

A Report on The Butterfield/Drew Chair in Breast Cancer Survivorship at The Princess Margaret



April 2010



Our Vision

is to conquer cancer in our lifetime.

Our Cause

is the patient.

Our Partner

is the research hospital.

Our Donors

lead the way.

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The Princess Margaret Hospital Foundation at University Health Network raises funds for research, education and the enhancement of patient care at Canada's leading cancer research hospital, Princess Margaret Hospital and its research arm, the Ontario Cancer Institute. University Health Network consists of Princess Margaret, Toronto General and Toronto Western Hospitals, and is a teaching hospital affiliated with the University of Toronto. For more information, please visit us at pmhf.ca

Introduction

Thank you for establishing The Butterfield/Drew Chair in Breast Cancer Survivorship at The Princess Margaret (PMH). Through this fund, Dr. Pamela Catton and her team have been able to continue their important work in the four foundational elements of the Breast Cancer Survivorship Program. The following pages will highlight some of the impressive activities that they have undertaken over the past year in this area.

Your support continues to help transform The Princess Margaret (PMH) into one of the top five research centres in the world. With your continued assistance, we can improve the lives of cancer patients and move one step closer in our goal of conquering cancer IN OUR LIFETIME.



Dr. Pamela Catton and her team have been able to continue their important work in the four foundational elements of the Breast Cancer Survivorship Program.

The Butterfield/Drew Chair in Breast Cancer Survivorship

Goals of the Survivorship Program

The goals of the Survivorship Program are to:

- Empower and prepare survivors to manage their health with appropriate self-management support
- Recruit and train cancer survivors as a human resource
- Reallocate health care human resources through changing scopes of practice
- Apply e-health technologies to engage survivors by providing information and support at point of need
- Organize patient and population data to facilitate education, survivorship research and efficient and effective survivorship care



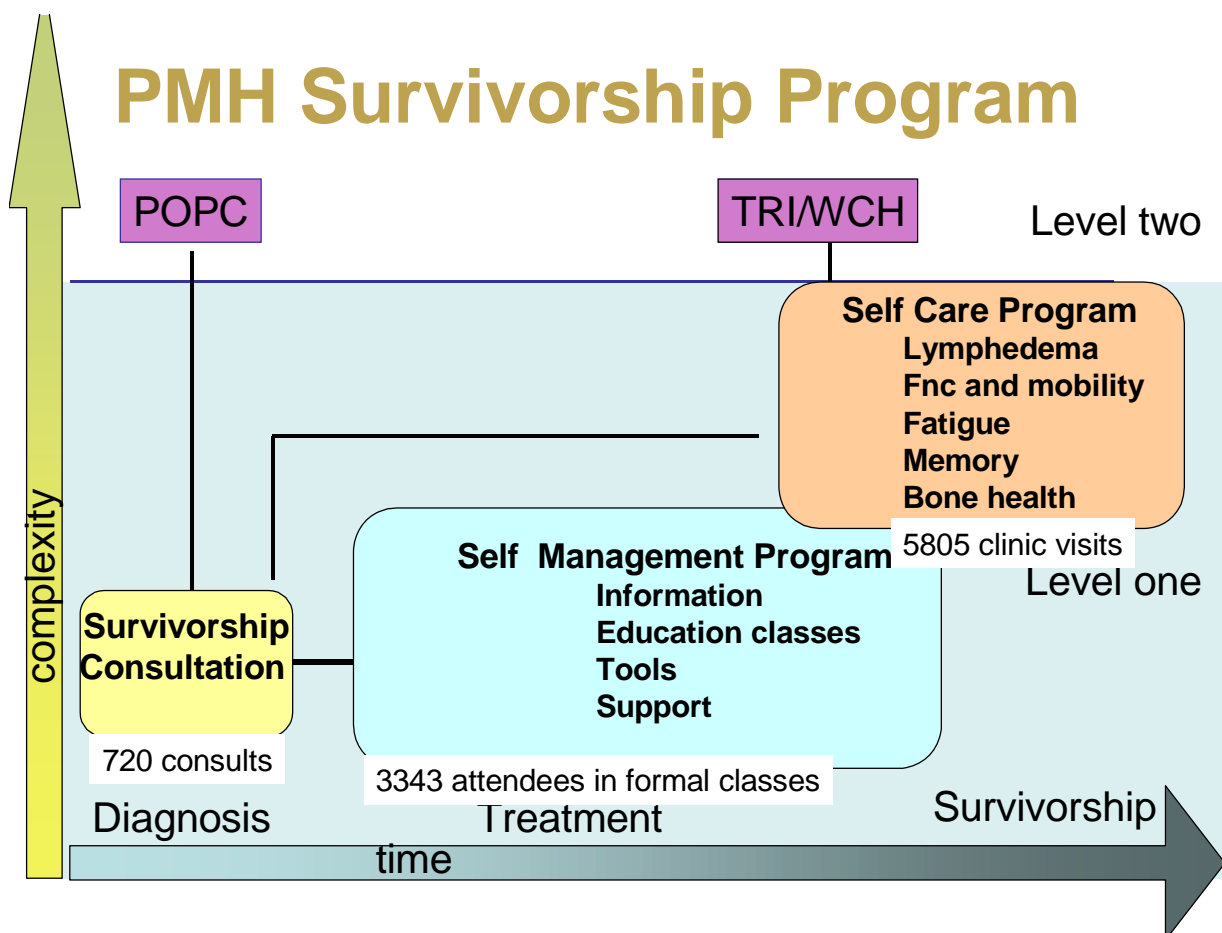
Dr. Pamela Catton

The Butterfield/Drew Chair in Breast Cancer Survivorship

Clinical Program

The Princess Margaret Survivorship Program remains unique in Canada for its vision, scope and goals. Patients become cancer survivors from the point of diagnosis and the issues and challenges they face change at different points on the cancer journey. The PMH Cancer Survivorship Program meets these needs at diagnosis, during treatment and after active treatment (survivorship phase). The clinical program is both consultative and risk-based and, based on clinical practice guidelines, anticipatory guidance in self-management is initiated at the start of treatment.

The Princess Margaret Survivorship Program remains unique in Canada for its vision, scope and goals.



The Butterfield/Drew Chair in Breast Cancer Survivorship

The clinical program is comprised of three core elements:

1. Survivorship Consult: This structured intervention is designed to engage survivors through a process of guided self-reflection, as they explore their cancer experience, set goals and develop an action plan. We are seeing a steady rise in referrals for consults and have performed 720 since 2006 and 362 since July 2008. Forty breast cancer survivors favourably evaluated the one-hour consultation. The following quote captures the sentiment commonly expressed... *“I found the entire session very helpful. When you are new to the cancer world, it is very daunting at first. Having all of this information at hand relieves me of some of the stress and has given me a confidence that I will be able to better manage this process.”*

2. Self-Management Program: Structured education and psychosocial interventions to address survivors diverse needs for information, education and support. The self-management program targets patients in treatment, and has been modified to help patients with any cancer diagnosis. There has been a major organizational commitment to provide pre-surgical classes (for breast cancer patients only), chemo and radiation classes (all cancer patients) and the self-management class “Managing Your Cancer Journey” (now all cancer patients). We have logged over 3343 attendees at self-management workshops since 2005.

3. Self-Care Program:
Level One Care

Self-care clinics: Standardized strategies teach patients how to prevent or reduce the impact of long-term post treatment effects on physical and emotional health. An interprofessional team runs these clinics that target side effects commonly

Highlights of the clinical program

▪ 2008-2009

Steady growth in referrals of new patients

- 42% increase in 2 years
- 643 NP in 2009
- 250 survivorship consults performed
- Fatigue, memory clinics for all patients

Self management classes

- Over 850 attendees in 2009
- Rolled out to all cancer patients
- 16% increase in attendance since 2008

Clinical research projects enriching program

- Helping Her Heal
- Getting Back on Track
- Taking Charge

The Butterfield/Drew Chair in Breast Cancer Survivorship

associated with breast cancer, in particular lymphedema, fatigue, memory, function and mobility, bone health, healthy weight and emotional health. Modifications are underway to make them relevant for many different cancer diagnoses. We have had over 5,808 visits since the clinical program opened in 2005.

Level Two Care

Professional help: There will always be patients who need more intense treatment for their late effects, and active partnerships have been established with clinical programs to provide the necessary care. New partners outside of the PMH include Women's College Hospital for lymphedema treatment and bone health, and Toronto Rehab Institute for functional deficits.

We have had over 5,808 visits since the clinical program opened in 2005.

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Survivorship Development and Research Activities Currently Underway

| |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Gynae Gals: An on-line structured group intervention to improve sexual health (study run by Dr. Catherine Classen). |
| Helping Her Heal: A group intervention to assist male partners of breast cancer patients to improve their support skills (part of pilot study). |
| Getting Back on Track: A group psychoeducational session to ease transition after breast cancer treatment (large RCT). |
| Taking Charge: A group Health and Wellness Program for women who have completed breast cancer treatment (collaboration with Mt Sinai Hospital and Dr. Pam Goodwin) (pilot study). |
| Caring Voices: Website with monthly on-line programming (up to 30 sessions per month on various topics). |
| Managing Your Cancer Journey: A structured group educational intervention for all cancer sites - two sessions. |
| Bone Health: i) Awareness raising session and ii) referral to Women's College Hospital referral to Women's College Hospital Osteoporosis program. |
| Fatigue: i) Awareness raising group educational intervention and ii) triage to multidisciplinary fatigue clinic. |
| Lymphedema: Multidisciplinary self management clinic. |
| Function and Mobility: Interdisciplinary assessment and triage to rehab services at Toronto Rehabilitation Institute. |
| Memory and Attention: i) Group educational intervention under development and ii) triage to neurocognitive clinic (run by a neuropsychologist). |
| Survivorship consult: (As described above) |
| Survivorship resource calendar: Updated monthly directing to community programs at Willow, Wellspring Gilda's Club, etc. |
| Survivorship needs assessment: In the Portuguese breast cancer community in preparation for a "breast cancer coach" program. |
| A self management tool: (Paper based) adopted for all cancer patients throughout their trajectory. |

There are a variety of other projects in development including: a cancer journey information map, an e-learning portfolio for survivors, needs assessments to determine information and support needs of patients at the beginning of cancer trajectory (prior to definitive diagnosis).

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The Virtual Survivorship Program

The goal of the Virtual Survivorship Program is to transform and improve the patient/survivor experience through the use of new health information and communication technologies.

Technology enables us to extend our relationship with our community of survivors beyond the physical and temporal boundaries of the health care facility, to provide the right information when people need it most.

In order to help improve the patient/survivor experience, our informatics program focuses on four platforms: 1) Navigating the system, 2) Tailoring Health Information, 3) Caring in the Community, and 4) Support Networks/Social Media. In addition to developing initiatives in each of these four areas, we explore ways to use technology to assist our patients/survivors in accessing the information that is necessary for them to be active participants in their own self-management and self-care. Through the use of technology we can provide individuals with access to four different levels of information ranging from general health information through to information tailored to an individual based on their personal health information. To achieve our goals, we support ongoing initiatives in each of the four platforms and continue to develop new initiatives to both respond to end user need and remain current in the use of technology.

Navigating the System: The PMH virtual tour can be accessed through the PMH home page. This interactive tour of the cancer centre is a way of promoting understanding through orientation. New patients can familiarize themselves with both the physical surroundings of PMH and the types of treatments they may receive while being treated here. Over the last year the tour has been updated to reflect renovations in the hospital and these

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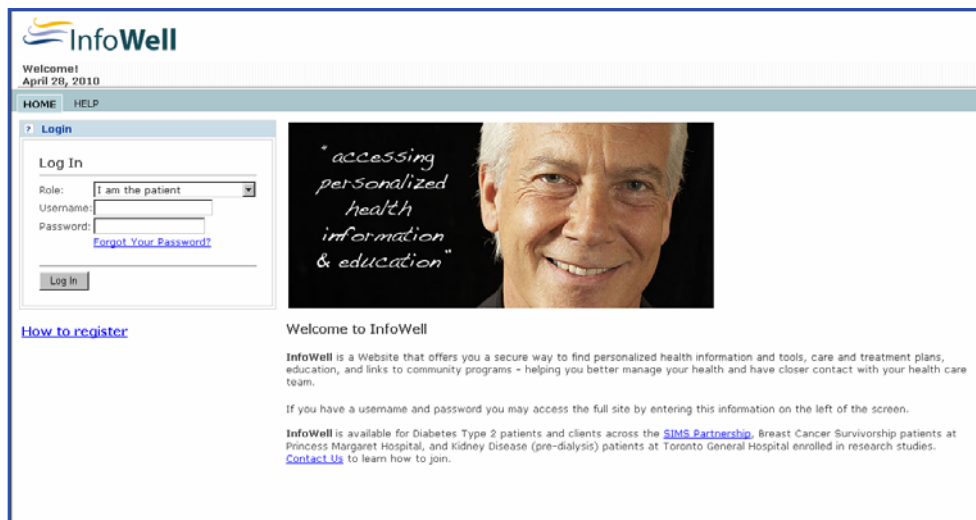
The Butterfield/Drew Chair in Breast Cancer Survivorship

updates will be released shortly. In 2008 there were 21,884 total visitors with 1,891 visitors in 2008.

Radiation for Kids is an interactive CD-ROM based virtual experience that helps prepare children and their families for the journey through radiation treatment. Over 1,500 copies have been distributed to pediatric cancer treatment centres across the country.

Tailoring Health Information: InfoWell, the patient portal of the Patient Education and Survivorship Program is a platform that provides access to personal health information presented together with tailored information to help users understand the content of their health record. InfoWell users can access over 20 laboratory results and imaging and pathology reports. In 2009 we completed a study of 250 breast patients to determine the impact of InfoWell usage on self-efficacy and anxiety. Although results of this study were inconclusive in relation to self-efficacy, it did suggest that there was no negative impact on levels of patients' anxiety. In addition, in 2009 the Cancer Program made a commitment to providing all breast cancer patients with access to InfoWell by 2010 and to all patients in the cancer program by 2011.

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InfoWell

Welcome!
April 28, 2010

HOME HELP

7 Login

Log In

Role:

Username:

Password:

[Forgot Your Password?](#)

Log In

"accessing personalized health information & education"

[How to register](#)

Welcome to InfoWell

InfoWell is a Website that offers you a secure way to find personalized health information and tools, care and treatment plans, education, and links to community programs - helping you better manage your health and have closer contact with your health care team.

If you have a username and password you may access the full site by entering this information on the left of the screen.

InfoWell is available for Diabetes Type 2 patients and clients across the [SIMS Partnership](#), Breast Cancer Survivorship patients at Princess Margaret Hospital, and Kidney Disease (pre-dialysis) patients at Toronto General Hospital enrolled in research studies. [Contact Us](#) to learn how to join.

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Caring in the Community: The Informatics team remains committed to the ongoing support and maintenance of the caringtotheend.ca website that was first launched in 2005. This interactive website provides access to resources and tools for individuals and families going through the palliative stage of the cancer journey. It features tools that help with problem-solving, planning, and resource and care management, this site provides the right information when it is needed. In 2009, the site had 805,015 page views with a monthly average of over 67,000 page views.

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Caring to the End of Life Home Page

Welcome to *Caring to the End of Life*, a Web site for anyone who needs information about palliative care for cancer patients.

Whether you are a patient, a caregiver or a health care professional, this is the place to find information, tools and community resources for the Greater Toronto Area.

I Have a Problem Now
This section will help in dealing with current problems, including tips on specific topics.

I Need to Know More About...
This section provides general information about many subjects for patients, caregivers and health care providers.

Managing and Planning Ahead
This section has tools, resources and forms to help you stay organized.



[View Transcript](#)

Resources 
This section is where you can find resources such as home care agencies, equipment suppliers and support groups in your area.

My Care Journal 
Logging in to the site lets you use the Care Journal where you can store items about your care such as treatment team information, useful resources and bookmarks. [Login now to start using your Care Journal](#)

[About this site](#) | [Legal](#)

[Click here](#) for more information on the Harold and Shirley Lederman Palliative Care Centre at PMH. For more about our other facilities see our [Virtual Tour](#).

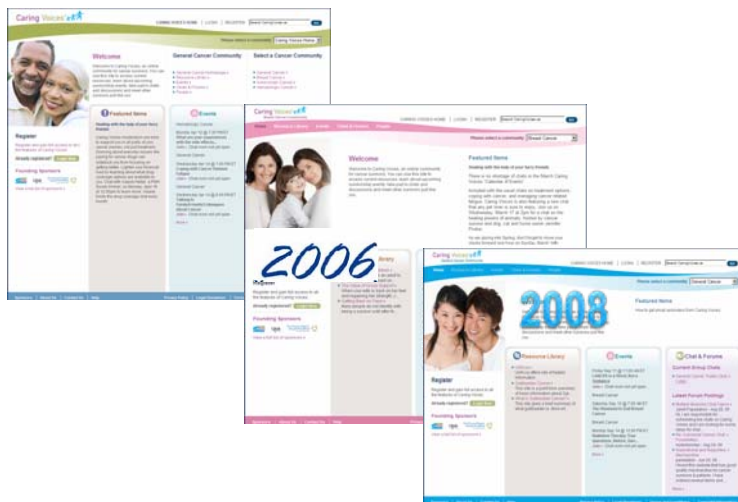


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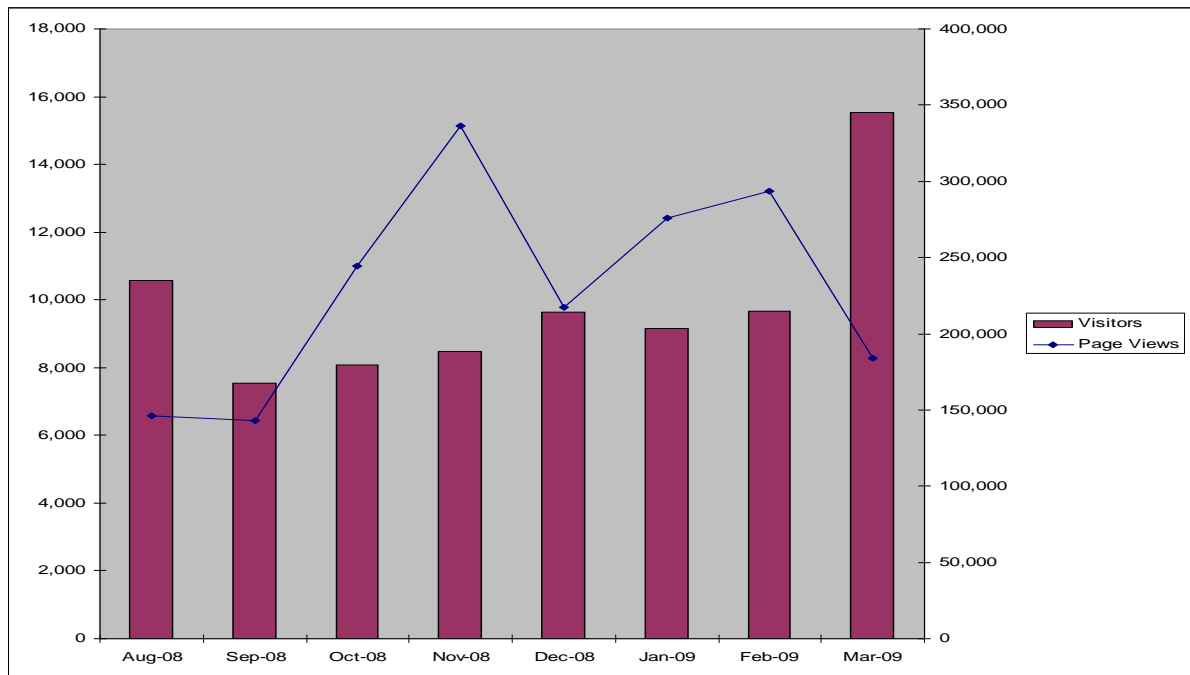
Support Networks: CaringVoices.ca is a social networking platform for people touched by cancer. It is an initiative of PMH and has been live since October 2006, providing cancer survivors across Canada with access to current educational resources, peer support, and advice and education from cancer survivors and health care and community experts. Through a people matching function, survivors are provided with the opportunity to talk with other individuals who may share similar experiences. This platform is a key element in providing virtual survivorship support to extend the reach of the Survivorship Program outside the four walls of the hospital.

The year 2009 marked a period of growth and expansion for the platform and the virtual community.

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Enhancing the National Presence

In keeping with our mandate of being a national site, we have fostered relationships with health care facilities and national organizations across the country. Our partners and collaborators help to spread the word about CaringVoices.ca in their communities and participate in online activities and forums. Our partners/ collaborators include:

- Hope and Cope, Jewish General Hospital (Montreal, QC)
- Health Promotion Clearinghouse, (Halifax, NS)
- Multiple Myeloma Canada
- Wellspring
- Ovarian Cancer Canada
- Pancreatic Cancer Canada

Our partners and collaborators help to spread the word about CaringVoices.ca in their communities and participate in online activities and forums.

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CaringVoices.ca began as a community of support for breast cancer survivors. In 2008 a general cancer community was added for survivors of any cancer and in 2009 we launched two new communities, one for gynecologic cancers and one for hematologic cancers. The community continues to grow with over 40 peer and professional moderators and close to 30 live events held each month. There are over 2,000 registered users in the community with new members registering monthly.

Research Program

Our goal is that all care that takes place within the PMH Survivorship Program be provided within the context of clinical research. Clinical program elements are evaluated for quality and feasibility. Efficacy is assessed in several domains including: physical and psychological outcomes, disability, quality of life, behavior change, and physical outcomes. The research program is conceptualized into three core areas.

Individual Survivors: We will discover new information about survivor self-managed care; translate this new information into alternative models of survivorship after-care; and use live and virtual survivorship community of practice education and support strategies. Benefits to emotional and physical health as well as the economic “health” of the health care system will be assessed.

Groups of Survivors: We will examine the effect of psychosocial, educational and behavioral interventions delivered by individuals with varying levels of professional and non-professional expertise on quality of life, access, cost-effectiveness and sustainability. The optimal nature, timing and sequencing of psycho-educational interventions, as well as the most appropriate platforms and formats for delivering and sustaining online organizational support will be determined.

There are over 2,000 registered users in the community with new members registering monthly.

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Communities of Survivors: We will collaborate with health care providers and survivors to enhance the quality of survivors' care and utilize innovative means to identify large groups of geographically diverse survivors who can participate in relevant studies.

We are developing a foundation for interdisciplinary collaboration and research through a number of initiatives highlighted below.

- Established the Butterfield Drew Nursing Fellowship with York University.
- Dr. Christine Maheu was named the inaugural Fellow, appointed in 2008.
- Established the Butterfield Drew Visiting Scholar Program.
- Established a Butterfield Drew Summer Studentship.
- Established a Butterfield Drew Research Travel Award.
- Began a formal research collaboration with Dr. Gary Rodin, Chief of Psychosocial Oncology and Palliative Care, to develop a psychosocial survivorship research program led by Dr. Jennifer Jones, who is cross appointed to the PMH Survivorship Program, as clinical research lead.
- Will collaborate in the development of a national survivorship research consortium.
- Established an ELLICSR (Electronic Living Laboratory for Interdisciplinary Cancer Survivorship Research) Research Advisory Board.
- Expanding the research presence in ELLICSR as membership grows.

ELLICSR ELLICSR CFI Milestones:

| | |
|-------------------------------|----------------|
| Grant approved | August 2007 |
| Project manager hired | September 2007 |
| Architectural team selected | December 2007 |
| Construction company selected | August 2008 |
| Construction initiated | August 2008 |
| Construction completion date | January 2009 |
| Researcher moved in | April 2009 |
| Equipment installation date | March 2010 |
| Grand opening | June 2010 |

The Butterfield/Drew Chair in Breast Cancer Survivorship

ELLICSR is located in the Clinical Services Building, Basement BCS021 in the Toronto General Hospital. This spacious community centre boasts teaching and self management areas that include: a full kitchen, a community resource space, consultation rooms, and an exercise room. It is fully wired to support virtual programming, community connections and global collaborations. The on-site research team is keen to investigate new and interesting strategies to improve the cancer experience, enhance self management skills, develop and apply strategies to reduce the burden of side effects, and explore new models of care delivery, supported by the Butterfield Drew endowment.

ELLICSR: Health, Wellness & Cancer Survivorship Centre

Grand Opening:

Save the Date!



Join us in celebrating National Cancer Survivors Day by officially opening *ELLICSR: the Collaborative Centre for Health, Wellness & Cancer Survivorship*

The leaders of three UHN programs came together to make this centre a reality: Dr. Pamela Catton, Medical Director of Cancer Survivorship, Dr Gary Rodin, Head of Psychosocial Oncology and Palliative Care, and Dr. Alex Jadad, Founding Director of the Centre for Global eHealth Innovation.

ELLICSR is located in the Clinical Services Building, Basement BCS021 in the Toronto General Hospital (visit the PMH Patient & Family Library for your map and directions). This spacious community centre boasts teaching and self management areas that include: a full kitchen, a community resource space, consultation rooms, and an exercise room. We are fully wired to support virtual programming, community connections and global collaboration. We have a research team on-site who are keen to investigate new and interesting strategies to improve the cancer experience, enhance self management skills, develop and apply strategies to reduce the burden of side effects and eliminate unnecessary suffering, and explore new models of care delivery.

Come and learn more about how programs at ELLICSR can be developed to improve the patient's experience with, through and beyond a diagnosis of cancer, and how you too can join the ELLICSR community.

For: UHN Staff, Volunteers and Community Partners

Date: Friday, June 4, 2010

Open House Time: 11:00 am – 3:00 pm

Directions to ELLICSR:

Enter using the University Avenue entrance.
Take West Elevators down to the basement level (B), turn right and ELLICSR is on the right side.

Contact Myann Marks for further details.
Tel: 416.531.8604
Email: myann.marks@mp.uhn.on.ca



The Butterfield/Drew Chair in Breast Cancer Survivorship

Thank you

As you can see, Dr. Catton and her team have had a productive year and we look forward to keeping you informed of more of this vital work. On behalf of the many breast cancer patients who are benefitting from this activity, we would like to thank you for your support. The groundbreaking research that is taking place here every day would not be possible without you.

We hope that this update will give you some indication of why The Princess Margaret is one of the top five cancer research hospitals in the world. With generous donors like you, we will continue to hold this position and conquer cancer IN OUR LIFETIME.

The groundbreaking work that is taking place here every day would not be possible without you.

Appendix 1: Fund Report

Butterfield/Drew Chair in Breast Cancer Survivorship Research #889125002160

| | Fiscal Year Ended March 31st | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 2/28/2010 |
|------------------------|------------------------------------------|---------------|----------------|------------------|------------------|------------------|------------------|------------------|-------------------|
| Endowment Fund | Opening Balance | - | 99,749 | 657,071 | 1,206,187 | 1,504,933 | 1,673,355 | 1,799,867 | 1,520,279 |
| | Donations | 100,000 | 552,125 | 701,790 | 212,708 | 215,428 | 217,916 | 169,000 | 6,175 |
| | Investment Income | 2,441 | 12,222 | 36,206 | 148,226 | 26,055 | (7,286) | (374,822) | - |
| | less transfer to Expendable Account | (2,692) | (7,026) | (34,880) | (62,187) | (73,061) | (84,118) | (73,766) | - |
| | Expenses and Charges | - | - | - | - | - | - | - | - |
| | Grants | - | - | - | - | - | - | - | - |
| | Transfers | - | - | (154,000) | - | - | - | - | - |
| | Closing Balance | 99,749 | 657,071 | 1,206,187 | 1,504,933 | 1,673,355 | 1,799,867 | 1,520,279 | 1,526,454 |
| Expendable Fund | Opening Balance | - | 2,692 | 9,718 | 44,598 | 106,785 | 179,847 | 207,989 | 248,988 |
| | Donations | - | - | - | - | - | - | - | 710 |
| | Investment Income transferred from above | 2,692 | 7,026 | 34,880 | 62,187 | 73,061 | 84,118 | 73,766 | - |
| | Expenses and Charges | - | - | - | - | - | - | - | - |
| | Grants | - | - | - | - | - | (22,976) | (32,767) | (10,464) |
| | Transfers | - | - | - | - | - | (33,000) | - | (165,000) |
| | Closing Balance | 2,692 | 9,718 | 44,598 | 106,785 | 179,847 | 207,989 | 248,988 | 74,233 |

Appendix 2: Survivorship Grants - Active during 2008/ 2009

Title: Lymph-Line: Feasibility of Online Lymphedema Care

Agency: Canadian Breast Cancer Research Alliance (DEX Grant)
Dollar Amount: \$47,550.64
Name of PI: Wiljer D
List of co-applicant: Catton P, Luke R, Urowitz S, et al
Dates/year(s): 2006-2008

Title: STEPping Stones: A Blended Learning Program for Breast Cancer Survivorship Transition to Employment Project

Agency: Canadian Council on Learning (CCL) Work & Learning
Dollar Amount: \$70,000
Name of PI: Luke R
List of co-applicants: Wiljer D, Catton P
Dates/year(s): 2006-2008

Title: A Victim of Fashion? Investigating the Apparel and Accessories Needs of Female Breast Cancer Patients

Agency: Ryerson University One-Time-Only Opportunity
Dollar Amount: \$9,721.70
Name of PI: Tullio-Pow, S
List of co-applicants: Nyhof-Young J
Date(s)/year(s): 2006-2008

Title: Attention and Executive Functions in Patients with Locally Advanced Breast Cancer

Agency: Canadian Breast Cancer Research Alliance
Dollar Amount: \$46,000
Name of PI: Bernstein L
List of co-applicants: Catton P, Tannock I
Date(s)/year(s): 2007-2008

Title: A Victim of Fashion: Modular Bag with Therapeutic Arm Sling for Breast Cancer Survivors with Lymphedema

Agency: Ontario Partnership for Innovation in Commercialization, Canadian Intellectual Property Office, Government of Canada & Technology Transfer Office Research Services at Ryerson University
Name of PI: Barnwell S
Dollar Amount: \$15,000
List of co-applicants: Nyhof-Young J
Date(s)/year(s): 2007-2008

Appendix 2: Survivorship Grants - Active during 2008/ 2009

Title: Development of an Internet-Based Support Group for Sexual Problems due to Gynecological Cancer

Agency: National Cancer Institute of Canada (NCIC)
Dollar Amount: \$35,000
Name of PI: Classen C
List of co-applicants: Urowitz S, Ferguson S et al
Dates/year(s): 2008- 2009

Title: The Electronic Living Laboratory for Interdisciplinary Cancer Survivorship Research (ELLICSR)

Agency: Canadian Foundation for Innovation / Ontario Research Fund (ORF)
Name of PI: Catton P, Wiljer D
Dollar Amount: \$3,600,000
List of co-applicants: Jadad A, Rodin G et al
Dates/year(s): 2007-2010

Title: Fertility in Young Cancer Survivors - Novel Assessment of Ovarian Reserve

Agency: Canadian Breast Cancer foundation
Dollar Amount: \$330,391
Name of PI: Hodgson D
List of co-applicants: McArdle O et al
Date(s)/year(s): 2007-2010

Title: Natural Language Generation Tools and Methodologies for Personalized e-Health Education Systems

Agency: Bell University Labs (BUL)
Name of PI: DiMarco,
Dollar Amount: \$50,000
List of co-applicants: Bray P, Lipa J, Bray P, Covey D, Cowan D, DiCiccio V, Harris R, Wiljer D
Dates/year(s): 2008

Title: Oncology Education Program R&D and Operating

Agency: Princess Margaret Hospital Foundation
Dollar Amount: \$1, 5000,000
Name of PI: Catton P
Dates/year(s): 2008-2010

Appendix 2: Survivorship Grants - Active during 2008/ 2009

Title: Cancer Survivorship Program R&D and Operating

Agency: Princess Margaret Hospital Foundation (WEBC)
Dollar Amount: \$2,000,000
Name of PI: Catton P
Dates/year(s): 2008-2010

Title: Advanced Patient Education for Cancer Survivorship Using the Internet to Build and Maintain a Community of Survivors

Agency: Social Sciences and Humanities Research Council
Name of PI: Luke R
List of co-applicants: Wiljer D, Catton P. et al
Dollar Amount: \$142,900.
Date(s)/year(s): 2007-2011

Title: Getting Back on Track: A Single Psychoeducational Group Intervention Post Completion of Adjuvant BRCA Treatment

Agency: Weekend Walkers Breast Cancer Innovation Fund
Name of PI: Jones J
List of co-applicants: Cheng T, Jackman M, Haines S, Catton P, Rodin G
Dollar Amount: \$62,805.00
Date(s)/year(s): 2007-2008

Title: Service and Network Formulation Needs of BRCA Survivorship Providers in the Toronto Central LHIN

Agency: Canadian Institute of Health Research
Dollar Amount: \$18,967
Name of PI: Gould J, Catton P
Date(s)/year(s): 2008

Title: Self-Managed Access to PHI through Automated Generation of Tailored Diagnostic Reports from EHR

Agency: NSSERC
Dollar Amount: \$50,000
Name of PI: DiMarco C
List of co-applicants: Wiljer D et al
Dates/year(s): 2008

Appendix 2: Survivorship Grants - Active during 2008/ 2009

Title: Extending the Continuum and Reach of Supportive Care in Ontario
Wellspring/Hospice Association of Ontario

Agency: Ontario Trillium Foundation
Dollar Amount: \$325,800
Name of PI: Wellspring Cancer Support
List of co-applicants: Nyhof-Young J et al
Date(s)/year(s): 2007-2009

Title: Systemic Therapy ReDesign: Patient Engagement Project

Agency: Princess Margaret Hospital Foundation and UHN Health
Dollar Amount: \$30,000
Name of PI: Wiljer D
List of co-applicants: Apatu E, Downey S, Fraser H, Leung M, Nyhof-Young J,
Urowitz S, Weinstock S.
Date(s)/year(s): 2007-2009

Title: Helping Her Heal: Pilot Educational Group Intervention for Male Spouses of
Women with Breast Cancer

Agency: Weekend Walkers Breast Cancer Innovation Fund
Dollar Amount: \$84,655.00
Name of PI: Jones J, Lewis F
Date(s)/year(s): 2008-2009

Appendix 3: Publications, Presentations, Awards, etc.

Select Peer-Reviewed Publications

Bender JL, Hohenadel J, Wong J, Katz J, Ferris LE, Shobbrook C, Warr D, Jadad AR. What patients with cancer want to know about pain: a qualitative study. *Journal of Pain and Symptom Management* 35:177-87, 2008.

Briceno AC, Gospodarowicz M, Jadad A. Fighting cancer with the Internet and social networking. *The Lancet Oncology*. [Volume 9, Issue 11](#): 1037-1038, 2008.

Leonard K, Wiljer D, Casselman M. An innovative information paradigm for consumers with chronic conditions: The value proposition. *The Journal on Information Technology in Healthcare*. 6(4): 274-282, 2008.

Leonard K, Casselman M, Wiljer D. Who will demand access to their personal health record? A focus on the users of health services and what they want. *Healthcare Quarterly*. 11(1): 84-87, 2008.

Leonard K, Wiljer D, Urowitz S. Yes, Virginia – there are system benefits to be gained from providing patients access to their own health information. *Healthcare Quarterly*. 11(4): 64-68, 2008.

Maheu C, Thorne SE. Receiving inconclusive genetic test results: An interpretive description of the BRCA1/2 experience. *Research in Nursing and Health*, 31, 553-562, 2008.

Rodin G, Mackay J, Zimmermann C, Mayer C, Howell D, Katz M, Sussman J, McNair S, Brouwers M. Provider-Patient Communication: A report of evidence-based recommendations to guide practice in cancer. *Supportive Care in Cancer*. Jun 17(6), 627-44, 2009.

Seruga B, Zhang H, Bernstein LJ, Tannock IF. Cytokines and their relationship to the symptoms and outcome of cancer. *Nature Reviews Cancer*, 8, 887-899, 2008.

Urowitz S, Wiljer D, Apatu E, Eysenbach G, DeLeonardo C, Harth T, Pai H, Leonard K. Is Canada ready for patient accessible electronic health records? A national scan. *BMC: Medical Informatics and Decision Making*: 8:33, 2008.

Lebel S, Rosberger Z, Edgar L, Devins GM. Predicting stress-related problems in long-term breast cancer survivors. *Journal of Psychosomatic Research*, 65, 513-523, 2008.

Lebel S, Rosberger Z, Edgar, L, Devins GM. Emotional distress impacts fear of the future among breast cancer survivors not the reverse. *Journal of Cancer Survivorship: Research and Practice*, 3, 117-127, 2009.

Appendix 3: Publications, Presentations, Awards, etc.

Maheu C. The search for an explanation: Breast cancer in the context of genetic inheritance. *The Qualitative Report*, 14(1), 129-139, 2009.

Maheu C. Implications to living with a family history of breast cancer. *Journal of Nursing Research*, 41(2), 100-112, June 2009.

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Jusko Friedman A, Turnbull G, Stacey AM, Murray A, Macvinnie J. Patient Education Working Group of the Education Committee, Cancer Journey Action Group Canadian Partnership Against Cancer. A Framework for Achieving Excellence in Cancer Patient Education in Canada. CPAC, 2009.

Jusko Friedman A, Cosby R, Boyko, S, Hatton-Bauer J, Turnbull G, CCO Patient Education Committee. Effective Teaching Strategies and Methods of Delivery for Patient Education. A Quality Initiative of the Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO). Evidence-Based Series #20-2. CCO, March 2009.

Appendix 3: Publications, Presentations, Awards, etc.

Accepted or in Press

Vodermaier A, Maheu C, Esplen MJ. Can self-esteem, mastery and perceived stigma predict long-term adjustment in women carrying a BRCA1/2-mutation? Preliminary evidence from a multi-center study. *Familial Cancer*. 2009

Wiljer D, Carter A. Guardians and gatekeepers: Whose record is it anyways? *Canadian Medical Association Journal*. 2009

Wiljer D, Urowitz S, Apatu, Leonard K, Quartey N, Catton P. Understanding the support needs of patients accessing test results online. *Journal of Health Information Management*. 2009

Wiljer D, Urowitz S, Frasca E, Nyhof-Young J, Secord S, Walton, T, Catton P. The role of a clinician-led reflective interview on improving self-efficacy in breast cancer patients. *Journal of Cancer Education*. 2009

Hodgson DC, Grunfeld E, Gunraj N, Del Giudice L. A Population-based Study of Follow-up Care for Hodgkin Lymphoma Survivors: Opportunities to Improve Surveillance for Relapse and Late Effects. *Cancer*, 2009

Jones JM, Cheng T, Jackman M, Walton T, Rodin G, Catton P. Predictors of distress in women completing adjuvant treatment for early breast cancer. *Journal of Psychosocial Oncology*

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Published Conference Proceedings

Jusko Friedman A, Cosby R, Boyko, S, Hatton-Bauer J, Turnbull G, CCO Patient Education Committee. Effective Teaching Strategies and Methods of Delivery for Patient Education. A Quality Initiative of the Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO). Evidence-Based Series #20-2. CCO, March 17, 2009.

Barnwell S, Tullio-Pow S, Nyhof-Young J. Enabling Design: Modular bag with a therapeutic arm sling for breast cancer survivors with lymphedema. Proceedings of Include2009: Inclusive design into innovation: transforming practice in design, research and business. Helen Hamlyn Centre, Royal College of Art, London. 5-8 April 2009. 9 pages, ISBN 978-1-905000-80-7 (complete paper blind peer reviewed). <http://include09.kinetixevents.co.uk/4dcgi/prog?operation=author&id=58>

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Wiljer D, Urowitz S, Chafranskaia A, Durkee L, Quartey N, Catton P. From Clinical Care to Online Communities, Exploring New Models for Survivorship Care in Lymphedema. In Proceedings of the 4th International conference on e-Learning International Conference on e-Learning Toronto, pp. 493-500. July 2009.

DiMarco C, Wiljer D, Hovy E. Self-Managed Access to Personalized Healthcare through Automated Generation of Tailored Health Educational Materials from Electronic Health Records. 2009. Published Proceedings, Association for the Advancement of Artificial Intelligence, Washington, November 2009.

Peer Reviewed Published Abstracts and/or Presentations

Urowitz S, Wiljer D, Friedman A, Secord S, Catton P. Caring Voices. Barrier free support for cancer survivors. Presented at: AACE 2008 Clearwater Beach October 2008. *Journal of Cancer Education*, 23 (S) #23, July-September 2008.

Urowitz S, Wiljer D, Friedman A, Secord S, Catton P. Caring Voices: An Online Community of Support for Cancer Survivors. Presented at: UICC World cancer Congress 2008, Geneva, August 2008.

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Hammond P, Chafranskaia A, Nyhof-Young J, Secord S, Catton P. An Innovative Self-Care Management Model for Lymphedema Care for Breast Cancer Survivors at Princess Margaret Hospital in Toronto. Presented at: Eighth National Lymphedema Network International Conference, Lymphedema: Riding the Wave of Discovery, San Diego, August 2008.

Urowitz S, Wiljer D, Willson D, Catton, P. Social networks to social medicine: Exploring the role of online interventions. Medicine 2.0 Conference, Toronto, September 2008. Published as a Multimedia Appendix in Eysenbach G (ed.). Medicine 2.0 Proceedings, p. 14. Toronto, September 2008. <http://www.jmir.org/2008/3/e22/>

Secord S, Catton P. Caring Voices: barrier free support for cancer survivors. Presented at: Joint annual meeting of CPEN/AACE. Clearwater, October 2008. Journal of Cancer Education, 23(S) 1, March 2008.

Edelstein K, D'Agostino N, Hodgson D, Nathan P, Greenberg M, Millar BA, Laperriere N, Spiegler BJ. Neurocognitive late effects in adult survivors of childhood acute lymphoblastic leukemia. The Clinical Neuropsychologist, 33, 442, 2008.

Secord S, Wiljer D, Urowitz S, Friedman A. The survivorship empowerment model for integrated cancer care (SEMICC): A survivor centred model for supportive care delivery. AACE 2008 Clearwater Beach October 2008. Journal of Cancer Education, 23 (S), July-September 2008.

Loiselle C, Koerner A, Wiljer D, Fitch M, Boyko S, Cook S, Jusko Friedman A, Harth T, Lorhan S, Stacy A-M, Trunbull G, Girouard L, Peters O. Integrated web-based cancer informational support and survivorship care: Bringing innovation to partnership, delivery, evaluation and sustainability. 2009 International Cancer Education Conference; Presented at: AACE-CPEN-EACE Joint Annual Meeting. Houston, Texas. October 15-17, 2009. Journal of Cancer Education, 24 (S) 1, March 2009.

McCallum M, Beattie S, Lebel S, Bezjak A, Irish JC, Devins GM. Positive health changes in head and neck and thoracic cancer patients. Psycho-Oncology, 18 (Suppl. 2), S179, 2009.

Maheu C, Gallaher G, Zanchetta M, Guruge S, Secord S, Maritt K, Catton P. Understanding and improving breast cancer self-management through social networks and infrastructures within Portuguese-speaking communities in Toronto: A pilot study. Presented at: UHN Nursing Research Day, University Health Network, Toronto. December 2009.

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Jusko Friedman A, Wiljer D, Urowitz S, Papadakos, J, Secord, S, Nyhof-Young, J, Catton, P. Empowerment: A Survivor-Centred Strategy for Self-Management and Supporting Cancer Survivors With, Through and Beyond their Journey. Presented at: CAPO annual meeting, Vancouver, April 2009.

Akinfemiwa Y, Chafranskaia A, Catton P, Nyhof-Young J. Designing and evaluating a bra-guide for female breast cancer patients. University of Toronto Medical Journal 86:S337(HC1). Presented at: Ontario Medical Student Research Day, Toronto, April 2009.

Laba J, Durkee L, Catton P, Nyhof-Young J. Investigating the use of educational resources for the management of persistent cancer related fatigue in breast cancer survivors at Princess Margaret Hospital. University of Toronto Medical Journal 86:S40(HC13). Presented at: Ontario Medical Student Research Day, Toronto, April 2009.

Wiljer D, Urowitz S, Leonard K, Apatu E, Massey C, Quartey N, Catton P. Patient access to personal health information: Exploring the impact on self-efficacy and anxiety. Presented at: COACH e-Health Conference 2009. Quebec City, May 2009.

Wiljer D, Urowitz S, Chafranskaia A, Durkee L, Quartey N, Catton P. From Clinical Care to Online Communities, Exploring New Models for Survivorship Care in Lymphedema. Presented at: 4th International Conference on e-learning, Toronto, July 2009.

Jusko Friedman A, Nyhof-Young J, Secord S, Catton P. Managing Your Cancer Journey: a Guide for Cancer Survivors. Presented at: GOPUBLIC – Global Leadership Forum for Cancer Control, Ottawa, September 2009.

Jones J, Jusko Friedman A, Catton P, Papadakos J, Turnbull G, Hatton-Bauer R, Harth T, Bennett C, McGrath K, Blacker S. Maximizing your patient skills: A multi-center mix methods Study Evaluating an Innovative Inter-Professional Patient Education Skills Training Course. Presented at: International Cancer Education Conference; AACCE-CPEN-EACE Joint Annual Meeting, Houston, October 2009. Journal of Cancer Education, 24 (S) 1, March 2009.

Urowitz S, Wiljer D, Friedman A, Papadakos J, Willson D, McBain S, Catton P. CaringVoices.ca: The next generation of support for Canadian cancer patients. Presented at: The 9th Princess Margaret Hospital Conference New Developments in Cancer Management, Toronto, October 2009.

Jones JM, Cheng T, Walton T, Catton P. Predictors of distress in women completing adjuvant treatment for breast cancer. Presented at: Canadian Association of Psychosocial Oncology Annual Meeting, Vancouver, April 2009.

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Wiljer D, Urowitz S, Secord S, Frasca E. The role of a clinician-led reflective interview on improving self-efficacy in breast cancer patients. Presented at: 2009 International Cancer Education Conference & AACE-CPEN-EACE Joint Annual Meeting. Houston, Texas. October, 2009. *Journal of Cancer Education*, 24 (S) 1, March 2009.

Invited Talks

Catton P. Survivorship – A Model of Care, Toronto Breast Cancer Symposium. Toronto, June 2008.

Catton P. Identifying Priorities for Cancer Survivorship Research: Pan-Canadian Invitational Workshop. Vancouver, November 2008.

Jusko Friedman A. Cancer Patient Education in Canada: Canadian Partners Against Cancer, National Consensus Building Workshop. Montreal, March 2009.

Wiljer D. One Patient, One Record. The creation of InfoWell. One day symposium to promote patient e-Health. Toronto, April 2009.

Jusko Friedman A. A Survivor-Centred Strategy for Self-Management and Supporting Cancer Survivors With, Through and Beyond their Journey. National Survivorship Working Group for CPAC. Toronto, May 2009.

Urowitz S, InfoWell: Patient Portals and Chronic Disease Management. Knowledge Translation Colloquium. Montreal, QC. May 2009.

Wiljer D, Brainstorming: The Future of testicular Cancer Survivorship Research. Rochester, NY. May 2009.

Wiljer D. Transformations along the patient journey. Infowell. CQCO-CCO Signature Event. Using technology to improve the patient experience in Cancer Care. Toronto, June 2009.

Wiljer D. Empowering the Health System: A New Information Paradigm. eHealth Summit. Montebello, QC. June 2009.

Jusko Friedman A. Patients, Providers & Communities Partners in Learning: An Organizational Strategy for Patient Teaching. St Michaels Hospital Education Summit. Toronto, June 2009.

Urowitz S. Connecting people: Cancer survivorship communities. Using Technology to Improve the Patient Experience in Cancer Care. Cancer Care Ontario and Cancer Quality Council of Ontario. Toronto, June 2009.

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Wiljer D. Cancer prevention grand rounds. Rosewell Park Cancer Institute. Buffalo, NY. September 2009.

Papadakos J. Caring Voices: A National Initiative to Support and Connect Myeloma Cancer Survivors. Myeloma Canada Patient, Family & Healthcare provider Conference. Calgary, September 2009.

Wiljer D. Empowering through innovation knowledge exchange. CRO Aviano. PMH Exchange Program. Pordenone, Italy. October 2009.

Wiljer D. Researching and developing patient centred strategies for knowledge management: An organizational approach. CRO Aviano. PMH Exchange Program. Pordenone, Italy. October 2009.

Jusko Friedman A. Advocating for your own care. Kidney Cancer Canada, Pan-Canadian Teleconference. October 2009.

Catton P. Chafanskaia A, PMH Survivorship Program: Taking Interdisciplinary Care to the Next Level. CCO Psychosocial Rounds November 2009.

Wiljer D. Patient health records – The who, what, where, when and why. ABJS Carl T. Brighton Annual Workshop. Tampa, FL. November 2009.

Wiljer D. Implementing and integrating e-health at the frontlines of care. Using IT to drive patient engagement and self managed care. Insight Conference. Toronto. December 2009.

Wiljer D. Diagnostic Assessment: The Role of New Technologies. Cancer Care Ontario Diagnostics Assessment Workshop. Toronto, December 2009.

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AWARDS

Jusko Friedman A: Cancer Patient Education Network Distinguished Service Award, August 2009

Nyhof-Young J, Akinfemiwa Y, Chafanskaia A, Catton P: Best presentation, Health Care category. Designing and evaluating a bra-guide for female breast cancer patients. Poster presentation, Ontario Medical Student Research Day, April 2009.

Nyhof-Young J, Papp S, Haji Z, Hardie H: People's Choice Award for 'One Minute Wonder' Presentation. Design and Evaluation of a New Website for the PMH Wig Salon & Accessories Boutique. Poster presentation, Wilson Center Research Day, October 2009.

Wiljer D, Urowitz S, Frasca , Secord S, Walton T, Catton P: AACE R. Davilene Carter Presidential Prize for Best Paper (2nd Place), October 2009.

How to Contact Us

If you have any questions about this report, please feel free to contact us.

Paul Alofs

President & CEO (416) 946-6573

Sherri Freedman

Vice President, Development (416) 946-4547

Greg Lichti

Senior Director, Major Gifts (416) 946-2168

Jill Nelson

Director, Planned Giving (416) 946-6562

Christina Lebesis

Associate Director, Major Gifts (416) 946-2138

Shannon Stuart

Associate Director, Major Gifts (416) 946-6571

Matthew Warszawski

Associate Director, Major Gifts (416) 946-2107

Clayton Atto

Associate Director, Major Gifts (416) 946-2128

Susan Carter

Associate Director, Research & Stewardship (416) 946-4554

Monica Gaudry

Associate Director, Donor Relations (416) 946-2906

Laura Byl

Senior Development Officer, Major Gifts (416) 946-4668

Genane St. Rose

Development Officer, Planned Giving (416) 946-2295



For more information, please go to: pmhf.ca