

InformAction

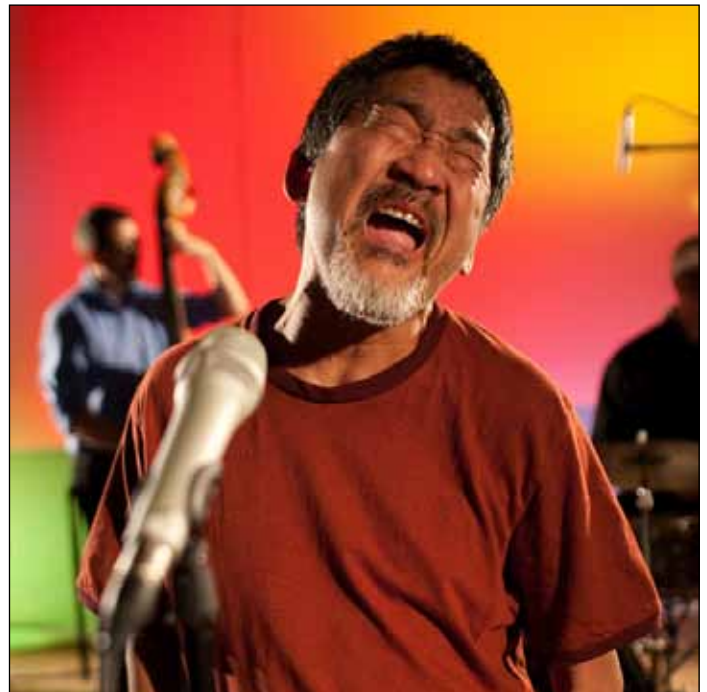
Ontario Federation for Cerebral Palsy Newsletter - December, 2011



How Does it Feel

*By Megan Stuart, Program Assistant, OFCP
Education and Recreation Department*

The OFCP had the privilege of screening the musical documentary “How Does it Feel” at our Annual Conference in October. The film features Kazumi Tsuruoka, a man who has cerebral palsy, and his journey learning how to express himself through singing. Kazumi grabs the audiences’ attention by demanding to be seen and heard, then reveals a startling and powerful performance that overflows with vulnerability and self actualization. As Kazumi candidly points out, people with CP are told from a young age that they can’t carry a tune. With the help of his vocal coach and mentor Fides Krucker, Kazumi builds a repertoire of classic love songs that illuminate his experience as a person who has a disability. Director Lawrence Jackman and Kazumi challenge notions of human perfection by putting the disabled body and voice on display in a series of public performances.



The film encourages the audience to re-think what it means to have a disability and explores our shared humanity. “How Does it Feel” was produced by the National Film Board and will be available for purchase through www.nfb.ca soon.



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Dinner & Dancing + Fundraising & Silent Auction Charity Ball

On November 12th the Math Society undergraduates of The University of Waterloo held its Annual Charity Ball with this year's proceeds going to a very grateful OFCP.

On behalf of the OFCP Long Term Planning & Support Program, Mike Duchene and his two sons, Mark and Kurtis, attended the Ball to raise awareness about cerebral palsy and extend a big thank you for all their efforts. By the end of the evening \$1,970 had been raised.

You might remember the Duchene family through a video presentation at our Annual Fall Conference entitled More Than Meets the Eye featuring Kurtis Duchene. This film, concerning inclusion, was a Filmpossible 2010 entry and can be viewed on YouTube at www.youtube.com/watch?v=ziUV4Ey4a5U

Both boys are also excited about an upcoming Rick Hansen, Man in Motion Relay coming through town in December as both will be participating in that event as well.

The OFCP would like to thank the Math Society of The University of Waterloo for such a thoughtful gesture.

Pictured are the Duchene's and Chang Liu, Director of the Charity Ball.



Planned Giving

Another Way to Give Back

By Cindy De Graaff, Program Manager, OFCP Planning Services

There are many ways that we benefit from living in community with each other, from the small things we do to help our neighbours and friends on an ongoing basis, or the small acts of kindness we perform for the strangers we meet as we go about our daily lives.

We can also play an important role in our community by contributing to the stability and financial security of non-profit organizations - the OFCP and others like it - by making plans to give back at a future date through a bequest in your will.

For many, tackling the daunting task of completing a will is a monumental undertaking; there is much involved in determining who is to inherit all that we have accumulated - whatever that may amount to - and then to make these decisions often leads many of us to inertia. It takes extra effort and energy, sometimes in short supply, to take this on. However, I would like to encourage you to do so! Taking the time to write down on paper what you wish to have happen with 'your stuff' allows you to have control over where it will go and who will benefit from this distribution. It will be *your* decision, not someone else's.

It is estimated that only 50% of Canadians have completed their will, which means that half of us have left it up to the government to determine what will happen when we die. I expect most of us are unfamiliar with the details of the Succession Law Reform Act, but without a will, its' statutes will determine to whom, and in what amounts, your estate will be divided.

One of the unintended consequences of not writing your will is that your family members will have to go through the courts to become your estate trustee, often an expensive and time consuming process. Imagine the good you can accomplish by taking the time to put your wishes on paper; the loved ones who will appreciate the time you took to acknowledge them personally by leaving something for them, whatever the size of the bequest, and the organizations that could benefit from a portion of your estate in the future. Think about it. And then... just do it!

**For more ideas on the topic of
Planned Giving or resources on
writing your will please visit
the OFCP website
www.ofcp.ca**

AbilityOnLine - A Thriving and Growing Community

Julie Plocki-Rygier, Community Partnership Coordinator, gave a talk at the Ontario Federation for Cerebral Palsy this fall to update staff on their new website and current activities within it. AbilityOnline welcomes all kids, teens and young adults (up to forty years of age) onto their website. There are lots of ways to get involved at Ability Online – as a member (child, parent, caregiver), as a volunteer, as a donor, or as a friend. Approximately 3,000 members of all abilities visit the website each year, and membership is free.

By joining AbilityOnline, members have 24/7 access to friendship, support, sharing of information and skill development opportunities in a monitored, bully-free and family friendly environment. Whether the issues are health-related, educational, vocational, or recreational there are people of all ages and abilities online waiting to answer questions, or at least point

members in the right direction. To make it easier to find the right connections, their website has been divided into four separate sections: “Kids and Teens”; “Young Adults and Alumni”; “Parents” and “Professionals”.

AbilityOnLine also has over 200 Community and Health Care Partnerships across Canada and United States. These partnerships are primarily with acute care and pediatric hospitals, rehabilitation centres, group homes, and other health-related organizations, as well as some schools and other community associations. The goal behind these partnerships is to reach people who are undergoing treatment and could use the extra support, friendship and knowledge from those who have been there.

AbilityOnLine’s website is www.abilityonline.org

Seasons Greetings

As another year comes to a close and the holiday season is upon us, we, at the OFCP, would like to extend the warmest of wishes to our readership with the hope that the coming year will bring you peace, good health, and much prosperity.



Ontario Introduces New Photo ID Card

It is now easier to achieve independence for Ontarians over the age of 16 who do not have an Ontario driver's licence.

The government issued Ontario Photo Card is now available at 21 ServiceOntario locations across the province and will have widespread availability at all 300 locations by December 2012.

This card will be beneficial to access government, business and financial services that require proof of ID. For example, you will be able to open up a bank account, vote, apply for a loan or a credit card, make travel arrangements, return merchandise to a store and perform other activities that require official government ID.

To apply for the Ontario Photo Card you must be an Ontario resident and provide original identification documents with your legal name, date of birth and signature. If you do not have an acceptable identity document with your signature, you will be required to have a guarantor fill out a declaration form.

If you chose to apply for a photo card and hold a valid Ontario driver's licence you will be required to give up your driver's licence as both pieces of identification cannot be held at once.

The cost of the photo card is \$35 and will be valid for five years at a time. The card will not be suitable as a passport replacement for international trips.

For more information please visit the Ministry of Transportation website:

www.mto.gov.on.ca/english/dandv/driver/photo-card.shtml

On this website you will find the application form and declaration form, a list of acceptable identity documents required when applying and a list of ServiceOntario locations where you can currently apply for the photo card.



Mark your Calendar

The 2012 OFCP Annual Conference will take place on September 28th - 30th at the Delta Chelsea Hotel, downtown Toronto

What I Would Tell You

A Mother's Story

By Julie Keon,

www.whatiwouldtellyou.com

I sensed someone watching me as I comforted my daughter after a particularly traumatizing dentist appointment at the Children's Hospital. I looked up and saw you staring at us from across the waiting lounge. I didn't pay much attention, as I have grown accustomed to the curious eyes of onlookers. Our daughter was born 7 ½ years ago and after an abrupt lack of oxygen at birth, she changed the course of our lives forever. Perhaps, our lives unfolded exactly as they were meant to — they just didn't unfold in the way we had imagined or planned.

I talked to my daughter, kissed her and hugged her. I was giving her a brief break before putting her through the next traumatic experience of the day ~ the car ride home. Having cerebral palsy is the least of her worries but this condition can turn a car seat into a torture chamber.

I stood up to gather our things, my daughter in my arms, and it was then that I noticed you were holding an infant. It was difficult to know for certain how old she was. I knew immediately, though, that you were one of us. I knew that only recently your life had changed drastically and you sat here in this Children's Hospital wondering, "How did we get here?" I should have recognized that shocked stare because I once had it, too. And I assume that the man sitting next to you, looking equally tired and shocked, was your husband.

I made my way toward the doors and as I passed you, our eyes met and I smiled at you. You smiled back and for a moment I knew that you knew that I understood.

If I could, I would tell you although you might not believe it right now, you will be okay. I would tell you to dig deep within yourself because you will find the strength and resilience somehow and it will surprise you. I would tell you to honour your feelings and let the tears flow when they need to. You will need the energy for more important things than holding in emotions.

I would tell you that the man sitting next to you might cope differently and he might even want to run the other way. But I would tell you to hang on because he is scared and he really doesn't want to leave you. I would tell you to look after yourself so that you can care for your daughter. Don't underestimate the power of good nutrition, exercise, sleep, supplements and an empathetic therapist.

I would tell you that grief will come and it will confuse you because how can something that brings such joy also bring such sadness? I would tell you to let people into your lives to help you. Our children really do require a village to raise them. Access all of the services and resources available. Find someone who can learn how to care for your child so that you can have breaks and so you and your partner can go on dates... even little ones like a twenty minute stroll outside holding hands, sharing wine on the deck or even catching a movie.

I would tell you that you know your child best of all and no matter what you are told by the doctors and other professionals who will be a part of your life, YOU know the answers. You will teach them about your child. At times you will question the validity of your intuition but after a while you will become profoundly aware of how accurate your gut feelings are when it comes to your child.

I would tell you not to be a martyr. Caring for your child will require tremendous focus and unimaginable energy and it can burn you out and make you sick when you least expect it. I would tell you to let your guard down along the way so that you can stay healthy in your mind and spirit.

I would tell you to seek out other mothers like yourself. This is, indeed, the road less travelled and you will feel very alone along the way especially in the company of healthy children and their parents. Yes, you will feel very isolated but know that we are here. Sometimes you have to look a little harder but we are here. You can find us online, in support groups and wandering the halls of the Children's Hospital.

I would tell you that you will know far too much about the human anatomy, neurology, gastroenterology, feeding tubes, pharmaceuticals, and so on, than a mother should ever have to know. I would also tell you to do some research to inform yourself but be very careful not to be overwhelmed by the internet and all of the information available to you. Having some trust in what your child's specialists tell you can be very grounding. Other mothers and fathers of children like ours can be a wealth of information.

I would tell you that this isn't an easy life. It is tough: there is no doubt about it but you are very capable and the rewards are great. You may never see your child graduate from university, walk down the aisle or give birth to your grandchildren but you will feel pure joy when your child laughs for the first time at the age of 3 years and 8 months. You will celebrate the moment when you connect with your non-verbal child. You will call your spouse at work to tell him that she has gained 4oz. because weight gain is always a struggle with our children.

I would tell you that you will have to witness procedures and surgeries and suffering well beyond what any parent should ever have to bear. But, I would tell you that you will be courageous and comforting because your child will be experiencing far more suffering than any child should ever have to endure.

I would tell you that your life will not resemble the life you had planned. It will be as though you landed in Holland instead of Italy but after some time, you will adjust the dreams you had and this reality will be normal to you. You will dream new dreams.

I would tell you that you might find yourself staring death in the face during close calls. You will be asked to fill out DNR (Do Not Resuscitate) forms and although you might make decisions to not resuscitate in the event of a cardiac arrest, when the moment arises, you will panic to think that it could all come to an end. And I would tell you to not feel guilty in the darkest moments when you pray to God to take your child if it would mean the suffering would end. This might horrify you but know that your love for your child is so great that at times you will believe that death would be a blessing.

I would tell you that others will not get it. They can't. This is a very unique and complex journey on all levels. We cannot expect anyone to get it. And I would tell you that people — the cashier at the grocery store or your insurance broker or even your hair stylist — will say stupid things like, "God only gives these special kids to special mothers" and "God will only give you what you can handle." You will nod and smile but eventually you will look them right in the face and tell them that those simple maxims are a bunch of bullshit.

I would tell you that imagining your future will be bittersweet and may involve a Plan A and a Plan B. Plan A will be what you will do if your child outlives the predicted life expectancy set forth by the experts and Plan B will come into play if they do not. You will catch yourself casually discussing your future with the code phrases of Plan A and Plan B.

I would tell you that grief will creep up on you after years have passed and you least expect it like at a wedding when the father and bride have their first dance or when you hear a birth announcement. It will also creep up on you when you see yourself in a new mother who is just beginning this journey.

I would tell you that you will recognize her because she is you from 7 ½ years ago. And you will want to run to her and hug her and tell her that everything will be okay. You will want to save her from the pain and the hardship and the unknown.

But I would tell you that when you find yourself sitting at the Children's Hospital and you see a new mom and dad who are just starting this journey, you smile at them and walk by as they have their own path to travel and it will be different than yours. It may be longer or shorter. It may be more or less complicated.

I would tell you that her searching eyes are looking for some sign that she will survive this. And you, smiling as you pass, with your child arching all over your shoulder, will let her know that yes, she will survive this and may even thrive.

Sardines

A Christmas Story

As shared by Paul Meyers and his sister, Christine.

One of my fondest Christmas memories as a young person with cp was a game we would play that I remember as Sardines. When you have cerebral palsy, you have to make modifications to darn near everything if you want to function and/or have some fun. And this is true of play time.

Sardines is like Hide & Seek, except the opposite. Since I could not run & hide, someone would hide me! I was sort of home base. If you found me, you were safe! This was done in my grandparents' three story home as the rest of the kids - eight in total - would wait in the den. Once I was well-stowed away, the kids were given the green light and they would head off "in search of Paul". When they found me they would hide *with* me. One by one each would join the ever growing crowd and we would end up looking like sardines crammed into a can, except it would be a closet or something, as the case may be. This made for lots of great memories for everyone.



Has your family found a way to include your child with special needs at family get-togethers? Send it in to us, we'd love to hear about it and share it with others.



Return undeliverable items to:
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Toronto, Ontario ■ M6L 1C5