
CILT's Volunteer Vibes

Volume 12 Issue 2

Spring 2013

Volunteer Program Update

Please welcome Pablo Hernandez and Rovelene Medina to CILT's Volunteer Team. Pablo was an accounts payable associate at Walmart Home Office for 13 years. He has a lot of experience in data entry and is interested in filing and typing.

Rovelene works as an attendant at Three Trilliums and has a University Degree in Banking and Finance, and has clerical work experience such as filing, photocopying. She is interested in learning more about computers, as she already has some basic computer skills.

Please give Pablo and Rovelene a warm welcome!

Volunteer Appreciation 2013

CILT's Volunteer Appreciation was an extra special event this year due to the fact that two of our volunteers have been volunteering with us for 11 years.

This year's event demonstrated the appreciation that each CILT staff member has for the generous support of our volunteers by expressing their thanks with a personal quote, followed by a catered lunch and certificate presentations.

In the spirit of volunteerism, we would like to acknowledge all of our volunteers for their tremendous dedication and hard work. Cheers!
Thanks to:

DENZIL BARKER
CRYSTAL BICKNELL
MIRIAM CHONG
HARIS FARID
MARY HENDERSON
PABLO HERNANDEZ
CLAIRE HURST
CATHY LINE
LUIGI LIS LISCIANDRO
BOBBI MOORE
ALNOOR NANJI
ELAINE STEWART
SUZETTE YEARWOOD

Volunteer Quotes by CILT Staff for Appreciation 2013

“It’s great to have so many wonderful volunteers at CILT. I appreciate their contributions.”

- Samantha Abel

“We wouldn’t be able to do what we do in this organization without you. There are no other words to explain it.”

- Carling Barry

“It makes me very happy to see that volunteers help us out. It is very important, even when we forget to say it. We all (staff) seem to get so caught up in our daily routines and pressures that sometimes the day goes by and I realize that I haven’t properly expressed my appreciation for all that you do! So this event is dedicated to expressing our appreciation, and frankly you deserve this and more recognition!”

- Sandra Carpenter

“Our volunteers rock! They are steady, responsible and reliable people who give their own precious, personal time to lend a hand. I cannot tell you how much I appreciate all the hours of support they have provided...many, many thanks!”

- Leisa DeBono

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“Volunteers are the backbone of non-profit organizations. Keep up the great work!”

- Abdullah Duranai

“Feeling gratitude and not expressing it is like wrapping a present and not giving it. So here I go, I am giving you my present. Thank you! Thank you! Thank you! Thank you to ALL the volunteers...you are seen, heard and appreciated. P.S. Miriam, keep those coffee candies coming, and Bobbi, please don’t buy yourself that suicidal fish.”

- Marisa Falzone-Bell

“We are very fortunate at CILT to have such talented and dedicated volunteers.”

- Melissa Graham

“Those who can, do. Those who can do more, volunteer. Volunteers don’t get paid, not because they are worthless, but because they are priceless. Thank you for your valuable help to CILT. Thank you for your time, efforts and knowledge which you dedicate to our organization.”

- Zdravka Gueorguieva

“The volunteers are great to see around CILT! Not only do they help out when we have a big project, but they bring a sense of community to the office.”

- Katherine Janicki

“Volunteers have helped us communicate with our consumers. They have helped us sort, fold, stuff and mail. They have

helped us set up before and clean up after our celebrations. It is their turn, now, to be celebrated for all that they do for us."

- Leanne Larmondin

"Volunteers are love in motion! Volunteers are priceless! Thank you for all your hard work."

- Judy Lu

"I would like to thank all the volunteers for their hard work, their commitment, and their belief in CILT. Whatever job you do is important. If you volunteer once a week or three times a week, your loyalty and hard work are truly appreciated."

- Melanie Moore

"Thank you for your help and commitment at CILT. Your hard work makes a meaningful difference for people with disabilities to live full and independent lives."

- John Mossa

"The volunteers who come into CILT regularly and whom I've met have impressed me in so many ways. They're always polite and I don't remember ever meeting a single volunteer who wasn't nice. They are all willing to adapt, for example, to work in a different space if we should need the place they've set up in, such as the board room. I've almost never been disrupted by a noisy volunteer. I think what is clear from each

one is a strong work ethic; CILT's volunteers come in and get down to the job in a very focussed way and it's obvious to see that each person takes his or her task seriously. And then besides outstanding helpfulness, there's so much experience and expertise that our directors on the board give freely to the organization often year after year after year. All in all there are some very generous and fine people we are honoured to count as CILT volunteers."

- Ian Parker

"The volunteers at CILT are a big help to all of our programs. Their work ethic is amazing, and their enthusiasm is contagious."

- Andrea Rae

"It's so thoughtful and kind of you to share your valuable time, talents and energy to help make our projects, events or days run better and smoother. You are appreciated. Thanks for volunteering!"

- Rolita Siu

"I just want to say a huge thank you to our amazing volunteers. You give up your free time to work for CILT unpaid. Every hour that you have spent here is a blessing to us. I can't say thank you enough for your dedications and contributions to us!"

- Jamie Wong

“I feel so honoured to have received the privilege of coordinating a program filled with wonderful people who make our hectic lives more fulfilled. Over the years I have had the joy and pleasure of meeting and working with many volunteers from all walks of life. You will never know how much your contributions and talents have helped to make CILT what we are today.”

- Nancy Barry

Building Bridge: Baby Boomer Volunteers Fact Sheet

<http://volunteer.ca/content/building-bridge-baby-boomer-volunteers-fact-sheet>

Conducted in the summer of 2010, a new pan-Canadian research study provides the most current national data about the changing culture of Canada’s volunteers, including information specific to the nation’s boomer population.

Unlike earlier surveys that emphasized overall participation rates, this new research captured:

- **What boomers want in their volunteer experiences;**
- **The issues boomers have in finding satisfying volunteer roles;**

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- **What organizations can do to enhance the volunteer experience for boomers**, which in turn can help them achieve their missions and ultimately build stronger communities.

The Importance of Boomers to the Canadian Voluntary Sector



Baby boomers are an important demographic. Of the 12.5 million Canadians who volunteer, 34 per cent fall into the boomer generation, making this demographic group the most active in volunteering.

The value of volunteering resonates strongly with boomers, who reference a deep sense of social commitment that drives them in their volunteering. Perhaps as a by-product of their upbringing during the civil rights and social change movements of the 60s and 70s, boomers consider volunteering a socially significant activity based on their commitment to support social justice.

Boomer Thoughts on Volunteering

Boomers who participated in this research felt that while many people want to volunteer, there is a lack of awareness of volunteer opportunities. For instance, although many organizations provide

retirement seminars for boomers about to retire, the focus is primarily on money management and there is little or no mention of volunteer opportunities.

Organizations often treat boomer volunteers as inexperienced in volunteering, and believed that this is in fact the opposite, as most boomers who volunteer have been volunteering throughout their lives.

Young boomers have a particularly strong work ethic and pitch in when something needs to be done. Many boomers felt it refreshing to do volunteer activities that are different from what they do at work.

Unfortunately, many boomers felt organizations did not always know how to engage skilled volunteers, and cited the importance of having a sense of ownership over their volunteer activities. Specifically, boomers indicated that being given responsibility on a very important project was a means of ensuring a sense of ownership, which in turn raised their level of commitment.

Boomers also value their independence while volunteering, preferring to do their job and feel engaged in the cause but not necessarily in the organization itself and its staff. A key factor in promoting satisfaction levels among boomers is for organizations to ensure individuals can see the impact they are making through their volunteer work.

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While boomers tend to be more willing and available to volunteer, their time needs to be respected and not over-extended. Experiences of being over-used, participating in volunteer activities that felt like a full-time job, and suffering from volunteer burnout were echoed consistently among boomers.

PAN- AM Toronto 2015

<http://www.toronto2015.org/lang/en/get-involved/get-involved-now.html>

*T*he 2015 Pan American Games, officially the 17th Pan American Games, is a major international multi-sport event that is scheduled to be held from July 10–26, 2015 in Toronto, Ontario, Canada, with some events held in Golden Horseshoe communities such as Hamilton and Markham among others.

Approximately 6,000 athletes from 41 nations are expected to participate in 36 sports. Both the Pan American and Parapan American Games are being organized by the Toronto 2015 Organizing Committee (TO2015).

The 2015 Pan American Games will become the third Pan American Games hosted by Canada and the first by the province of Ontario. Previously, Canada hosted the 1967 Pan American

Games and the 1999 Pan American Games, both in Winnipeg, Manitoba. The 2015 Parapan American Games will be held twelve days after the Pan American Games.

The PAN AM Games is currently in the process of building a team and there are many exciting ways for you to get involved.

Employment – PAN AM staff will consist of close to 400 highly motivated individuals who, as a team, will plan and deliver a transformative sporting and cultural event to the Greater Golden Horseshoe region.

Volunteer - Are you interested in building your skills while working alongside some of the top professionals in the region? Volunteers will play a vital role in 2015, but will also support the Organizing Committee in its planning stages. Opportunities to join the team to support Games planning will appear below as they become available.

Internship - As a requirement of your accredited college, university or transition/bridging/training program, you may need to gain some work experience. Why not learn and contribute to a unique organization in a 'once-in-a-lifetime' opportunity! The TO2015 internship program will reward participants with a rich learning experience while

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contributing to delivering this exciting event.

TO2015 is committed to employment equity and encourages applications from women, Aboriginal people, persons with disabilities and members of visible minority groups. Please tell the TO2015 human resources representative of any accommodation needs you may have when you are contacted for an interview.

To volunteer in 2015, visit the 'Get Involved Games Time' page at <http://www.toronto2015.org/lang/en/get-involved/get-involved-games-time.html>

Phone: 416- 957- 2015

Fax: 416- 957- 3999

Email: info@toronto2015.org



Disability Awareness

Pompe Disease

http://www.muscle.ca/fileadmin/National/Muscular_Dystrophy/Disorders/450E_Pompe_Disease_2007.pdf

What is Pompe Disease?

Pompe Disease occurs in many different age groups, anywhere from babies to adults, and is classified as a rare neuromuscular disorder. While the most common name may be Pompe disease, after Dr. J.C. Pompe, the first man to have described this disorder back in 1932, it can also go by Acid Maltase Deficiency and Glycogen Storage Disease type 2.

If a child is diagnosed with Pompe disease within the first year of life, it is generally considered to be the infantile-onset form of the disease and in most cases the disease is so progressive it becomes fatal before their first birthday. If a child is diagnosed after the first year of life they may get the diagnosis of having late onset Pompe disease that, while still progressive, progresses much slower than infantile-onset and can also be diagnosed during adult hood. Approximately one third of people diagnosed with Pompe disease are diagnosed with infantile-onset while the

other two thirds are diagnosed with late-onset.

What causes Pompe Disease?

Pompe disease is caused through a genetic defect in the chromosomes. Everybody has 23 pairs of chromosomes. Pompe disease is caused when there is a defect on both chromosomes of the 17th set. Since the child gets one chromosome from each parent, both parents have to have the defective chromosome to give their child.

If only one of the two chromosomes from the 17th spot is defective in the child, then it will simply become a carrier like its parents were. There is also the possibility that the child will not inherit any defective gene from their parents and in this case they have no chance of giving their future children the gene. Basically, if there are two carrier parents there is a 25% chance that the child will have Pompe disease.

What are the Symptoms of Pompe Disease?

Muscle weakness is one of the main symptoms for Pompe disease and is evident in both the infantile- and late-onset forms of the disorder. In addition to mobility, muscle weakness will affect the respiratory system to the degree that mechanical ventilation may become necessary. Some

people find they have morning headaches and have trouble concentrating due to the lack of oxygen. Other symptoms associated with late-onset Pompe disease include difficulty with chewing and swallowing; lower back pain; scoliosis; and frequent falls.

In infantile-onset Pompe disease, the infant is too weak to breathe on its own or to suckle its milk. The heart becomes enlarged, growing to three times its normal size. This reduces the size of the heart's chambers, forcing it to pump much harder. Other symptoms of infantile-onset Pompe disease include the failure to gain weight; enlarged tongue and liver; frog-like position of legs; and floppiness due to lack of muscle tone.

How Does Pompe Disease Progress?

Pompe disease is a progressive disorder. As with most neuromuscular diseases, Pompe disease begins with a loss of muscle control. For infants there is a lack of the basic motor skills such as learning to hold their head up, walking and crawling.

For adults they begin with having difficulty walking and, eventually, difficulty climbing stairs. Respiratory symptoms begin with slight difficulty breathing leading in many cases, as described above, to mechanical ventilation. Pompe disease progresses at different rates among those affected by the disorder.

How is Pompe Disease Diagnosed?

Pompe disease can be hard to diagnose as other neuromuscular disorders share many of the same symptoms. For example, Duchenne muscular dystrophy shares progressive muscle weakness, respiratory impairment and difficulty walking with Pompe disease.

To confirm a diagnosis of Pompe disease a test that will measure acid alpha-glucosidase enzyme activity can be ordered. This can be done through blood samples or more invasive procedures such as a skin or a muscle biopsy.

Individuals whose tests come back with a relatively high level of acid alpha-glucosidase will need to get them analyzed to determine if they are a carrier of the defective gene or actually have Pompe disease.

What is the Age of Onset?

Age of onset varies greatly. In the early Infant-onset kind of Pompe, it can happen between a few weeks to a few months from birth. For late-onset, symptoms may be delayed until the person is in their 40's or 50's.

Research

There is much research focused on infantile-onset. Great promise is appearing in research and tests being

done using enzyme replacement therapy. This involves injecting acid alpha-glucosidase directly into the blood streams of affected infants. In Europe the use of this gene therapy has been approved for patients regardless of age.

Symptom Management

There are several different ways to manage the symptoms of Pompe disease. Starting with a specific diet plan can help. Seeing a dietician will provide knowledge on what kinds of foods are best. Physical therapy will help keep muscles mobile and will help manage other symptoms of Pompe disease. Occupational therapy can help people learn use different adaptive devices in an effort to make everyday living easier. When breathing becomes difficult, the use of a ventilation machine can be prescribed.

Disability News

Harper Government Reaffirms Commitment to Persons with Disabilities

<http://www.accessibilitynewsinternational.com/harper-government-reaffirms-commitment-to-persons-with-disabilities/>

Ottawa, Ontario, May 2, 2013—The Honourable Diane Finley, Minister of

Human Resources and Skills Development, today announced the Government's support for private Member's motion 430, Strengthening Employment for Canadians with Disabilities.

This motion endorses the findings of the report of the Panel on 'Labour Market Opportunities for Persons with Disabilities' and commits to furthering public-private cooperation to improve the employment situation of Canadians with disabilities.

"Canada needs all of our available talent at work," said Minister Finley. "That is why Economic Action Plan 2013 is increasing opportunities for people with disabilities, helping them gain the skills and training they need to better participate in Canada's labour market."

The Harper Government created the Panel on 'Labour Market Opportunities for Persons with Disabilities' in Economic Action Plan 2012 to identify private-sector successes, challenges and best practices in employing people with disabilities. Motion 430, presented by Phil McColeman, Member of Parliament for Brant, calls for the Government to support the Panel's findings, recommending greater education and training to overcome barriers, dispel myths and better engage people with

disabilities in contributing to a stronger economy.

“With the recent Panel report, the importance of



strengthening

employment opportunities for people with disabilities is gaining national attention,” said Mr. McColeman. “Employers need to be looking at the strong business case for hiring people with disabilities.”

“I am happy to see the Government taking action to help more Canadians with a disability enter the workforce,” added Kathy Martin, Senior Vice-President, Loblaw Companies. “The motion is another positive step towards more employment and opportunities for people with a disability.”

Economic Action Plan 2013 proposes new measures to connect Canadians with available jobs and equip them with the skills and training they need. These include the Canada Job Grant, creating opportunities for apprentices and providing support to under-represented groups such as people with disabilities, youth, Aboriginal people and newcomers. To help people with disabilities in the workforce, the Government has committed to:

- negotiate a new generation of the Labour Market Agreements for

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Persons with Disabilities by 2014 to better meet the employment needs of businesses and the employment prospects of people with disabilities;

- provide ongoing funding of \$40 million per year starting in 2015–2016 for the Opportunities Fund for Persons with Disabilities;
- extend the Enabling Accessibility Fund on an ongoing basis at a level of \$15 million per year;
- additional funding of \$7 million for the Social Sciences and Humanities Research Council; and
- a \$2-million investment to support the creation of the Canadian Employers Disability Forum.

The measures announced in Economic Action Plan 2013 will help ensure continued economic growth, job creation and long-term prosperity, while better aligning training solutions to labour market demand. For more information, visit www.actionplan.gc.ca.

People in Motion 2013

*P*eople in Motion is for people with disabilities, seniors with special needs, family members and friends, therapists, home care providers, facility managers,

special educators and insurance representatives.

Everyone is welcome to this fun and enlightening event which features mobility aids, adapted vehicles, rehabilitation, home healthcare products, travel and leisure activities, corporate and government services, employment opportunities, computer aids, disability publications, associations and more.

See and compare everything under one roof at one time. ***More than 120 exhibits!*** If you have attended before, see it again! There are always new exhibitors with exciting new products and it is important to be aware of changes to existing technology.

CILT will be there as well. If you are interested in helping us at the show, let us know.

**Queen Elizabeth Building
Exhibition Place**

Friday May 31, 2013
10:00 a.m. to 5:00 p.m.
Saturday June 1, 2013
10:00 a.m. to 5:00 p.m.



CILT News

Oral History Project

Our Histories - Building leadership and engagement in the Disability Community: Lessons Learned from Toronto's Disability Leaders.

The overall goal of the project is to promote leadership and community engagement by learning from the history of leaders in the disability community.

The project will:

- Promote Disability Culture by collecting stories from Toronto Disability leaders themselves.
- Develop and distribute two toolkits: A Leadership and Engagement Toolkit of based on the personal histories from those that we did interview and a toolkit that teaches the basics of oral history interviewing, collection and analysis.
- Conduct at least one leadership and engagement workshop aimed at youth and young adults within the disability community.

Disability and Rights for Citizens (DRC) Project

The Disability and Rights for Citizens (DRC) Project is a one-year cross-disability initiative that will run educational workshops on the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and create a series of plain language tools to be distributed to people with disabilities living in Toronto.

The Centre for Independent Living in Toronto (CILT) is the trustee of the DRC Project, and is working in partnership with ARCH Disability Law Centre and the Council of Canadians with Disabilities. The DRC Project is funded by City of Toronto's Access Equity & Human Rights Fund.

Aging With a Disability Initiative

CILT has been working on an initiative around what it's like to go through the aging process when you have a disability. In partnership with other community agencies, CILT has developed and circulated a survey to both consumers and service providers to determine:

(a) what is being done, if anything, on

this topic; and (b) what are the concerns of consumers as they enter into the later stages of life.

We have found interesting results and are currently in the process of delivering conclusive summaries of each. In the future steps of this project, we, as a team, hope to bring innovative possible solutions to consumers by hearing from them in focus groups so we can ease their anxieties around aging with a disability, as well as advocate for appropriate services to make the transition of aging easier on adults with disabilities.



CILT's Volunteer Vibes is a quarterly publication of the **Peer Support Program**. If you are interested in volunteering at C.I.L.T. please call Nancy to request a Volunteer Application Package.

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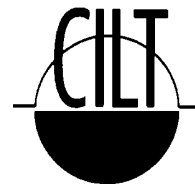
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Website: www.cilt.ca

Volunteer Vibes is also available on audiotape upon request.

Articles on products, agencies or services are for information only and are not meant as endorsements.

The opinions expressed in this newsletter are those of the contributors and may not reflect the views of CILT.



**Canadian Association of
Independent Living Centres**
Promoting a new perspective on disability
**Association canadienne des
centres de vie autonome**
Voir au-delà du handicap

CILT is a member of Independent Living Canada

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