

The Self-Manager

CILT • Centre for Independent Living in Toronto

Winter 2018

Taking aim at ALS with bucket list hunting trip

LEANNE LARMONDIN
PROVINCIAL PROGRAM CO-ORDINATOR

EDDY LEFRANÇOIS has crossed another item off his bucket list: the Self-Manager from Dubreuilville recently took part in a hunt for white tail deer. Not unusual for someone living in northern Ontario, but Eddy has been living with Amyotrophic Lateral Sclerosis (ALS) for more than 25 years and he can't move or speak without assistance.

In a message to CBC News, Eddy said he takes on his bucket list items to bring awareness to ALS. A Self-Manager since 2002, his other adventures have included travelling the world, skydiving and attending a Stanley Cup final game. In 2017, he decided to mark his quarter century living with ALS by raising \$25,000; the final tally of \$52,000 was more than double his target.

Fulfilling his wish to deer hunt meant making more than a few modifications and accommodations. Neil Debassige, a Manitoulin Island filmmaker and hunter was happy to help out, in what



Eddy Lefrançois, Self-Manager, on bucket list hunting trip

he told CBC was a filming experience of a lifetime. Debassige, owner of Fuel the Fire TV, documented the special hunting trip for an episode which will

air in January on Wild TV on Canada's Outdoor Network.

Please see **BUCKET LIST**, p. 8

Congratulations

Kaley Roosen, a Toronto Self-Manager, has experienced a few life changes since she started on Direct Funding in January, 2017. She got married and,

together with husband, David, she recently welcomed baby Gwendolyn.

Please see **CONGRATULATIONS**, p.3





Keep in touch

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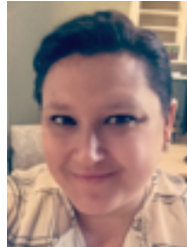
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Meet the new Direct Funding



Louanne Dubosq

**Program Assistant
Disability Resource
Centre for Independent
Living, Kapuskasing**

It is with great pleasure that I introduce myself as the new Program Assistant at the Disability Resource Centre in Kapuskasing.

Having a passion for helping others, I am excited about the opportunity to work for an organization that is focused on understanding and responding to the needs of our communities. I am confident that my past experience working with health services, including four years as a personal support worker at the North Centennial Manor and 11 years at the Porcupine Health Unit, will be an asset for me in my new position.
programassistant@vianet.ca



Teresa Gal

**Executive Director
Breaking Down Barriers,
Collingwood**

Teresa is a competent, reliable professional who is resourceful in solving problems and maximizing resources. She has international work experience and has held key administrative roles. She is skilled in handling people from all walks of life with diplomacy and professionalism. She possesses strong leadership and communication skills. Teresa obtained a B.A. and graduated with honours, from a self-selected curriculum completing a double major in business administrative studies focusing on international marketing, promotions and publicity and

in Latin American Caribbean Studies from York and obtained a master of education degree from Framingham. Teresa is happy to apply her talents and to form part of the Breaking Down Barriers Team, that is an Independent Living Resource Centre and to work with the Direct Funding Program, all of which are comprised of like-minded individuals.

executivedirector@breakingdownbarriers.ca



Kylee Labrosse

**Direct Funding Support
Assistant
RISE: Resource Centre
for Independent Living,
Parry Sound**

Kylee is a returning local to Parry Sound, after many years spent living in various cities completing school and working in various customer service positions. Her educational background consists of a Liberal Arts Certificate from Fanshawe College, a bachelor's degree in psychology and an Honours Bachelor of Social Work, both of which were completed at Laurentian University at the Barrie satellite campus. Her passion for working with people has drawn her to work with consumers in the Direct Funding program. She conducted research on transgender healthcare in the Simcoe/Muskoka districts, in partnership with Orillia Soldiers Memorial Hospital and the Gilbert Centre of Barrie. She also completed a placement with Simcoe Community Services working with various client populations. Her personal hobbies and passions include travel, spending time on Georgian Bay, and snowboarding in the winter.

rise-dfsupport@cogeco.net

staff ...



Monica Tafe

Direct Funding Resource
Facilitator
Independent Living
Resource Centre,
Thunder Bay

Monica was born and raised in Thunder Bay. She studied at Carleton University in Ottawa and obtained her Honours BA in English and Philosophy. After graduation she lived in Japan for one year and then made South Korea her home for another 7. Monica loves to travel and has enjoyed visiting 16 countries, with hopes of traveling to many more! Since returning to Canada, Monica has been working as a support worker. She is excited to start her career as a Direct Funding Resource Facilitator and hopes to contribute her experience to the Independent Living Resource Centre in Thunder Bay.

mtafe@ilrctbay.com



Hannah Zettler-Graca

Direct Funding Assistant
Niagara Centre for
Independent Living

Hannah Zettler-Graca recently graduated with a Bachelor's of Science in Social Work degree from Niagara University. Upon completing a student placement with the Niagara Centre for Independent Living, Hannah began her career working with Direct Funding, as well as a disabled youth leadership program, Next to Lead. She hopes to one day obtain a master's degree and work in the field of policy research and community development. Hannah is a steadfast believer in the Independent Living philosophy, and would like to contribute to a world where everyone has the opportunity to reach their full potential.

dfniagara@abilityforlife.ca

Congratulations



Adriana Ratcliffe, a Self-Manager in Bruce Peninsula, wrote recently to share her family's joy with the Direct Funding community: she and her husband Shane are expecting a new brother or sister for their son, Ash, in April and "could not be a more excited family".



Kaley Roosen, a Toronto Self-Manager, was married in 2017; one of her bridesmaids was another Self-Manager, Gabby Carafa, pictured second from the left.



Meenu Sikand, a Self-Manager in Woodbridge since 1999, was recently presented with a Canada 150 Community Leader Award and Sesquicentennial Commemorative Pin in recognition for her community service and leadership. The copper used to make the pin once covered the roofs of the Parliament Buildings from 1918 to 1996. Joining Meenu for the presentation were (from left, rear), her son, Manav; family friend Ishaanbir; Meenu's mother, Amrit Kaur (who is another Self-Manager); Amrit's attendant Jackie; and Francesco Sorbara, member of Parliament for Vaughan-Woodbridge.

“

I laugh more and I enjoy life more.

This is my first year with Direct Funding (DF), after 19 years of receiving assistance through a community attendant service program. DF has completely changed my life. It has given me an independence I've never known before. I laugh more and I enjoy life more. I have the freedom to bathe when I wish and I never worry about going hungry because I have someone to help make food for me. I can get out of bed every day and get dressed. I know there will be someone available to help me get ready for bed each night. The best part of it all is that I can create my own schedule.

With some help in understanding how to make it possible, I was able to go on a trip to Ottawa in October with my attendant and my service dog.

It was absolutely fabulous. I had the time of my life and my attendant helped me feel what freedom was like again, just like a child. It has been over 34 years since I had my accident and we happened to come



across an accessible playground and she helped me enjoy all the accessible equipment.

There have been some learning curves as I've become accustomed to DF and the independence I now have but with time and guidance, I've learnt to truly enjoy life again. My whole world has changed from top to bottom and I'm extremely grateful to Direct Funding for making my world a better place.

Kelly Fleming, Guelph

“

DF has made a huge difference in my life.

I have been with the program for almost a year, and it is great. DF has made a huge difference in my life—enabled me to do more, get back into the community a bit and enjoy life again.”

**M.
Burk's Falls**

Testim

“

I slept in my own bed in my own home.

On July 7, 2017, I was discharged from the hospital and for the first time since Oct 23, 2014 (987 days), I slept in my own bed in my own home. Unusual feelings since getting out:

- sitting by an open window and feeling the breeze;
- listening to the rain last night as I laid in bed;
- listening to birds.
- smelling cut grass;
- no hospital white noise, bells ringing, no screaming patients.

The hospital never knew how to categorize me, so I was hospitalized in long-term care (equivalent to a nursing home). Try living in that environment for a period of time when you're sane!

Al Hare, Peterborough

onials

“

I am able to stay in my own home.

I live on an island near Smooth Rock Falls in northern Ontario. I was diagnosed with primary progressive Multiple Sclerosis at the beginning of 2011 and due to my gradual decline in my abilities the Direct Funding has offered me financial assistance to provide me with an attendant.

My attendant started working for me in January, 2015. The weather (as those of you in the north know) meant there was plenty of ice and snow on the lake. My attendant would arrive here with the assistance of my husband on our snowmobile. But she later decided it would be an enjoyable walk across the ice. When spring arrived a boat/pontoon was used for her transportation. Eventually, my attendant was willing to drive a small boat across herself, which is very convenient.

I am now able to stay in my own



Linda McCafferty, left, with Jennifer Marchand and Tina Cataford from the Disability Resource Centre for Independent Living, Kapuskasing.

home and enjoy the pleasures of an island life that includes wonderful scenery, peacefulness and incredible wildlife, including moose, birds, glistening water and the unforgettable smell of the outdoors. This also has benefits for my husband who had been my only helper. The Direct Funding assistance now allows him to leave the island and do many errands for him and me without the constant worry about me being alone.

Linda McCafferty, Smooth Rock Falls

“

Direct Funding provides the resumption of autonomy, dignity and control in my life.

Direct Funding provides a marked improvement in my quality of life. Autonomy is the key ingredient for living my life well. The ability to dictate life on your terms is sadly lacking for people with disabilities due to our cultural stereotypes of disability and helplessness.

When one is reliant on receiving assistance for the necessary tasks of daily living the ability to have consistent, trustworthy and compliant help is paramount.

Hiring my own responsible staff has also alleviated frantic hours spent in bed waiting for a transfer to get up and start my day; and, no more nights sleeping in my wheelchair because no one came that night to help me to bed. I've had experience with unprofessional, irresponsible agencies which are not proactive in providing staff coverage for absenteeism of workers.

Direct Funding provides the resumption of autonomy, dignity and control in my life which was previously lacking in provincially funded and private home care agency services.

Barb MacDonald, Ottawa

“

I can continue living my life instead of just existing.

In 2014, I became a Self-Manager in charge of hiring people to assist me with my daily needs. These caring and compassionate people have made it possible for me to continue living at home instead of a nursing home. More so, my quality of life has since been enhanced resulting in less time spent in a hospital leaving more time enjoyed with family and friends.

I continue to be grateful for the ongoing support from the program and I can continue living my life

instead of just existing. Before the Direct Funding program, I spent a lot of my time waiting not knowing who, when, and if someone would arrive to help me with my daily needs.

I would like to thank everyone at Direct Funding that have supported me by answering questions and their feedback in making my ongoing services and funding a success.

Denise Valade, Sudbury

WE'VE MOVED

Two Independent Living Centres in the province have moved and taken up new addresses in recent months. The new contact information for the centres in Collingwood and Kapuskasing are as follows:

Breaking Down Barriers

234 Ste. Marie Street
Collingwood ON L9Y 3K5
705-445-1543
Fax: 705-445-1656
www.breakingdownbarriers.ca

Disability Resource Centre for Independent Living

39 Brunelle Rd. N
Kapuskasing ON P5N 2M1
705-335-8778 / 1-800-236-7417
Fax: 705-335-5666
www.drcil.org

Peer Support

Are you an experienced Self-Manager looking to pass on your knowledge and wisdom? Why not mentor a new Direct Funding (DF) participant?

Being a new Self-Manager can be a little overwhelming. There's paperwork, new responsibilities and challenges. Being supported by someone who's been through the same experience can make the transition easier.

We are looking for people who would like to offer peer support to people who are applying to DF or just starting on the program. Perhaps you'd like to share what you've learned about interviewing attendants, or sit on a DF interview panel. Or, perhaps you have a brand new idea about how to support the community! Please get in touch with your local Independent Living Centre to discuss your options for being a peer resource.



Protect yourself in case of flu

As flu season is upon us, the Toronto Central Local Health Integration Network (TCLHIN) is advising consumers to ensure their health care needs will be covered in the event of illness.

Since attendants employed by Self-Managers are as susceptible as anyone to influenza, program participants should have a backup plan in the event their staff cannot work:

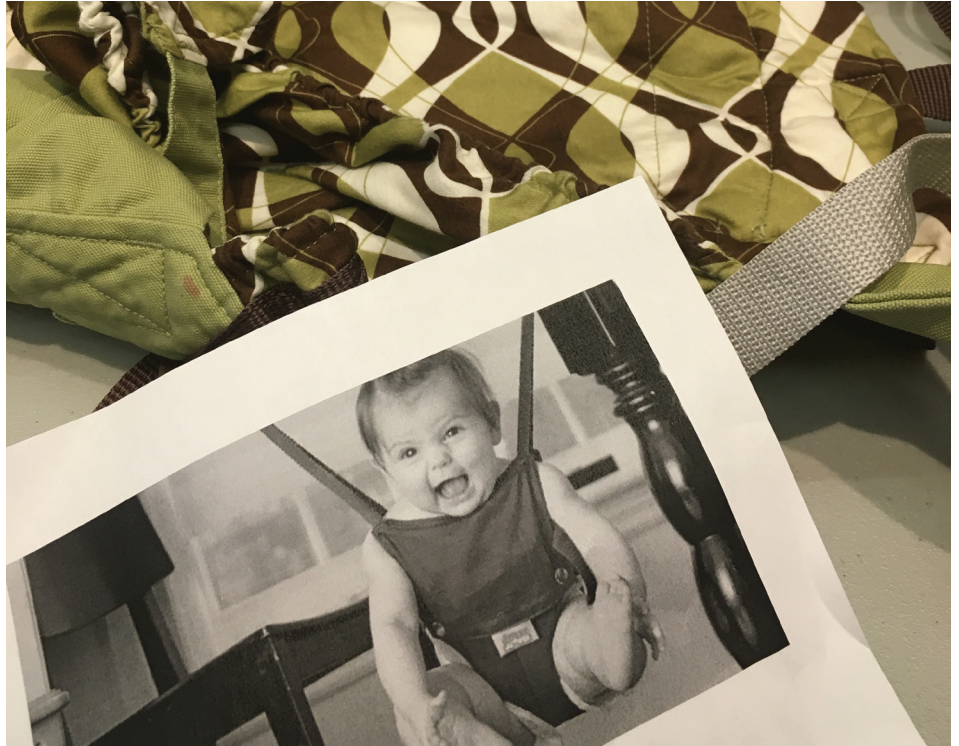
"Flu surge is an annual occurrence and it is the responsibility of both the system and health care providers to take actions to meet this increased demand," the TCLHIN wrote in a recent communique. "At this time, we would like to stress the importance of ensuring patient access across the health care system is maintained

throughout this period. In particular, we ask that all health service providers have appropriate staffing and contingency plans in place to ensure that people receive appropriate access to the right place of care, and to reduce bottlenecks across the system."

While all Self-Managers are expected to have sufficient staffing to ensure their needs are met, if you do encounter a situation where all of your attendants are ill and/or otherwise unavailable, you are encouraged to contact your local Independent Living Centre in an emergency; you may have the option of using an agency for a short period, until your regular staff can return to work.

Parenting with a disability

SPIN (Strength Based Parenting Initiative) recently held its Inclusive Parenting Conference 2017 in Toronto. The conference, which was co-sponsored by the Direct Funding program and the Centre for Independent Living in Toronto, brought together community members, allies, and service providers who were interested in learning about parenting with a disability. The gathering also featured a display of innovative equipment and accessories for parents with disabilities, including accessible baby and toddler carriers, harnesses and multi-sensory books.



Agreement renewals and updated consent forms and contact information

Just a heads-up to all Self-Managers that starting in the new year, we will begin mailing out Direct Funding Agreement renewals and requests for updated information to all program participants. Please watch for the new documents and return your agreements and updated Release of Information forms (the same form that was originally signed as part of your application), and ensure that we have your most up-to-date contact information. We thank you for your patience and your assistance in getting our files freshened up!

My journey with my new service dog

DEB WILLOWS, SELF-MANAGER

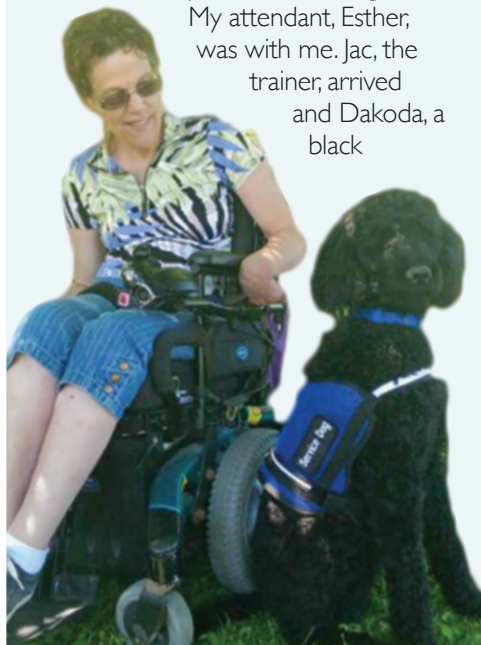
On May 1, 2016, I flew out to British Columbia to meet and train with my fifth service dog.

My attendant, Esther, was with me. Jac, the trainer, arrived and Dakota, a black

standard poodle, bounded into the house and into my life.

Having a service dog was not new for me. All my dogs have been trained to open doors, pick up things, and bring them to me, but this one was also trained to tell me when I have low blood sugars (I have Type 1 diabetes). Having cerebral palsy, I cannot check my own blood sugar. So if my dog can tell me before they get too low, then I can get something to eat before I slip into a coma. He has learned this well and he gives me a 20-minute warning. He was trained for other tasks too. He can open and close doors; turn on lights; and pick up things I drop or need, like the phone.

Yes, a service dog is a lot of work, but knowing I have him to help me is worth it.



Bucket list

Continued from p. 1



Debassige says Eddy (who travelled to the hunt camp with his attendant, Eric) had the entire hunt camp experience, complete with a custom-build hunting blind. His hunting bow was also adapted, so all he had to do was blow into a tube to engage the trigger.

"The first night we missed twice, then we made some corrections," Debassige said. "And then on the second night, the last night of the hunt, we took [a young buck] down."

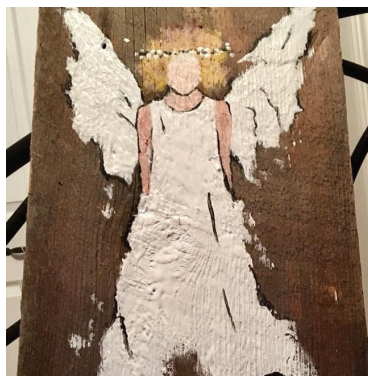
Eddy sports a tattoo on his forearm that reads, "EXP: 04.97", a reference to his 1992 diagnosis, when doctors gave him a life expectancy – or, expiry date, as he jokes – of three to five years.

Readers can learn more about Eddy's ALS awareness campaign at www.lets-roll.ca.

Crafts and artwork

Three Self-Managers in the Niagara region recently held their annual open house to sell their crafts and artwork. Shelley Tudin, John Kormos and Michele Good, who are siblings, rotate as hosts each year.

On display this year were works of art, Christmas tags, recycled blankets, pillows and scarves and canvas signs – all handcrafted by the siblings.



Direct Funding Program

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Ontario

Toronto Central Local Health
Integration Network