work with provincial and territorial governments on issues relating to health policy. The QELCCC and Health Canada have been working closely to launch The Way Forward initiative. The Way Forward initiative is projected to launch in spring 2012.

SOCIAL MEDIA

The CHPCA has spent the past year strengthening our online presence through the use of various social media tools. Our Twitter and Facebook followers have grown exponentially this year. We have been using these tools to: promote national and local events, like the Hike for Hospice Palliative Care; stimulate discussion and awareness; and to disseminate press releases. We also routinely participate in Tweetchats, effectively creating relationships with journalists, clinicians, hospices, caregivers and many others interested in hospice palliative care.

In September of 2011, the CHPCA launched the Online Event (Webinar) Series. Every month the CHPCA facilitates webinars on various topics, including "How to Host a Successful Hike" and "What about me?" Including children when a family member is dying," hosted by experts in the field. These online events have proven to be incredibly successful and we have had upwards of 300 registrants. Moreover, past events are archived on our website, allowing people to watch them when they like, and reference them at a later date.

AVISO

AVISO is the association's membership newsletter. Published in January, May and September in electronic format, it offers information to the CHPCA membership regarding research and policy developments in hospice palliative care, news and events, and other interest pieces both in Canada and internationally. In 2011-2012, the CHPCA officially changed AVISO to be available in digital only format with great success. Regular features include: President's Report, Executive Director's Report, Provincial Association Updates, updates on the CHPCA projects and updates from the CHPCA Interest Groups and Committee work. AVISO also regularly features articles submitted from the hospice palliative care community on a variety of topics. In 2012-2013, the CHPCA will





continue to offer AVISO to members and encourage local service providers to submit local interest stories so that all members will have a greater understanding as to what is happening at the local level.



CHPCA WEBSITES

The CHPCA launched a new website in March of 2012! The new website, along with a search tool, makes it easier for visitors to find valuable resources like the Hospice Palliative Care Fact Sheet, resources for professionals and Living Lessons tools. And like always, we are committed to providing content in both official languages. We are also pleased to announce that the entire website is now bilingual! The only exception is for events that are only available in English – such as the Online Event Series and the Learning Institute.

The CHPCA continues to post press releases and we are also now including articles of interest written by CHPCA staff and other professionals in the field. Do you have an article you would like us to include on our website? Visit www.chpca.net and fill out the “Contact Us” form.

As part of our website redesign, we are also in the process of re-launching our Marketplace! The new format will allow for an easier search and checkout process. As always individuals will be able to pay by cheque and credit card and we have added a PayPal options for those interested. So be sure to visit www.chpca.net often and look for the new Marketplace in August 2012!

Please also visit www.advancecareplanning.ca and www.hpcintegration.ca to view other CHPCA projects.



THE MONTHLY UPDATE AND E-BLASTS

The Monthly Update is prepared and sent electronically to the CHPCA members and those with an interest in hospice palliative care issues, allowing for timely communication to a broad stakeholder base. The Updates focus on providing information about recent key activities related to hospice palliative care policy issues, as well as the CHPCA activities. The Updates also allow for other members of the hospice palliative care community to announce recent findings or events that may be of interest. The CHPCA continues to use an HTML e-mail service provider to allow for more efficient and effective communication, as well as more reliable e-mail delivery, and easier administration of e-mail addresses. Currently the Monthly Update is sent to approximately 4,000 individuals. The CHPCA also sends out periodic E-Blasts for certain events or research studies. Persons wishing to receive the CHPCA Monthly Update and E-Blasts can be added to the distribution list by sending a request to info@chpca.net.



POLICY CHAMPIONS AND POLICY ALERTS

The CHPCA maintains an e-mail list of policy champions who are periodically sent information and breaking news regarding hospice palliative care issues. This e-mail list is designed to quickly contact key individuals interested in hospice palliative care advocacy and public policy issues.

The Champion e-mail list was used a number of times in 2011-2012. Policy blasts included the release of the report Not to be Forgotten: Care of Vulnerable Canadians in November 2011, and the





announcement of The Way Forward Initiative funding in March 2012. Many members responded to these e-blasts, giving us insightful feedback which can be used in future policy and advocacy efforts. Having 4,000 policy champions at our fingertips is exciting and we hope to continue to use this avenue for future advocacy.



CIRCLE OF CARING

Now more than ever, it is vital to recognize that a responsible and caring society is one that includes a commitment to and understanding of hospice palliative care and the impact and importance of dying in peace and with dignity.

Thank you to the CHPCA's group of generous donors who continue to make a difference in the lives of Canadians through the Circle of Caring, the CHPCA's national giving program, bringing donors together who share a common hope – that when the end of life comes to us or a loved one, that it may be peaceful and free from pain.

The CHPCA is focused on building stronger communities, with its incredible dedication to a cause that is often difficult for many to contemplate, but one that will affect us all. We continue to make a difference by working together with the Circle of Caring to raise the profile on the importance of hospice palliative and end-of-life care.

In 2011-12, the Circle of Caring introduced its Virtual Memory Garden, a special area that was created on the CHPCA website to purchase flowers in support of hospice palliative care. The Circle of Caring Memory Garden was created as a place to celebrate life and a place to come together in solace; to celebrate friends and family; to honour the memory of a loved one; and to pay tribute to someone who has touched your life.

<http://www.chpca.net/donations/circle-of-caring-virtual-memory-garden.aspx>



THE CHPCA CHAMPION'S COUNCIL

It has been an eventful year for the CHPCA's Champion's Council as they continue to work together with the CHPCA to expand the profile of hospice palliative care in Canada. This past year focused on engaging different stakeholder groups in understanding end-of-life care, its importance to Canadians and the role that they can play in working together to ensure that high quality care is available for Canadian families.

Fall of 2011 marked the first of several speaking engagements for the Champion's Council, when Paul Lucas challenged Corporate Canada to increase support for hospice palliative care by providing compassionate care benefits for employees. He encouraged employers to take a leadership role and help their employees in a time of need, thereby ensuring a healthier and more engaged workforce.

Kathryn Butler Malette delivered an address in winter 2012 on workplace implications of employees caring for critically ill family members. This was the first direct foray into the Human Resources community, and will open doors for further activity in this sector.





In early spring 2012, The Honourable Sharon Carstairs presented her vision for quality end-of-life care and how all levels of Canadian society can work together to mobilize a range of resources, delivering the best care possible while using these resources efficiently.

The Champion's Council will continue to advance the profile of hospice palliative care with its continued emphasis on compassionate care support and will continue to challenge public sentiment and attitudes towards death and dying, creating public awareness and engaging key societal leaders to lend their voice and help build capacity around end-of-life issues.

For a list of our Champion's Council members, see page 22 or visit:
<http://www.chpca.net/about-us/our-team/champion's-council.aspx>

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CHPCA MARKETPLACE

The CHPCA marketplace is working towards adding to its content with new material and resources in order to help provide health care providers, volunteers and family and informal caregiver's with a more diversified shopping experience. We will continue to offer the resources and information materials that our customers have come to know, such as:

- information brochures
- training manuals
- research documents
- DVDs
- caregiver handbooks
- online resources

New to the CHPCA Marketplace are "Life and Death Matters" materials that focus on increasing the capacity of individuals to provide excellent care for the dying. These resources include, Essentials in Hospice Palliative Care, Second Edition and Essentials Study Guide for Nurses and Health Care Workers; and are available as writing journals, teaching videos and teaching presentations.

A Caregiver's Guide: A Handbook About End-of-Life Care continues to be our most popular resource. In an effort to help support reprinting of this book, the CHPCA in collaboration with the Order of St. Lazarus has implemented a \$2 per book fee for all organizations other than registered charities or provincial health care systems. This nominal charge for a much valued resource has not affected sales volume since its implementation.

Moving forward, we look to further expand our marketplace and will endeavor to keep in mind the needs of the health and caregiver community. In summer 2012 we will be launching a new and more user friendly marketplace to encourage clients to return on a regular basis. All items can be viewed and ordered online at www.market-marche.chpca.net

We will continue to erect the CHPCA marketplace booth at national and provincial conferences when possible.





THE LIVING LESSONS PARTNERSHIP

The Living Lessons® Partnership involves a number of components including national policy development, communication support and the Living Lessons® Information Service. The Living Lessons® Information Service continues to provide valuable end-of-life information and support to organizations, caregivers, health care professionals and the general public across Canada and beyond. It is still as important as ever to raise awareness of the importance of hospice palliative (end-of-life) care, not only to the patients, families and caregivers, but to the general public.

As in past years, the Living Lessons® Information Service continued in 2011-2012 to respond to requests and provided assistance with inquiries regarding: resources for patients, caregivers, volunteers, family members, doctors, nurses, social workers, spiritual counsellors, researchers, those working in pediatrics, rural health workers, pharmacists, alternative medical care providers, aboriginal issues, volunteer groups, students, media and the general public. Requests for information on the availability of hospice palliative care programs and services throughout Canada and other countries; and resources and information for bereaved caregivers, volunteers, family members and friends continues to make the Living Lessons® Information Service invaluable.

The CHPCA thanks and gratefully recognizes The GlaxoSmithKline Foundation for their continued partnership in support of the Living Lessons® Information Service.



HIKE FOR HOSPICE PALLIATIVE CARE

The Hike for Hospice Palliative Care took place across Canada on Sunday May 1, 2011. 2011 marked the ninth year for the hike and was the most successful to date. The event hosted more participants than any other year, with over 6,000 hikers and over 100 participating sites raising more than \$1,600,000. Funds raised during the Hike for Hospice Palliative Care stay in the community in which it was raised and is intended to help fund their specific hospice palliative care programs. The Hike for Hospice Palliative Care continues to be successful in helping to raise awareness of the many challenges within the hospice palliative care field and continues to be a wonderful avenue to promote the phenomenal work that volunteers and professionals perform daily.

2011 also marked the fourth year for the Hike for Hospice Palliative Care online fundraising website. This tool continued to work well as it allowed hikers to easily collect and manage donations online.

Again for 2011 the CHPCA was pleased to have retained Peter Mansbridge as the Honorary Chair for both the 2011 Hike for Hospice Palliative Care and the National Hospice Palliative Care Week.

The CHPCA would also sincerely like to thank and recognize the National Sponsors for their commitment to this important event. This year's sponsors were:

- The GlaxoSmithKline Foundation
- Bayshore Home Health





NATIONAL HOSPICE PALLIATIVE CARE WEEK

The theme for the 2011 National Hospice Palliative Care Week (May 1-7) “Communities Share the Care” “How Can I Help?” Lets Share the Care. The theme was built upon the World Hospice Palliative Care Day’s campaign, “Sharing the Care.” National Hospice Palliative Care Week (NHPCW), the CHPCA’s annual awareness campaign, celebrates and shares the achievements and advancements of hospice palliative care throughout the nation. It also educates Canadians about hospice palliative care and is a time to reflect on many of the challenges facing professionals, families and informal caregivers. Many people do not understand what hospice and palliative care is and how it can benefit people. The CHPCA wanted to hear from Canadians living with life-limiting illness, their care givers, family members, friends, health care professionals, and volunteers who have been touched by hospice palliative care. A website resource was developed through the CHPCA for Canadians to reflect and learn about hospice palliative care. The CHPCA created a space where people could share their story and voice around what hospice palliative care meant to them. Organizations across Canada hosted a variety of events which included: a palliative care fundraising concert; volunteer appreciation activities; ribbon campaigns; palliative care education seminars; ‘lunch and learns’; hospice open houses; and palliative care conferences. We were honoured to once again have Peter Mansbridge of the CBC act as the honorary chair for the campaign.

The sponsors of the 2011 National Hospice Palliative Care Week were:

- The GlaxoSmithKline Foundation
- Health Canada
- Valeant Canada Limited

Planning for the 2012 National Hospice Palliative Care Week campaign began in the fall, and Peter Mansbridge was recruited to participate as the Honorary Chair once again.

CANADIAN HOSPICE PALLIATIVE CARE CONFERENCE

At the Delta St. John’s Hotel and Conference Centre in beautiful St. John’s, Newfoundland from September 8 to 11, 2011, the CHPCA hosted over 500 health professionals, comprised of physicians, nurses, administrators, social workers, therapists, pastoral care providers, academics, volunteers and students for the annual CHPC Conference.

The 2011 CHPC Conference was themed: “Navigating Safe Pathways to Quality Hospice Palliative Care”, and the CHPCA worked in unison with the Newfoundland and Labrador Palliative Care Association to plan this event. The CHPCA coordinated the logistics and planning of the conference at the national level, and a committee comprised of representatives from the NLPCA assisted in coordination pieces including securing volunteers and local logistical support.

The program consisted of seven conference streams consisting of challenge panel sessions, plenary sessions, 81 scheduled workshops and oral presentations, 40 poster presentations and two symposiums. These seven streams included:

- Advocacy and Leadership
- Education
- Innovations and Partnerships in Service Delivery





- Interdisciplinary Patient and Family Centered Care
- International Issues
- Research

The sponsors of the 2011 Canadian Hospice Palliative Care Conference were:

- Government of Canada
- Bayshore Home Health
- The GlaxoSmithKline Foundation
- Canadian Partnership Against Cancer
- TELUS
- Purdue Pharma
- Canada's Research-Based Pharmaceutical Companies – Rx&D
- Valeant Canada Limited
- We Care Home Health Services

2011 also kicked off the planning and beginning phases of preparation for the CHPCA's first ever Learning Institute. The Learning Institute, which is to be held June 1 to 3, 2012 in Banff, Alberta, is an intimate gathering of hospice palliative care practitioners with a focus on intense learning.

The program is directed to intermediate to advanced learning levels and is to be delivered by 40 of the finest hospice palliative care professionals from across the country while overlooking the mountain ranges in one of the most beautiful settings in Canada!

Throughout the year, the CHPCA worked with a large group of volunteers, comprising of people who represented the various areas and aspects of palliative care, this group formed the Learning Institute Program Committee. The function of the committee was to assist in framing and outlining the five streams that are to be presented during the Learning Institute. The Program Committee met several times with the CHPCA in an effort to assist in shaping the direction of learning that is scheduled to happen throughout the three day event. The Program Committee also worked together to select a list of the most qualified faculty for each stream. The CHPCA is pleased to report that the suggested faculty has been approached and nearly all have agreed to be a part of this special event.

The CHPCA looks forward to bringing together this group of faculty, Program Committee, and learners in the first ever event of its kind!

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NATIONAL ONLINE DIRECTORY OF HOSPICE PALLIATIVE CARE PROGRAMS AND SERVICES

Since launching the Canadian Directory of Hospice and Palliative Care Programs and Services in 2002, the CHPCA has leveraged broad access to information concerning the availability of hospice palliative care programs and services in every province and territory in Canada. The searchable Directory currently contains contact information for more than 525 hospice palliative care programs and services in Canada. The directory underwent an update in 2011 to match the look and feel of the new CHPCA's website. This update also consisted of the integration of updated fields of infor-





mation which were collected as a part of a directory update project occurring in 2010. The CHPCA continues to work on maintaining the directory to ensure that the information contained is the most up-to-date information available.

Programs and Services can register at: <http://www.chpca.net/family-caregivers/directory-of-services/add-a-service.aspx>

CHPCA INTEREST GROUPS

The Canadian Hospice Palliative Care Association continues to encourage its members to join and utilize its eleven Interest Groups. These Interest Groups were created by the members as a means of sharing information across Canada and abroad and creates an opportunity for individuals working or volunteering in hospice palliative care to share best practices and to network with other individuals in the same area of work. The members of the Interest Groups typically meet face to face each year just before the association's Annual General Meeting.

Information can be shared by the groups in the following ways:

- free space in the Association's newsletter AVISO
- space on the CHPCA website devoted to each of the eleven Interest Groups
- Yahoo list serve

For more information about the CHPCA interest groups please visit: <http://www.chpca.net/become-a-member.aspx>

NATIONAL/PROVINCIAL ASSOCIATION RELATIONSHIP

The CHPCA continues to work in close partnership with the provincial hospice palliative care associations. Throughout 2011 the CHPCA and the provincial hospice palliative care associations continued to work according to the Memorandum of Understanding further strengthening the valuable relationship between the organizations. The main joint initiatives occurring throughout the year were in areas of information sharing, education and advocacy, and memberships. A new membership committee was created and met semi-annually with representatives of each provincial association to discuss issues of joint membership strengthening.

SUSTAINABILITY AND GOVERNANCE

BOARD OF DIRECTORS

The CHPCA is led by an active, dedicated Board of Directors. In September 2011, the Board of Directors hosted the association's Annual General Meeting in St. John's, Newfoundland in conjunction with the CHPC Conference. The Board of Directors has four main committees that help support the association in effective operation. These committees are the:

- Executive Committee
- Organizational Development Committee
- Finance Committee
- Awards Committee





The Board of Directors also manages two awards. These awards are the Award of Excellence, received by Dr. Mary Lou Kelley, and the Balfour Mount Champion Award received by Dr. Neil MacDonald. The Board was pleased to have been able to present these awards at the opening ceremonies of the CHPC Conference.



ORGANIZATION DEVELOPMENT COMMITTEE

The Organizational Development Committee (ODC) is a committee of the Board of Directors charged with overseeing the ongoing development and governance of the CHPCA. The ODC operates with the following three sub-committees:

- Policy Sub-Committee: The Policy Sub-Committee oversaw the annual perpetual calendar ensuring that current policies were reviewed and affirmed as per the perpetual calendar.
- Nominations/By-Laws Sub-Committee: The Nominations/By-Laws Sub-Committee oversaw the nomination Process for a Member-at-Large, elected by the general membership during the 2011 Annual General Meeting. The Nominations/By-Laws Sub-Committee also oversaw the beginning phases of preparing the CHPCA to come into compliance with a new National Not-For-Profit Act that was passed in early 2011.
- Membership Committee: The Membership Sub-Committee oversaw the joint membership initiative occurring between the CHPCA and the provincial associations.



EUTHANASIA AND ASSISTED DYING WORKING GROUP

In response to the resurfacing of the issue of euthanasia and physician assisted dying, the Euthanasia and Assisted Dying Working Group held several meetings throughout 2011-2012. The Committee wrote and disseminated a press release in response to the Special Commission on Dying with Dignity’s (Commission spéciale sur la question de mourir dans la dignité) report, Dying with Dignity.

As euthanasia continues to be debated at the parliamentary level, the Working Group decided to refresh and relaunch the “Let’s Talk About Hospice Palliative Care First” campaign, and send out more policy alerts to membership. 2012-2013 will be busy for this Working Group, so please stay tuned!



EXTERNAL ORGANIZATION LIAISON

HEALTH CHARITIES COALITION OF CANADA (HCCC)

HCCC, a member based organization, is dedicated to advocating for sound public policy on health issues and promoting the highest quality health research. HCCC strives for excellence in health policy and seeks to ensure that the federal government and policy makers look to the Coalition and its members for timely advice and leadership on major health issues of concern to Canadians; and that they recognize the competence, commitment and contributions of health charities in improving the health and well-being of Canadians.





Currently, HCCC has 28 national health charities as members, including CHPCA. HCCC's priority areas are: (1) Advocacy on health policy and health research; (2) Networking (which includes an Annual Roundtable for the members and two CEO Forums); (3) Membership and Revenue Generation. HCCC's Governing Council provides leadership to the Coalition, which also has standing committees on health policy and health research.

The CHPCA is an active member of HCCC, sharing office space and personnel. CHPCA also provides financial services to HCCC for an annual fee.

Sharon Baxter, Executive Director of the CHPCA, is currently the chair of the Standing Committee on Health Policy.



INTERNATIONAL ISSUES

Worldwide Palliative Care Alliance (WPCA)

The CHPCA is also an active member of the Worldwide Palliative Care Alliance (WPCA). Sharon Baxter sits on the Board of Trustees of the WPCA as well as chairs the WPCA Advocacy Committee. The WPCA is active in international, regional and national advocacy. The WPCA is the secretariat for World Hospice Palliative Care Day held in early October each year.



INTERNATIONAL CHILDREN'S PALLIATIVE CARE NETWORK (ICPCN)

ICPCN sits on the board of trustees of WPCA and there was an opening on the board of ICPCN for an official WPCA representative. Sharon Baxter was nominated and assumed this position. ICPCN is a UK registered charity working out of South Africa and is charged with raising issues around children's hospice palliative care worldwide. ICPCN is doing wonderful work.





NATIONAL OFFICE STAFF (EFFECTIVE MARCH 31/12)

Executive Director	Sharon Baxter
Administrative Coordinator	Cheryl Spencer
Administrative Assistant	Laureen Nickerson
Communications Officer	Vanessa Sherry
Fundraising and Communications Assistant	Julia Ehrhardt
Partnership and Development Officer	Caroline Kayll
National Conference Coordinator	Michael Peterson (Until December 2011)
Project Coordination – Hike	Cheryl Spencer & Julia Ehrhardt
Project Coordination – Week	Vanessa Sherry & Julia Ehrhardt
Finance Officer (Part-time Contractor)	Sandie Lessard
Administrative Assistant – ACP Project	Gillian Fernie





SUPPORTERS

The CHPCA gratefully acknowledges all contributions received in the 2011-2012 fiscal year and thanks those who made our work possible. Although we appreciate all gifts and support, only contributions of \$5,000 or more are listed:

PARTNER LEVEL (\$50,000+)

Canadian Partnership Against Cancer
Canadian Institutes of Health Research
GlaxoSmithKline Foundation
Health Canada

COMPASSION LEVEL (\$25,000 - \$49,000)

Bayshore Home Health
Human Resources and Skills Development Canada
Purdue Pharma

DIGNITY LEVEL (\$10,000 - \$24,999)

Canada's Research-Based Pharmaceutical Companies (Rx&D)
Quality Palliative Care in LTC Alliance
MacMaster University
The Military and Hospitaller Order of St. Lazarus of Jerusalem
We Care Home Health Services

COMFORT LEVEL (\$5,000 - \$9,999)

Nycomed, a Takeda Company
TELUS
Valeant Canada

The CHPCA would like to acknowledge the considerable in-kind donation of time made by our dedicated and hard-working Board of Directors. Without their efforts, the CHPCA would not be able to accomplish so many of the important activities outlined throughout this report. We would also like to offer special thanks to our lawyer, John Peart of Nelligan O'Brien Payne, who has given generously of his time over the past 10 years. His guidance and knowledge has served us beyond measure.





BOARD OF DIRECTORS 2011-2012

EXECUTIVE COMMITTEE:

President – Sarah Walker
Past President- Wendy Wainwright
Vice President – Laurie Anne O’Brien
Treasurer – Ed MacLaren

PROVINCIAL MEMBERS:

Alberta – Pansy Angevine
British Columbia – Terri Odeneal
Manitoba – Pamela Hawranik
New Brunswick – Rinette Cote
Newfoundland – Donna Kavanagh
Nova Scotia – David Henderson
Ontario – Rick Firth
Prince Edward Island – Mary Hughes
Quebec – Maryse Bouvette
Saskatchewan – Carla Carlson

MEMBER-AT-LARGE:

Heather Mohan Van Heerden

CHPCA BOARD COMMITTEES

EXECUTIVE COMMITTEE

Chair: Sarah Walker

ORGANIZATION DEVELOPMENT COMMITTEE

Chair: Wendy Wainwright

POLICY SUB-COMMITTEE

Chair: Pansy Angevine

NOMINATIONS/BY-LAWS SUB-COMMITTEE

Chair: Wendy Wainwright

MEMBERSHIP SUB-COMMITTEE

Chair: Rick Firth

FINANCE COMMITTEE

Chair: Ed MacLaren

AWARDS COMMITTEE

Chair: Laurie Anne O’Brien

CHPCA TASK GROUPS

CANADIAN NETWORK OF PALLIATIVE CARE FOR CHILDREN (CNPCC)

Co-Chairs: Simone Stenekes & Hal Siden

EDUCATION TASK GROUP

Chair: Sharon Baxter

INTERNATIONAL COOPERATION TASK GROUP

Chair: Bernard Lapointe

VOLUNTEERS ISSUES TASK GROUP

Chair: Joan Williams





CHPCA CHAMPION'S COUNCIL

Ms. Kathryn Butler Malette, Chief Human Resources Officer
The House of Commons of Canada

Hon. Sharon Carstairs, Senator (retired)
The Senate of Canada

Mr. Bill Greenhalgh, CEO
Human Resources Professionals Association

Mr. Paul Lucas, Former President and CEO
GlaxoSmithKline

Hon. Michael MacDonald, Senator
The Senate of Canada

Dr. Balfour Mount, Emeritus Professor of Medicine
McGill University

Mr. Michael Sangster, Vice President
TELUS

Mr. Russell Williams, President
Canada's Research-Based Pharmaceutical Companies (Rx&D)





FINANCIAL STATEMENTS

The Canadian Hospice Palliative Care Association is pleased to present the Financial Statements for the period of April 1, 2011 – March 31, 2012.

The Board of Directors each year reviews the audited statements as prepared by our external auditor, McCay Duff LLP Chartered Accountants, and the results of that review are the approved financial statements as seen here in this report. We are pleased to be able to share with you our Statement of Financial Position and Statement of Revenue and Expenditure.





CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION

STATEMENT OF FINANCIAL POSITION

AS AT MARCH 31, 2012

	<u>2012</u>	<u>2011</u>
ASSETS		
CURRENT		
Cash	\$ 306,514	\$ 280,604
Investments	250,000	150,000
Accounts receivable	209,364	180,373
Prepaid expenses	<u>100,013</u>	<u>60,632</u>
	865,891	671,609
CAPITAL (note 5)	<u>955</u>	<u>-</u>
	<u>\$ 866,846</u>	<u>\$ 671,609</u>
LIABILITIES		
CURRENT		
Accounts payable and accrued liabilities	\$ 266,968	\$ 195,816
Deferred revenue (note 6)	<u>421,801</u>	<u>298,262</u>
	688,769	494,078
NET ASSETS		
BALANCE - END OF YEAR	<u>178,077</u>	<u>177,531</u>
	<u>\$ 866,846</u>	<u>\$ 671,609</u>

Commitments (note 8)

Approved on behalf of the Board:

Director

Director





CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION

STATEMENT OF REVENUE AND EXPENDITURE

FOR THE YEAR ENDED MARCH 31, 2012

	<u>2012</u>	<u>2011</u>
REVENUE		
Conference	\$ 330,601	\$ 337,442
Donations	290,547	450,987
Grants	455,644	366,106
Interest	788	1,207
Membership fees	52,341	46,491
Administrative services	41,562	28,392
Resource materials	40,732	30,704
Miscellaneous	<u>18,702</u>	<u>11,950</u>
	1,230,917	1,273,279
EXPENDITURE		
Advertising and promotion	4,151	3,155
Amortization	478	-
Bank charges	27,039	21,841
Contracted services	335,630	406,796
Dues and subscriptions	4,301	4,179
Facility rental	141,668	147,994
Human resources	381,947	408,984
Insurance	3,449	4,351
Meeting costs	7,216	2,576
Office supplies	25,000	5,988
Postage	28,820	32,062
Printing	37,082	42,401
Professional fees	8,731	6,797
Rent	44,281	36,735
Teleconferences	5,027	6,105
Telephone and facsimile	8,627	11,598
Training and professional development	1,960	2,390
Translation	50,928	51,412
Travel	113,521	106,169
Voluntary recognition and honoraria	<u>515</u>	<u>-</u>
	<u>1,230,371</u>	<u>1,301,533</u>
NET REVENUE (EXPENDITURE) FOR THE YEAR	<u>\$ 546</u>	<u>\$(28,254)</u>

