

ISSUE

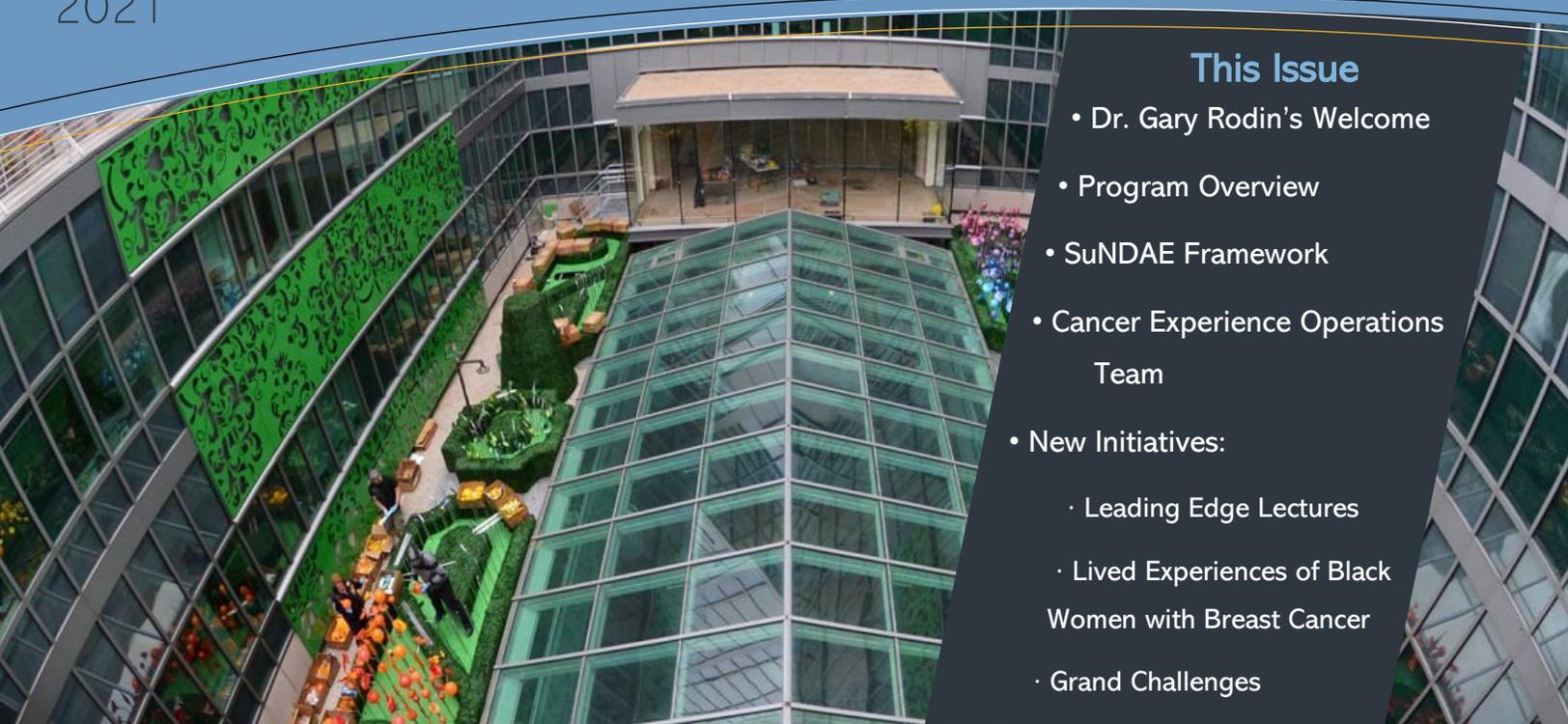
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SUMMER

2021

UHN Cancer Experience

The Human Touch in Cancer Care



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Dr. Gary Rodin's Welcome



Welcome to the inaugural issue of the Cancer Experience Newsletter, a quarterly newsletter about the Cancer Experience Program at UHN. This program was created to support and develop initiatives that improve the interconnected well-being of patients, families, staff and trainees in the Cancer Program. Our ultimate goal is to ensure that cancer care and opportunities for staff and trainees are inclusive and equitable. Initiatives in the Cancer Experience Program have been prioritized according to the SuNDAE framework - which includes **Supportive Communication; Navigation; Diversity; Ambiance; and Engagement.**

We hope that this newsletter will be an easy to navigate forum that highlights the projects, initiatives, and key partnerships of the Cancer Experience Program as they develop. This edition will introduce the operational team of the Program and will highlight some of the initiatives that are now underway. We welcome suggestions, feedback and proposals for new projects to ensure that Princess Margaret is as exceptional in the human touch in cancer care as it is in its state-of-the-art cancer treatment.

Cancer Experience Program Overview

The Cancer Experience Program at UHN was created to ensure that cancer care is not only medically rigorous, but also empathic, inclusive, and accessible, with resources and support to ensure the interconnected wellbeing of all who receive or provide care or training in the cancer centre. This program aims to build capacity for such care for patients families, trainees and staff, with novel solutions developed in relation to the SuNDAE framework. The structure of this program and some of the innovative projects that are already underway are highlighted in this inaugural newsletter edition.

Supportive Communication – Better Communication Increases Patient Satisfaction

Communicating important information about diagnosis and treatment to patients and their loved ones must be done in a sensitive and empathic manner. Work in this pillar will increase patient and family satisfaction, reduce distress, promote faster recovery, and improve quality of life.

Navigation – Helping Cancer Patients and their Caregivers Find Their Way

Online navigation tools are paramount to ensuring equality and inclusivity within the cancer care continuum and to help maintain patient well-being. Work in this pillar will provide ready access to cancer care providers, psychosocial supports and both traditional and non-traditional supportive care resources.

Diversity, Equity, Inclusion and Access (IDEA) – Ensuring Equal Access for All

Access to cancer care is not the same for all Canadians in our public health system. We must ensure that diverse and marginalized patient groups have equitable access to cancer care and consequently better health outcomes. Work in this pillar will improve our understanding of who our patients are and the barriers they face in accessing and experiencing treatment.

Ambience – Creating an Environment for Excellent Patient-centered Care

The environment in which cancer care, research, and education is experienced can have a significant impact on the well-being of our patients, families and healthcare providers. The work in this pillar extends beyond improving the physical space to enhance the sensory and psychological experience at Princess Margaret through art, technology, and other means.

Engagement—Partnering with Patients for Better Care

The prioritization of the patient and family voice and the well-being of all individuals in the care team is paramount to establishing sustained and productive partnerships in cancer care. The work in this pillar will foster two-way communication between patients and their care team, and assist healthcare providers in reducing workplace burn out. The importance of this work is highlighted clearly in the challenges we are all facing during the COVID-19 pandemic.

Cancer Experience Operations Team



Meena Merali, PEng, MBA

*Director, Transformation and Strategic Partnerships;
Administrative Partner, Cancer Experience Program*

Meena is a results driven healthcare leader with a track record of building strong, collaborative partnerships at the local, national, and global scale. She has led sustainable and culturally congruent international programs to build capacity, improve access to cancer care, and advocate for global cancer control. In her current role, she provides leadership to drive strategic priorities and integrate research, education and clinical care.

Heather Soberman, MA, MHSc, CHE

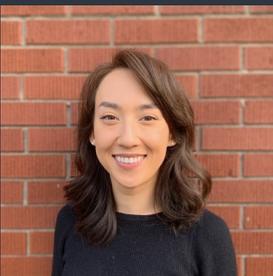
*Senior Manager, Transformation and Strategic Partnerships;
Operational Lead, Cancer Experience Program*

Heather is an experienced healthcare management professional with a strong record of organizational leadership, strategy and business development, guiding clinical operations, and stakeholder management. Heather is a graduate of McGill University (with distinction), where she completed a BA Hons. degree in Psychology/Behavioural Science. Heather also holds a Master of Arts in Psychology, as well as a Master of Health Science in Health Administration from the University of Toronto.



Hanae Davis, PhD

Planning Associate, Cancer Experience Program



Hanae is an experienced researcher and project manager in experimental psychology and paediatric disability, having led and coordinated projects related to research, pedagogy, and community outreach. She is passionate about patient and family-centred care for those impacted by chronic conditions, given her lived experience as a family member to a sibling with a disability.

Calvin D'Souza, MHA

Planning Associate, Transformation and Strategic Partnerships

Calvin is experienced with and passionate about program delivery, particularly in cancer care. With an educational background in biophysiology and health administration, professional experience with Nova Scotia Health, and lived experience as a family member impacted by cancer, he is looking forward to growing the UHN Cancer Experience Program.





Krista Hoch, BA

Graduate Student, Cancer Experience Program

Krista is a second year master's student studying health promotion at the University of Toronto. She studied international affairs as an undergraduate and is passionate about the global side of public health. Her interests include health security policy, maternal and child health, and the dual burden of communicable and non-communicable diseases.

Jenny Cho, BSc

Medical Student, Cancer Experience Program

Jenny is entering her third year as a medical student at the University of Toronto. Previously, she completed her Bachelors of Science with an Honours Specialization in Translational and Molecular Medicine at the University of Ottawa. Jenny has been involved with initiatives that seek to provide mentorship to students from marginalized communities and is interested in pursuing a career that helps all patients live a high quality of life throughout their illness trajectories.



Alexander (Kai) Marks de Chabris

Student, Transformation and Strategic Partnerships

Kai is a fourth-year undergraduate student of International Business at the University of Carleton, with a concentration in Global Financial Management and Systems and a minor in Spanish. Previously, he worked at Princess Margaret's Orsino Cell Therapy Facility as a student assistant.

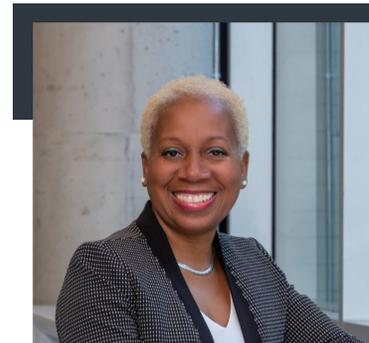


New Initiatives

Leading Edge Lecture Series

The new academic year will see the launch of the **Leading Edge Lecture Series** by experts in the domains of cancer experience to stimulate discussion regarding the innovation and refinement of our initiatives. The engagement of these healthcare experts will seek to bring forth beneficial health outcomes pertaining to the SuNDAE framework.

The first speaker in this lecture series will be Dr. Juliet Daniel speaking on **Race and Structural Barriers to Cancer Care** from September 22nd from 12:00 to 1:00pm. Dr. Daniel is a Professor, Cancer Biologist and Associate Dean of Research & External Relations for the Faculty of Science at McMaster University. Dr. Daniel is a basic scientist who is internationally renowned for her genetic research leading to the discovery of the Kaiso gene, responsible for cell proliferation and adhesion. She is equally renowned for her research on factors that control tumour progression and spread, as well as her work surrounding mutations or markers that may explain racial disparity. Dr. Daniel has also been engaged in advocacy to improve health equity for marginalized groups and is the recipient of numerous awards including the African Canadian Achievement Award, the Ontario Premier's Excellence Award and the Barbados National Honour Gold Crown of Merit.



Dr. Juliet Daniel

Lived Experiences of Black Women with Breast Cancer

Led by Drs. Andrea Covelli and Jaime Escallon, this project will examine to what extent barriers and inequities in access to cancer care shape the lived experience of black women with breast cancer. Previous research has shown that women with breast cancer from minority communities present more frequently at advanced stages of disease and are less likely to receive optimal treatment than the demographic majority. The goal of this study is to understand the lived experience of black women across both the GTA and Ontario who have or are currently undergoing treatment for their breast cancer. By partnering with the Olive Branch of Hope (a community-based breast cancer support service intended for black women), black women who have experienced breast cancer will be able to share their journeys with us. Through a rich narrative, this team will understand these experiences and identify challenges, barriers, inequities and/or variations in care to elucidate the impact of sociocultural factors and the health-care environment on breast cancer care for black women.



The Lived Experiences of Black Women with Breast Cancer Team (from top-left, in clockwise order): Dr. Andrea Covelli, Dr. Juliet Daniel, Dr. Gayathri Naganathan, Dr. Aisha Lofters, Leila Springer.

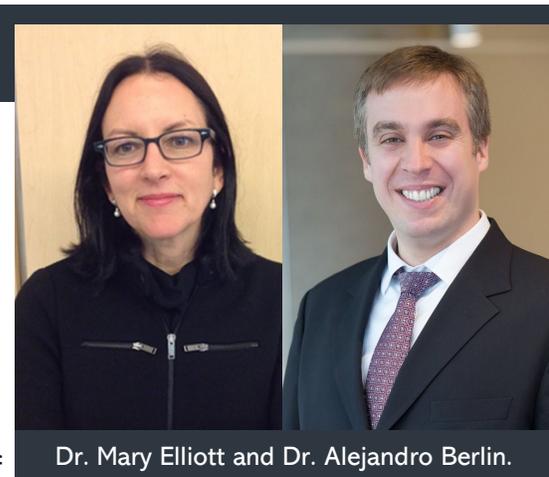
Grand Challenges

For the first time this year, there was a Grand Challenge competition in Cancer Experience - the Human Touch in Cancer Care. This competition was intended to support bold, innovative, and high impact projects aimed to improve the cancer experience across the spectrum of care. The projects selected for funding from the twenty-five submissions were:

The Lift: Responsive Well-Being Practices Delivered to Healthcare Workers

To protect the healthcare system and quality outcomes, it is imperative to address the well-being of healthcare workers (HCW). Up until now, there have been barriers to the implementation of sustainable and scalable programs to promote HCW well-being. In 2018, a team at PM, informed by research findings, developed a Building Resilience with Institution Together with Employees (BRITE) to provide HCW with foundational resiliency skills to foster individual resilience and enhance engagement. The Lift will build upon and extend BRITE practices.

The Lift, co-led by Drs. Mary Elliott and Alejandro Berlin, harnesses the latest from clinical neuroscience, foundational of aspects of BRITE, and delivers well-being practices directly to HCW for use throughout their workday. It addresses identified limitations, and with the shift to social media platforms has the capacity for both for real-time and on-demand options, and resulting in enhanced flexibility and responsiveness to the impact from the ever-changing landscape of the healthcare system and the distinct needs of HCW. The Lift social media well-being program aims to provide staff with content focused on building individual resiliency, reducing HCW burnout, and managing stress – and in doing so impact the experience of HCW, patients, and families.



Dr. Mary Elliott and Dr. Alejandro Berlin.

Accelerating SuNDAE Through Proactive Psychosocial Oncology

Led by Dr. Madeline Li and Megan Wexler, this Grand Challenge project seeks to ensure access to Psychosocial Oncology (PSO) to patients who might otherwise be excluded from such care. Only about half of all cancer



Dr. Madeline Li and Megan Wexler.

patients who might benefit from psychosocial care currently receive it and this proportion is much lower for patients from marginalized communities. Li and Wexler have proposed a proactive, equitable and in-depth approach to PSO care by identifying individuals who have the highest levels of distress while also ensuring greater breadth of support for low distress individuals. This will be achieved through improvements in PM's New Patient Experience Pathway along the SuNDAE framework. These changes include a New Patient Registration Referral (NPRR) workflow, Distress Assessment and Response Tool (DART) integration into Princess Margaret's (PM) Virtual Patient Management System (VCMS) as well as

greater awareness of PSO resources both on site and online. As the effects of the COVID-19 pandemic continue to linger, this project will allow PM to reorganize the existing PSO infrastructure, establishing a new global standard in PSO care.

Caregiver Support Program

Cancer caregivers (CGs), who may be family caregivers (FC), are central members of a patient's cancer care team. They often are important sources of emotional and practical support and participate in treatment decisions and in the successful delivery of cancer care. However, there has been no systematic approach to supporting and educating CG's in these important tasks. To fill this gap, three teams have come together to create a new PM Family Caregiver Support Program.

Dr. Meredith Giuliani and Dr. Janet Papadakos and their study team have developed a psychoeducational program for CGs that aims to provide psychological supports (e.g. building resiliency), cancer knowledge, decision-making skills,



Dr. Meredith Giuliani, Dr. Janet Papadakos, Dr. Sarah Hales, Dr. Rinat Nissim, Dr. Jennifer Croke and Dr. Breffni Hannon (from left to right).

systems navigation, and clinical/technical skills (e.g. food safety, medication management). This program will be delivered in person and via an asynchronous 12-module digital education course, with evaluated outcomes of caregiver burden, satisfaction with care and perceived caregiving competency. Drs. Sarah Hales and Rinat Nissim and their team have newly adapted a psychotherapeutic intervention originally for patients with advanced disease, Managing Cancer and Living Meaningfully initiative (CALM), for FCs of patients with cancer. This FC version, now known as iCALM-FC will be delivered as an online self-directed intervention. In this format, iCALM will provide psychoeducation, reflective exercises, and e-Coach support to address the practical and profound problems that CG's of patients with advanced disease face in a convenient, de-stigmatized, and resource efficient format. Finally, Drs. Breffni Hannon, Jennifer Croke, Rinat Nissim and their team have identified the need to better support FCs of patients with advanced disease who are attending outpatient palliative care. They have proposed a service by which these FCs will be provided support by a specialized FC, triggered by online patient-reported outcomes. This service will also act as a hub, providing FCs with ease of access to educational materials via the Virtual Patient Education System; referrals to Social Work, the Caregiver Clinic in the Department of Supportive Care and/or cancer psychiatry; and facilitated connections to caregiver support groups.

Understanding the Effects of the Digital Divide at PM and Comfort & Care for All

Toronto is the world's most culturally and linguistically diverse (CALD) city in the world, one in which nearly 50% of households identify as speaking a language other than English at home. Unfortunately, this population remains understudied and at a heightened risk of medical errors, poor illness understanding and poorer medical outcomes. Additionally, the increased use of digital health tools at PM can create educational and linguistic barriers for these patients, which further alienates them from accessing information and other communication technologies. Indeed, individuals most affected by digital health inequalities have been found to be those requiring the greatest healthcare needs .



Dr. Stephanie L'Heureux and Dr. Alejandro Berlin.

Although medical interpreter services have been effective in improving patient satisfaction and health outcomes, patients' usage of these services is low – this puts these patients at an even greater risk of adverse outcomes. The Comfort and Care for All team, led by Dr. Stephanie L'Heureux, aims to create a feasible solution with tangible impact on these patients' care pathways by conducting a trial implementation of iPads (iCALD) and e-interpreters for patients of CALD backgrounds.

In a similar vein, Smart Cancer Care, led by Dr. Alejandro Berlin, aims to create an evaluation infrastructure with the purpose of gauging the effects of initiatives aimed towards improving under-served populations' cancer care experience. Should significant discrepancies be found between socio-economic groups with regards to email correspondence and other survey participation, the team will act to propose methods to increase engagement amongst these under-served communities.



Moving forward, the Cancer Experience Program will aim to facilitate, integrate and synergize activities and initiatives to enhance the cancer experience on a local, national and global scale. This will be achieved by engaging projects and initiatives focused on improving the following domains: Education Trainee Wellness; Staff Wellness; Patient and Family Experience; Space & Arts and Humanities; Underserved and Underrepresented Populations; Quality of Cancer Care; Research; and SmartCancerCare. Details regarding these projects, partners, and leads will be presented in subsequent editions of our newsletter.

For more information about the Cancer Experience Newsletter and Program, please contact cancerexperience@uhn.ca.