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EDITORIAL

BY KAREN MARTIN

Whether at school, work or play, people with disabilities should have access to the same emergency information, notification, evacuation, and response services and facilities as other members of their community. In an emergency or disaster, no one should be left behind.

BCCPD has been working since 2006 to ensure this access and inclusion for people with disabilities in emergency planning and response in British Columbia and nationally. We have been educating local governments, training community organizations, businesses and post-secondary institutions, and empowering individuals living with disabilities to be prepared.

This emergency preparedness edition of TRANSITION highlights some of the important work being done. Just as important, we provide people with tips on how to be proactive in their own preparedness as possible.

There are also some links to stories about people with disabilities and their experiences during Hurricane Sandy in New York in November 2012. They show the ongoing need for communities and governments to work with the disability community and to plan for the needs of people with disabilities.

As we continue our work in emergency planning and response, there are two key areas for consideration. First, emergency communications and the growing use of social media in disasters. Second, is the impacts of climate change on the health and safety of people with disabilities.

Using Social Media

Social media and new technologies are changing the face of disaster communications. There is a need to explore how social media can be used to benefit populations at high-risk during emergencies, such as people with disabilities and seniors.

During Hurricane Irene in the US, one-third of the population affected used social media to let loved ones know they were safe. During the 2007 San Diego County fires, there were one million hits on Twitter.

Twitter, Facebook and YouTube were used during earthquakes in the past few years in Chile, Haiti, New Zealand and Japan. People report on emergencies in real-time, from the streets. People created information about specific locations—warnings, help requests, environmental conditions, food and water shortages—which complemented traditional media and government reports. This powerful

Just as important, we provide people with tips on how to be prepared and highlight some key resources that BCCPD has developed: handbooks, e-courses and workshops. We want to encourage people with disabilities to be as proactive in their own preparedness, as possible.
During Hurricane Irene in the US, one-third of the population affected used social media to let loved ones know they were safe. During the 2007 San Diego County fires, there were one million hits on Twitter.

The Impact of Climate Change

As Canada’s population grows and climate change expands the geographical range, frequency and intensity of many existing climate-related hazards, people’s exposure to extreme weather events, airborne or water-transmitted diseases, extreme heat and air pollution, will increase.

In addition, expected population growth and chronic disease trends tell us that the proportion of Canadians highly sensitive to climate-related health impacts will grow over the coming decades. This may vary by region and be influenced by factors such as access to health care and community support services (Human Health in a Changing Climate, Health Canada).

Climate change literature shows that there are underlying risk factors and a higher vulnerability to the effects of climate change for certain populations: those with underlying health conditions (chronic conditions, cardiovascular, respiratory, renal disease, diabetes, psychiatric illness, alcohol and drug dependency); age (seniors and children); people living in poverty; and, those living in more densely populated urban areas, often associated with greater environmental exposure.

As you’ll see in this TRANSITION, we’re beginning to see the fruits of our labour. Key organizations like the Justice Institute of BC, BC Institute of Technology, BC Ambulance Service and others, are incorporating disability-related perspectives in their training programs and services. We’re so pleased to develop these community partnerships.

BCCPD will continue to engage the disability and emergency management communities in British Columbia and Canada. Together, we hope to address the ongoing and emerging issues for people with disabilities in emergencies and disasters. We welcome any interested stakeholders to work with us.

KAREN MARTIN IS BCCPD’S EMERGENCY PREPAREDNESS PROJECT COORDINATOR. SHE ALSO LOOKS SMASHING IN A TIE.
Many people do the best they can to prepare for emergency situations. They install fire extinguishers and sprinkler systems in homes and workplaces. They may plan evacuation routes in the event of fires, earthquakes and floods, and might have first aid kits and emergency food supplies on hand. All this planning is based on the assumption that you can get to safety and out of harm’s way. During an emergency, most people do not know how to quickly and safely move someone who has limited mobility, is in a wheelchair or is seriously injured.

I have worked many years as a physiotherapist treating people with injuries that resulted from unsafe lifting and moving practices. So, I began to teach injury prevention methods and worked with professional caregivers, teaching them “no-lift” skills that relied on using equipment to move their patients.

Moving People Without Equipment

I wondered: “In an emergency, without electricity, how would the caregivers move patients quickly without all of this equipment?” This led me to develop the Emergency Evacuation Program Get Me Out of Here!® that teaches safer methods for evacuating people with varying levels of ability—without using equipment. Specific techniques include assisting evacuees who are disoriented or confused, need help walking, are on the floor or in a wheelchair, or can’t manage stairs. The primary focus is to help prevent injuries to the rescuer, while keeping the evacuee as safe as possible and “getting them out of here.”

I’ve taught this course to hundreds of employees in many care facilities. I’ve had over 99% positive course evaluations from people who left the classroom more confident that they could better evacuate people and not risk injury to themselves.

Everyone Can Use This Training

People with limited mobility are everywhere in our communities. More and more of us are choosing to care for others—or to be cared for—in our homes and away from hospitals or care facilities. Many of us live in multi-generational family homes. And any one of us is subject to illness or injury that leaves us temporarily immobile. We can never tell when that situation will arise or when an emergency will happen.

You might not live somewhere prone to earthquakes, floods or tornadoes, but because of climate change, extreme weather events are on the rise. Other emergencies—gas leaks, fires, water main breaks, lightening strikes—can happen anywhere, at any time.

The Get Me Out of Here!® program is for anyone who is confronted with an emergency who may have to move someone out of harm’s way.

The unique procedures incorporate ergonomically safer moving and transfer techniques for the most efficient combination of speed and safety. The skills taught are straightforward and easy-to-learn. The course principles and
methods can be applied in workplaces, homes, schools, entertainment or commercial areas—anywhere an emergency might happen. Once you learn them and practice a few times, you’ll have them in your toolbox for the rest of your life.

With the practical exercises and expertise of the trainer in a *Get Me Out of Here!*® class, participants identify what works best for them.

The sessions emphasize learning specialized skills and body moves, rather than practising lifting heavy bodies. Once you understand Centre of Gravity, Stability, Waterfall and Fatal Move, along with Power Position and Safe Zone and more, you will be able to apply these unique emergency evacuation techniques.

**Fall forward out of a chair onto side, using gravity**

### TAKE THE WORKSHOP

The Get Me Out of Here!*® course offers a full-day, hands-on workshop and a three-day intensive Train the Trainer Instructor’s Program™ that trains people in your organization to deliver the program to your staff.

Barbara Purdy, Registered Physiotherapist, is also available for assessments of individual clients.

**For More Information:** Visit [www.freetobe.ca](http://www.freetobe.ca) or contact Barbara at [barbpurdy@freetobe.ca](mailto:barbpurdy@freetobe.ca) or phone 604-739-7315.

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Our 35th Anniversary Celebration and Fundraiser
What a Great Party! BY JOHANNA JOHNSON AND JANE DYSON

The BCCPD Board and staff wanted our 35th Anniversary Celebration to be a party, short on speeches and big on fun—and a party it was! We laughed at the antics of the hilarious David C. Jones, grooved to the music of the amazing Don Alder, were charmed by our lovely host Mark Madryga and wowed by the Salsa Studio dancers.

It was truly heart-warming to see so many BCCPD friends, old and new, come together to reminisce, chat, and enjoy the entertainment and food.

We were honoured that many of our funders and community partners came out to support us. There were plenty of good natured bidding battles in the Silent Auction and all the fun was very ably captured by photographer Vickie Marie Ayers.

Thanks to everyone’s efforts, we met our fundraising goal for the evening. The money we raised will be used to continue our various programs for people with disabilities.

This was our 35th anniversary celebration, but birthdays come every year. We had so much fun and raised money, we’re already thinking, maybe again next year?

A huge thank you to everyone who bought tickets, donated items to our Silent Auction, and volunteered to make our April 4th sold-out celebration such a great success. And a special thank you to our sponsors the Vancouver Taxi Association, Advanced Mobility Products Ltd., the Trial Lawyers Association of BC, and to WestJet for their wonderful donation of two return tickets to anywhere they fly. We would also like to thank Jim Watson and Simon Cox for all their generous help, and Julianna Torjeck for her donation of profits from sales of Arbonne products. Thanks everyone! 👏

David C. Jones and the BCCPD Rockettes!

Don Alder made beautiful music on his harp guitar.

The Salsa Studio dancers heated things up.

Host Mark Madryga, with WestJet tickets winner Jill Stainsby (centre) and Jane Dyson
Preparing for Decontamination

BY LAURIE PEARCE, JIBC RESEARCH CHAIR

We were so impressed with the brave people who agreed to put aside their fears and physical comfort to take part in the drill. The weather was 10°C and drizzling leading up to a Vancouver rain.

The Justice Institute of British Columbia (JIBC) was very proud to partner with the BC Coalition of People with Disabilities (BCCPD) in a Decontamination Drill held on March 13th, 2013 in Mahon Park in North Vancouver. Read on to find out about the brave people who volunteered for this drill!

Hundreds of people every year face the process of getting decontaminated in British Columbia. Most people think contamination is something that may occur as a result of terrorist activities and, while that is true, the reality is that people are also contaminated as a result of exposure to a variety of commonplace hazardous materials.

Examples include toxic smoke from house fires; accidental releases of pesticides and insecticides; exposure to chemicals (inadvertently mixing household chemicals or being exposed to clandestine meth labs); being pepper-sprayed in a robbery; or, being exposed to a chemical leak. People who have gone through a decontamination process have found it frightening, humiliating or even traumatizing.

Involving People with Disabilities

Decontamination drills involve soldiers or first response personnel. It is not very often that consideration has been given to the psychosocial effects on people and rarely have people with disabilities been actively involved.

So, as the researchers here at JIBC were looking at how to make sure the decontamination process built in as many psychosocial protocols as possible, we also wanted to make sure that we took into consideration the needs of people with disabilities and other special needs (e.g., mothers with infants). It seemed to us to be the perfect opportunity to involve BCCPD in a partnership—to learn from people with disabilities what works and what doesn’t work. After all, who knows best?
Karen Martin, BCCPD Emergency Preparedness Project Coordinator, was enthusiastic and willing to lend us her support. She began recruiting volunteers for testing our protocols.

We were keen to test cold-weather self-decontamination protocols. In many situations, it can take over an hour for the “HazMat” team to arrive, so our aim was to have people self-decontaminate as much as possible. We were not sure we would find many volunteers, especially because our drill involved cold, rainy weather and agreeing to strip down to one’s underwear to rinse off the “contaminant”!

We were so impressed with the brave people who agreed to put aside their fears and physical comfort to take part in the drill. The weather was 10°C and drizzling leading up to a Vancouver rain. The fire department set up a smoke machine to simulate a chlorine leak coming from a community swimming pool. A group of about 30 volunteers huddled by the “smoke” and the exercise began.

What We Learned
We haven’t yet completed all of the interviews and analyzed the results to have a good sense of how everyone was impacted. But there were a couple of early impressions worth mentioning.

One is the use of the “buddy” system. We asked everyone to find a buddy to help them through the decontamination process. This appeared to work well because people cared about making sure that everyone was helped. Buddies talked to each other to help decrease anxiety—having a buddy made the process less scary.

Self-decontamination kits, developed in conjunction with First Aid Survival Technologies Limited (FAST), helped lead people through the cleaning process. For example, people took off their jewelry and put their cellphones in special bags they could keep with them. Clothes went in separate bags.

People wiped down their face, hands and bodies, and put on a Tyvek smock and flip-flops. Then volunteers waited in a bus to get warm, until the showers were up and running. People were very grateful for the hot shower! The final stage was a medical assessment.

Disaster Psychosocial Services volunteers escorted people to the reception centre which helped to ensure that everyone was okay emotionally, as well as physically.

We also learned we needed to speed up the process of self-decontamination and that more guidance was needed for people who were visually impaired or who did not speak English.

Many thanks to BCCPD and to all the volunteers. I’m sure it was an experience you won’t forget (!) and we look forward to interviewing you in the weeks to come.

With your help, we’ll know more about what worked well and how things could be improved to better meet your needs.
Personal Preparedness Tips and Resources

There is a lot you can do to be prepared in case of an emergency. We’ve put together this list of tips and resources for you.

Have a Personal Network

A personal network can help you:
- plan and identify resources you need.
- practice evacuating your home and workplace.
- assess your needs during and after a disaster.

Use a Self-assessment Checklist

Check off the items in this list and you’ll be well prepared!
- Customize an emergency health information card (see opposite page)
- Develop a personal team
- Master the skill of giving quick information
- Plan your way out
- Determine if you are able to operate a fire extinguisher and turn off water and gas on your own
- Learn what to do in case of power outages and personal injury
- Learn your community’s warning procedures, evacuation plans and shelter locations
- Prepare an emergency “Grab and Go” kit (see next section)

Create a “Grab and Go” Kit

- Bottled water
- Flashlights—keep one by your bed and others around the house
- Battery-operated radio
- Non-perishable food
- First-aid kit
- Any items specific to your needs, using the C-MIST framework
- 7-day supply of medications and supplies needed
- Personal hygiene items

Use the C-MIST Framework

We recommend beginning your personal emergency planning process using the five categories of the C-MIST or Functional Needs Framework. This approach looks at the needs you will have in an emergency, rather than just your disability. For example, rather than having emergency information that says you are a person with Cerebral Palsy, the C-MIST Framework describes your needs in five functional areas:
- Communication
- Medical
- Independence
- Supervision
- Transportation

You can use the C-MIST framework to self-assess and organize information for your personal network and emergency personnel. Here are a few examples of needs that fall into the C-MIST categories.

Communication needs include people who:
- have reduced or no ability to speak, see or hear
- have limitations in learning and understanding.

Medical needs includes people who need assistance with:
- managing chronic, terminal or contagious health conditions
- dialysis, oxygen, suction.

Functional independence includes people who use assistive equipment and devices to function independently such as:
- mobility aids
- communication aids
- medical equipment.
Supervision needs includes people who have the following:
- developmental disabilities
- dementia, Alzheimer’s.
Transportation needs includes people who cannot drive due to:
- disability
- age
- temporary injury.

Documents and Key People
- Make copies of your ID
- Identify legal documents you may need
- Record your family doctor’s name and number
- Note family member or friend to be contacted
- List people in your network and how to contact them
- Pharmacy name and number.

Assistive Equipment and Medical Supplies
- Identify what you need
- Organize back up power—batteries, generator, etc.
- Have photos of how to use your specialized equipment
- Include extra supplies you need in your “grab and go” kit.

Other Resources
Obituary | Ted Hobbs

Ted Hobbs died suddenly and peacefully on February 20, 2013, after a brief illness.

Ted was diagnosed with Parkinson’s disease at the age of 45. He became involved with the BC Parkinson’s Disease Association (BCPDA), including counselling others who were newly diagnosed.

In 1989, Ted was hired by the BCCPD, first as the Coordinator of Coalition Enterprises, then as a disability rights advocate with Advocacy Access. Ted delivered workshops, and helped to develop many of BCCPD’s advocacy manuals and resources.

He was very proud of his advocacy work and grateful to both the Parkinson’s Association and BCCPD for allowing him to serve the community.

He once told his wife, Karen, about a client who said, “I have Parkinson’s. You have no idea what I am going through.” Ted decided not to correct the man and said, “Why don’t you tell me about it.” Ted felt his job was not to share his difficulties, but to listen.

Ted is survived by his wife Karen, his children Clayton and Julie, their mother Leah, Ted’s mother Edna, his brother Robert and sister Mary Lou. Ted has two nieces, one nephew and two great nieces.
BCIT Expands Planning

BY CHERYL SOKOL

In spite of some excellent planning already in place, we found the BCIT community would benefit from an increased awareness around planning for emergencies for those of us with disabilities.

Last summer, the Disability Resource Centre (DRC) and Emergency Management at the British Columbia Institute of Technology (BCIT) hosted a workshop on Strategic Inclusive Training for Emergencies (SITE), presented by Karen Martin of BCCPD.

In preparation for the workshop, we met with Karen to discuss BCIT’s planning for students and staff with a disability.

In spite of some excellent planning already in place, we found the BCIT community would benefit from an increased awareness around planning for emergencies for those of us with disabilities.

We decided to include students with disabilities in the Disaster Day 2012 exercise that occurs every two years at BCIT to give us a better understanding of their unique needs. The Disaster Day scenario was a mock earthquake, plus a hazardous materials spill.

Karen gave us information to help us be more comprehensive and inclusive planners. We looked at case studies of people with disabilities whose functional limitations included mobility and communication needs that would not likely be visible to first responders.

The noise level in the room went way up as the groups brainstormed and discussed possible solutions. Karen helped us to generate simple, but powerful suggestions such as the following:

- Adding a notepad and Sharpie felt pen to the personal emergency kits to enable communications with people who are deaf or hard of hearing.
- Development of visual illustrations and charts of what to do during drills.
- Collecting information from students who may need assistance in case of an emergency.
- Using self-assessment information to ensure that students with disabilities are properly assisted in case of emergency.

In preparation for an emergency event that affects the operation of all or a significant portion of our activities, every BCIT department and school prepares a Business Continuity Plan that enables us to resume the business of education as soon as possible. After the SITE workshop, we revised some sections of the plan to reflect our better understanding of planning for people with a disability.

Working with Karen and the BCCPD was very positive and we encourage other groups and companies to do the same.

CHERYL SOKOL, MRC, CCRC IS THE VOCATIONAL REHABILITATION SPECIALIST COORDINATOR AT BCIT’S DISABILITY RESOURCE CENTRE.

Hurricane Sandy

How were people with disabilities affected by Hurricane Sandy? Check out these links to read people’s stories.

____________________________

Crystal Evans-Pradha, a wheelchair user with muscular dystrophy, blogged about helping Nick Dupree, a disability rights advocate with a metabolic muscular disease, when he and his partner were stranded on the 12th floor.

http://littlefreeradical.com/2012/10/31/

You can read about the touching stories of several people with disabilities during Hurricane Sandy at this link: http://media-dis-n-dat.blogspot.ca/2012/11/disabled-people-especially-vulnerable.html/
During the terrorist attacks on the World Trade Center in September 2001, we all heard stories of unbelievable heroism. In one story, two men carried a woman using a wheelchair down 68 flights with the help of nine co-workers. Unfortunately, many of the stories from that day ended in tragedy: immobile victims were left waiting for help.

Twelve years, and numerous disasters later (both man-made and natural), most emergency management plans don’t fully address the evacuation needs of people who are immobile or have a physical disability.

As a person with a disability, get involved with the emergency planning process where you work and where you live. Ask critical questions and ensure plans, equipment and training address the need for full evacuation.

For example, does your facility’s plan address worst-case scenarios with loss of power and debris-filled hallways? How are they addressing the needs of people with a disability? Are they leaving those that are injured or with a disability behind (in an “area of refuge”) hoping first responders will get there on time to save them too?

When deciding to buy equipment, a building-by-building and floor-by-floor assessment needs to be conducted to ensure the facility is properly equipped. MedSled® evacuation sleds are the most effective device, both in its ability to slide over all types of debris and for protecting the person. MedSleds are intuitive, easy to use and come ready for horizontal or vertical evacuation.

When an EF5 tornado struck Joplin, Missouri in 2011, St. John’s Mercy Hospital was completely demolished and first responders would not arrive for 14 hours. With the MedSled®, patients were transported over debris-filled hallways to safety. During Hurricane Sandy, an ICU liver transplant patient at NYU Langone Hospital couldn’t be evacuated from the building by being carried. With the MedSled®, she was quickly and safely evacuated down 14 stories.

Wheeled devices, such as stair chairs and wheelchairs, can’t roll over debris. Consider that NYU Hospital moved over 300 non-ambulatory critical-case patients from a 17 story high-rise without a single injury or loss of life.

Also, are evacuation drills realistic? When drills are run, are they including people with disabilities? Training is time-consuming, expensive and usually unappreciated until the time comes and people have to evacuate.

We work closely with customers to provide multiple forms of training and drill support.

So, are the places you live and work evacuation ready? Get involved, be part of the solution.

Contact MedSled® at 314-965-7533 or http://www.medsled.com/.
Thanks to participants in our SITE workshop at the North Shore Disability Resource Centre in March 2013. We had great discussions and wish the NDRC success in implementing some of the ideas and procedures from the SITE planning.

Emergency Planning Workshops

BCCPD has two workshops to train businesses, government departments, local governments and community organizations in how to create emergency plans that include people with disabilities and seniors.

**Strategic Inclusive Training for Emergencies (SITE)**
Teaches businesses, government departments and community organizations how to create inclusive emergency plans.

**C-MIST and the Duty to Accommodate**
Learn what Canadian and BC laws say about local governments’ responsibility to provide emergency response programs in a way that is accessible to all citizens.

www.bccpd.bc.ca/epworkshops.htm
Details on content and costs available online, or contact Karen Martin at 604-875-0188 or karen@bccpd.bc.ca.

How can BC Ambulance Services (BCAS) better respond to people with disabilities during emergencies?

BCCPD worked with the BCAS to answer this question. The result was the incorporation of the C-MIST model in the BCAS dispatch database (*learn about C-MIST on page 12*).

This means that people with disabilities or seniors with functional limitations can voluntarily and confidentially provide BCAS with information. This personal information will help BCAS respond better to your needs, if you ever have to make an emergency 9-1-1 call from home.

There has been a very good response from people sending in the form from communities around BC.

“It’s been a bit too successful,” says Derek McClure, Superintendent of BCAS, Vancouver Dispatch Operations. “We’ve just had our people inputting the data from the faxed in forms off the side of their desks, but we’ll soon have an electronic version that people can fill in online and send to us. That way, the information can be inputted more directly.”

If you are using this service, it is important to resubmit your form each year to BCAS to keep your information up-to-date. BCAS will only keep the information in their database for one year.

You can download a copy of the C-MIST form from the BCCPD website at [http://tinyurl.com/d6gd3fd](http://tinyurl.com/d6gd3fd).
New Resource for Local Governments

Though emergency planning and response involves many sectors of our communities, local governments have the core civic and legal responsibility.

BCCPD has created a new booklet, Creating Safe Communities: Local Governments’ Legal Duty to Accommodate People with Disabilities in Emergency Response, to help local governments understand this legal responsibility. Canadian law tells us it’s discriminatory to provide public services in a way that excludes protected groups, such as people with disabilities.

We’ve also produced a short video to introduce the booklet.

You can find both resources at http://www.bccpd.bc.ca/emerg-prep.htm. Or, if you would like to receive hard copies of the booklet for your local government department, please contact Karen at karen@bccpd.bc.ca.

Thank you to the Law Foundation of BC for generously funding this legal education booklet and video.

YOUR VOICE COUNTS
BECOME A BCCPD MEMBER

Numbers matter. The more members we have, the stronger our voice in the community.

Please become a BCCPD member today. You can be a voting member or a non-voting member, and we welcome both individuals and groups.

I accept your invitation to join the BC Coalition of People with Disabilities and enclose my membership fee of $15 (groups and individuals).

I am also including a tax-deductible donation of $__________. (Donations over $10 are tax deductible).

Please check the correct boxes:
- New membership or
- Renewal
- Voting Member or
- Non-voting Member

Voting members are people with disabilities and self-help groups where at least 50% of members have a disability.

Name ____________________________________________
Organization ______________________________________
Address __________________________________________
City/Prov___________________ Postal Code ____________
Phone _______________ Email _______________________

Please return your payment/donation with this form to:
BCCPD, 204-456 W. Broadway, Vancouver, BC V5Y 1R3.
You can also become a member or donate online at:
www.bccpd.bc.ca/supportadvertise.htm.

THANK YOU FOR YOUR INVALUABLE SUPPORT.
ME/FM Awareness Day

“I split my clinical time between [ME and HIV] and I can tell you, if I had to choose between the two illnesses in 2009, I would rather have HIV.”

May 12 was ME/FM Awareness Day. Both ME (Myalgic Encephalomyelitis, also known as Chronic Fatigue Syndrome) and FM (Fibromyalgia) can be severely disabling and are widely misunderstood.

Here are some facts and figures about these illnesses.

- ME and FM affect close to 100,000 British Columbians. In Canada, each of these diseases is almost 4 times as common as Multiple Sclerosis or Alzheimer’s Disease, and over 10 times as common as Parkinson’s Disease. ¹

- Some people believe having ME means you’re tired all the time and having FM means you’re sore all the time, but they are much more debilitating. People with ME can be so disabled by fatigue and other symptoms that they’re unable to prepare a basic meal, make a phone call or even sit up. People with FM can be in such pain that walking, taking a shower or even light pressure on their skin is excruciating.

- These illnesses present with numerous symptoms including headaches, nausea, neurocognitive dysfunction, sleep disorders and autonomic and cardiovascular disturbances. Both diseases are lifelong, full recovery is rare and they show the highest rate of disability among chronic diseases in Canada, after only Alzheimer’s/dementia and the effects of stroke.²

- The media, the general public and many doctors easily and often confuse Chronic Fatigue Syndrome with chronic fatigue. Chronic fatigue can be caused by sleep disorders, vitamin deficiencies and illnesses, and can usually be relieved once the underlying cause is treated.

- Many people with ME and doctors familiar with the illness prefer the name “ME” because “Chronic Fatigue Syndrome” is very misleading. Dr. Bruce Carruthers, one of the earliest physicians to recognize and treat ME, said that, “Using ‘fatigue’ as a name of a disease gives it exclusive emphasis and has been the most confusing and misused criterion. No other fatiguing disease has ‘chronic fatigue’ attached to its name, e.g. cancer⁄chronic fatigue, multiple sclerosis⁄chronic fatigue—except ME⁄CFS.”³

- The causes of ME and FM are unknown, there is no cure and there are still no effective treatments. Yet, compared to other chronic diseases, ME and FM have the second and third lowest federal research funding per capita in Canada. ⁴

- Dr. Nancy Klimas, an AIDS researcher in the 1980’s and now prominent in ME/CFS research, stated in a New York Times interview: “My HIV patients for the most part are hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested. Many of my CFS patients, on the other hand, are terribly ill and unable to work or participate in the care of their families. I split my clinical time between the two illnesses, and I can tell you, if I had to choose between the two illnesses in 2009, I would rather have HIV.”⁵

For information or to help raise awareness of ME/FM, please contact the ME/FM Societies of BC at 604-878-7707, info@mefm.bc.ca or www.mefm.bc.ca.

¹,² Statistics Canada, 2010 Canadian Community Health Survey.
The Japan Disability Forum

BCCPD’s Nicole Kiyooka spoke with a family member about how the 2011 tsunami brought together disability groups.

Across the street from BCCPD is a small Japanese-Canadian hybrid of a café, with eggs benedict and octopus on the menu. Walk inside the café, past the dangling Christmas lights in the front window (in March) and there is something that might catch your eye—a donation bucket for the Red Cross, artfully decorated in red and white. A small reminder of a giant tragedy.

It was on March 11, 2011 at 2:46 pm that a 9.0 magnitude earthquake struck northeast Japan and a major tsunami followed. The horrific facts are still hard to imagine or comprehend. More than 18,000 people lost their lives and 300,000 people were displaced. Reconstruction has been estimated at over $200 billion and the country is still recovering.

Two years ago, I remember watching a story on TV about Sendai, the Japanese city closest to the epicentre of the earthquake. This is my sister-in-law’s hometown. The images showed Kaori’s local airport completely flooded, with runways under water. A mix of airplanes and cars were piled up in one surreal photo, carried by the tsunami and tossed back to the earth like miniature toys.

Kaori is a Vancouverite now and was at home when the earthquake happened. Her parents, sister and grandma were in Sendai. Thankfully, they were all ok.

Kaori told me that, during and after the earthquake, people went out of their way to help one another, especially those who were most vulnerable. They came together and the rest of the world reached out to help too. Unfortunately, kindness and compassion could not protect everyone. At the flooded Sendai airport, people were stranded and went without food and power for days. Much needed medical resources were just not available. People with disabilities who needed medication, equipment and supports were isolated and this resulted in many lives being lost.

The aftermath was unpredictable and astounding.

Soon after the disaster, 11 disability-related organizations, from a coalition called the Japan Disability Forum (JDF), wrote a detailed petition to the Prime Minister of Japan and other top government officials on behalf of people with disabilities. Lack of accessibility, missing medication and equipment, housing, resources and supports were widespread problems. JDF also issued a request to the Japanese government that they research: the number of people with disabilities who lost their lives, living conditions of people with disabilities after the disaster and a review of disaster reduction policies from the perspective of people with disabilities.
A year and seven months after the earthquake, JDF continued to wait for a formal reply. Now over two years have passed and I still could not find any information in my research to suggest that JDF ever received a response to their petitions and requests from the Japanese government.

Here in BC, we’ve been told for many years to expect the “Big One.” Sometimes this refrain about an earthquake sounds like a broken record.

The events in Japan showed us the reality of that possibility. When BC’s coast felt a 7.7 magnitude earthquake in October 2012, BCCPD fielded an increase in calls and requests for information about our Emergency Preparedness Program for people with disabilities.

These thoughts were in the back of my mind, when I recently visited the café across the street. I noticed the familiar donation bucket was not there. It was gone and so was that initial shock and urgency I had experienced when I first heard about the earthquake in Japan and realized that the same thing could happen here in BC.

Its absence was a bit unsettling. I knew that being ready for an emergency is something we can’t forget—for all of us and for people with disabilities.

I took this thought with me as I closed the café door and walked back to BCCPD.

Nicole Kiyooka is Administrative Director at BCCPD.

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Are you experiencing symptoms such as:

- excessive fatigue not related to activity or relieved by rest
- increased weakness in unaffected and/or previously affected or paralyzed areas
- muscle and joint pain
- reduced endurance
- sensitivity to cold
- difficulty sleeping
- problems breathing and swallowing
- sensitivity to anaesthetics and medication

If you are having difficulty with one or more of these symptoms and you had polio previously, you may have Post Polio Syndrome.

It is important to inform yourself about this condition. Tell your doctor.

For more information contact our office:

Post Polio Awareness and Support Society of British Columbia

Phone: 1-250-655-8849
Fax: 1-250-655-8859
E-mail: ppass@ppassbc.com
www.ppassbc.com
Studies show that healthy social relationships—positive interaction with family, neighbours, colleagues and friends—are important in maintaining physical and mental health. Adults with social relationships, also called social networks, live longer than those without these connections. Social support increases our ability to cope with stress and nurtures a sense of meaning and purpose in life.*

Both the size of our social networks and the quality of individual relationships affect our health. Social isolation and unsatisfying relationships have been linked to heart disease, high blood pressure, cancer, slower wound healing and impaired immune function.*

Just as positive relationships can foster good health, poor relationships negatively influence health through stress, anger, sadness or poor lifestyle choices such as substance misuse and an unhealthy diet.

It’s Not Always Easy

Building and maintaining social networks can be difficult for people with disabilities or chronic illness. Day-to-day coping with disability can drain energy, affect our mood and limit our desire to interact with others. Fatigue, pain, medication side-effects, low self-esteem and low income can hinder social interaction. Difficulty with social connection can also be related to our disability or illness. For example, poor short-term memory, negative perspective or worldview, anxiety or difficulty making conversation can affect our willingness to engage in social interaction.

Loneliness Can Become a Habit

Researchers have found that social isolation and loneliness can become a vicious cycle.** Feeling lonely because we have few or unsatisfying social relationships causes us to be overly sensitive to negative events and feedback. And this can create a self-fulfilling prophecy by negatively influencing the way we behave and interact with others. Social isolation leads to negativity, which in turn leads to continuing social isolation.

There is Good News

Building new social connections and maintaining existing ones becomes easier with practice. And not all connections require the same degree of effort. A social support network is made up of a variety of relationship types, including close friendships, family members, neighbours, classmates from school, co-workers or people we know from support groups.

Sometimes it is appropriate to call on more distant relationships—when looking for a job or an apartment for example. In other situations, it’s important to have a closer relationship before sharing something personal with a member of our support network.

Some experts point out the value of having five or more people in your social network. Different people will provide diversity of insight and feedback, through varying interests, perspectives and experiences. Other researchers note that our sense of connection is internal and related to the quality of our relationships, not the number.

If you are interested in adding to your social support network, you’ll find lots of ideas and suggestions on the Internet or at your public library. Before you begin your research, remember to “start small.” Think about opportunities that may be right outside your door. Social connection can be as simple as making friendly eye contact with neighbours on the street, saying “hello” at the bus stop and listening for receptive responses.

In growing your own social support network, you also become part of another’s network. Everyone wins!


Disability arts takes centre stage at the upcoming **Kickstart 5 Festival** in Vancouver, in September 2013. Performers will come from across North America to the festival, slated to include a variety of performances for Vancouver audiences, as well as two visual arts shows, a series of workshops and processions.

“It’s all about working together as we blaze a path,” says Artistic Director, Emma Kivisild. “As well as a roster of dynamic performances, festival-goers will engage in collaboration and mentorship, work together on a variety of projects, and learn about building partnerships.”

There’s something for everyone here and many different levels of engagement, too.

Leading up to the festival, collaboratively produced banners and processions will provide opportunities for participation. Workshops at the conference will also look at the artists’ working process.

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**Kickstart 5** is the culmination of 15 years (and five festivals) from the disability arts organization which hosted Canada’s first international disability arts Festival in 2001. Audiences can expect returning festival favourites, like the Swamp Angels Choir and performer, David Roche, as well as several artists making their festival debut.

For information about the **Kickstart 5 Festival**, visit [http://www.kickstart-arts.ca](http://www.kickstart-arts.ca).

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BCCPD.BC.CA
Online E-Training: Workplace Emergency Planning

In 2008, the BCCPD produced the research report, *Workplace Emergency Planning Inclusive of People with Disabilities*, funded by WorkSafe BC. The findings of our research highlighted the need for more workplace emergency planning in British Columbia that included the needs of workers with disabilities.

We then produced a handbook for employers and workers, *Workplace Emergency Planning for Workers with Disabilities*. We have distributed over 2,000 handbooks and we are pleased to see continuing interest in this topic.

To build on this interest, WorkSafeBC provided funding to BCCPD to create an e-learning training module based on the handbook.

With this newly-launched course, we will be able to reach a larger geographical area, and a broader base of businesses and organizations across Canada.

The training content is also transferable to a broad range of work sectors.

E-training Highlights

- Employers and employees will learn about emergency planning and the disability-specific needs of workers.
- Employers will have a tool to educate their workers.
- Content includes:
  - Determining staff needs;
  - Assessing worksite hazards for workers with disabilities;
  - Planning for emergency communications;
  - Planning for safe egress;
  - Personal preparedness of workers.

The free e-training module allows people to work at their own pace. On completion, learners receive a certificate, as well as downloadable resources. For more information, visit our website or contact Karen at karen@bccpd.bc.ca.

Register for this free online course at: emergprepcourse.bccpd.bc.ca.
BC Coalition of People with Disabilities (BCCPD) has been working with the City of Surrey to help us develop inclusive emergency planning and response for people with disabilities.

In 2011, BCCPD delivered presentations to the Surrey Emergency Social Services (ESS) Team and to ESS volunteers. The City of Surrey provided information on C-MIST to the annual Youth TRANSITION Fair and has presented to the Community Living BC (CLBC) Community Council (please see page 12 for more on the C-MIST model).

We are also currently talking with local community-based organizations, such as the Surrey Association for Community Living to work with them to identify their potential role in an ESS disaster response. We hope to work with interested community organizations as much as possible.

The City of Surrey conducted a Mock Emergency Exercise in Cloverdale last year, based on the premise of evacuating over 100 people from their homes. We used the C-MIST framework in the exercise and used some scenarios on how to support people with disabilities.

City staff and volunteers led the Special Needs Unit in this full scale reception centre exercise conducted by the ESS team. They handled 10 scenarios that included situations involving people with disabilities very well. Everyone learned a lot from responding to these real-life scenarios.

They handled 10 scenarios that included situations involving people with disabilities very well. Everyone learned a lot from responding to these real-life scenarios.

We built on these experiences in January 2013, when Surrey and the BCCPD conducted a two-hour C-MIST training session for staff and ESS volunteers in preparation for another emergency exercise in May 2013. Our focus for 2013 is working with ESS staff and volunteers, and the C-MIST framework to assess the functional needs of evacuees.

The City of Surrey is dedicated to community accessibility and inclusivity, and to developing strategies to fulfill the Surrey Parks, Recreation and Culture’s mission. Surrey’s population continues to grow rapidly and become increasingly diverse ethnically, culturally and socio-economically. We hope to meet this challenge by continuing community partnerships, like our ongoing work with BCCPD.

For more information on ESS in Surrey, please visit the website: www.surrey.ca/ess.

Share information about your business or organization with our growing network. It’s a way to invest not only in your business, but in the dignity and independence of people who live with a disability. Advertising revenue helps support BCCPD services and programs.

TRANSITION MAGAZINE

We have a wide range of ad sizes to choose from, on either black or colour pages, with prices for budgets large and small.

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- Choose from three ad types to fit your needs and budget.

INFORMATION AND BOOKINGS

For information on advertising with BCCPD, please contact Valerie at 604-875-0188 or transitionads@gmail.com.
Frequently Asked Questions
BY KAREN MARTIN

Question: How do I tell the fire department that I need assistance during a fire drill, fire, or other emergency? In our building, once you exit onto the stair landing for the floor, the door locks behind you. Other than asking people descending the stairs to let the emergency responders know that you are on the landing waiting to be evacuated, there is no other way to notify responders. This is also a problem if it’s a false alarm because people don’t come up the stairs to return to the floor because the doors are locked.

Answer: Absolutely no one should be left on a stairwell landing during an emergency. It’s unsafe for all concerned. Every building should have a plan—and practise it—on how to evacuate everyone (including people with disabilities).

If people are unable to evacuate, building floor wardens should tell fire services exactly where people are in the building. You can also contact your local fire department yourself and let fire services know where you live, what your disability is and if you will need help evacuating during a fire. This should be part of your personal preparedness planning.

However, it is important to know that fire services are not trained in lifting and carrying people with disabilities.

Good question and good luck with your planning!
I recently drove into Vancouver from my home in Lillooet. There were several things I wanted to do and a few events I needed to attend. I also wanted to sell my RV which I was able to do.

I had with me two yellow shirts. They are large, long-sleeved shirts very much like men’s white shirts, but they were both designed for women. One was to wear to a choir concert, as Patti our much loved leader had instructed us: “black on the bottom, one solid colour on top.” This plastic (yes, plastic) shirt was bought mail order and the colour was beyond bold and not at all mixed or diluted with any other colour. Sunflower yellow, corn yellow, Big Bird yellow, blindingly yellow.

On choir night, I saw that most of the singers had chosen deep red, deep purple or a lightish green. My yellow shirt really stood out. But that is not the important bit. The important bit is that night, I felt very loved. I was helped to find my spot, by people who knew I have trouble tracking things like which song is next and with whom am I singing it. People led me or pushed me here and there, smiled at me even when I sang flat, and grinned when I did something silly.

I loved it, I loved them, I even felt OK about our mistakes. Making music is always a very bold noisy thing to do. A plastic shirt, the colour of the midday sun is perfect for it.

The second yellow shirt, for the other event I was attending, is anything but bold. It’s a silk Holt Renfrew with its label intact and I am unclear where I got it. I could never have afforded it, so I must have found it at a thrift shop. I’ve used it at family events where I want to look good.

In April, BCCPD held a fundraising dinner. I wore the pale yellow shirt and I felt well dressed.

Because I had just sold the RV (see, the story does start to come together), I bought a ticket in the BCCPD’s raffle’s Grand Prize which was an airplane ticket for two anywhere that WestJet flies.

Amazingly, my number was called. Out of the—yellow—sometimes good things happen. I will use the tickets to give myself a real holiday, somewhere in the sun, later this year.

I wonder who will go with me, to where and when. I think I will buy another long-sleeved yellow shirt to wear on the jet. It’s a good sunny life! 🌞
Committee Has Wide Community Involvement

The BCCPD coordinates the Emergency Preparedness for People with Disabilities Committee (EPPDC) which has been hard at work since 2006. The EPPDC develops partnerships with many community sectors to improve emergency programs and services for people with disabilities.

Our goal is to work together to educate emergency managers and responders in inclusive approaches that will support people with disabilities throughout BC. We welcome new members to the committee.

The EPPDC is made up of disability organizations, individuals with disabilities, and emergency management sector representatives.

Current members of the committee are: the BCCPD, Cerebral Palsy Association of BC, Neil Squire Society, Voice of the Cerebral Palsied of Greater Vancouver, Positive Living BC, Vancouver Coastal Health Emergency Management, Western Institute for the Deaf and Hard of Hearing, City of Surrey Accessibility and Inclusion Program, Lions Bay Emergency Social Services, MVT (HandyDART), Richmond Society for Community Living, Free to Be Rehab Consulting, Burnaby Mental Wellness, and March of Dimes Canada.

A Guide to User-Friendly Trails

Go beyond the parking lot and pick up your copy of “A Guide to User-Friendly Trails” featuring easy-to-use walking, hiking and wheeling trails in Greater Victoria, BC.

Features:
- Trails suitable to individuals of diverse ages, levels of mobility and endurance.
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Pick up your copy at Capital Regional District Offices, West Shore Parks & Recreation and municipal halls in the Westshore area.
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Planned Giving

You’ve always been there for others. It’s part of who you are. Now, you can continue to give beyond your lifetime.

The BCCPD has a Planned Giving program. Planned Giving is the opportunity to think ahead about causes or organizations that you may want to financially support beyond your lifetime.

You can take the time now to gather information and leave instructions in your will.

By planning ahead, you can research charities, or have someone research charities for you, that fit your values. You won’t feel rushed or pressured to make a decision and you can ensure that your money is spent in the way you want.

Benefits

There are many benefits to Planned Giving. By writing down your wishes, you will have increased peace of mind and control over your finances.

Through Planned Giving, you can provide a significant future donation without reducing your income today.

A gift in your will to a registered Canadian charity is tax-deductible.

And, your Planned Gift helps the BCCPD to be here in the future for those who need us.

Tax Savings

You can realize significant tax savings with Planned Giving. For example, stocks, bonds and mutual funds that you may have in a trust can be transferred in your will to a charity and a tax receipt will be issued.

A bequest from your estate of cash or RRSPs will reduce the taxes that your estate will be required to pay.

Other ways of donating give twofold value: by naming the BCCPD as the beneficiary in a life insurance policy, you do not incur any costs now and a tax receipt is issued when the estate is settled.

To Learn More

Our donors are important to us and we’ll work with you to be recognized in the way that you’d prefer.

If you would like more information about Planned Giving, please contact Nicole at the BCCPD at nicole@bccpd.bc.ca or 604-875-0188. She will send you BCCPD Planned Giving information for you to review with your financial planner or lawyer, family and friends.

OWN BEAUTIFUL ART

BY PJ ARTMAN

With devices supplied through the Equipment and Assistive Technology Initiative, Kelowna Artist PJ Artman is making amazing art. Two pieces he generously donated to a recent BCCPD fundraiser were some of the most bid-upon items.

When you see his paintings, it’s hard to believe PJ has a visual impairment. He uses varied styles and subjects in his work.

“I love life and art, and being creative keeps me in tune with the world because art is my therapy for what ails me. I am a legally blind artist, but I never let little things like that stand in my way. Every day, I just march forward into a new bright and creative day where I feel safe, happy and free.”

SEE PJ’S WORK AT PJARTMANSTUDIO.COM
To many readers, hippotherapy is probably an unfamiliar term. While Therapeutic Riding encompasses a range of horse-human therapy programs, hippotherapy has developed as a distinct discipline that has wonderful benefits for children and adults with disabilities.

According to the American Hippotherapy Association, hippotherapy is “a physical, occupational and speech-language therapy treatment strategy that utilizes equine movement as part of an integrated intervention program to achieve functional outcomes. The horse provides a dynamic base of support, making it an excellent tool for increasing trunk strength and control, balance, building overall postural strength and endurance, addressing weight bearing and motor planning. Patients respond enthusiastically to this enjoyable experience in a natural setting.”

Physiotherapists (PTs), Occupational Therapists (OTs), and Speech-Language Pathologists (SLPs) are among those who practise hippotherapy.

Danielle Champagne, an Occupational Therapist with the Les Amies de Joey says, “I find that the horse allows me to obtain [from my riders] levels of motor intensity less easily achieved using more conventional occupational therapy techniques. On the horse, the rider’s central nervous system is more strongly stimulated, obliging it to adapt to this more challenging motor demand. Because the benefits are gained under natural circumstances, they are more easily transferred into the rider’s daily life.”

It is easy to understand why PTs and OTs would be involved with this therapy, but why SLPs? The Speech-Language Pathologist makes use of the horse’s movement to stimulate the physiologic systems that support speech and language—especially effective breathing. When combined with other speech-language interventions, SLPs can improve communication disorders and functional communications.

Hippotherapy, like therapeutic riding, takes a team approach. In this partnership, the rider focuses mainly on the horse, leading him or using long lines to ensure the desired combination of even pace, energy and direction. But any old horse won’t do! A trained horse partner with appropriate temperament is important for the success of this therapy.

Excerpted from “Hippos in the Barn?” Reprinted with permission. CanTRA Caller, January 2013. Contact: ctra@golden.net.
We’re Here To Help With CPP Disability

Were you previously working and now have a disability?
Do you need help to apply for CPP Disability or appeal a denial of benefits?

How Can BCCPD Help?
BC Coalition of People with Disabilities is an expert in Canada Pension Plan Disability (CPP-D) advocacy. We provide:
• in person, one-to-one assistance
• assistance by phone
• free self-help publications on what CPP is, how to apply and how to appeal a denial (available in English, Traditional Chinese and Punjabi)

What do I need to know about CPP-D?
CPP-D has several advantages over provincial disability benefits. And, recipients may receive provincial (PWD/PPMB) disability benefits in addition to CPP-D in the form of a top-up, if their CPP-D benefits fall below the provincial minimum.

Please contact us to learn more.
CPP-D Advocacy Program
Telephone: 604-872-1278 | Toll-Free: 1-800-663-1278
Website: [www.bccpd.bc.ca](http://www.bccpd.bc.ca)
Online Program information: OurWork/Advocacy Access
Online Self-help CPP resources: Library/Money & Income Supports

- Funded through the generosity of the Law Foundation of BC
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There are so many people and organizations to thank for BCCPD’s sold out 35th Anniversary Celebration, April 4. We’d like to single out these amazing and generous supporters for a huge thank you.

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