Welcome message

Welcome to our fourth issue of *The Butterfly*, a newsletter connecting SickKids families affected by burn injuries. The butterfly is the symbol of 8C, the Burns and Plastics Unit at SickKids. It represents transformation. If you have missed our past issues and would like to receive a copy, please let us know!

We continue to strengthen our burn survivor support community through this newsletter, ongoing program events and other outreach initiatives. But we can’t do it without you – please let us know if you’d like to share your family’s story or write for *The Butterfly* – it’s another way of ‘paying it forward’ to benefit other families. In this issue, you can read about the Wilkinson family’s process of transforming their burn story to pay it forward, and about the experience of the Burke family, who attended the 2013 Phoenix Society’s annual World Burn Congress. As well, our lead story takes aim at scar myths and illuminates scar healing processes and rehabilitation. And, as always, we share event news and resource tips to keep you informed.

We are always grateful for your feedback and suggestions. The next issue of *The Butterfly* will be published in September and delivered to you by email. If you are picking up this copy in a clinic at SickKids, please sign up on the sign-up sheet provided or email me directly at lysa.toye@sickkids.ca.

On behalf of our Burn Program team, we hope that you enjoy this issue.

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**Debunking 5 Common Scar Myths**

By Lisa Lazzarotto, Occupational Therapist

Having treated scars for almost 20 years, I have become aware of many common misconceptions or myths related to scars and their treatment. It is important to remember that scars are a natural part of healing -- if we didn’t scar, our skin wouldn’t heal. Scars are areas of fibrous tissue that replace normal skin after injury. Scar tissue is made up of the exact same protein (collagen) as the tissue that it replaces, but the alignment of the collagen and quality of the tissue is different. Scars are more than a pigment or colour change; scars feel thicker, firmer or raised compared to non-scarred skin. Unfortunately, our body sometimes creates too much scar while trying to heal a wound.

Scars can cause pain, itch and may restrict the movement of joints. They can also have emotional consequences for the person with the scar, as well as for family members or those involved with the incident which resulted in the formation of a scar. Therefore, it is important to know what information is accurate and valuable for scar treatment and what is actually a scar myth. Below are some of the more common myths about scars:

**Myth 1: Vitamin E will improve the look of my scar**

Vitamin E is a commonly recommended remedy for post-operative and traumatic scars. It is recommended by friends, co-workers, relatives and some medical professionals. It can be purchased in capsule or liquid form or as an ingredient in other products, such as moisturizers. When applied too early Vitamin E can actually interfere with healing. It can also negatively influence the production of collagen, which provides strength and elasticity to the skin. There is no scientific evidence to show that vitamin E improves the outcome of a scar when looking at scar thickness, size or overall appearance. Dermatitis, a localized skin rash, has been observed after topical use of vitamin E.

**Myth 2: My scars will completely disappear**

The ideal long-term outcome of a scar is for it to be soft, flat and similar in colour to the uninjured skin. Unfortunately, it is not realistic to expect a scar to completely disappear. How much any given individual will scar is determined by a number of variables, including:

- Colour of skin: the darker the pigment, the more an individual is likely to scar. Also, people with very fair skin are likely to produce increased scar tissue.
- Location of injury: for example, the chest and shoulders are known to produce more scar than the leg.
- Length of time the wound took to heal: a burn that takes less than 2 weeks to heal will not scar. A burn that takes 2 to 3 weeks to heal may scar. A burn that takes 3 or more weeks to heal will scar.
- Age of the individual: children scar more than adults.

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- History: if an individual has produced a hypertrophic or keloid scar in the past, they are likely to have the same overproduction of scar tissue.

We have many non-surgical treatments to help improve the appearance of a scar, including custom-made pressure garments, massage and silicone. The SickKids Burn Program has also introduced in-hospital laser treatments this year to improve the appearance of burn scars. These treatments will not make the scar disappear but are likely to improve the overall appearance of the scar.

Myth 3: All scars are ‘keloid’ scars
Keloid scars are quite rare. They tend to occur on individuals with darker skin. Keloid scars grow beyond the edges of the original injury. For example, individuals with the tendency to form keloid scars may form a scar the size of a grape after piercing their ear lobe. Keloid scars are raised, firm and can be itchy, and do not tend to settle down within a year as other scars generally do. A raised, firm scar that remains within the borders of the original injury may be classified as a hypertrophic scar.

Myth 4: Tanning will improve the look of my scar
New scars (one to two years old) should not be exposed to the sun as there is less pigment in the scar, causing the skin to be at risk of burning more easily. Exposure to the sun can also permanently darken a new scar. Sunscreen with a minimum of SPF30 should be applied over the scar, even when wearing thin cotton clothes, as UV rays can penetrate fabric. Sunscreen should be reapplied regularly, especially after swimming. Hats and clothing that cover the scars are also recommended for the first few summers after the burn injury.

Myth 5: There is a miracle cream that will take away a scar … just look in magazines!
Despite what fashion and beauty magazines publish about creams that make scars disappear, in our many years of experience working with burns there is unfortunately no “miracle cream.” If these creams are used on surgical incisions or wounds that take less than 3 weeks to heal, the injured area was unlikely to scar whether the cream was used or not. On grafted skin or wounds that take more than 3 weeks to heal, the scar will not disappear no matter what the advertisements promise.

Many of our families receive recommendations for ‘miracle creams’ from well-meaning friends and relatives. These creams are often from countries where products may use different ingredients than those typically found in North America. We are happy for families to try any cream for scar massage, but please remember that while research continues into topical treatments to improve scar outcomes, we have not found any one cream better than any other and there is no support for this in scientific literature. It is the mechanical pressure and motion of the massage that reduces the scar and the moisturizing properties of any water-based cream that softens the skin and reduces itch.

We recommend a water-based cream, so the first ingredient on the packaging should be aqua. The brand does not seem to make a difference to the outcome of the scar. If the scar is itchy, adding a few drops of oil (such as Bio-Oil or emu oil) may reduce the itch. More frequent massage or anti-itch medication may also reduce this challenging problem.

Please consult with your Occupational Therapist or another member of the Burn Team if you have any questions or concerns about your child’s scars.

Youth Arts-based Research Project

Calling youth to participate in arts-based research on self-image following burn injury. We are in the early stages of developing a participatory research project that will work with a small group of youth with burn scars to document their lives and stories. Youth will be taught to use analogue cameras, develop photos in the darkroom, and video document their creative process. We plan to exhibit the work in several formats at the end of the project and use your voices to inform our work and services. Watch for more details to come or contact Lysa Toye for more information at lysa.toye@sickkids.ca or 416.813.7654 x. 204862.

Joey Conte Foundation

Join us for the 3rd Annual Joey Conte Foundation Dinner and Dance Gala, taking place April 4, 2014 at the Paramount Conference & Event Venue in Woodbridge.

All proceeds help to fund the SickKids Burn Program. For information or tickets please visit www.joeycontefoundation.com or email info@joeycontefoundation.com.
Bravery Day: Our Journey of Healing

By Danielle Wilkinson

The trauma of a burn injury invades every single facet of your life in some way, shape or form. It transforms you. There are haunting reminders everywhere, which often trigger painful thoughts and memories. The weight of this trauma is almost too much to bear. And the questions that come with it are downright exhausting. Why did this happen to our little girl, to our family? What purpose does this serve in our lives? Because after all, it can’t possibly be in vain.

After Willow’s injury, I was desperate not only to see but also to feel all of the love and kindness the world had to offer. And I wanted the same for my kids. I was tired of feeling sad and angry and scared. And then one day I happened upon some roofers. It was cold that day – Canada cold. And I couldn’t help thinking how an already difficult and dangerous job was made that much worse due to the weather. So I decided to bring them some hot chocolate. It was a simple gesture but it had an unexpected and profound effect on my emotional well-being. In that moment, I just felt happy. Nothing else. It was uncomplicated and devoid of any negative emotion. It was bliss and it was healing to my soul. Kindness ultimately pulled me out of darkness and began to push me forward.

So, as Willow’s one-year anniversary approached, I was driven to figure out a way to mark it, in a very special way – after all, it should be a day to remember and to celebrate. This beautiful little girl survived a fall into a campfire. She survived because of her sheer determination, resilience and strength. She survived because of the unfailing love and support of her family. And she survived because of the kindness of strangers, strangers at the campground who came running to our aid when we needed it most: the paramedic who tended to Willow’s injuries; the engineer who helped calm with stories and distraction; the nurse who physically supported my body in a squat position for more than 20 minutes so that I could cradle my sweet girl in my arms under a tap of frigid water, used to treat her injuries; the other men and women who selflessly helped our in-laws pack up our campground after we left in the ambulance; the nurses and doctors and therapists at SickKids who took the most amazing care of not only Willow, but our entire family during our stay, and who continue to do so. I still marvel at how things played out that fateful day. How lucky we were that a paramedic and nurse just so happened to be camping close to our site. And how lucky we were that all of these strangers wanted to help out of the goodness of their hearts. They will all be forever connected to our family and we are unendingly grateful for their kindness.

It was this kindness that ultimately inspired Bravery Day, as Willow’s anniversary is now lovingly titled. This first anniversary was a big step forward in the journey of healing. Above all, it was a celebration of the survival of an immensely brave little girl and also a celebration of everything positive that came out of a terrifyingly horrific accident: strength, courage, love, perseverance, teaching and awareness, self-confidence, conviction, compassion, acceptance and, of course, kindness. To celebrate our first Bravery Day, we took to our front sidewalk armed with chalk and drew positive images and messages for our neighbours and passersby. After Willow and her older brothers raided their piggy banks we walked up the street to our local farmers market to spread some love. Our community means a great deal to us, so what better place to give back. I had approached our local ice cream shop, Carter’s Ice Cream, as well as our favourite local toy store, Silly Goose, to be a part of our little mission and they graciously gave us gift certificates which the children handed out with glee. We also taped change to the parking meters, left trails of good luck pennies and paid for a lovely woman’s blueberries. Little things. But to be solely focused on making someone else smile without expecting anything in return felt nothing short of amazing. I was overwhelmed with pride watching my children in this experience, as they came up with ideas of their own to make others smile. The great thing about kindness is that it is contagious. And hopefully those touched by our kindness were able to pay it forward.

I find myself equally moved and overwhelmed by all of the good that has come from such a terrible experience, as I am about all of the negative as well. However, the further along our family journeys together in healing, slowly the negative effects of trauma are overshadowed with good. It is with this thought that I am reminded of a favourite proverb: “Just when the caterpillar thought the world was over, it became a butterfly.” This is our journey together and for that, I am proud. I will wear it like a badge. I look forward to celebrating Bravery Day with each passing year. It holds powerful lessons that will grow like little seeds of happiness planted inside our family.
Family Support Forum

On Sunday, Jan. 19, six families and their 20 family members came together at our first Family Forum. This new program of quarterly support sessions will allow parents to meet together to share their experiences, challenges and successes while children and toddlers are cared for and provided with therapeutic activities.

For two hours, parents were able to share in their struggles, as well as their sense of strength around the burn injury that has changed their lives, and explored ideas around how to strengthen support for burn-affected families in Ontario. Children participated in a variety of activities that included making “mind bottles” to aid them with relaxation and an impressive performance of the Katy Perry song Roar for an appreciative adult audience to close the day. All involved agreed this should be a more frequent event and we heard you: we’ll be offering Family Support Forums on a quarterly basis, with the next one to take place on April 13 from 1-3 pm.

We hope that you will be able to join us! For more information or to register, email lysa.toye@sickkids.ca or call 416.813.7654 x. 204862.

Laser Therapy Program Update

After much anticipation and preparation, we are pleased to report that our new Laser Therapy program is now underway and patients have begun to receive treatments using this new technology.

Laser therapy has been shown to help some burn scars that are itchy, red and raised, even years after the injury. These lasers do not remove the scars but have been shown in some cases to reduce the height of the scar, add softness and decrease the redness. While these lasers are not a replacement for traditional rehabilitation, which includes massage, range of motion exercises, stretching and pressure garments, the use of lasers for burn scars has been growing and has shown benefit for scars that require subtle change.

If you would like more information on this program, speak to your rehab therapist or a member of your team. We are grateful to generous community supporters who made it possible for us to purchase the equipment needed for the program.

Camp Bucko is Now Accepting 2014 Camper Applications

Camp BUCKO (BUrn Camp for Kids in Ontario) is a residential summer camp intended to provide a fun-filled, adventure-packed week for children between the ages of seven and 17 who have sustained a burn injury. Campers will get to know others who have similar experiences, while at the same time enjoying the outdoors and camp spirit. Whether your burn was 10 years or six months ago, you are welcome to attend Camp BUCKO!

Camp BUCKO 2014 will be hosted at Camp Kodiak near Parry Sound. Last year was amazing and the campers were thrilled with the many activities! Horseback riding, go-karting, water skiing, rock climbing, canoeing, kayaking, arts and crafts were a few highlights of our campers’ week!

If you are interested in attending Camp BUCKO please contact 647-343-2267 or 1-877-272-8256. Please feel free to visit the camp’s website for any additional information, at www.campbucko.ca.

- Campers must be between the ages of 7 and 17 and have received two weeks or more of treatment by a physician/health-care practitioner in order for their burn injury to heal
- There is no fee to attend Camp BUCKO
In October of 2013, I had the pleasure of attending my first Phoenix Society World Burn Congress (WBC), which took place over four days in Providence, Rhode Island.

The Phoenix Society is the pre-eminent burn survivor organization in North America, based in Michigan, and is dedicated to empowering anyone affected by a burn injury through peer support, education and advocacy. This 25th annual WBC hosted over 870 attendees, composed of burn survivors, their families, caregivers, burn care professionals and firefighters to facilitate the sharing of stories, provide support and offer education on burn recovery. It also coincided with the 10th anniversary of the Station Night Club fire in Rhode Island and featured many health-care professionals and survivors of that tragedy reflecting on their experience.

Adult attendees participated in workshops, discussion groups, special speaker sessions and support groups, and special programming was also offered to children, youth and young adults through Phoenix Society’s UBelong program. For me, it was an emotional four days and left me with a lot to think about both professionally and personally. Being with hundreds of burn survivors of all ages and stages, different cultures and communities, and varying degrees of injury, and with their family members, friends and caring professionals, brought home to me on a new level the power and importance of community for those learning to live with scars or other differences as a result of burn injury.

“I was very moved and inspired by the congress, and felt blessed to have been in the presence of so many amazing people,” says Crystal Burke. Burke’s son, Daymein, suffered an extensive burn injury three years ago and Crystal, Daymein and her daughter Nikita were supported by Camp BUCKO to attend the 2013 Congress.

“The love and strength that was shown throughout the week was heartwarming and really made me gain a new perspective on where we were, versus where we are now. I felt healed after being able to partake in some of the adult workshops provided and was able to meet many wonderful people that didn’t judge, but instead embraced my family’s journey. I have many new supports that I was unaware of before the Congress and many of the incredible people I met will stay with me in my heart.”

Daymein Burke says, “I had fun at the congress and met lots of really fun people. It showed me that I am strong, and I learned to share my story without being so sad, because there were other people there that had burns and injuries too.”

Daymein’s sister Nikita adds, “I was unsure at first about going to the Congress and didn’t know really what to expect, but once there I felt good and met a bunch of really cool people. That helped me understand that I wasn’t all alone in the sibling position, and have many friends now that not only had to go through similar things, but that showed me I am really a good person. I look forward to doing the UBelong program again next year and meeting new friends and helping with my experiences.”

“I was also amazed,” reflects Crystal, “at the difference in my kids who were healing over the last two and a half years. They came home with a new confidence and a new strength, that I knew was within them somewhere. My son’s uncertainty to share his journey has now diminished all together, and both were able to express themselves without the feeling of being judged or misunderstood.”

For more information on the World Burn Congress, go to www.phoenix-society.org/programs/worldburnCongress/world-burn-Congress-2014/.

And for more community-building opportunities closer to home, please join us for at our Family Forums, our annual Burn Family Picnic and our annual Family Day for Burn Survivors.
Seasonal Safety Tip:

Scald Prevention

Burns that are caused by contact with a hot liquid are called scalds, and they are the major cause of burn injuries in young children. Here are some safety tips to help keep children safe from scald injuries:

- Keep young children away from food preparation areas.
- Use the back burners of the stove and keep pot handles turned in.
- Use stovetop element guards.
- Never hold a child when drinking a hot liquid.
- Place hot drinks out of reach of children.
- Reduce your hot water temperature to 49°C (120°F) or lower.
- Always watch children during bath time. Never leave a child alone in a tub of hot water.
- Use an anti-scald tap device.
- Keep appliances and their cords away from the reach of young children. Appliances include irons, kettles and curling irons.

Burn Prevention Outreach Team Works to Raise Awareness and Promote Safety

It has been almost a decade since members of the Burn Team at SickKids began their quest to prevent the devastating injuries we see each day. The Burn Prevention Outreach Committee was launched to try to raise awareness of the causes of burn injuries and teach prevention strategies and first aid to children and families. This small but committed group has been working within SickKids and throughout the broader Toronto community ever since.

In partnership with Toronto Fire Services and other community partners, the group has developed a public service announcement and designed numerous posters (including the award-winning poster featured in our last issue), as well as other first aid and home safety outreach tools. Committee members participate in Toronto Fire Services Fire Prevention Open Houses held twice annually all over the Greater Toronto Area and in burn prevention events held several times each year at SickKids in the Garden Patio. These events are a big draw, as kids get to play games, learn correct first aid, make crafts, visit with Sparky the Fire Dog and explore a big fire truck that comes to visit. Parents have an opportunity to learn more about maintaining a safer household environment to prevent tragic burn injuries from occurring.

To view one of our videos featuring Dr. Joel Fish and Charis Kelly speaking about burn first aid, visit https://www.youtube.com/watch?v=kwsiqf-1DzM. We are always looking for great new ideas to prevent burn injury and reach out to the broader community, so feel free to speak to a member of the team to share your thoughts!

SickKids Burn Program Verified by the American Burn Association

This past September, the SickKids Burn Program received verification through the American Burn Association and the American College of Surgeons Committee on Trauma as the first verified paediatric burn centre in Canada. Following a long process to prepare and submit the application data and a two-day site visit and rigorous review by adjudicators, this approval offers a distinguished recognition of our burn program and our multidisciplinary team within Canada and internationally. It is an honour of which the team is very proud – way to go! In honour of this achievement, the 39th Scout Troop here at SickKids made a plaque and presented to staff on 8C. It is now proudly displayed on our wall.
Please join us and meet other families, burn team staff, and firefighters for a picnic in the park.

Picnic Lunch, Arts & Crafts, Toddler Play Park, Games, Entertainment

Admission to the park is free. A volunteer will meet you at the park gate to assist you in locating the picnic site.

Lunch is provided (veggie burgers available). Please note that we are unable to provide for special diets.

Families are asked to bring a contribution for our dessert table.

We recommend that you bring sunscreen, insect repellent, children’s bathing suits, towels, hats, and lawn chairs.

The Picnic will be held rain or shine – If you have any questions on the day of the picnic, please call 8C at 416-813-6932

If you require transportation to the park, there will be a shuttle bus available to transport you from SickKids to the picnic in the AM and then transport you back to SickKids in the PM.

If you have any questions or to RSVP please call (416) 813-7654 x 228198 or send an email to: burn.events@sickkids.ca
Thank you to everyone who attended our 2013 Family Day for Burn Survivors on Oct. 19, 2013.

This may have been our best year yet! In partnership with Sunnybrook’s Ross Tilley Burn Centre, survivors, family members and friends of all ages and stages came together for laughter, some tears, and the chance to connect and share their experiences. With a wonderful turnout of almost 120 people and an excellent keynote by survivor Ralph Walker on his own burn injury and rehabilitation, the event was very successful. The kids engaged in improv games, drumming and painting activities and got to tour the Fire Academy and use a real fire hose! Special thanks, as always, goes to our generous sponsors who provided amazing food for all to enjoy: Greg’s Ice Cream, Tim Hortons and Pizzaiollo. Thanks also to the Toronto Professional Fire Firefighters, who donate the venue each year and offer the Interactive fire tour session to kids, and to Second City, who donated their services for the improv session.

We look forward to seeing you again this year, on Saturday, Oct. 18, 2014!

Resource Tips

Best Start: Ontario’s Maternal Newborn and Early Child Development Resource Centre
www.beststart.org/index_eng.html

BestStart supports service providers across the province of Ontario who are working on health promotion initiatives to improve the health of expectant parents and their young children, offering workshops, resources, consultations and information.

The Remarkable World of Your Toddler is one of their many publications available online and is a terrific resource providing information on children’s social, emotional and intellectual development in the toddler years. This is just one of numerous online parenting resources offered by Best Start.

TVOParents: Nurturing Early Brain Development
tvoparents.tvo.org/topic/health-development

TVOParents has partnered with the Infant Mental Health Promotion program at SickKids to educate parents about the importance of healthy brain development in the early years of a child’s life. This website offers a series of print and video resources on questions relating to physical and mental health, brain and whole-child development, and special needs.

Canadians Against Stevens Johnson Syndrome & Toxic Epidermal Necrolysis
www.CASTInternational.org

CAST is a Toronto-based organization formed by Sonia Whyte-Croasdaile, a survivor of toxic epidermal necrolysis (TEN). CAST aims to promote awareness and provide education and support for patients, families and caregivers facing these serious illnesses.

We would love to hear from you! If you have feedback, story ideas or would like to get involved with The Butterfly, please let us know! Contact Lysa Toye at lysa.toye@sickkids.ca or 416-813-7654 x. 204862.