

THE CBSC

newsletter

SUMMER 2020



Welcome

Welcome to our seventh newsletter. The Canadian Burns Survivors Community (CBSC) is a community of burn survivors, firefighters, burn unit staff member and advisors who have come together to offer support and education to any person or people that have been affected by the trauma of burns. We have been working since 2007 to offer support to burn survivors and family members of

survivors in a variety of ways. Our main work is to ensure that biennial conferences for burn survivors take place across the country; we select the host groups and help with the planning and execution of the conferences. We also maintain a website that is often used by Canadians who have experienced burns to help them get connected in their own communities to local organizations or survivors.

COVID-19

A big thank-you to all our Health Care Workers, First Responders, and essential service workers during this unprecedented time. Please follow the health guide lines to protect yourselves and your families.

Stay home to help flatten the curve of this virus, hopefully this is short term, and this will pass sooner than later.

CORONAVIRUS DISEASE (COVID-19)

YOU MAY HAVE COME IN CONTACT WITH THE VIRUS THAT CAUSES COVID-19

The Government of Canada has put in place emergency measures to slow the introduction and spread of COVID-19 in Canada. All persons entering Canada **MUST self-isolate for 14 days and monitor themselves for symptoms** subject to the *Minimizing the Risk of Exposure to COVID-19 in Canada Order (Mandatory Isolation)*.

Compliance with this Order is subject to monitoring, verification and enforcement. Those in violation may face detention in a quarantine facility as well as fines and/or imprisonment.

PERSONS EXEMPT FROM MANDATORY QUARANTINE (SELF-ISOLATION)

The mandatory isolation order does not apply to certain people who may be returning to or entering Canada for work, and who are not experiencing signs or symptoms consistent with COVID-19 at the time of entry.

You are identified as an individual who is exempted from this Order because you meet the definition of an essential service worker.

As such, you are required to respect the intent of the order to minimize spread of COVID-19 in Canada.

You must continually monitor your health for symptoms of COVID-19 including for 14 days each time you re-enter Canada. You are also reminded to be aware of and respect the public health guidance and instructions of the area where you are located.

This exemption does not apply to anyone who has symptoms of COVID-19.

If you have the symptoms below before or upon entry into Canada, you must disclose this information to the border services officer or quarantine officer who will provide additional instructions.

MONITOR YOUR HEALTH

FEVER



COUGH



DIFFICULTY
BREATHING



For 14 days after each time you enter Canada, if you have symptoms of COVID-19 (cough, shortness of breath, or fever equal to or greater than 38°C, or signs of fever e.g. shivering, flushed skin, excessive sweating):

- ▶ immediately isolate yourself from others in your living space;
- ▶ contact the public health authority in the province or territory where you are located as soon as possible and follow their instructions (see back of sheet); and
- ▶ contact your employer for further instructions related to your work.



Public Health
Agency of Canada

Agence de la santé
publique du Canada

Canada

Public Health Authorities Provinces & Territories Phone Number/Website

Province/Territory	Phone Number	Website
British Columbia	811	www.bccdc.ca/covid19
Alberta	811	www.myhealth.alberta.ca
Saskatchewan	811	www.saskhealthauthority.ca
Manitoba	1-888-315-9257	www.manitoba.ca/covid19
Ontario	1-866-797-0000	www.ontario.ca/coronavirus
Quebec	1-877-644-4545	www.quebec.ca/en/coronavirus
New Brunswick	811	www.gnb.ca/publichealth
Nova Scotia	811	www.nshealth.ca/public-health
Prince Edward Island	811	www.princeedwardisland.ca/covid19
Newfoundland and Labrador	811 or 1-888-709-2929	www.gov.nl.ca/covid-19
Nunavut	1-867-975-5772	www.gov.nu.ca/health
Northwest Territories	911	www.hss.gov.nt.ca
Yukon	811	www.yukon.ca/covid-19



Canadian Burn Survivors Community – AGM – June 20, 2020

As this year's conference was postponed due to COVID -19, a Bi-Annual AGM was held via Zoom Meeting on June 20, 2020.

CANADIAN BURN SURVIVORS COMMUNITY ANNUAL GENERAL MEETING

Zoom Call
June 20, 2020

The Annual General Meeting of the Canadian Burn Survivors Conference was held via Zoom on June 20th, 2020 at 1:00 pm CST. There were 10 present.

The minutes of the 2018 were circulated ahead of the meeting and the Motion to accept minutes was made by Sandy Cook and seconded by Don Adamson.

The financial report for 2019/2020 was reviewed and accepted.

Old Business:

1. Converting the CBSC to a registered non-profit organization
 - a. This is in the works and Kyle Hynes is currently working with a volunteer advisor to have our bylaws be rewritten to comply with current not-for-profit laws.
2. Next Canadian Bun Survivors Conference was postponed due to COVID and we will hear from the BCPFFBF group as to the new dates, potentially in March of 2021.

New Business:

1. Election of Officers to the CBSC Conference Board

- a. John Westhaver has decided to step down as Co-Chair due to personal reasons. We thank John for his years of dedicated leadership and service in this role and are fortunate that he is willing to remain on the Board. Michelle Valladares was nominated for the role of Co-Chair by Barb Hodge, seconded by John Westhaver. All approved. Motion Carried.

- b. Other Board positions were as follows:
Barbara Anne Hodge – Chair
Deborah Ward – Secretary/Treasurer

Board Members:

Ashley Wilson	Andrew Ward
Don Adamson	Heather Beverage
Mike Cook	Martin Johnson
Kim Sutherland	Sandy Cook
Kyle Hynes	Michelyn Grenier

Motion by Barb Hodge to accept the Election of Officers, 2nd by Mike Cook. All in favor.

Next AGM to be held in 2021, time and place to be determined.

Meeting was adjourned at 1:08 pm CST

Outside of the ordinary:

by Charlene Pell

The CBSC Board of Directors wish to thank Charlene Pell and the Canadian Skin Alliance for allowing us to publish this article in our newsletter.



We live in a society obsessed with outward beauty. We are bombarded with media images of airbrushed celebrities who give us unrealistic expectations of the “perfect image”.

If you have a facial or physical difference that causes you to look out of the ordinary, odds are that you have been the target of social challenges, negative comments and/or stares.

As a result, this can leave you feeling embarrassed, self-conscious, angry and rejected. Visible differences include any kind of condition that affects the appearance of any part such as skin conditions, burns, cancer, cleft lip and palate, birth marks, craniofacial anomalies and injuries. So why do people stare, and what are the emotions experienced by both the person staring and the individual who is

the object of a stare? What communication skills and tips can reduce the anxiety related to appearance, stares and social interactions?

The science of staring It’s normal to stare; it’s rude to glare! There is growing evidence to prove that we all stare at anything or anyone out of the ordinary, and there is nothing in the definition of a stare that denotes malice. However, staring is often perceived as hurtful and unwanted. Some researchers have found that our brain uses more energy to process images that are unfamiliar while anthropologist Donald Giddeon has demonstrated that a discrepancy as small as 1/25 millimeter in the placement of a facial feature triggers our brain causing us to do a double take. Flawless skin is the most universally desired human feature (flowing hair runs close behind). Staring is also believed to be a defence mechanism of self-preservation and survival carried over for centuries.

Snapshots: appearances matter

Research suggests that we form opinions about one another in 90 seconds, primarily by interpreting visual and auditory information.

Staring: reducing barriers

First, know that your “response” (not “reaction”) to a stare often determines the outcome. When meeting a stranger, use positive non-verbal body language,

such as a simple smile, to display a reassuring sign of friendliness and approachability. Your smile helps put the stranger at ease. If you frown or look at strangers with scorn, you may cause them to feel awkward, annoyed or anxious. Also, becoming upset can drain you of energy. Instead, become an agent for change—first for yourself and, in the process, for society.

One of my heroes, Kevin Michael Connolly, was born without legs. In 2006, he won a silver medal and a \$6,000 prize at the Winter X Games. The athlete used his prize money to travel to 17 countries and snapped 33,000 photos of people staring at him. Each eye-opening photo has something in common—the look of disdain on his subjects' faces. Rarely did anyone greet him with a smile, which unmistakably portrays the global rejection of those who “look different.”

Getting a positive response from strangers

People are rarely taught what to do when they meet someone who looks different, and so they feel awkward and frequently look away. Almost everyone admits to being curious and wondering what caused the difference, but rarely do they act with malice or intend to be rude. Sometimes, strangers assume that a physical difference suggests a mental deficiency or that it is associated with challenging behaviours. Rather than avoiding difficult situations, use positive coping skills, take the initiative, and let good social and communication skills elicit a positive response from strangers. How you present yourself to the world with gestures, facial expressions and body language comprising 93 per cent of communication.

My experience

As a result of a private plane crash in 1994, 64 per cent of my body, including my face, was burned. I prefer to put others at ease in social situations and take the opportunity to educate them and dispel false myths associated with disfigurement. This is particularly important when addressing the blatant but innocent stares of young children. My charity, Facing Forward, strives to educate middle-school students about the challenges of living with a disfiguring condition and to foster acceptance of individuals who have physical differences through a program called “Outside, Inside; You Decide.” Face It Online is a support tool developed by the Centre for Appearance Research (CAR) to help adults who have a physical difference manage their appearance-related distress more effectively. Facing Forward offers this comprehensive eight-week program is currently free of charge. To register, contact charlene@facingforwardinc.org. cs

Charlene Pell is the founder of Facing Forward, a national nonprofit that provides support, programs and advocacy to help individuals with congenital or acquired visible difference. She offers lectures and workshops to encourage acceptance.

Contact Charlene at www.facingforwardinc.org

When People Stare - 8 tips to take control

- 1 If you are physically able to, smile whenever possible. A smile is a universal passport.
- 2 If all or part of your face is paralyzed or if you have only one eye, be as direct as you can—don't hide your mouth or look down. Use gestures, posture and body language effectively.
- 3 If your speech is not clear, instruct others to listen carefully, and tell them, "It's okay to ask me to repeat what I said."
- 4 Make eye contact whenever possible; it expresses interest and acknowledges the other person.
- 5 Initiate a conversation so you can control the direction of the interaction (for example, "Is that your son on first base?").
- 6 Direct the focus of the conversation to your environment (for example, "Is this the first time you have attended this conference?").
- 7 Discuss your similarities and what you have in common, not your differences (for example, "Does your daughter also attend this school?").
- 8 Maximize your appearance with careful attention to grooming, dress, makeup, tasteful jewellery and accessories.



Bi-Weekly – Zoom Meeting Wednesday Evenings

CBSC is hosting bi-weekly meetings on Zoom to chat with other survivors and community advocates.

Next meeting;

July 22 - “tricks of the trade” for burn survivors

Upcoming dates include:

August 5, 19

September 2, 16, 30

Discussion Topic:

Changes each week

Time:

6pm PST / 9pm EST

Event Link:

<https://zoom.us/j/93115911933>

For more information, follow us on Facebook and Twitter.

Join us! Come, share and/or listen as we discuss together.

<https://www.facebook.com/>

CanadianBurnSurvivorsCommunity/

Firefighters’ Burn Fund Inc. (Manitoba) – Updates

From Martin Johnson - One of the things we do is run a province wide raffle with 2 trips to hotter destinations such as Mexico, Cuba, Dominican Republic, etc., as well as a variety of electronic prizes such as large screen TVs, computers, etc. We’ve been doing this fundraiser since the 1980’s.

At the same time, there were coupon books being sold by a team from Media Scene. Each book has over \$500.00 worth of free items, selling for \$25.00, with \$5.00 from each sold coming to the Burn Fund. They did a great job two years ago but had sales have slowed quite a bit due to COVID-19.

On a lesser scale, we receive funds through payroll deductions, general and memorial donations, and from the odd estate.

Early on we anticipated that COVID 19 would still be an issue in early summer, and we reluctantly decided not to conduct a Camp for our younger burn survivors.

Current guidelines still prohibit overnight camps, and many of our kids come from remote communities

that have closed traffic coming and going in order to protect their residents.

Two years ago we established a \$2,000,000.00 endowment with the Health Sciences Centre Foundation. The earnings are earmarked to do research into harvesting stem cells from person’s own fat and use them to help heal burn injuries.

Last year we established a \$1,000,000.00 endowment with the Children’s Hospital Foundation with proceeds set to support the care for children with burn injuries.

For the last 3 years we have been in a partnership with the Office of the Fire Commissioner and Red River Mutual to supply Smoke detectors to Fire Departments throughout the Province. Their personnel will see to installing them in homes that either have none or where the detector is more than 10 years old.

In the last year, we started supplying combination smoke/CO detectors instead of smoke detectors. Overall, some 6,000 units have been purchased for the program.

www.canadianburnsurvivors.com

Greetings To All From CAMP BUCKO!!!!!!

Camp BUCKO would like to extend a warm Hello to all Canadian Burn Survivors and their extended families. We wish that everybody is healthy and happy during these crazy times.

On the Camp BUCKO front, we have taken the sad, but necessary steps to insure that all of our Campers, their Families and our Volunteers are safe during the recent Covid-19 Pandemic. Camp BUCKO respects and is adhering to the Directives and Guidelines from the Premier's Office and the Ontario Board of Health regarding the measures that have been put into place to effectively protect everybody in Ontario during the Pandemic. This unfortunately means that we have had to cancel all of our Camp BUCKO activities and events for 2020; this includes our Summer Camp Week in August, our Family Camp Weekend in September and our Volunteer Appreciation Dinner in November. Camp BUCKO has assured our Campers and their Families as well as our Volunteers and Sponsors that this means, an even BIGGER, Better and Show Stopping Camp and Family Camp in 2021 in where we will be Celebrating Camp BUCKO'S 25TH Anniversary!!!!

Camp BUCKO has been staying in touch with our Campers and Families through email and updates on our website, and has recently produced our first

ever Karaoke Video for our Campers in an effort to bring a smile to their beautiful faces.

Please visit our website www.campbucko.ca to see our video and to gain more information about our amazing Camp and Campers. Camp BUCKO is a Registered Charity; if you are interested in supporting/donating to our Camp, information is also available on our website.

From Camp BUCKO to All of you and your Families, please stay safe and enjoy your summer!!!!



BC Professional Firefighters Burn Fund – Virtual Engagements

The BC Professional Fire Fighters' Burn Fund is providing a number of virtual engagement opportunities this summer. For more information, please contact: info@burnfund.org

Little Lionhearts

We are pleased to be hosting a virtual reunion for our inaugural Little Lionhearts (LLH) group on Sunday, Jun 28. A chance for families to connect and share learnings on life since the first LLH in 2019, news from the Burn Fund and some extra special games! Our second Little Lionhearts Camp is scheduled to go ahead in October 2020 (pending government restrictions).

Burn Camp

After the cancellation of our Summer camping programs, Burn Camp 2020 is going virtual! We are thrilled to bring our Burn Camp experience to the virtual world by hosting two online events - Virtual

Camp Kick-Off and Virtual Campfire. While it won't be the same as in-person Burn Camp, the Burn Fund is dedicated to supporting campers and families virtually this year.

Adult Burn Survivor Community

As our world changed in March this year, the Burn Fund responded to our Adult Burn Survivor community's need to stay connected by providing virtual offerings for continued growth and healing. We host monthly virtual coffee hours for a safe and open discussion, led by Lead Volunteer and burn survivor, Stasi Manser, virtual yoga classes and after a successful first session on "A Conversation On Confidence", we will be continuing our educational series for burn survivors across North America, with the next instalment, "A Conversation On Resilience". Dates for our next virtual sessions will be confirmed soon.

Submitted by Kirstie McRae, Executive Manager - BCPFFBF



Getting to Know You Interview:

Andrew Ward – CBSC Board Member

Briefly describe your family role with a burn survivor?

I am the son of Debbie Ward. I have been able to witness and watch her over the last 20 years grow from victim to survivor. While watching her grow it's allowed me to learn many things about myself as much as she has.

Why you expanded your support?

I'm not sure when it happened, but I became causally involved when Halifax hosted their first Canadian Burn Survivors Conference. From there I was hooked. I have been involved in some manner since. It has been one of the greatest and most humbling experiences to be able to meet and grow with this community.

Reason for your involvement with CBSC?

I became part of the CBSC because, seeing my mom grow as a survivor made me want to make a difference. Being able to be a part of this community has been personally rewarding because being a part of the CBSC allowed me to be apart of something bigger than just ourselves.

Positive changes to you due to helping others?

I've been very blessed to become involved in this community at a fairly young age. Over the years, I have been able to meet some extremely wonderful



people. I have been able to learn some truly great lessons and that I have been able to use in both my personal and professional life. I feel that being able to listen to other people has really allowed me to find a deeper understand of who I am, as well be able to support others.

Andrew Ward's Story As A Burn Survivor

Hello, my name is Andrew Ward, and I am Debbie Ward's son. I have two older sisters, and like anyone who is the youngest in the family, I believe that it took my mom three times to get it right. There is no one to dispute this fact, so I can say it's true. The one thing most people don't know about me is that, like many of you, I am also a burn survivor.

Now, I'm not a survivor in the sense that I own physical scars and had to deal with the trauma you have had to deal with. I could never imagine



what you have had to endure. I was born into being a survivor. A large part of who I am today, I can attribute to the fact that I was raised by a single mother who spent most of her life coming to terms with being burned as a child. Believe it or not, a large part of my success in my professional and personal life I can thank the burn community for.

I didn't realize I was different until I sat in a sharing circle in the 2012 Calgary conference. I went to a family and support sharing circle. I sat there listening and was amazed at everyone's stories and learning about the things they were dealing with on a daily basis. When it came to me, I remember thinking, I hear what everyone is saying, but I didn't experience what they were dealing with. I remember saying that I didn't have to deal with the trauma of things like induced comas and the initial recovery stages. I actually said "I don't think I belong in this breakout". The moderator asked me what I had dealt with and I shared my experience with the group. I talked about spending so much time in the hospital with my mom, helping her where I could. I talked about not having her around all the time, and how we only really started talking about what she went through recently. When I was finished,

the moderator looked at me and said, "You are a burn survivor as well". Just as much as my mom, I was dealing with surgeries and after care, nurses, missing time for my activities and the stresses of recovery. It was something that has stuck with me for many years, and I needed to come to terms with the idea myself before I could share my story with others.

I was trying to remember when I first realized, but more importantly comprehended, that my mom was burned. The first time I think I really understood that my mom was a little different was when I was about 11 years old. I remember my friend Matt and I were in my bedroom; we had a lighter and we were taking pieces of paper and lighting them on fire and throwing them into my garbage can. One piece fell on the floor and slightly burned the carpet. My mom came into my room and was furious. I remember her yelling at us. I don't remember what she was saying, but I know she yanked her sleeves up and yelled at the two of us "Do you want to look like this forever!" I remember Matt and I looked at each other with blank faces, we were dumbfounded. When my

mom left my room, Matt looked at me and said “Hey man, did you know your mom was burned? How come you never told me?”. Hindsight is a wonderful thing; this was the moment that I realized my mom may be different from other moms.

I remember another time, I was in elementary school and there was a kid that would drive me absolutely crazy and so I started to pick on him. In today’s standards, we would call it bullying. I’m assuming my mom must have received a call from my school because when I got home, my mom sat me down and told me multiple stories about how she was bullied at school and how it made her feel. How she wished someone was there to help her. She told me about when she first came home from the hospital, and kids would run from her because they thought she was diseased. She taught me a valuable lesson that day, something I still stand by today. We don’t know people’s stories, and before we judge we need to know the person. I can tell you, the next day I went to school and talked to the guy I was “bullying”, I apologized to him, and never bullied another person again. I became the guy who would

stick up for people when they were being picked on. I learned it is okay to be different, in fact, it’s what makes the world great.

Throughout my childhood, scars and bandage were just a way of life. Every year my mom had to have some kind of surgical procedure. I remember spending weeks at my grandparents’ house because my mom had to go for a skin graft or a release. I never really understood what was going on, just that I was going to spend time with my grandparents. I thought it was great because I had a bunch of friends that lived close by and I could go play with them, not just the ones who lived by us. As I became older and was able to take care of myself, I would go to the hospital after school and sit with my mom to make sure she wasn’t alone all the time. I remember while she was sleeping, I would sit in the chair by her bed and work on my homework. The nurses would see and come and talk with me. More times than I can remember, they were the ones helping me with homework assignments. In between homework and my mom waking up, I would run to the kitchenette and grab her ice water or tea.



I can tell you if it wasn't for a handful of the nurses on the Burn Unit, I don't think I would have passed math and biology classes! Thank you to all the burn nurses, because if it wasn't for your kindness, I probably wouldn't have loved science the way I do. When mom was released from the hospital, I would get to know the VON nurses who would come in and help Mom with her bandages. When I look back, my mom's burns helped me become more social. It forced me to be able to reach out and ask for help from people, sometimes perfect strangers. Now I can talk to anyone, almost anywhere.

I would have to skip out on a lot of activities in my teenage years, because for a long time it was just my mom and me. I remember skipping school dances and hanging out with friends to go sit in the hospital. I felt it was my obligation to be there. I remember girlfriends would get mad, because they wanted to go to the movies with friends, or dances, but I told them I couldn't because I had to go to the hospital.

My mom never really made it to any of my sporting events, as between work, surgeries and recovery, she missed out on a lot of that stuff. In fairness,

the one time she was able to make it, I was injured pretty badly in a wrestling match. I didn't invite her anymore and I feel it was for the best.

My mom and I have talked about this many times over the last few years: Growing up, my mom was a victim of her burns. It wasn't until she went to her second burn camp, maybe her first or second conference that she finally started to become a survivor. I can't say it happened after her first camp because firstly, she was overwhelmed with emotion and secondly, while she was at her first camp, I fell asleep with a burner on and melted the handle on a teapot which caused a bunch of smoke damage in our kitchen! (I'm not an expert, but I'm pretty sure that negated the experience of her first camp.) That being said, before she experienced the Burn survivor's community, she would never talk about what had really happened to her, unless you dragged it out. Even then, it was the shortest answer possible. Most of what I knew about my mom's accident came from my Aunts explaining to me what they knew about it. Over the last 20 years, I have seen my mom grow and come to terms with her accident. She grew from not talking about her accident to openly discussing it.

Calendar of Future Events – July 2020 to September 2020

CBSC – Vancouver, BC – Postponed due to COVID-19 – Tentative Date - March 2021

Newsletter Submissions

Please submit any submissions for our quarterly newsletter to Michael and Sandy Cook: michaeldcook@shaw.ca