

## THE CBSC newsletter

WINTER 2019



Welcome to our fifth 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.

## Mamingwey Burn Survivor Society October 2019 Conference

The Mamingwey Burn Survivor Society held its 22th annual Burn Survivor gathering on October 19 and 20, 2019 at the Canad Inns Polo Park Hotel in Winnipeg. The theme this year was "Awakening the Warrior Within".

One hundred burn survivors, their family members, as well as Burn Unit staff from Manitoba attended this 2-day conference. The atmosphere was very uplifting and had a feeling of a family gathering, as people reconnected with other survivors, family members and hospital staff.

Keynote speaker **Samoana Matagi** opened the conference and spoke on the theme "**Awakening the Warrior Within**". Samoana was working in Utah as a linesman



where his job was to build and maintain powerlines. In December of 2010, he was in a horrific accident with live powerlines. which resulted in him а bilateral becoming upper limb amputee. He talked about key ways to build resilience in order to overcome the major setback of being burned. He displayed the many ways he has learned to thrive and even to live life more fully than when he had his hands. He also talked about using one's

roots and culture to bring



strength and renew purpose in your life - this was done in a very concrete way when he taught us to do the "Haka".





Daniel Dacombe, a
Prevention Education
Consultant with the
Addictions Foundation
of Manitoba spoke on
the topic of Addictions.
He led the discussion
on how to look at

addictions using a different frame work, and his positive message resonated with many of the attendees.

John Koop Harder presented on "Walking with Grief" and he gave us a new perspective on how to look at grief as something we have to dive into and learn to be comfortable with, as it is undoubtingly inevitable. He explained why avoiding grief can end up being damaging in the long run.

**Dr. Maxine Holmqvist** spoke on the topic of "Sleep". She talked about the different types of sleep disorders and presented tips and tricks to get a more restful sleep. She left us with the following message:



The best bridge between despair and hope is a good night's sleep.

Breakout sessions this year provided information for burn survivors to take away. **Kim Dodds**, from

the Tissue Bank of Manitoba, discussed how human tissue gifts benefit many people, not just burns survivors who may have had cadaver skin aid in their recovery. **Tara Torchia-Wells** talked about the benefits of Para-Medical Tattooing and scar camouflage, which was very interesting and informative for many of our survivors.

Three burn survivors and two family members of burn survivors spoke as a **panel**, discussing their lives after being affected by a burn injury and how they each awoke their inner warriors. Telling their struggles and triumphs from the heart, many in our audience could relate to their journeys. It was a very moving and meaningful session.

Conference attendees participated in **sharing circles**, which are considered a most valuable healing experience. Survivors, family and friends of survivors



as well as the health care professionals had separate meetings and were able to share their distinct journeys. The conference closed with a banquet dinner including a

great band called "The Steamers", an 80's live cover band who ensured we had some great entertainment and an upbeat atmosphere.

The Mamingwey Burn Survivor Society would like to thank our sponsors: The Firefighters' Burn Fund Inc., the Health Sciences Centre Foundation, as well as the Workers Compensation board of Manitoba, Bio Oil, United Firefighters of Winnipeg, Canad Inns Polo Park, Institut Esthederm, Manitoba Hydro, Red River Mutual, and Marie Alkana for their generous contributions that made this event possible.

We are very excited for the next conference, which is booked for October 23 and 24, 2020, at the same location. For more information, please email chair-person Barbara-Anne Hodge at barb@hodgefamily.ca or visit our website at www.mamingwey.ca



## Canadian Skin Patient Alliance - Grant \$3000.00

Our group applied to the Canadian Skin Patient Alliance grant program, the "Tanny Nadon Affiliate Members Grant".

On October 11, we received a letter advising our group that our application has been reviewed, and the Canadian Burn Survivors Community was the highest-ranked score in the pool of grant applications received. They congratulated us on winning a \$3000.00 grant. That money has been allocated to upgrade our brochure, which we will make available on our website. We will also have paper copies printed and circulated – if you would like some of our brochures, please email Debbie Ward at debbieward.cbsc@eastlink.ca with your request.

## CBSC Awards Program - Open for Nominations

Nomination Forms are available on the Canadian Burn Survivors Website. Please forward your nominations and why you feel they are deserving of recognition by our CBSC Board to Michael Cook prior to December 31, 2019 via email to: michaeldcook@shaw.ca



### **CBSC Awards Nomination Form**

The Canadian Burn Survivors Community Awards are given out bi-annually to deserving recipients in the following categories. The winners are determined by the CBSC Board of Directors from nominations from the community.

### **Peer Support Award**

- To recognize a person(s) and or group who have gone above and beyond with supporting of other burn survivors and their family members.
- Target Burn Survivors and family members of burn survivors.

### **Burn Care Award**

- To recognize person(s) in the health care sector staff who have gone above and beyond with support of burn survivors and their family members.
- Target Doctors, Nurses, Occupational Therapists and Physiotherapists.

### Fire Fighters and Builders Award

- To recognize person(s) in the Firefighters and Builders sector staff who have gone above and beyond with support of burn survivors and their family members.
- Target Firefighters, Builders from public and private sector.

### **Nomination Process for All Awards**

- CBSC members will nominate an individual or group – closing date December 31 prior to each conference the following year. (i.e. December 31, 2019 for 2020 conference).
- Board executive will review and determine the winner during a conference call in the spring, to be announced at the next Burn Conference.
- Winners to be advised by the CBSC Board in writing and asked to keep it confidential until announced at the conference.
- Winner to be given an engraved plaque 8 x10.
- Winner of each award to have their registration fees covered for the next conference.

Name of Nominee:	
Award:	
Peer Support Award	
Burn Care Award	
Fire Fighter and Builder Award	
Reasons for the Nomination:	
No	
Name of Nominator:	
Email:	
<del></del>	
Phone:	
Submit to Michael Cook: michaeldcook@shaw.ca	
Submit to Michael Cook. Michaeldcook@snaw.ca	

### Calgary Firefighters Burn Treatment Society - Update

On Thursday, November 14, the Calgary Firefighters Burn Treatment Society presented a cheque to the Alberta Children's Hospital Foundation in the amount of \$80,000.

The funds from this donation will be used to purchase specialized custom burn garments for children as well as a pilot project using virtual reality as a way of pain management and distraction for children undergoing a number of different burn related treatments.

"We are very excited to announce this new relationship between the Alberta Children's Hospital and the Calgary Firefighters Burn Treatment Society." said CFBTS president Thomas Kerr.

The funds for the burn garments will supplement an evergrowing need for customized burn garments. Members of the CFBTS were able to see an area in the hospital where these custom garments are sized specifically to each child's needs before ordering. As children grow, they can be re-measured, and new garments are ordered for them.

The virtual reality pilot project is part of the Alberta Children's Hospital "Commitment to Comfort" program. This initiative focuses on offering children and their family's strategies for painful procedures to reduce stress, enhance recovery and decrease the use of sedation. The use of virtual reality will help immerse the children in fun and relaxing sensory environments to help distract them during painful procedures.

"This relationship is another important step in supporting burn care in Southern Alberta. This partnership energizes and enables our organization to expand our support of burn treatment in Alberta." stated Kerr.

This is the first donation of its kind from the Calgary Firefighters Burn Treatment Society to the Alberta Children's Hospital Foundation.



## Overview and Management of Hypertrophic Scars and Keloids

Dr. Ian Tin Yue Wong and Dr. Vincent Richer

Whenever the skin is injured, whether by accidental trauma or a precise surgical incision, the skin follows a natural healing process that closes the wound and leaves a scar. When the natural healing process is compromised, however, excessive scarring can result. This scarring can be aesthetically disfiguring or functionally impairing and may also result in itching and pain that can contribute to low self-esteem and poor quality of life.

### Types of scars





Hypertrophic Scar



Keloid Scar

### What happens?

Excessive scarring can be categorized as hypertrophic scars or keloids. Both are the result of certain components that are normally involved in the healing process, including collagen and fibroblasts being overproduced. Common areas for excessive scarring include the earlobes, helices (top portion of the ear), upper and lower extremities, chest and shoulder area. As such, piercings can often lead to keloids.

Keloids are raised, thick scars that continue to grow and extend beyond the original wound dimensions. Keloids occur in people of all races but are more common in individuals of African or Asian descent. In contrast, the more common hypertrophic scars have not been found to demonstrate a genetic tendency. Hypertrophic scars appear similar to keloids, but their growth does not extend beyond the original wound dimensions. They are usually smaller than keloids and may improve over time.

### Scar care

The goals of treating keloids and hypertrophic scars are to relieve symptoms, improve characteristics of the scar such as its appearance and thickness, and reduce functional loss.

Scar care starts with prevention. Where possible, individuals with a history of keloids and hypertrophic

scars should avoid unnecessary procedures where the skin can be injured, such as piercings. In addition, tension on wounds should be minimized and skin infections or active skin conditions (e.g., acne flares) should be promptly treated. In most cases, wounds should be kept moist and covered to help with healing, which can be done with plain petrolatum ointment. The resulting scar should be protected from sunlight with sunscreen to limit excess darkening of the skin.

Given the persistent nature of keloids, treatment typically focuses on symptomatic keloids. Initially, your doctor might suggest corticosteroid injections in conjunction with pressure therapy and silicone gel sheeting. Other options that may be offered in particular circumstances include 5-fluorouracil injections, surgical removal, radiation therapy, cold therapy and laser therapy. Laser options include pulse-dyed laser and fractional laser resurfacing.

Surgical removal is likely to be more effective if combined with non-surgical treatment. It's also

important to know that a keloid may grow back in the same place after surgery.

Despite the variety of treatment options available, excessive scarring can be challenging to manage. Therefore, treatment should be individualized bearing in mind the characteristics of the scar, the patient's preferences and the amount of the physician's experience.

Ian Tin Yue Wong, BSc (Pharm), MD, is a dermatology resident at the University of British Columbia with a special interest in photomedicine.

Vincent Richer, MD, FRCPC, is a clinical instructor and director of continuing medical education in the Department of Dermatology and Skin Science at the University of British Columbia.

We would like to acknowledge the Canadian Skin Patient Alliance and thank Drs Wong and Richer for allowing us to share this in our newsletter.



# Getting to Know You Interview: Burn Survivor, CBSC - Director/Board Member - Michael Cook

### Briefly describe how you were burned?

- May 1998, while lighting a charcoal BBQ at Scout Camp I accidently spilt starter fluid on myself resulting in 17% burns to my body from the waist up.
- Spent 17 days in the Burn Unit in Victoria, BC, had one skin graft surgery.



- Burn Survivor colleague from my work came up to see me in the burn unit on day 3, that support changed my recovery in so many positive ways.
- Firefighters Burn Fund Victoria sent my wife Sandy and I to World Burn in Atlanta, Georgia 1999. At the conference, I struggled at first as my burns are hidden compared to others. Then another survivor pointed out that my mental scar is no different than his. This was key to me feeling part of the group and helped me to thrive.
- Following two more trips to World Burn Conferences,
  the Firefighters Burn Fund Victoria approached
  several of us to start a support group. I played a lead
  role in getting the group up and running and it was a
  privilege to be the co-ordinator of the group for the
  first 5 years. I have been involved with the group
  ever since.

### Reason for your involvement with CBSC?

 To continue to support burn survivors here in Canada, became a Director to assist the group to grow and pay if forward.



### Positive changes to you due to helping others?

- I never thought in my wildest dreams following my burn injury that I would be volunteering to this level.
   Truth be known, my life is enriched by being able to help others in a positive way.
- Thanks to all the survivors, family members, health care providers and firefighters that have supported me and my family though this life changing journey.
- When asked to tell my story of recovery to service groups or others, I do not accept money or charge any fees. I ask that they make a donation to the burn fund of their choice. This is my way of giving back for all the support that my family and I have received.
- I would like to thank the Firefighters Burn Fund
   Victoria for their continuing support, which has played a significant role in my recovery.

### Where you see yourself in 5 years?

 Continuing to volunteer with CBSC, assist a needed as our group continues to grow.

## CBSC Asks for Your Support - Flame Arrestor Petition

My name is Monica Reid, and I am, along with many supporters, petitioning the Government of Canada to require flame arresters on all consumer use disposable fuel containers. A flame arrester is a small mesh or perforated disc costing 3 to 5 cents, that prevents flame jetting accidents in disposable fuel containers. The accident that affected our family was a fondue burner being refilled, which is a very surprisingly common accident; using alcohol burning candles, decorative table top fire bowls, and outdoor fire tables are just a few more of the simple everyday activities that can quickly turn tragic because of the lack of a flame arrester on the fuel container. In fact, an average of 11 times a day, a person gets burned in these types of accidents, over 4000 injuries per year, 450 deaths.

On Christmas day of 2015, our family experienced a fuel container related fire explosion, resulting in several family members being injured including my ten-year-old son Lucas.

There is no way to comprehend the feeling a parent has seeing their child on fire. And there is no other way to explain it, he was literally engulfed in flame in seconds, his clothing just a pile of ash after my husband ripped them from his body. In literal seconds, his clothing was reduced to ash. It is unfathomable how fast it happens unless you see it yourself, and we are working to make

sure that nobody else ever as to. He was rushed to hospital immediately with traumatic injuries to his entire upper body including his face, requiring multiple skin grafts. It has been almost 4 years since this tragic accident, Lucas has had 9 surgeries to date, and is not done yet. I could write pages and pages about our experiences through all of this, the good and the bad, but the biggest tragedy is that a simple five cent piece of mesh or a perforated disc on the opening of the fuel bottle we used to fill an average fondue type burner would have prevented it all.

While it is difficult to relive the fire in conversation, and hard to read this small part of our journey, I know the importance of using our experience to help educate others and prevent another injury.

I feel a responsibility of advocacy on my heart to help make this happen.

Please support our cause by signing our online petition.

The petition number is e-2331.

https://petitions.ourcommons.ca/en/Home/Index

## Next CBSC Conference – Vancouver, BC 2020

Registration is now open for the Blue Skies 2020 Canadian Burn Survivor Conference!

As you may know in May of 2020, burn survivors, first responders, and medical professionals will come together for the Blue Skies 2020 Canadian Burn Survivors Conference, hosted by the BC Professional Fire Fighters' Burn Fund. We are reaching out as we need your help to get the word out.

This is the first time that the Canadian Burn Survivors Conference will be hosted in Vancouver and we look forward to welcoming guests from across Canada and the US. These guests include the full spectrum of the burn survivor community, from those who have survived burn trauma to the first responders and medical community whose dedication and specialization helped them survive and thrive.

Mental health is the focus of the conference, with the goal of improving the wellbeing journeys of both burn survivors and those who contribute to their critical care.

We invite you to register today at an early bird rate of \$325 per person.



#### **LOCATION:**

Pinnacle Harbourfront—To book your room at a discounted rate online, please use the link: bit.ly/burnsurvivors2020

(Group rate also in effect up to three days before and after the conference.)

PINNACLE HOTEL

#### **REGISTRATION:**

Before February 20, 2020: \$325 per person After February 21, 2020: \$375 per person On-Site Registration: \$375 per person Optional Day Rate: \$145 per person

## Calendar of Future Events – December 2019 to February 2020

February 2 - 8, 2020 - Burn Awareness Week

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## Conference Agenda -Draft – Will have update for next Newsletter

### **WEDNESDAY, MAY 20**

- Registration 2–5 PM
- Walk of Remembrance 5:30–6:30 PM

### DAY 1 THURSDAY, MAY 21

- Welcome Remarks & Keynote Speaker 9-10 AM
- Seminars & Presentations 10-3:45 PM
- Hospitality Suite 4-6 PM

### DAY 2 FRIDAY, MAY 22

- Seminars & Presentations 9-3:45 PM
- BC BBQ Social 5:30 PM

#### DAY 3 SATURDAY, MAY 23

- Seminars & Presentations 9–3:45 PM
- Conference Banquet & Awards cocktails 5:30 PM

Each Day: Breakfast 8-9 AM · Lunch: Noon-1 PM

### **CONFERENCE EXTENSIONS & ANCILLARY EVENTS**

- WALK OF REMEMBRANCE WEDNESDAY, MAY 20 5:30-6:30 PM
- HOSPITALITY SUITE THURSDAY, MAY 21
  - The first day of the conference will end with a two hour hospitality suite open for networking.
- BC BBQ SOCIAL FRIDAY, MAY 22
  - Conference attendees will experience BC at its best during this social barbecue.
- CONFERENCE BANQUET & AWARDS SATURDAY, MAY 23

The conference finale will be a celebration of Face Equality Week, a global movement which celebrates all differences. The evening will begin with cocktails at 5:30 PM. A banquet will follow that will set the background for closing remarks and the annual awards for those who have made a difference in their own community. Three award categories will be acknowledged: survivors, health care professionals, and fire fighters.

Hope to see you in Vancouver next May!

The BC Professional Fire Fighters' Burn Fund

#### **Newsletter Submissions**

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