

# Living Independently

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November — December 2011

## What's Inside

The Gift of Life cont.....	2
Customer Service.....	3
ILCLA Bd of Directors .....	3
Inspiring Video .....	3
RDSP.....	4
What's Happening @ ILC: November .....	5
What's Happening @ ILC: December .....	6



Our mission is to provide information and support to all people with disabilities as they take risks in directing and managing their lives.

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If you would like our newsletter in an alternate format, please contact us.

## *The Gift of Life*

By Gary Doerr

We've all had to deal with unique challenges and, over time, learn to adapt and overcome. My particular challenge began when, at the age of 12, I was diagnosed with juvenile rheumatoid arthritis. I am proud to say despite this challenge I've been able to overcome limitations with the help of family, friends and a healthy dose of determination. As a result I was able to live independently just like everyone else; I had mastered my personal challenges and there was nothing else to worry about. Life was good!

In January 2008 I never imagined a routine visit to my rheumatologist would send me on a downward spiral that would almost cost my life. During the check up I was informed there were high amounts of enzymes in my blood. This concerned my doctor but meant nothing to me.

I continued on with my life oblivious of my situation until my next visit which revealed I was getting worse. I had trouble keeping food down, I became fatigued easily and I would drop off into a light sleep at any time of day except at bedtime when I experienced insomnia. Things came to a head when I developed shallow breathing which almost made me pass out from the slightest bit of exertion. I was referred to a respiratory specialist who extracted a litre of fluid from my right side, next to my lung. This procedure was repeated twice in as many weeks.

In June 2009 I was admitted into University Hospital and, by the end of the week, was referred to a liver specialist in the Multi Organ Transplant Service (M.O.T.S.)

I was diagnosed with cirrhosis of the liver, the result of a lifetime of arthritis medication combined with a lifestyle of fast food and poor eating habits.

I was very fortunate to have a doctor who clearly laid out what I was up against. He would monitor my progress, prescribe regular visits and tests and prepare me for my ultimate challenge... having a liver transplant.

I was lucky, I only had one organ fail; all my other organs were healthy and strong. I also live in an age where surgical techniques in the field of organ transplants have advanced so much that a liver operation has an extremely high success rate. There was only one problem (cont..)

... donors. Of all western countries, Canada has one of the worst percentages of donors per population. In Canada, someone dies every three days waiting for a transplant. A living donor, someone compatible to your blood type, size and weight could give part of their liver. They would have a similar operation as the recipient, experiencing the same difficult recovery while their organ regenerates and both parties, recipient and donor, have to take anti-rejection drugs for the rest of their lives.

My sister Sharon offered to give part of her liver but she did not meet the requirements. Thus it was decided a non-living donor who would be needed to save my life and in early September 2010 I was placed on the waiting list for a transplant. The average wait time is from 18 months to 2 years ... if you're lucky.

That was when my life started going really badly. I knew there would be a long, difficult wait ahead but I was determined to continue on with my life and career no matter what.

Unfortunately, my liver had other plans. My already failing health developed the next level of liver cirrhosis. I became weaker and weaker; I developed a yellowish colour in my skin and eyes: my liver was starting to increase the toxins in my system. I became extremely bloated and started to experience mental disorientation. It was difficult to focus on anything: work, movies, books or magazines, even reading a Christmas card. My disorientation would cause me to black out for minutes and eventually hours. Following each episode I would not know what happened, where I was or how I got there. The worst episode happened in February 2011: I was the last person to leave my department at work that night. I locked the door to the office but left my keys in the door and must have been taken home by Para Transit but I don't know when or by whom. My superintendant found me sitting in the lobby; I was incoherent and he called 911. Toxins were found in my stomach this time. The fluid was drained and a day later I was released. As a result of this episode my manager placed me on sick leave until further notice. I experienced similar bouts over the next couple of weeks until my girlfriend, also named Sharon, called from her workplace. I was once again incoherent; she left work immediately, came to my apartment and called 911. I had developed a viral infection that was compromising my health along with the liver. This meant I had to be removed from the waiting list until the virus was neutralized. Doctors, nurses and physiotherapists worked relentlessly and, one month later, I was once again well enough to be placed back on the waiting list.

On April 17th 2011, the night before my discharge, I was awakened at 4:30 am by my nurse informing me a donor had been found and I was being prepped for surgery. At 5:30 that morning I was in the operating room and 6.5 hours later I was moved to the Intensive Care Unit for two days. Soon my colour was returning and my eyes were white again. I became more coherent. My balance was nonexistent at first but slowly I grew stronger. I was lucky not to experience any symptoms of rejection to my new liver or from the medication. After 3 long difficult years I was officially released from the U.H. M.O.T.S. unit May 10th 2011.

I regularly go for blood tests and visits to the M.O.T.S. clinic, each time my results have been normal and I have physiotherapy 3-4 times a week.

With the help of my doctors, nurses, physiotherapists, family, friends and especially my two Sharons, I drew the strength and determination to never give up. As a result, this past June I participated ILCLA's Come Walk with Me fundraiser and resumed my volunteer work with the City of London's Accessible Public Transit Services Advisory Committee.

My latest achievement has been returning to work on Monday September 12th 2011!

Though this is by no means an end to my story, I can say I have learned life deals you many different challenges, good and bad. It's up to you to be ready as best you can.

I stand here today in humble appreciation of what happened to me and how every day since has been a gift I will always treasure.

The gift of being alive is more than I ever could have imagined.

## Minding My Mitochondria

Minding My Mitochondria is a new book by Dr. Terry Wahls about her journey with MS. This book chronicles the therapies Dr. Wahls uses and includes advice on dietary choices and over 100 recipes. To read more about the book go to <http://www.thewahlsfoundation.com/mmm/> Here are three sample recipes: <http://www.thewahlsfoundation.com/mmm/recipes.html>

## Accessible Customer Service

Accessible customer service laws are coming to Ontario. All persons or organizations that provide goods or services to the public and have at least one employee must follow the new standard by January 1, 2012. Find out what this means to you in this free handbook: <http://tiny.cc/nrhgr>



## Sledge Hockey

Sledge hockey is an exciting sport designed for people with special needs. Anyone unable to play stand-up

hockey due to physical restrictions or special needs is welcome. Fees include a team sweater, sledge sticks, sledge and ice time. Players must provide their own hockey equipment and transportation. For more information visit [www.londonblizzard.com](http://www.londonblizzard.com) or call 519-660-1705.

# AAC



The Accessibility Advisory Committee of London advises and assists in promoting and facilitating a barrier-free London for citizens of all abilities. Find out more at [www.accessibility.london.ca](http://www.accessibility.london.ca)

## ILCLA Board of Directors 2011-2012

Elected by the members at our Annual General Meeting on September 14, 2011.

Kash Husain  
Lynne Littler  
Bruce Wright  
Gary Doerr

Kimber Bogema  
Steve Balcom  
Karen Tomlin  
Brenda Ryan

facebook

## Do you like us?

Yes, we are on Facebook!

Visit and “like” our page to receive updates about activities, community events, interesting websites and more! Go to [facebook.com/IndependentLivingCentreLondon](http://facebook.com/IndependentLivingCentreLondon)

## Annual Holiday Gatherings



Join us for one or both of our annual holiday celebrations!

**December 8**, 5 p.m.—8 p.m. at Shelleys Restaurant, Best Western Lamplighter Inn, 591 Wellington Road South. Reserve your spot by December 7. Each person pays for their own meal.

**December 12**, 12:30 p.m.—3:30 p.m. At the Centre. We will order Swiss Chalet dinners, please call 519-660-4667 for prices and place your order by December 9.

## Around the Web

This video features 54 women activists with disabilities from 54 countries. Loud, Proud and Passionate was filmed during the International Women’s Institute on Leadership and Disability. Enjoy it at [tinyurl.com/397gohj](http://tinyurl.com/397gohj)

*“To achieve greatness, start where you are, use what you have, do what you can.” Arthur Ashe*



# Registered Disability Savings Plan

In December 2008, the Government of Canada introduced the Registered Disability Savings Plan (RDSP), Canada Disability Savings Grant and Canada Disability Savings Bond to help Canadians with disabilities and their families save for the future.

The RDSP is available to Canadian residents under the age of 60 who are eligible for the Disability Tax Credit, which is also known as the Disability Amount. People who are eligible, and the parents or guardians of eligible minors, can open an RDSP at one of several financial organizations across the country.

There is no annual contribution limit to an RDSP. The lifetime contribution limit is \$200,000. Friends and family can also contribute to a plan with written permission of the plan holder. Any investment income earned in the plan accumulates tax free, until money is withdrawn. The contribution deadline this year is December 31, 2010.

To encourage savings, the Government of Canada introduced the Canada Disability Savings Grant and the Canada Disability Savings Bond.

The **Canada Disability Savings Grant** is a matching grant that the Government deposits into the RDSP. Each year, the Government will match contributions made by paying up to \$3 for every \$1 paid into the plan, depending on the amount contributed and the beneficiary's family income. The Government will deposit a maximum of \$3,500 each year, with a lifetime limit of \$70,000. Grants will be paid into the RDSP until the year the beneficiary turns 49 years old.

The Government of Canada will also pay a **Canada Disability Savings Bond** of up to \$1,000 to low-income and modest-income Canadians. The good news is that no contributions are necessary to receive the bond; simply open an RDSP and fill out an application form at the financial organization where you have your RDSP. Bonds will be paid into the RDSP until the year the beneficiary turns 49 years old.

Money paid out of an RDSP will not affect a person's eligibility for federal benefits, such as the Canada Child Tax Benefit, the Goods and Services Tax credit, Old Age Security or Employment Insurance benefits. In addition, RDSPs will have little or no impact on provincial and territorial social assistance payments. For further details, contact your provincial or territorial government.

For more information on the RDSP, grant and bond, including a list of participating financial organizations, please visit the Human Resources and Skills Development Canada Web site at [www.disabilitysavings.gc.ca](http://www.disabilitysavings.gc.ca) or call 1 800 O-Canada (1 800 622-6232). You can also contact the Independent Living Centre London & Area at 519-660-4667 or email [info@ilcla.ca](mailto:info@ilcla.ca). In addition, we are happy to do information sessions for groups and organizations.

Funding for these information sessions is provided by the Government of Canada. / Ces séances d'information sont financées par le gouvernement du Canada.