



OCC Fall 2017 Newsletter

Strategic Refresh and Tribute to Lisa Levin, Past Chair, OCC:



On September 13, 2017, OCC members gathered at the Parkinson Canada Conference Centre in person, and with members from around the province joining us by teleconference, to set our OCC *strategic priorities* for the next 12-18 months. It was a very successful and productive meeting and we can now look forward to moving ahead with renewed energy and focus. Before the meeting began, Lisa Levin, Past Chair of OCC, was recognized for her many years of dedicated work on behalf of caregivers. (See above: left to right, Lisa Levin, Joanne Bertrand, OCC Coordinator and Cheryl Perera, OCC Chair).

Three key priorities were agreed upon in this meeting:

- To clarify the distinct role and mandate of OCC, i.e., that of being the organization that represents the 'voice' of unpaid caregivers in Ontario, and to

promote increased caregiver membership in order to establish OCC as an authority on caregiver issues in the province.

- To further our key advocacy positions with all political parties in a non-partisan way with a focus on ensuring all parties consider issues of significance to caregivers in their party platforms before the June 2018 election.
- To work towards becoming incorporated as a not-for-profit entity in 2018 and to ensure that we have in place a transition plan that includes due diligence and consultation with key stakeholders and current members.

Please don't forget – if you are interested in being involved in one of our sub-committees that will be working on these priorities, contact Joanne at jbertrand@alzheimeront.org and she'll refer you to the Chair of the sub-committee most aligned with your interests.

We currently have **4** working sub-committees – Research & Advocacy, Awareness & Communications, Membership & Governance and a Caregiver Advisory Council.

Caregiving in the News:

OCC Caregiver Participates in CBC Radio Program

Recently, one of our members, Denyse Lynch, agreed to participate in an episode of the CBC Radio program, *Out in the Open – Caregivers by Circumstance*. This remarkable and compelling program tells the stories of 7 different caregivers – in their own words. In the program, the diverse and complex aspects of the caregiving experience are sensitively and honestly explored. Click on the link below to listen:

<http://www.cbc.ca/radio/outintheopen/caregivers-by-circumstance-1.4291578>

Thank you, Denyse, for participating!

Member News:

Action for Dementia Day at Queen's Park

On September 27, 2017, the Alzheimer Society of Ontario (ASO) was pleased to host a luncheon at Queen's Park with the goal of informing MPP's about dementia and the need for '*solutions*' that will make a difference to improving the quality of life for those living with dementia. Lauren Rettinger, member of the OCC Research & Advocacy Committee and *Public Policy and Stakeholder Relations Coordinator* with the Alzheimer Society of Ontario assisted with the organization of this event. Joanne Bertrand attended, representing OCC.

It was heartwarming to hear the personal stories of those living with dementia. It was also clear that the important role played by the care partners of those with dementia is acknowledged and valued by many in government.

One of the top 3 solutions proposed to government by ASO includes the recommendation that every care partner in the province has access to high quality respite care including extended day programming throughout the province and more flexible/self-directed respite options.

Upcoming Events:

Drug Pricing Summit Coming in November – submitted by Antonella Scali, Schizophrenia Society of Ontario

On November 15-16, 2017 from 8:30 a.m. - 5:00 p.m., you are invited to join the Save Your Skin Foundation, the Canadian Cancer Survivor Network and the Schizophrenia Society of Ontario and other patient groups for the second annual Drug Pricing Policy Summit – Measuring Progress and Making Our Mark.

This year's Summit will build on the inaugural 2016 Summit with updates from across the regulatory, public and private policy environments. In addition, the 2017 Summit will present different views on drug pricing policy in Canada, including perspectives on value-based healthcare with a focus on patient outcomes and putting the patient at the centre of the process. Panelists will include leaders in the public and private payer environments, pharmaceutical industry and prescribers.

Patient groups will also build on the working committee action plans that were developed through the 2016 Summit based on the work that has been done to date and on information from the 2017 Summit. This includes reviewing and renewing working committee composition and strategic objectives and tactics for 2017-2018.

To learn more on this event and to register, please visit: <https://www.eventbrite.ca/e/drug-pricing-in-canada-mobilizing-patients-to-action-tickets-37731814874>

Resources of Interest:

Compensating Caregivers

For some time, OCC has been aware that an issue of concern is the need for a better understanding of the challenges many caregivers face when asked to become engaged in policy development through participation on various government or non-government committees or projects. Caregivers and patients are often told that their input and perspective is both necessary and valuable to setting good policy – which it is. However, are caregivers always being treated fairly and equitably in this process and is their participation adequately compensated? The Change Foundation (TCF) has published an excellent guide to answering some of these questions '***Should Money Come Into It?***' See the link below.

<http://www.changefoundation.ca/patient-compensation-report/>

This is a 'must read' and highly recommended to all OCC members!

As Christa Haanstra, *Executive Lead Strategic Communications*, TCF, recently observed in the TCF September newsletter, "We need to ensure that patients and caregivers are equal partners in the process" and if we are asking them to commit time, energy and expertise we have to recognize that sometimes they need to have compensation that goes beyond simply reimbursing them for things like travel, parking, or respite. Otherwise, there is an inequity between caregivers and paid employees who are participating.

Note: See next article for more on the importance of an equity approach.

Wellesley Institute Submission to Law Commission Argues Health Equity Approach

Thank you to the Wellesley Institute for forwarding OCC a copy of their recent *Submission to the Law Commission of Ontario: Improving the Last Stages of Life (September 2017)*. **See attached to this newsletter.**

This is a very thoughtful, compelling document and you are encouraged to read it. It is particularly of interest in highlighting how social determinants of health are critical to ensuring an equitable system of care for all – including low-income and culturally diverse populations.

New Blog for Caregivers

Thanks to Roseanne Meandro, *Director of Communications*, Alzheimer Society of Canada, for the following tip:

Check out our blog on caregivers not having to go it alone...a collaboration of ASC, the MS Society and Parkinson's.

<http://alzheimersocietyblog.ca/you-are-not-alone/>

Research Opportunity:

Although the opportunity for caregivers to participate in this project is limited, geographically, to the Greater Hamilton Area, it may be of interest to someone you know in that area – and there is a \$100 (cash or gift card) honorarium offered to participants who qualify. Anastassios Dardas is the Project Investigator. She is a doctoral student at McMaster University. She is looking for caregivers who are employed and also providing unpaid care to a friend or family member. Participants will

carry a GPS unit and log in to a trip diary for one week. As well, they will complete a questionnaire.

For more information, contact Anastassios at – dardasa@mcmaster.ca or call 905-525-9140 – Ext. 28617.

The study has received ethics clearance through the McMaster Research Ethics Committee.

Welcome to New Members:

Judith James, Erin, Ontario

Emily King, Waterloo, Ontario

Next OCC newsletter deadline for submissions – **Thursday, November 30, 2017.**

***Disclaimer:** This newsletter is for information purposes only.*

