

# CILT's Peer Links

**Volume 10, Issue 1  
Fall 2008**

## CILT is Moving

We will be closed December 4th – 8th. We will re-open for business December 9th, 2008. Our new address will be:

365 Bloor Street East  
Suite 902  
Toronto, Ontario  
M4W 3L4

Phone numbers and email addresses will not change.

## Health Canada warns Canadians not to use two Vitamin C supplements due to potential health risk

Health Canada is warning Canadians, especially expectant mothers, not to use two vitamin C products sold under the brand names New Roots Herbal Vitamin C8 and Vitazan Professional Vitamin C Advanced Ascorbate. These products were improperly manufactured using vitamin A instead of vitamin C, exposing consumers to potential risks of adverse events.

Capsules may also contain excessively high doses of vitamin A. The maximum recommended daily dosage for vitamin A without a prescription is 10,000 International Units (IU). Consumers taking two capsules of the affected products daily as suggested on the product label, or more, may exceed this amount and could be at risk of serious health effects. Symptoms of vitamin A overdose include headaches, fatigue, appetite loss, nausea and diarrhea. Women in the early months of pregnancy who take excessive doses of vitamin A risk serious birth defects in their unborn children.

Canadian manufacturer, New Roots Herbal, has initiated a Canada-wide recall of the two affected lots, which are indicated on the label as LOT 2689 (exp. 08/2012) and LOT 9719 (exp. 01/2012). The vitamin supplements come packaged in bottles of 90 or 180 capsules. Images of the product labels are provided below.

Canadians who have the affected products are advised to immediately

discontinue use and consult their health care professional if they have related health concerns. Consumers should return the products to the point of purchase or the manufacturer for safe disposal. No adverse reactions related to these products have been reported in Canada. Health Canada will be working with the manufacturer to determine where the products were distributed in Canada and to ensure they are immediately removed from the market.

Drugs and natural health products that are authorized for sale in Canada will have an eight-digit Drug Identification Number (DIN), a Natural Product Number (NPN) or a Homeopathic Medicine Number (DIN-HM) on the label. These numbers indicate that the products have been assessed by Health Canada for safety, effectiveness and quality.

Consumers requiring more information about this advisory can contact Health Canada's public enquiries line at (613) 957-2991, or toll free at 1-866-225-0709. Report online at the MedEffect™ Canada Web site. Call toll-free at 1-866-234-2345. Complete a Canada Vigilance Reporting Form and either Fax toll-free to 1-866-678-6789 or Mail to Canada Vigilance Program, Health Canada, AL 0701C Ottawa, ON K1A 0K9.

To have postage pre-paid, download the postage paid label from the MedEffect™ Canada Web site. The Canada Vigilance Reporting Form and the adverse reaction reporting guidelines may also be obtained via this Web site.

### Safety Message from the Office of the Chief Coroner removal of Liko Lift devices

The Office of the Chief Coroner has strongly recommended that all Liko Uno 102EE lifts be taken out of service. The Office of the Chief Coroner made this recommendation as part of the investigation into the death of a Long Term Care Home resident following a fall from a Liko Uno 102EE lift. According to the Office of the Chief Coroner, the lifts should not be placed back into service until the manufacturer, Liko, determines the cause of the lift failures and can advise on corrective measures.

According to the Office of the Chief Coroner, there are a total of 224 LIKO Uno 102EE lifts in Ontario. As you know, all Long Term Care (LTC) homes are required to ensure that each resident's environment be maintained to minimize safety and security risks and that action shall be taken to protect each resident from potentially hazardous substances, conditions and equipment.

The Ministry of Health and Long Term Care strongly advises that every long term care home and service provider who uses the identified Liko lift, review the information released by the Office of the Chief Coroner. The Ministry urges you to take whatever measures appropriate to ensure resident safety.

## **Press Release:**

### **Safety message from the Office of the Chief Coroner removal of Liko Lift devices**

TORONTO, November 5, 2008: Dr. A.E. Lauwers, Deputy Chief Coroner of Investigations, today announced that the investigation launched in May 2008 into the death of an individual who died as a result of a fall from a lift device at Leisureworld Caregiving Centre—O'Connor Gate, has concluded.

The expert engineer was unable to determine the cause of the failure of the Liko Model UNO 102EE that resulted in the death. During the investigation, it became apparent that other Liko Model lifts failed at another Leisureworld site. It was the opinion of the engineer that the Leisureworld staff were utilizing the lift appropriately in the failure which occurred at O'Connor Gate. In keeping with its public safety mandate, the Office of the Chief Coroner is strongly recommending that all Ontario hospitals, long-term care facilities and other public/private institutions that employ this device, take them out of service. They should not be placed back into service until the manufacturer, Liko, determines the cause of the failures and can advise on corrective measures.

For further information: Dr. Jim Edwards, Regional Supervising Coroner for Central Region, Toronto East Office, Ministry of Community Safety and Correctional Services, (416) 314-4000.

### **Independent Living Canada AGM in Beautiful Victoria, B.C.**

*By Nancy Barry, Peer Support/Volunteer Coordinator*

I was lucky enough to be invited to attend IL Canada's Annual General Meeting in beautiful Victoria, British Columbia, where I was asked to present on the Gateways to Cancer Screening Project.

Conference proceedings took place at Laurel Point Inn, and I resided for three days with my husband, who accompanied me as my attendant, at the gorgeous and luxurious Grand Pacific Hotel. I must say that I felt like a queen for three days, in a five star hotel with all the amenities one could ask for. I was impressed with the conference, the hotel, the people and the lovely picturesque atmosphere that Victoria has to offer.

IL Canada (formerly, CAILC), had an exciting and full agenda which included a visit to the new storefront Victoria Independent Living Centre, formally called The Victoria Personal Supports Centre. Located on Fort Street, in beautiful downtown Victoria, the Personal Supports Centre (PSC) assists adults 18 years of age and older with disabilities to access information and/or personal supports from government, not-for-profit and private sector organizations. The centre is a single-window process to help connect people with disabilities to the resources

and supports they need. The eighteen-month demonstration project will facilitate access to assessments, trialing of equipment and assistive devices and, where appropriate, training. Assistance is guided by the individual needing personal supports based on his/her goals. As an individual's needs change, the PSC will provide ongoing support if needed. This service is to support and enhance, not replace, the individual's efforts to manage their life.

A major theme inherent throughout the conference was that of Revenue Generation within the IL Centres; looking for money from places other than the usual funding sources. Mr. Burt Danovitz, Executive Director of the Independent Living Center in New York, talked about IL Centres developing partnerships with institutions that social service agencies would never think of creating. For example car dealers, banks and insurance companies who want your business would be interesting parties with whom to create partnerships. By giving something (\$\$\$) to the disability community, we would give something back by giving them our business. The whole platform is based on generating funds from sources other than the government, who basically never gives non profits sufficient funds anyway. While I found this to be an interesting concept, I'm not so sure that it would work in Canada. By large, the USA has many more IL Centres than Canada will ever see in one lifetime. For instance, there are 38 IL Centres in the state of New York alone.

Burt Danovitz is the Executive Director of the Resource Center for Independent Living (RCIL) located in upstate New York. With four locations spread over a dozen countries, the Center provides both advocacy and independent living services to thousands of New Yorkers making it one of the largest independent living centers in the United States. During his tenure at RCIL, Burt has been involved in a number of public policy and legislative initiatives including: voting rights, accessible transportation legislation, and consumer directed personal care attendant services (similar to our Direct Funding Program). Burt served on the New York State Senate's Medicaid Committee which resulted in legislation requiring New York to implement a nursing home transition program. Currently, legislation developed by RCIL is pending that will eliminate the institutional bias of all public dollars in New York. In order to develop the resources necessary to support public policy initiatives, RCIL developed four new corporations including a for profit subsidiary.

Three projects from the Canadian Independent Living Centres were highlighted: one, which I am proud to say, was the Gateways to Cancer Screening Project, the Lifelong Education and Recreation Needs (LEARN) Program from the Calgary IL Centre, and the Investing in Futures RESP Program from the Thunder Bay Centre. Each was very well received by the AGM participants. For more information on the RESP Program, visit [www.ilrctbay.com](http://www.ilrctbay.com) and for further details on the LEARN Program from the Calgary Centre, visit [www.ilrcc.ab.ca](http://www.ilrcc.ab.ca).

## Food for Thought: A Pan-Canadian Initiative Addressing the Healthy Eating Goals of Persons with Disabilities

### **Overview:**

Upon conducting a literature review it was clear that people with disabilities are more likely to experience reduced well-being because of obesity, or being underweight, malnourished. They face higher rates of dehydration, heart disease and diabetes than their able bodied counterparts. It also became evident that nutritionists and other educators and stakeholders lack information specific to the disability community.

With funding provided by the Physical Activity and Healthy Eating Contribution Program – Centre for Health Promotion, Public Health Agency of Canada, our initiative (to be completed by March 31, 2009) aims to build on the successful tools and resources that were created in our previous physical activity initiative “Healthy Lifestyles for Independent Living”. We will do this by adding new accessible tools on healthy eating including program models. We want to explore how food can also be used a vehicle to connect people, encourage physical activity and reduce isolation.

### **Objectives:**

- To conduct participatory action research/national needs assessment to gather information on Canadians with disabilities and the issue of healthy eating itself.
- To establish cross-sectoral partnerships with a focus on healthy eating (i.e. nutrition educators, grocery providers, community agencies, food security organizations etc) and establishing an advisory committee to steer project and development of tools.
- To develop accessible alternate formats, plain language, bilingual and user friendly healthy eating tools specific to the needs of people with disabilities based on the new food guide. (including a perpetual calendar).
- To host a Train-the-trainer event for all ILRC representatives (e.g. community ambassadors) whereby participants learn: the results of the national needs assessment; new accessible tools; and explore the implementation of various program models that improve and encourage healthy eating for people with disabilities.
- To pilot various consumer driven program models across Canada using healthy eating as a vehicle for reducing isolation of people with disabilities while promoting healthy eating habits.

- To create a handbook on the research, tools and lessons learned on healthy eating as a person with a disability, including tips for meal preparation for people with various disability issues.
- To evaluate the project and disseminate the results and the handbook throughout Canada.

To accomplish the goals of this project we will have an advisory committee comprised of individuals from both inside and outside of the network. These partners may include and is not limited to:

- ILRCs -Pilot Site staff
- Dieticians of Canada
- Active Living Alliance of Canadians with Disability
- Santropol Roulant

In keeping with the principles of IL, the Food for Thought Initiative will use Participatory Action Research (PAR) as the means of discovering what models work in various communities. This will be done by tracking a selected group of individuals with disabilities over the course of the initiative. Consumers will work with their local ILRCs while they test out various program models that encourage peer support and physical activities in 8 regions throughout Canada. They will also provide ongoing feedback to the project team to ensure that the project remains grounded in consumer needs and the developing model evolves in response to these stated needs. Although only 8 ILRCs will participate in the actual program pilots, the remaining 20 ILRCs will also participate in the training and provide healthy eating educational workshops for people with disabilities across Canada.

Please note that during the project we will produce communiqués and an online area on the IL Canada / Virtual ILRC website that will provide timely and relevant information on the project. For more information contact: [foodforthought@ilc-vac.ca](mailto:foodforthought@ilc-vac.ca)

### Addressing Disability in Cancer Care: CancerCare Manitoba/University of Manitoba

The purpose of this study is to document the experiences of people who experience disability and cancer and to explore how the Cancer Care System understands and addresses disability.

There are 4.4 million people with disabilities in Canada and close to one million

cancer survivors, many of whom experience disability as the result of cancer and/or its treatment. There has, however, been very little research on cancer and disability in Canada. Within the cancer care system, disability is not well understood and many cancer care providers are not well-informed about the care needs and issues of people who experience cancer and disability. Research in the U.S. has found that people with disabilities are often less likely to be screened for cancer, may not receive the most effective treatments, and have poorer prognoses and survival rates. Research in Canada and elsewhere has found that people who have had cancer are more likely to experience disability than persons who have not had cancer.

The leaders of the project are Deborah Stienstra and Harvey Chochinov. Deborah Stienstra is a Professor in the Interdisciplinary Master's Program in Disability Studies at the University of Manitoba. Harvey Chochinov is a palliative care researcher at CancerCare Manitoba and a Professor of Psychiatry at the University of Manitoba. The study coordinator is Gary Annable of Cancer Care Manitoba. An advisory committee of people with disabilities and cancer care experts (oncology, palliative care, rehabilitation, epidemiology) provides guidance and advice.

The study is funded by the Canadian Partnership Against Cancer (CPAC) which is responsible for implementing the federal government's Canadian Strategy for Cancer Control (CSCC). The main objective of the study is to develop an understanding of:

- the barriers that people with pre-existing disabilities in Canada encounter when they experience cancer and the cancer care system;
- the challenges encountered by people who experience disability as the result of cancer and/or its treatment; and
- how the cancer care system in Canada understands and deals with disability.

Through focus groups, Cancer Care Manitoba hopes to hear the perspectives of people with disabilities, including those who experienced their disability both prior to getting cancer and as a result of cancer. They also want to hear from cancer care providers including oncologists, nurses, psycho-social specialists, palliative care specialists and rehabilitation specialists; they want to hear about experiences in the full cancer spectrum: prevention, detection, diagnosis, treatment, survivorship and palliation.

**Definition of Disability:**

- The study is using a cross-disability perspective to identify things that are common to most people who experience disability and cancer.

- Disability is defined broadly according to the framework utilized for Statistics Canada's 2006 Participation and Activity Limitation Survey, and includes persons who experience limitations related to vision, hearing, mobility, agility, pain, memory, learning, development, and emotions/psychology.

### **Data Collection:**

- Separate focus group meetings with (1) people who have experienced cancer and disability and (2) cancer care providers will be held in seven Canadian cities during the fall of 2008.
- Independent living centres in each city is being funded to coordinate the meetings and recruit participants.
- The focus groups will be facilitated by at least one of the project leaders and the study coordinator.

### **Data Analysis:**

- The research team will prepare a draft report summarizing the findings from the focus groups, which will be provided to the study participants for review and comment in early 2008.
- A final report incorporating participant feedback will be published in the spring of 2009.

### **Ethical Issues:**

- The study has been reviewed and approved by the University of Manitoba's Health Research Ethics Board.
- People with disabilities were offered a \$25 honorarium to compensate them for their time, transportation, parking, and other expenses they may incur to attend the focus group meeting.
- CILT has been working with Cancer Care Manitoba in hosting two focus groups in Toronto: the first one was for people with disabilities on November 13th, 2008 from 6:00 pm to 9:00 pm at CILT. The second focus group was for cancer care providers which was held November 14th at Sunnybrook

## CILT NEWS

### Introducing Carling Barry

Please welcome Carling Barry as the Peer Support Program Assistant, formerly a CILT volunteer. She will be assisting the Peer Support Coordinator with special projects related to peer support, including the Cancer Care Manitoba Project. She will also be assisting with general inquiries related to the Parenting With a Disability Network while Kimberly McKennitt is on an extended medical leave of absence.

Carling will be in the office two to three days a week, and can be reached by email at [carling.barry@cilt.ca](mailto:carling.barry@cilt.ca). You may also call her at (416) 599-2458, and leaving a message for her at extension 27.

### United Way Fundraising Campaign 2008

The staff of the Centre for Independent Living are a generous and supportive group of people. We managed to exceed our goal of raising \$3,000.00 this year by a wide margin due to the efforts of all staff.

We had an amazing bake sale in the lobby of 205 Richmond St. West on October 9th during which staff managed to raise over \$400.00 from patrons in the building.

When combined with other small events & staff pledges, the staff raised well over \$3,300.00 which exceeded our goal by \$300.00 or 10%! This was an outstanding effort by all staff.

This year's committee Chair was Leisa DeBono of the Direct Funding Program, who was accompanied by her fabulous teammates Susan DeLaurier, John Mossa, and Victoria Pica.